

Intersex, Discrimination and the
Healthcare Environment – a Critical
Investigation of Current English Law

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Table of Contents

Table of Contents	i
Table of Figures	v
Table of Abbreviations	v
Tables of Cases	vi
Domestic cases...vi	
Cases from the European Court of Human Rights...vii	
International Jurisprudence...vii	
Tables of Legislation	viii
Table of Statutes- England...viii	
Table of Statutory Instruments- England...x	
Table of Legislation-Scotland...x	
Table of European and International Measures...x	
Conventions...x	
Directives...x	
Table of Legislation-Australia...xi	
Table of Legislation-Germany...x	
Table of Legislation-Malta...x	
Table of Legislation-New Zealand...xi	
Table of Legislation-Republic of Ireland...x	
Table of Legislation-South Africa...xi	
Objectives of Thesis	xii
Acknowledgments	xiii
Declaration	xiii
Abstract	xiv
Part 1 of Thesis	xv
Chapter One: <i>Primum non nocere</i> ‘First do no Harm’...1	
1.1 Introduction ...1	
1.2 What is Intersex? ... 6	
1.2.1 The Evolution of a Name- Hermaphrodite ...6	
1.2.2 A Modern Approach – ‘Intersex’ and ‘DSD’ ...12	
1.2.3 The Rise of the Activists, the Demise of a name. ... 13	
1.3 Potential Discrimination - Current English Law...19	
1.3.1 Discrimination in Practice ...21	
1.3.2 Sport ...23	
1.4 Hippocrates, a Code of Ethics... 27	
1.5 Medical Ethics ...29	
1.5.1 Virtue Ethics... 30	
1.5.2 Deontology ...31	
1.5.3 Consequentialism...33	
1.6 Medical Ethics in the 20 th Century... 33	
1.6.1 John Money...38	
1.7 The Four Principles...40	

Table of Contents

1.7.1 Autonomy ...	41
1.7.2 Non-maleficence ...	42
1.7.3 Beneficence ...	43
1.7.4 Justice ...	44
1.8 Health Care Law and the Intersexed ...	45
1.9 Following Chapters ...	47
Chapter Two: Literature Review and Methodology ...	49
2.1 Literature Review ...	49
2.1.1 Scientific Authorities ...	51
2.1.2 Gender Studies and Sociological Texts...	52
2.1.3 Medical Ethics ...	53
2.1.4 Legal Writing...	54
2.1.5 Consent to Treatment ...	57
2.1.6 Intersex Organisations ...	62
2.1.7 Summary ...	62
2.2 Methodology ...	63
2.2.1 Doctrinal Research Analysis...	63
2.2.2 Comparative Law Methodology...	64
2.2.3 Empirical Research ...	67
2.2.3.1 Phenomenology ...	67
2.2.3.2 Quantitative Data...	71
2.2.4 Summary ...	72
Chapter Three: Medical Science and Intersex Conditions...	74
3.1 Introduction ...	74
3.1.1 Scientific Background ...	75
3.2 Alterations to the Karyotype: Sex Chromosome Anomalies- DSD Associated Conditions ...	76
3.2.1 Klinefelter's Syndrome (KS) ...	79
3.2.2 Turner Syndrome (TS) ...	82
3.3 Alterations to the Karyotype: Sex Chromosome DSD ...	83
3.3.1 Mixed Gonadal Dysgenesis (MGD) ...	85
3.4 Genetic Modifications: Congenital Development of Ambiguous Genitalia (46 XX DSD). ...	87
3.4.1 Congenital Adrenal Hyperplasia (CAH) ...	89
3.4.1.1 Grades of Severity ...	92
3.4.1.2 CAH due to 21-Hydroxylase deficiency...	94
3.4.1.3 CAH due to 11 β -Hydroxylase deficiency and 3 β -dehydrogenase...	96
3.5 Genetic Modifications: Congenital Disjunction of Internal and External Sex Anatomy (46, XY DSD) ...	98
3.5.1 XY Gonadal (testicular) Dysgenesis ...	98
3.5.2 Androgen Insensitivity Syndrome (AIS) ...	99
3.5.2.1 Complete Androgen Insensitivity Syndrome (CAIS) ...	100
3.5.2.2. Partial Androgen Insensitivity Syndrome (PAIS) ...	102
3.5.3 5-alpha-reductase deficiency (5-ard) ...	102
3.5.3.1 5ard- its developmental effect ...	104
3.5.3.2 17-beta hydroxysteroid dehydrogenase 3 deficiency (17bHSD3) ...	106
3.6. Incomplete Development of Sex Anatomy ...	106
3.6.1 Hypospadias...	107
3.6.2 Cloacal Exstrophy ...	110
3.7 Summary...	111
Chapter Four: Society, the Intersexed and the Law, a Historical Prospective	4.1113
4.1 Introduction...	113
4.2 The Views of Society...	115
4.3 The Views of Scientists...	124
4.3.1 The legacy of John Money ...	128
4.4 Gender Studies and the Intersexed...	134
4.4.1 Sexuality ...	136

Table of Contents

4.4.2 Sex and Gender...	137
4.4.3 The Rise of Gender Studies and the Fall of Money...	138
4.5 Gender Allocation and Legal Support- Concluding Thoughts...	148
Chapter Five: 'Informed' Consent and the Intersexed: Myths and Realities...	153
5.1 Introduction...	153
5.2 The Nature of Consent ...	154
5.2.1 'Informed Consent'? ...	156
5.2.2 Consent and English Law...	157
5.2.2.1 Disclosure...	162
5.3 The Legal Meaning of 'Capacity'...	165
5.4 Children and Consent...	170
5.4.1 Mature Minors and Medical Treatment ...	173
5.5 Treatment of the Intersexed-International Jurisprudence ...	179
5.5.1 The Columbian Decisions ...	179
5.5.2 Other Cases...	183
5.6 Legislative Measures, a Comparison with other Jurisdictions...	185
5.6.1 Young Children ...	188
5.6.2 Mature Minors...	190
5.7 Conclusion...	194
Part Two of Thesis ...	196
Chapter Six: Discrimination Before Birth; Assisted Reproductive Techniques, Pre-implantation Genetic Diagnosis and Abortion...	197
6.1 Introduction...	197
6.2 Assisted Reproductive Techniques (ART) ...	198
6.2.1 Fluorescence in situ hybridization (FISH) ...	199
6.2.2 Intrauterine insemination (IUI) ...	199
6.2.3 In Vitro Fertilization (IVF) ...	200
6.2.4 Intra-cytoplasmic Sperm Injection (ICSI) ...	202
6.3 Embryo Monitoring ...	202
6.4 Ethical Concerns with ART...	203
6.5 Pre-implantation Genetic Diagnosis (PGD)...	205
6.5.1 PGD Legal Provisions and the Extent of Discrimination ...	208
6.6 Antenatal Testing and Abortion ...	214
6.7 Antenatal Testing ...	215
6.7.1 Invasive Testing ...	216
6.7.2 Non-Invasive Testing- Ultrasound scans...	218
6.7.3 Non-Invasive Prenatal Diagnosis using Cell-free Fetal DNA (cffDNA) ...	222
6.7.4 Ethical Concerns ...	223
6.8 Testing for and Treating CAH during Pregnancy...	224
6.9 The Abortion Act 1967 ...	226
6.9.1 The Abortion Act 1967- background ...	227
6.10 'Substantial Risk' and 'Seriously Handicapped'...	230
6.11 Parental Choice...	234
6.12 Reflections on Section 1(1)(d)	
6.13 Conclusions...	240
Chapter Seven: Birth, Neonatal Testing and Discrimination ...	242
7.1 Introduction...	242
7.2 Routine Neonatal Assessments and the Intersexed ...	244
7.3 Newborn Blood Spot Screening (NBS) ...	246
7.3.1 The Argument in favour of Introducing NBS for CAH...	249
7.3.2 Arguments against Introducing NBS for CAH...	251
7.3.2.1 Inaccurate test results...	251
7.3.2.2 Prohibitive Cost?...	256
7.4 Consideration of NBS screening for Sex Chromosome Anomalies...	259

Table of Contents

7.4.1 The Importance of Testing for KS at birth...	260
7.5 Conclusion...	266
7.5.1 Recommendations...	267
Chapter Eight: Conformity; Early Childhood and Enforced Operations Introduction ...	269
8.1 Introduction...	269
8.2 Consent and Emergency Neonatal Testing...	269
8.3 Early Genital Assignment Surgery...	272
8.3.1 Male circumcision...	275
8.3.2 Sterilisation...	277
8.3.3 Female Genital Mutilation (FGM) and the Intersexed ...	281
8.4 The Female Genital Mutilation Act 2003 ...	286
8.5 Conclusions...	289
Chapter Nine: The Young Intersex Person's Right to Know...	291
9.1 Introduction...	291
9.2 Access to Health Records, Current legislation...	292
9.2.1 Online Access to Health Records...	294
9.3 Young People's Access to Health Records...	295
9.4 Methods of Redress...	299
9.5 Views on 'open' access and veracity...	300
9.6 Conclusion ...	303
Chapter Ten: Births, Deaths, Marriages and the Intersexed; Concluding Thoughts. ...	306
10.1 Introduction ...	306
10.2 Registration of Birth- Male or Female?...	307
10.3 The Parallel law for Transsexuals...	312
10.4 Marriage...	313
10.5 Deaths ...	316
10.6 International Approaches to 'Third Gender' Recognition...	317
10.6.1 Asia ...	317
10.6.2 Australasia...	320
10.6.3 Europe : Germany and Malta ...	323
10.7 Conclusions to this Chapter ...	325
10.7.1 'Third Gender' on Official documentation...	326
10.7.2 'No Gender' on Official documentation ...	327
10.7.3 'Flexible Gender' on Official documentation...	329
10.8 Conclusions to the Thesis...	331
10.8.1 Final Thoughts...	336
Additional Material	338
Appendix A: Public Statement by the Third International Intersex Forum	339
Appendix B: Hippocratic Oath; Classical Version	341
Appendix C: WMA Declaration of Geneva	342
Appendix D: The Nuremberg Code	343
Appendix E: Questionnaires	345
Questionnaires sent to ART Clinics.....	345
Responses to Questionnaires sent to ART Clinics.....	347
Questionnaires sent to Individuals.....	350
Consent Form.....	353
Appendix F: The HDC Code of Health and Disability Services Consumers' Rights	
Regulation 1996 New Zealand.....	354
Right 5: Right to Effective Communication.....	354
Right 6: Right to be Fully Informed.....	354
Right 7: Right to Make an Informed Choice and Give Informed Consent.....	355
Right 10: Right to Complain.....	357
Bibliography	359

Table of Contents

Table of Figures

Figure 1: West Wycombe Hermaphrodites ‘approach view’	9
Figure 2: West Wycombe Hermaphrodites ‘reverse view’	10
Figure 3: Diagram of the Chemical (<i>Enzymatic</i>) Pathway: Production of Hormones from Cholesterol.....	91
Figure 4: Diagrammatic Representation of the Three Aspects of Persona.....	135

Table of Abbreviations

AIS	Androgen Insensitivity Syndrome
AISSG	Androgen Insensitivity Syndrome Support Group
AMA	American Medical Association
ART	Assisted Reproductive Techniques
BMA	British Medical Association
CAH	Congenital Adrenal Hyperplasia
CAIS	Complete Androgen Insensitivity Syndrome
cffDNA	Cell-free Fetal DNA
DSD	Disorder/difference/diversity of sex development
FGM	Female Genital Mutilation
FISH	Fluorescence in situ hybridization
GMC	General Medical Council
HPA	Health Protection Agency (now Public Health England)
ICO	Information Commissioner’s Office
ICSI	Intra-cytoplasmic Sperm Injection
ILGA	International Lesbian, Gay, Bisexual, Trans and Intersex Association
ISNA	Intersex Society of North America
IUI	Intrauterine insemination
IVF	In Vitro Fertilization
KS	Klinefelter Syndrome
MGD	Mixed Gonadal Dysgenesis
NBS	Newborn Blood Spot Screening
NHS	National Health Service
PHE	Public Health England
TIIF	Third International Intersex Forum
TS	Turner Syndrome
UK NSC	United Kingdom National Screening Committee
WHO	World Health Organisation
3β-HSD	3-beta-hydroxysteroid dehydrogenase
5-ard	5-alpha-reductase deficiency
17βHSD3	17-beta hydroxysteroid dehydrogenase 3 deficiency
21-OH	21-hydroxylase deficiency

Table of Contents

Table of Cases

Domestic Cases

A (male sterilisation), Re [2000] 1 FLR 549.....	278
B (a minor) (wardship: medical treatment), Re [1981] 1 WLR 1421.....	171
B (adult refusal of medical treatment), Re ; Sub nom Ms B v An NHS Hospital Trust [2002] EWHC 429 (Fam)	158
B (Care Proceedings: Appeal), Re [2013] UKSC 33.....	285
B and G (children) (No 2), Re [2015] EWFC 3	285
B v South Tyneside Health Care NHS Trust [2004] EWHC 1169 (QB)	216
Barclays Bank v O'Brien [1994] 1 AC 41.....	41
Bank of Credit and Commerce International SA v Aboudy [1990] 1 QB 923.....	41
Bellinger v Bellinger EWCA Civ 1140 [2001] 3 FCR 1.....	312, 315
Bolam v Friern Hospital Management Committee [1957] 1 WLR	114
Bolitho v City and Hackney Health Authority [1998] AC 232.....	114
Brindley v Queen's Medical Centre University Hospital NHS Trust [2005] EWHC 2647 (QB).....	216
C (adult: refusal of treatment), Re [1994] 1 WLR.....	165
Chester v Afshar [2004] UKHL 41; [2005] 1 AC 134.....	26, 163
Corbett v Corbett [1971] 2 All ER 33.....	64, 310, 311, 315
Department of Health v Information Commissioner and the Pro Life Alliance EA/2008/0074 (Information Commissioner's Ref: FS50122432)	232
Devi v West Midlands Regional Health Authority [1980] CLY 687.....	161 , 184
DPP v Smith [1961] AC 290.....	157
E (a minor) (wardship: medical treatment), Re [1993] 1 FLR 386.....	162, 178
F v West Berkshire HA (1989) 86 (10) LSG 42.....	160
F v West Berkshire HA also known as F (mental patient: sterilisation), Re [1990] 2 AC 1 HL; [1989] 2 WLR 1025; [1989] 2 All ER 545.....	78, 158 , 159, 277
FP v Taunton and Somerset NHS Trust, [2009] EWHC 1965.....	219
Gillick v West Norfolk and Wisbech Health Authority, [1986] AC 112.....	154 , 175, 296
Houston, Applicant, Re (1996) 32 BMLR 93.....	190
J (a minor) (wardship: medical treatment), Re [1990] 3 All ER 930.....	172
J (child's religious upbringing and circumcision), Re [2000] 1 FCR 307.....	276
Jepson v The Chief Constable of West Mercia [2003] EWHC 3318.....	232
Jones, Katherine, alias Nowland (t17190903-50).....	123
L (medical treatment: Gillick Competence), Re [1998] 2 FLR 810.....	162
LC (medical treatment: sterilisation), Re [1997] 2 FLR 258.	278
MB (an adult: medical treatment), Re [1997] 2 FCR 541	167
R (a minor) (wardship; medical treatment), Re [1992] 1 FLR 190.....	43, 176, 177
R v Arthur (1981) 12 BMLR 1.....	171
R v Bourne [1939] 1 KB 687	227
R v Brown [1994] 1 AC 212 [1993] 2 All ER 75.....	157
R v Cunningham [1982] AC 566.....	157
R v Donovan [1934] 2 KB 498	157
R v Mid Glamorgan Family Health Services Authority and Another ex parte Martin [1995] 1 WLR 110.....	292
R v R [1991] UKHL 12; [1991] 2 WLR 1065	114
R (Axon) v Secretary of State for Health [2006] EWHC 37 (Admin); [2006] All ER 148.....	192, 193
R (Burke) v General Medical Council [2004] EWHC 1879 (Admin); [2005] 3 FCR 169.....	154, 158
R (Department of Health) v Information Commissioner and the Pro Life Alliance [2011] EWHC 1430 (Admin).....	232
RM v St Andrew's Healthcare [2010] UKUT 119 (AAC)	297
Roberts v Nottinghamshire Healthcare NHS Trust [2008] EWHC 1934 (QB).....	297
S (adult: refusal of medical treatment), Re [1992] 4 All ER 671, [1992] 3 WLR 806.....	167
S (a minor) (independent Representation), Re [1993] 2 FLR 437	193
S (contact: Children's views), Re [2002] 1 FLR 1156	193
Secretary of State for the Home Department v K; Fornah v Secretary of State for the Home Department [2006] UKHL 46	283, 284
Sidaway v Bethlem Royal Hospital, [1985] AC 871.....	162
St. George's Healthcare N.H.S. Trust v S; Regina v Collins and Others, ex parte S [1999] Fam 26...167	

Table of Contents

T (adult) (refusal of treatment), Re [1992] 4 All ER 649, [1992] 3 WLR 782.....	158,166
T (a minor) (wardship: medical treatment), Re [1997] 1 ALL ER 906; [1997] 1 WLR 242.....	172
W (a minor) (medical treatment: court's jurisdiction), Re [1992] 4 All ER 627; [1992] 3 WLR 758.....	177
W (an adult: sterilization), Re [1993] 2 FCR 187.....	278
W v W [2001] Fam 111.....	64,178, 314
X (adult patient: sterilisation), Re [1999] 3 FCR 426.....	278
Z (a minor) (identification: restrictions on publication), Re [1997] Fam 1.....	172

Cases from the European Court of Human Rights

Christine Goodwin v The United Kingdom (Application no 28957/1995)	312
Costa and Pavan v Italy (Application no. 54270/10).....	213
David Glass v The United Kingdom (application no 61827/00) (2004) 39 EHRR.....	173
KH and others v Slovakia (Application no 32881/04)	293
McGinley and Egan v The United Kingdom (Case no 10/1997/794/995-996) 27 EHRR 1.....	293
MG v United Kingdom (Application no. <u>39393/98</u>) [2002] 3 FCR 413.....	299
RR v Poland, (application number 27617/04)	217
Salgueiro Da Silva Mouta v Portugal (Application no 33290/96)	242
Ternovsky v Hungary (Ref no 67545/09)	169
Tyrer v The United Kingdom (Application no 5856/72)	285
Vo v France (application number 53924/00)	217

International Jurisprudence

A, Re (1993) 16 FLR 715 (Family Court of Australia)	279
AC, Re (1990) 573 A 2d.....	167
AC v Manitoba (Director of Child and Family Services), 2009 SCC 30, [2009] 2 SCR 181.....	191
C and D, Re (In the Marriage of C and D (falsely called C)) (1979) 35 FLR 340 (Aust).....	314
B v Medical Council of New Zealand, [2005] HC 3 NZLR 810.....	186
Canterbury v Spence (1972) 464 F 2d 772.....	156, 162
Cruz (Sentencia No T-551/99).....	182
Gonzalez (Sentencia No T-477/95)	179, 275
Breen v Williams [1994] 35 NSWLR 522	293
Breen v Williams [1997] 1 LRC 212.....	293
Dion'e Kaeo-Tomaselli v Jennifer Butts Iwalani Souza Civ No 11-00670 LEK/BMK_United States District Court, D Hawaii.....	22
EG, (a minor) Re (1989) 133 Ill 2d 98, 549 NE 2d 322.....	190
Grandjean, Anne/Jean-Baptist.....	121
Jamie (special medical procedure), Re [2011] FamCA 248.....	280
Jamie, Re [2013] FamCAFC 110	280
Landgericht Cologne judgment No 151 Ns 169/11.....	275, 276
Lemarcis, Marie/Marin.....	121
MC v Aaronson (ongoing)	184
Marion's Case (Sterilization of an Intellectually Disabled Child) (Department of Health and Community Services v JWB and SMB (1992) 175 CLR 218	78, 279
Marshall v Curry (1933) 3 DLR 260, 275.....	160
Mount Isa Mines Ltd v Pusey (1970) 125 CLR.....	45
Muasya (Richard) v the Hon Attorney General, High Court of Kenya Petition No 705 of 2007 (2 December 2010)	21
Murray v McMurchy, [1949] 2 DLR.....	161
National legal Services Authority v Union of India & others Writ Petition (Civil) No 400 of 2012 with Writ Petition (Civil) No604 of 2013,	319
Norrie v Registrar of Births, Deaths and Marriages (GD) [2011] NSWADTAP 53.....	321
Norrie v NSW Registrar of Births Deaths and Marriages [2013] NSWCA 145.....	321
Pant (Sunil Babu) and others v Nepal Government, Office of the Prime Minister and Council of Ministers, Legislature-Parliament 21 December 2007.....	161
Pratt v Davis (1906) 224 Ill 300.....	160
Ramos (Sentencia No SU-337/99)	181

Table of Contents

Republic of the Philippines, Petitioner, VS Jennifer B Cagandahan, Respondent [G.R. No. 166676, September 12, 2008]	96
Richards v United States Tennis Association, 400 NYS 2d 267 (Sup Ct 1977).....	25
Rogers v Whittaker [1992] 109 ALR 625; (1992) 175 CLR 479.....	162, 186
Salgo v Leland Stanford Jr University Board of Trustees (1957) 154 Cal App 2d 560, 317 P 2d 170.....	156
Sarah, Re [2014] Fam CA 208.....	281
Schloendorff v Society of New York Hospital 105 NE 92 (NY, 1914)	158
Wells v VanNort (100 Ohio St. 101) 1919.....	161
Wood v CG Studios Inc 660 F Supp 176 (E D Pa 1987)	22
USA v Karl Brandt, et al (aka the Doctors' Trial) NMT 01 Medical Case.....	34
Völling, re Regional Court Cologne, Germany (6 February 2008) Case 27 O 179/07.....	183

Tables of Legislation

Table of Statutes- England

Abortion Act 1967...215, 226, 332
—S1 (1) (a) ...215
—S1 (1) (b) ...229
—S1 (1) (c) ...229
—S1 (1) (d) ...215, 226, 229, 239, 297, 332
Access to Health Records Act 1990 ...292
Births and Deaths Registration Act 1836...123
Births and Deaths Registration Act 1953...307
c 20, Part I...307, 329
—s 2...307
—s10A...309
—s13 (1) (a)...309
—s29 (1) ...309
—s29 (2) ...309, 310, 311
—s29 (3) ...309
—s33 (2) ...308
Children Act 1989 ...177
—s31 (2) ...285
Civil Partnership Act 2005...313
Data Protection Act 1998. ...242, 293
—s 7 ...293
—s7 (1) (c) ...296
—s7 (2) ...294
—s7 (9) ...299
—s7 (10) ...294
—s66 (2)...295
—s68(2) ...294
Domestic Violence, Crime and Victims Act 2004
s 5 (6)...
Domestic Violence, Crime and Victims (Amendment) Act 2012...174
—s5 (6)...175

Table of Contents

Equality Act 2010...1, 19, 48, 55, 148, 242

—s4...20

—s7...316

—s 11...21, 149, 150,

—s11(a)...337

—s13(1) ...20

—s19 (1) ...20, 242

—s19 (2) (a) ...20

—s19 (2) (b) ...243

—s19 (2) (c)...

—s19 (2) (d) ...20, 47, 243

—s19 (3) ... 20, 243

—s24(1) ...20

—Part 3 s29 ...20

—s149 ...266

Family Law Reform Act 1969

—s1 (8)...45, 154, 174, 296

—s8 (2) ...174, 193, 194

Female Genital Mutilation Act 2003 ...**281-9**

—s (1) (2) (a) ...288, 334

Gender Recognition Act 2004...312, 313

—s1 (1)

—s2 (1) (a) ...47, 313, 330

—s9 (2)...47, 330

—s22316

—s22 (1)...316

—s22 (2) ...228, 316

Health and Social Care Act 2001 ...242

Health Service Commissioners Act 1993

—s3...300

Human Fertilisation and Embryology Act 1990...197

—s13 (9)...212

—s13 (9) (c)... 212, 331

—s13 (10)...212

—s13 (11)...212

—s25 (6)...

—s37...228

Schedule 2, Section 1ZA as amended...208, 209

Human Fertilisation & Embryology Act 2008197

—s14...212

—s54...154

Human Rights Act 1998

—s6 (3) (b) ...46, 192

Human Tissue Act 2004...37, 242

Infant Life (Preservation) Act 1929...227

Marriage Act 1836 ...123

Marriage (Same Sex Couples) Act 2013...123, 313

Mental Capacity Act 2005

—s (3) (1) ...165

—s (3) (2) ...165

—s (4)...166

Table of Contents

Offences Against the Person Act 1861

- s18 ...157
- s20...157
- s47 ...157
- s57...123
- s58...227

Senior Courts Act 1981, s90...277

Surrogacy Arrangements Act 1985...114

Welfare Reform Act 2009 c. 24...307, 330

Table of Statutory Instruments- England

Data Protection (Subject Access Modification) (Health) Order 1987 (SI No 1903)...292

Data Protection (Subject Access Modification) (Health) Order 2000 (SI 2000/413)

- art 5 (1) ...296

Table of Legislation-Scotland

Age of Legal Capacity (Scotland) Act 1991

- s 2(4)...190

Offences (Aggravation by Prejudice) (Scotland) Act 2009

- s2 (8)...150

Table of European and International Measures

Conventions

European Convention on Human Rights

Article 2 (Protection of right to life)...217, 265

Article 3 (Prohibition of torture, inhuman or degrading treatment or punishment)...218, 285

Article 8 (Right to respect for private and family life)...169, 173, 193, 213, 293, 312

Article 9 (Freedom of thought, conscience and religion)...275

Article 12 (Right to marry and found a family) 312

Article 14 (Prohibition on Discrimination)....265, 313

United Nations Convention on the Rights of the Child

—Article 24.3.....275

Directives

EU Directive 95/46/EC...293

Table of Legislation-Germany

Personenstandsgesetz (PStG) § 22: (3)....323

Strafgesetzbuch § 223(1)...

Table of Legislation-Malta

Gender Identity, Gender Expression and Sex Characteristics Act 2015...150

—s14.....190, **287, 324**

Table of Legislation-Republic of Eire

Gender Recognition Act 2015,

—s14 (4) (B) (i) (D)150

Table of Contents

Table of Legislation-Australia

Births, Deaths and Marriages Registration Act 1995 (NSW)...320
Family Law Act 1975
—s 67ZC.....280

Consent to Medical Treatment Palliative Care Act 1995 (SA)191
Part 1
Part 2 Division 1, (6)

Table of Legislation-New Zealand

Age of Majority Act 1970
—s4 (1)...187

Bill of Rights Act 1990
—s11...187

Births, Deaths, Marriages, and Relationships Registration Act 1995,
—s28...322
—29...322
—s85... 322

Care of Children Act 2004
—s36...188

Code of Health and Disability Services Consumers' Rights 1996...186

Health and Disability Commissioner Act 1994 (NZ)...186

Marriage Act 1955
—s2...323

Regulations:

Code of Health and Disability Services Consumers' Rights 1996
Right 5...186
Right 6...186
Right 7...186, 187

Table of Legislation- South Africa

Children's Act 2005 ...192
—s129 ...192
Choice on Termination of Pregnancy Act 1996...192
s5...192

The Objectives of this Thesis:

To undertake this thesis the following objectives were employed:

1. To identify and analyse literature in the field of intersex and the law, in order to discover the extent of writing on intersex conditions in a legal context, and the areas in need of additional research.
2. To investigate the variety of ‘intersex/DSD’ conditions, and following from this to analyse why having such conditions may lead to discrimination within the English healthcare system.
3. To identify and evaluate current healthcare practices that might interact with intersexed patients, and analyse these alongside the legal provisions in English law which currently endorse them, to assess; firstly, whether potential discrimination occurs, and secondly to assess whether such discrimination can be justified in the wider societal context.
4. To identify and analyse comparative international law to assess whether English law may benefit from such international jurisprudence and legislative measures.
5. To identify specific areas in need of minor or major legal amendments in English law. In such situations, where appropriate, legal solutions have been offered with the aim of reducing, and ultimately eradicating, current discrimination of the intersexed in specific healthcare situations.

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Thank you ALL.

Declaration:

I declare that all the work is my own and no work is unacknowledged or plagiarised.

The law is correct as of 1st September 2015.

Karen Brown (aka Karen Dyer)

Abstract

Of the two thousand babies born each day in England and Wales, at least twenty will have an intersex condition (also known as Disorder of Sex Development). For some, the condition lies dormant for many years, if not for the remainder of their lives, whilst others are born with genital differences to such a degree that it is not possible at birth to inform parents whether their child is ‘male’ or ‘female’. This ‘devastating’ announcement commences a lifetime of potential discrimination for these children (and arguably for their parents) both in the healthcare environment and in society in general. It might have been thought that when the Equality Act 2010 was passed such discrimination would cease as, according to the summary of the Act, its two main purposes are to harmonise discrimination law and enhance legal mechanisms to allow equality for everyone. However, the category of ‘intersex’ is not included in the Act.

This thesis aims to build on existing literature, and to investigate and analyse whether current English law prevents or promotes discrimination against the intersexed in the healthcare environment in England today. It further endeavours to propose suitable amendments to current law where such discrimination is identified. Previous literature has indicated that discrimination may arise as a result of pre-implantation genetic diagnosis (PGD), selective abortions of the intersexed fetus, and ‘normalising’ genital operations of the intersexed child. Further, activists have noted that the withholding of medical records is detrimental to the person concerned. However, to date there has been sparsity of literature to address current English law in these areas.

Results of investigations carried out for this thesis indicate that in some aspects, for example access to medical records, current English law supports the rights of the intersexed patient. Research also indicates that in regard to selective abortions current law can be justified. However, in other areas, notably PGD and genital modification operations, English law can be said to discriminate against the intersexed, whilst for neonatal testing, current healthcare policies and procedures can be considered discriminatory. Such provisions require reconsideration. In this respect, legal amendments are proposed to assist in overcoming discrimination. This includes an amendment to the Equality Act itself.

Intersex, Discrimination and the Healthcare Environment – a Critical
Investigation of Current English Law

Part One:

Introduction, Investigation and Identification

Chapter One: Introduction: *Primum non nocere*– ‘First do no harm’

1.1 Introduction

In 2008 a new Single Equality Bill was introduced into the UK Parliament. After various discussions and amendments in both the House of Commons and the House of Lords the Bill received Royal Assent in April 2010, becoming the Equality Act 2010.¹ According to the summary, ‘(t)he Act has two main purposes – to harmonise discrimination law, and to strengthen the law to support progress on equality’.² The Equality and Human Rights Commission go further: they specify that the Equality Act 2010 ‘provides a legal framework to protect the rights of individuals and advance equality of opportunity for all’.³ However, as will be seen throughout this thesis, not all individuals are supported by the Act, and currently some face inequality in services they receive.

Statistics indicate that in the region of 1950 babies are born in England and Wales every day,⁴ with 105 boys born to every 100 girls.⁵ However, this gender ratio is too simplistic a picture of real-life occurrences. Some babies cannot be classified as ‘boy’ or ‘girl’ at birth and the numbers of *intersex* children (children with an indeterminate sex) lie hidden amongst these statistics. Now referred to by doctors as ‘disorders of

¹ The majority of which came into force in October 2010.

² Explanatory Notes, Background and Summary, point 10.
<http://www.legislation.gov.uk/ukpga/2010/15/notes/division/2/1/2> accessed 25 August 2015.

³ Equality and Human Rights Commission, ‘What is the Equality Act?’ (6 May 2015)
<http://www.equalityhumanrights.com/legal-and-policy/legislation/equality-act-2010/what-equality-act>
accessed 24 July 2015.

⁴ In 2012 there were 729,674 live births, in 2013, 698,512 live births. Office for National Statistics, *Births in England and Wales, 2013* (16 July 2014)
<http://www.ons.gov.uk/ons/rel/vsob1/birth-summary-tables--england-and-wales/2013/stb-births-in-england-and-wales-2013.html> accessed 13 August 2015.

⁵ Department of Health, *Birth Ratios in the United Kingdom, A Report of Gender Ratios at Birth in the UK* (May 2013)
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/313559/Sex_Selection_in_England_and_Wales_analysis_April_2014_NM_comments.pdf accessed 10 August 2015.

sex development' (DSD), intersex/DSD conditions have been described as occurring when there is a 'disagreement' between a person's karyotype (their genetic make-up) and their phenotype (their actual physical appearance).⁶ To the lay person the terms 'intersex' or 'disorders of sex development' are meaningless, but to the parents of such a child the labels are 'devastating, and often incomprehensible'.⁷ It is even more inconceivable to appreciate living as that child, to potentially experience a lifetime of medical intervention and/or social discrimination. This thesis investigates and analyses the extent to which current English law prevents or promotes discrimination against the intersexed in the healthcare environment.

Although official statistics are scarce, intersex/DSD conditions occur more frequently than is generally realised. Researchers estimate that as many as one in 4500 children will be born with some condition resulting in abnormalities of the external genitalia.⁸ It has been suggested that two per cent of all births have a degree of minor genital difference,⁹ with yet other sources referring to a four per cent global estimation of those with some disorder of sex development.¹⁰ In addition to those born with visible sexual variances, some children who appear to have 'perfect' bodies at birth discover later in life that within that 'perfect' body lies a genetic 'mismatch'.¹¹

⁶ Amy B Wisniewski, Steven D Chernausk, Bradley P Kropp, *Disorders of Sex Development* (The John Hopkins University Press, 2012) 1.

⁷ AL Ogilvy-Stuart, CE Brain, 'Early Assessment of Ambiguous Genitalia' (2004) 89 *Arch Dis Child* 401.

⁸ V Pasterski, P Prentice, IA Hughes, 'Impact of the Consensus Statement and the New DSD Classification System' (2010)24 (2) *Best Practice & Research Clinical Endocrinology & Metabolism* 187. I am informed by Dr Sanders that the term 'genital difference' is preferred to that of 'ambiguous genitalia' and this thesis will endeavour to use 'genital difference' where possible. Email from Caroline Diane Sanders to author (12 January 2015).

⁹ Ogilvy-Stuart (n 7).

¹⁰ Organisation Intersex International Australia Limited, 'Submission on the Consolidation of Commonwealth Anti-Discrimination Laws'. [www.equalitylaw.org.au/literature/75787/Organisation Intersex International Australia Limited Submission](http://www.equalitylaw.org.au/literature/75787/Organisation%20Intersex%20International%20Australia%20Limited%20Submission) accessed 24 August 2015.

¹¹ By mismatch I mean that the karyotype does not match the observed phenotype, or has a variation to it which will affect the whole of that developing body, such as occurs in Androgen Insensitivity Syndrome.

In recent years many stories have emerged of physical and mental harm inflicted by doctors acting in haste or in ignorance (albeit with the best of intentions) to ‘correct’ or ‘perfect’ an intersexed child, so that they can be categorised as ‘boy’ or ‘girl’. In the absence of any defining laws, scientific ‘advancement’ has been given free rein to promote novel techniques or inventions. This can lead to disaster.¹² Intersexed patients who have experienced radical genital surgery argue that the ‘treatment paradigm’ advanced by John Money falls into this category.¹³ Money’s experimental treatments of the intersexed, originally heralded as examples of excellence internationally, were wholeheartedly adopted in England by the medical profession. The results of these treatments still affect a number of UK citizens today, their lives ‘tinged with melancholy’.¹⁴

There are no global procedures in place to monitor the births of intersexed babies, and no methods available to accurately record the number of people who have some differentiation of sex, therefore the extent of such enforced medical treatment is difficult to quantify. However, the reported numbers of children who have undergone corrective surgery globally is considerable, resulting in long-term physical and psychological harm.¹⁵ Ironically, there have been, and remain, a significant number of intersex/DSD people who have *not* received sufficient, if any, healthcare attention, and have suffered with health problems throughout life as a result.

For the past 25 years, this discriminatory treatment has been challenged by intersex activists throughout the world, and they have organised conferences and written

¹² ‘Now I am become Death, the destroyer of worlds. I suppose we all thought that, one way or another.’ (J Robert Oppenheimer on Hiroshima) Atomic Archive, ‘J Robert Oppenheimer on the Trinity Test’ (1965) <http://www.atomicarchive.com/Movies/Movie8.shtml> accessed 24 March 2015.

¹³ Money will be discussed in section 1.6.1 and in chapter four at 4.4.3.

¹⁴ Colette Bernhardt, ‘The Third Sex: The Truth about Gender Ambiguity’, *The Independent* (London, 20 March 2010) <http://www.independent.co.uk/life-style/health-and-families/features/the-third-sex-the-truth-about-gender-ambiguity-1922816.html> accessed 14 July 2015.

¹⁵ Zwischengeschlecht.org (International Intersex Human Rights NGO) ‘NGO Report on the Answers to the List of Issues (LoI) in Relation to the Initial Periodic Report of Germany on the Convention on the Rights of Persons with Disabilities’ (CRPD) http://intersex.shadowreport.org/public/2015-CRPD-LoI-Germany_NGO-Report_Zwischengeschlecht_Intersex-IGM.html accessed 24 July 2015.

papers on the devastating nature of their treatments. In 2013, Malta hosted the Third International Intersex Forum (TIIF). This event brought together representatives of 30 intersex organisations, with the aim to ‘end discrimination against intersex people and to ensure the right of bodily integrity, physical autonomy and self-determination’.¹⁶ Amongst the demands of the Forum are the cessation of pre-implantation genetic diagnosis and selective abortions of the intersexed, the cessation of ‘normalising’ genital operations, the creation of ‘safe and celebratory environments’ for the intersexed, and the adequate training of healthcare providers.¹⁷ These are not unreasonable demands. However, as will be discussed throughout this thesis, to achieve any of these goals in England will require a significant shift in current awareness and attitudes, not only of healthcare practitioners, but also of society as a whole. In this respect, the profound lack of knowledge of intersex/DSD conditions will prove to be a major obstacle. According to Drop et al., ‘nearly every practising specialist in the field of DSD is confronted with e-mail requests for medical advice, guidance or information’.¹⁸ This situation is exacerbated by the general unwillingness of those with intersex/DSD conditions to put forward their stories as a result of the shame caused by the condition to the people concerned.¹⁹ If healthcare practitioners are unaware of such conditions and their effects on patients, it is no wonder that society at large has been left ignorant, leaving those responsible for developing English law unaware of these conditions and any associated difficulties.

To date there has been a paucity of information regarding the relationship between the intersexed and English law. This thesis aims to draw out and expand upon this comparatively uncharted area. It will not be possible to undertake a detailed investigation into *every* area of legal discrimination that those with an intersex condition may face during their lives. For this reason, this thesis will focus on

¹⁶ IGLA Europe, ‘3rd International Intersex Forum Concluded’ 02/12/2013 http://www.ilga-europe.org/home/news/latest/intersex_forum_2013 accessed 12 August 2014.

¹⁷ TIIF’s complete demands are listed in Appendix A.

¹⁸ SL Drop and others, ‘E-consultation for DSD: A global platform for access to expert advice’ (2012) (8) J Pediatr Urol 629, 630.

¹⁹ Suzanne J Kessler, *Lessons from the Intersexed* (Rutgers University Press 1998) 5.

conflicts arising in the healthcare environment. Within this field, some aspects of medico-legal tension have been discussed in depth by other authors; for example, there has been extensive writing on the physical and emotional effects of enforced operations on individuals.²⁰ Therefore reference to such areas will be brief. However, there is still a lack of sustained academic research on associated medico-legal dimensions in this field.

With this in mind, the aims of this thesis are threefold:

Firstly, to investigate the variety of ‘intersex/DSD’ conditions, and identify how such conditions may lead to discrimination within the English healthcare system.

Secondly, to identify and to evaluate current healthcare practices interacting with intersexed patients, and analyse legal provisions which endorse them, to assess whether potential discrimination can be justified in the wider societal context.

Finally, to identify areas that are in need of minor or major legal amendments and, where appropriate, offer legal solutions in order to reduce, and ultimately eradicate, current discrimination of the intersexed in specific healthcare situations.

The research will intertwine theoretical backdrops. Firstly, this thesis will consider the impact of society by considering social identity and social constructivist theories in regard to the lives of the intersexed.²¹ Additionally, the legal position will be considered alongside ethical theories, since ‘we cannot properly understand medical law without understanding the ethical tensions in play’.²²

The structure of this thesis falls into three parts. The first section (chapters one to five) deals with the social, ethical, scientific and literary backdrop to the remainder of the thesis. The second part of the thesis (chapters six to nine) is further subdivided into different stages of human development, namely pre-birth, birth, childhood and adolescence. The final part (chapter ten) considers the role of recording gender for

²⁰ This will be addressed in chapter two.

²¹ This will be considered in chapter four.

²² Shaun D Pattinson, *Medical Law and Ethics* (3rd edn, Sweet & Maxwell 2011) 3.

births, deaths and marriages, and the need for gender assignment on documentation. In this regard, international jurisprudence is consulted. The closing aspect of this chapter promotes the conclusions from all previous chapters and highlights areas for legal reform.

Before turning attention to any specific area, the first challenge facing those who work with people of an indeterminate sex is to ensure that suitable nomenclature is used. Significant controversy has been caused in recent times by attempting to identify an all-encompassing word to describe a wide variety of medical conditions. Indeed, it is evident from interviews and surveys carried out for this thesis that many healthcare workers do not know how to refer to such patients. It is only on hearing the term ‘hermaphrodite’ that people understand the nature of this study. As will become apparent ‘hermaphrodite’ is no longer an acceptable name to use.

1.2 What is Intersex?²³

1.2.1 The Evolution of a Name –Hermaphrodite

In recent times, attempts have been made to find a suitable term to describe the multitude of physical conditions causing an altered physical sex/gender differentiation. The traditional term hermaphrodite has long since lost favour with such individuals, primarily because it is scientifically inaccurate. However, this term has been used for centuries in folklore (as discussed below) and in medico-legal writings,²⁴ and consequently remains the most accepted term in current colloquial language. As Daniela Crocetti writes,²⁵ ‘many in the current era might not have heard of Intersex or DSD, but everyone has an idea of what hermaphroditism is, correct or

²³ A question that I am constantly asked when discussing my PhD.

²⁴ For example, the medical author Josephi Jacobi Plenck (1738-1807), in his book *Elementa Medicinae et Chirurgiae Forensis* (Elements of Forensic Medicine and Surgery) (1781 Viennae), divides hermaphrodites into three groups: male ‘Androgynus’ those with a penis, female ‘Androgyna’ those with a uterus and ‘Hermaphroditus verus’ (true hermaphrodites) 122.
<https://archive.org/stream/elementamedicina00plen#page/122/mode/2up> accessed 24 March 2015.

²⁵ Daniela Crocetti ‘Medicalizing Gender: From Intersex to DSD, From Laboratory to Patient Groups.’ (PhD thesis, Universita di Bologna 2011).

not'.²⁶ It is submitted, therefore, that the term 'hermaphrodite' will remain in use throughout society in the near future.²⁷

The word '*hermaphrodite*' comes from the traditional myths and teachings of Ancient Greece. In philosophical discourse, Plato mused on the possibility of hermaphrodites being the original form of humankind, before its meiosis into two sexes. In 'Symposium', he wrote that there were:

not merely the two sexes, male and female, as at present: there was a third kind as well, which had equal shares of the other two, and whose name survives, though the thing itself has vanished. For 'man-woman' was then a unity in form no less than name, composed of both sexes and sharing equally in male and female; whereas now it has come to be merely a name of reproach.²⁸

This tale charts how physically powerful the 'man-woman' was, to the point where, as a group, they planned to conquer Mount Olympus and overthrow the gods. In order to protect himself and his fellow Olympians, Zeus divided the hermaphrodites' bodies into two, ordering Apollo to sew them up and turn their faces around so that they should forever see what they had lost. Accordingly, so says Plato, ever since then humans have been driven by the desire to find their other half.²⁹ This story is not dissimilar to the biblical text of Adam and Eve. Adam, a 'self-sufficient being', was

²⁶ This is a situation which can be borne out from discussions that took place with others during my research; whilst attempting to explain the nature of my research I often received a glazed look, until I then mentioned the word 'hermaphrodite'. This in itself shows how much work there is to be done in society.

²⁷ Ironically they have been accepted in some societies. For example, Ardhanarishvara (which from Sanskrit means 'Lord Who Is Half Woman') (Encyclopaedia Britannica) is a composite male-female figure of the Hindu god Shiva; together with his consort Parvati, he was honoured in many societies.

²⁸ Plato, Symposium, 189e. *Plato in Twelve Volumes*, Vol 9 (Harold N Fowler tr, Harvard University Press, William Heinemann Ltd 1925). Plato's work dates from c 385-380 BC.

²⁹ *ibid.*

divided to form two persons,³⁰ albeit only a small portion of Adam's body, namely a rib, was used to create Eve.³¹

When writing the Symposium, Plato would have been well versed in the older tradition of myths, including that of Tiresias, a transsexual as opposed to an intersexual,³² who is mentioned in Homer's epic poem the *Odyssey*,³³ and also of the intersexed Agdistis. According to legend, Gaia (Earth) was accidentally impregnated by her son Zeus. The resulting child, Agdistis, was hermaphroditic and the gods, fearing for their safety, castrated the child.³⁴

The term 'hermaphrodite' was inspired by the story of Hermaphroditos, who was the love-child of Hermes and Aphrodite. In early art, Hermaphroditos was often

³⁰ George Androustos, 'Hermaphrodites in Greek and Roman Antiquity' (2006) 5 (3) *Hormones* 214.

³¹ The Bible, Genesis Chapter II verses 21-23 (King James' Version Online). <https://www.biblegateway.com/passage/?search=Genesis+2%3A21-23&version=KJV> accessed 24 May 2015.

³² Tiresias appears in a number of classic texts including Euripides' 'Bacchae' and Ovid's 'Metamorphoses'. According to legend, Tiresias turned into a woman for seven years, after hitting a female snake with a stick. In the female form s/he gave birth to at least one son. S/he eventually turned back into male after finding a male snake to hit.

³³ These poems were written towards the end of the eight century BC. In the *Odyssey*, Tiresias is visited in the underworld by Odysseus, and gives Odysseus good advice as to how to deal with certain perils on the rest of his journey (which unfortunately was ignored). 'Still, after much suffering you may get home if you can restrain yourself and your companions when your ship reaches the Thrinacian island, where you will find the sheep and cattle belonging to the sun, who sees and gives ear to everything. If you leave these flocks unharmed and think of nothing but of getting home, you may yet after much hardship reach Ithaca; but if you harm them, then I forewarn you of the destruction both of your ship and of your men.' Homer, *The Odyssey* Book XI Samuel Butler tr, <http://classics.mit.edu/Homer/odyssey.html> accessed 24 March 2015.

³⁴ The story continues that on removing of Agdistis' tentacles, blood fell onto the ground creating an almond tree. On eating an almond, a nymph became pregnant with Attis, who ironically became a consort of his father/mother. Some consider Agdistis to be one and the same as Cybele, a sixth century BC Phrygian goddess. Certainly Agdistis' prominence in literature dates from this time, and was still active some 500 years later. Strabo a Greek geographer wrote:-

'But as for the Berecynthes, a tribe of Phrygians, and the Phrygians in general, and those of the Trojans who live round Ida, they, too, hold Rhea in honour and worship her with orgies, calling her Mother of the gods and Agdistis and Phrygia the Great Goddess, and also, from the places where she is worshipped, Idaea and Dindymene and Sipylene and Pessinuntis and Cybele and Cybebe.' Strabo, *Geography* (HC Hamilton W Falconer trs, George Bell & Sons 1903) available on Perseus Digital Library

www.perseus.tufts.edu/hopper/text?doc=Perseus%3Atext%3A1999.01.0239%3Abook%3D10%3Achapter%3D3%3Asection%3D12 accessed 24 June 2013.

portrayed as a female with male genitalia, such as can be seen in the statue below.³⁵



Fig. 1: Hermaphroditos 'approach view'. Reproduced with the kind permission of the National Trust.

This 'uneasy seemingly tormented'³⁶ Hermaphroditos appears to date from the Hellenistic period,³⁷ and certainly has the 'typically Hellenistic theatrical surprise'.³⁸ It is presumed that the sculptor intended his work to be viewed firstly by looking at the subject's back. When viewed from this angle, the statue appears to be a female, but if the spectator walks around the statue, male genitalia will be seen.

³⁵ This sleeping Hermaphroditos, lies in the South Colonnade of West Wycombe Park, (now managed by the National Trust) and was originally brought to West Wycombe in the mid-eighteenth century, by the second Baronet Sir Francis Dashwood. It is a painted plaster cast of the famous Borghese statue which can be found in the Louvre Museum, Paris. Photograph, by author, August 2015.

³⁶ J J Pollitt, *Art in the Hellenistic Age* (Cambridge University Press 1986) 149.

³⁷ The Hellenistic period in Ancient Greece is the time from death of Alexander the Great in 323BC and the Roman conquest of Egypt in 30BC.

³⁸ Pollitt (n35) 149.



Fig 2: Hermaphroditos 'reverse view.' Reproduced with the kind permission of the National Trust.³⁹

One version of the myth portrays Hermaphroditos as an extremely beautiful boy. When he became a young man, a nymph called Salmacis fell in love with him. Despite his protestations, Salmacis ensnared him and prayed to the gods to keep them together for eternity. The gods responded by joining their bodies and forming one person from the two. In another version of the myth Hermaphroditos was born sporting the sexual attributes of both his parents in the form of mixed genitalia.⁴⁰ This latter version is, of course, a more realistic version of physical events and it is likely that the myths originated to explain why, in that society, there existed life forms

³⁹ The reverse of the West Wycombe statue. Photograph by author, August 2015.

⁴⁰ One version of the story by Ovid, can be found in his writings *Metamorphoses* Book 4, 346-388. 'Now the entwined bodies of the two were joined together, and one form covered both. Just as when someone grafts a twig into the bark, they see both grow joined together, and develop as one, so when they were mated together in a close embrace, they were not two, but a two-fold form, so that they could not be called male or female, and seemed neither or either.'

Ovid, *Metamorphoses Book IV*, 'The Ovid Collection' AS Kline tr, University of Virginia, <http://ovid.lib.virginia.edu/trans/Metamorph4.htm%23478205196&rct=j&q=salmacis+ovid&usg=AFQjCNEyLL2JbxGCEWtWKAQITjvQM98raw&sa=X&ei=5OtiUczpK8zMPambgYAM&ved=0CDkQygOwAigK> accessed 8 April 2013. Recent academic commentary includes, M Robinson, 'Salmacis and Hermaphroditus: When Two Become One: (Ovid, Met. 4.285-388)' (1999) 49 (1) *Classical Quarterly New Series*, 212.

apparently with both sets of genitalia. Interestingly, in contrast to the stories of Tiresias and Agdistis, there does not appear to be any mention of fertility in relation to Hermaphroditos.

By comparison, in science a *true* hermaphrodite is the label given to an organism that has a *working* pair of sex organs, and can create offspring as a ‘mother’ and a ‘father’ simultaneously (such as snails and worms), or if needs be can swap its sex to be a ‘father’ on one occasion and ‘mother’ the next. (Such actions can be observed in fish as a regular occurrence.) Hermaphroditism in mammals and birds is almost always a genetic error, and consequently to allot such a title to a human is a misnomer. Modern artificial reproductive technologies and legal frameworks now assist us (through physical engineering, adoption processes and fertility treatment) to become both a mother and a father *legally*, but no one can physically *procreate* in both roles at the same time.⁴¹ Further, in a cruel twist of fate, a significant number of those labelled ‘hermaphrodite’ cannot procreate in either role at *any* time.⁴² To make matters worse, natural difficulties with fertility have been magnified by countless ‘normalising’ operations performed on the intersexed. This includes the castration and orchiectomy of male children,⁴³ removing any chance of future fertility for these people. Additionally, difficulties with legal documents, in particular birth certificates, apparently condemn the intersexed to the gender role cast by physicians at birth, hence rendering the possibility of adopting children (even) more difficult than for the non-intersexed.⁴⁴

⁴¹ Although advances in science may make it possible for women to have sperm cultivated from stem cells, hence women could in theory, be a genetic mother and father in years to come. Rebecca Robey, ‘Sperm from stem cells sparks media furore’ BioNews 12 July 2009, <http://www.bionews.org.uk/> accessed 15 August 2014.

⁴² Early scientists looked for the ability to procreate when attempting to assign sex. This is still the process today, albeit it is one of many areas to investigate, rather than the main criteria for gender selection. Not all those who are ‘intersexed’ are sterile. As a group women with CAH are usually fertile, but those with a severe form are often subfertile. Maud Bidet and others, ‘Fertility in Women with Nonclassical Congenital Adrenal Hyperplasia due to 21-Hydroxylase Deficiency’ (2010) 95 (3) J Clin Endocrinol Metab 1182.

⁴³ The removal of testes.

⁴⁴ Whilst recognising the intersexeds’ significant battle for the legal right to adopt children, this complex issue is beyond the scope of this thesis.

1.2.2 A Modern Approach –Intersex and DSD

For centuries the term hermaphrodite was freely used in society to describe individuals born with genital difference. During the Victorian age, slight alterations from this can be seen from terms such as male pseudo-hermaphrodite and female pseudo-hermaphrodite being introduced to discuss various conditions. These labels have been used until recently,⁴⁵ and many academic articles still refer to them.⁴⁶

During the twentieth century the label ‘*intersex*’ came into use by clinicians,⁴⁷ which according to the Intersex Initiative website stood to mean a ‘congenital anomaly of the reproductive and sexual system’.⁴⁸ The term ‘intersex’ is still used today, although this, too, is out of favour in some quarters, being described as ‘particularly controversial (and)...potentially pejorative’.⁴⁹ Indeed, in its own way it *is* as misleading as the label ‘hermaphrodite’, as many individuals are not intersex: they are ‘completely’ female or male. For example, Turner Syndrome women, who do have a DSD⁵⁰ are not and do not see themselves as ‘intersexual’ at all: they are women.⁵¹ Further, Milton Diamond considers the term ‘intersex’ to mean a person ‘whose biology includes an identifiable mixture of male and female characteristics, regardless of the appearance of genitalia at birth’.⁵²

This wider definition appears to encompass those who are transsexuals, albeit they may be considered anatomically ‘pure’. This is unsurprising as Professor Diamond is

⁴⁵ With the introduction of the term DSD after the DSD Consortium Meeting 2006. Peter A Lee and others, ‘Census Statement on Management of Intersex Disorders’ (2006) 118(2) *Pediatrics* 488.

⁴⁶ Those considered to be male pseudo-hermaphrodites have a female phenotype, but male karyotype, female pseudo-hermaphrodites have the reverse physicality. The development of these terms will be discussed in more depth in chapter three.

⁴⁷ David D Kulcsar, ‘Intersexuality (with report of a case)’ (1948) 59 *Canad M A J* 144, 148.

⁴⁸ www.intersexinitiative.org/articles/intersex-faq.html accessed 14 April 2012.

⁴⁹ Lee (n 45).

⁵⁰ In that they have a missing sex chromosome, their karyotype being 45 X0.

⁵¹ Email Correspondence Turner Syndrome Support Society to author 13 September 2011.

⁵² Milton Diamond, ‘Pediatric Management of Ambiguous and Traumatized Genitalia’ *Contemporary Sexuality*, 38:9: i-vii, as quoted by Catherine Harper *Intersex* (Berg 2007) 5.

of the opinion that ‘transsexuals are intersexed in their brains’.⁵³ This is the view of one such transsexual help group –the Harry Benjamin Syndrome Site. This site refers to research conducted in the 1990s,⁵⁴ which demonstrated ‘a totally female pattern (...) in six male to female transsexuals’. The website argues that this pattern is one of the human brain structures that separates ‘male’ and ‘female’, and that this biological arrangement distinguishes male to female (MTF) transsexuals from ‘men’.⁵⁵ The conclusion drawn is that MTF transsexuals’ brains are ‘truly female’ whilst the body they inhabit is ‘truly male’.⁵⁶ Although the research is a topic of controversy (analysts of social construction theories argue that society moulds gender orientation), this is significant for those born with genital difference. It confirms what the intersexed have known for a long time– that they cannot be classified as ‘male’ or ‘female’ on anatomical examinations alone, but by consideration of the ‘whole’ person.⁵⁷

1.2.3 The Rise of the Activists and the Emergence of DSD

Before 1990, the intersexed were predominantly a hidden and voiceless minority. Then new publications that challenged the actions of ‘binary system’ clinicians⁵⁸ prompted the intersexed into action, notably Cheryl Chase.

⁵³ Milton Diamond, ‘Pediatric Management of Ambiguous and Traumatized Genitalia’ web version of the National Kidney lecture and publication 17 October, 1998 San Francisco www2.hu-berlin.de/sexology/BIB/DIAM/pediatric_management.htm accessed 17 August 2014.

⁵⁴ JN Zhou and others, ‘A sex difference in the human brain and its relation to transsexuality’ (1995) 378 (6552) *Nature* 68, as published on the website The Original Harry Benjamin Syndrome Site ‘Harry Benjamin Syndrome is a neurobiological condition’ www.shb-info.org/hbsbio.html accessed 28 May 2015. and in Karen Gurney, ‘Discussing “sex” at work can be a costly business: Translating the science, language and law behind M v A & U [2007] QADT 8’ (2007) 7 (2) *QUTLawJl* 13 <http://www.austlii.edu.au/au/journals/QUTLJ/2007/13.html> accessed May 2015.

⁵⁵ Zhou, *ibid*.

⁵⁶ Likewise the reverse situation occurs. Although discussions on transsexualism overlap in some aspects with the main content of this thesis, the law is comparatively settled for those who are transsexual and therefore a detailed discussion in this respect will be beyond the scope of this thesis.

⁵⁷ This argument will be developed further in chapter four.

⁵⁸ Suzanne Kessler and Wendy McKenna, *Gender: An Ethnomethodological Approach* (University of Chicago Press 1978); Suzanne J Kessler, ‘The Medical Construction of Gender: Case Management of Intersexed Infants’, [1990] *Signs* 3; Suzanne Kessler, *Lessons from the Intersexed*. (Rutgers University

Chase, now known as Bo Laurent, was born with a ‘micropenis’ and first assigned male. Some 18 months later, the doctors changed their minds, noting that the child’s penis was ‘too small’ for a boy. They stipulated that Chase should be a girl (minus the penis/clitoris which was ‘too large’ for a female to own). They further recommended that Chase’s parents move out of the area, and deny her all traces of her medical history. However, Chase’s early treatment could not be concealed from her indefinitely, and she fought to obtain answers. Eventually she found out that she had been diagnosed as a ‘true hermaphrodite’.⁵⁹ This discovery caused her to suffer shock, denial and a breakdown.

Chase’s recovery began after reading Kessler’s articles.⁶⁰ She put a plan into action, which ultimately led to the creation of the first patient advocacy group for the intersexed. In 1993, Chase contacted Kessler and also wrote a letter of praise of Fausto-Sterling’s recently published article.⁶¹ This letter announced the formation of a help group that was to become the Intersex Society of North America (ISNA). According to Karkazis,⁶² at the early stages of her work Chase met a number of people with a wide variety of conditions. She found that those with Klinefelter Syndrome or TS had little in common with her experience as these individuals had a better doctor–patient relationship generally, and did not feel the same need to discuss gender issues.⁶³

As will become apparent throughout this thesis, the range of intersex and associated conditions creates considerable difficulties when trying to find common ground

Press, 1998; Anne Fausto-Sterling, ‘The Five Sexes: Why Male and Female are Not Enough’ (1993) (March/April) *The Sciences* 20.

⁵⁹ Karen Matthews, ‘Debate Grows Over Using Surgery on Infants with Ambiguous Genitals’ *Los Angeles Times* (Los Angeles, 22 October 2000) <articles.latimes.com/2000/oct/22/news/mn-40207> accessed 25 August 2013.

⁶⁰ Suzanne J Kessler, ‘The Medical Construction of Gender: Case Management of Intersexed Infants’, [1990] *Signs* 3, amongst others.

⁶¹ Anne Fausto-Sterling, ‘The Five Sexes: Why Male and Female are Not Enough’ (1993) (March/April) *The Sciences* 20.

⁶² Katrina Karkazis, *Fixing Sex: Intersex, Medical Authority and Lived Experience* (Duke University Press 2008) 252.

⁶³ My research indicates that this is still the case today.

between the different types of conditions covered by the terms ‘intersex’ or ‘DSD’, and unsurprisingly Chase was unable to create an all-encompassing help group. This diversity will prove to be the most difficult challenge in establishing clear legal guidelines within a general framework. Consequently, a number of solutions will need to be considered.

Despite the inability to mould all intersex groups together, Chase made a monumental contribution to raising the intersex profile both in her native US and internationally. She produced the ‘Amicus Brief on Intersex Genital Surgery’,⁶⁴ presented to the Columbian Court in 1998, which formed the basis of the Court’s rationale behind the decisions it made.⁶⁵ Both Chase and her ISNA colleague Alice Dreger worked with the group which became known as ‘Disorders of Sex Development (DSD) Consortium’, leading to clinical guidelines on treatment published in 2006. One of the consequences of this meeting was that ISNA moved its focus from patient support to professional support, and in June 2008 ISNA was ‘put to sleep’ in order for it to be reborn as Accord Alliance.⁶⁶

Later that same year Chase participated in the ‘Consensus Statement on Management of Intersex Disorders’.⁶⁷ One proposal to emerge was the adoption of the new term ‘disorders of sex development’ (DSD).⁶⁸ According to Professor Iuean Hughes, this meeting led to ‘a sea change in the medical lexicon ... (t)he key and revolutionary step was to banish to antiquity the term intersex and instead introduce an all-embracing Disorders of Sex Development terminology’.⁶⁹

⁶⁴ Although ISNA no longer operates as such, previous publications, including the Amicus Brief, are still available on the website www.isna.org accessed 14 August 2014.

⁶⁵ The Columbian Cases will be discussed in chapters five and eight.

⁶⁶ www.accordalliance.org

⁶⁷ Lee (n 45).

⁶⁸ *ibid.*

⁶⁹ Iuean A Hughes, ‘The Quiet Revolution.’ (2010) 22 (2) Best Practice & Research Clinical Endocrinology & Metabolism 159.

Dreger notes:⁷⁰

When we started working (with the DSD consortium) it became clear that we couldn't reach agreement on practice unless we came to agreement on terminology. ...Everyone recognized that it was critical to avoid all terms based on the misleading and stigmatizing 'hermaphrodite'.

A number of potential terms were nominated. 'Development' was chosen over 'differentiation' as differentiation led to 'disciplinary disagreement'.⁷¹ Ultimately the consortium chose 'disorders of sex development' rather than 'disorders of sexual development', because they wanted the focus to be on anatomical issues rather than a perceived erotica.⁷²

This new 'trademark' found favour with many academics, but it lacked acceptance amongst the general intersex population. Many were angered by the adoption of the term 'disorder'. The Organization Intersex International (OII)⁷³ published cutting comments on its website stating that intersex individuals were not consulted before this new term was launched.⁷⁴ This is all the more ironic as the Consensus Statement firmly states that it is 'appropriate to use terminology that is sensitive to the concerns of patients'.⁷⁵ This appears to be yet another 'enforced operation' on these people. The dislike of this term continues. OII-UK write, '(j)ust as Milton Diamond and others still do, OII-UK also still objects to the use of DSD in a way that uses

⁷⁰ Alice D Dreger and April M Herndon, 'Progress and Politics in the Intersex Rights Movement; Feminist theory in Action' [2009] GLQ: A Journal of Lesbian and Gay Studies 199, 211.

⁷¹ *ibid.*

⁷² *ibid.*

⁷³ One of the international help groups.

⁷⁴ Curtis E Hinkle, 'I would like to point out that OII is not of the opinion that this is a controversy simply about terminology. OII's members have discussed this in great detail and have taken the time to read the documents and familiarize ourselves with the different experts and activists involved. OII has objections to the DSD Guidelines and the underlying abuse of power used in imposing this term on us without consultation. If others around the world had been consulted and treated with respect and human dignity, there would not be such a controversy.' [www.intersexualite.org/Response to Intersex Initiative.html](http://www.intersexualite.org/Response%20to%20Intersex%20Initiative.html) accessed 14 April 2012.

⁷⁵ Lee (n 45).

“disorder” to describe intersex variations’⁷⁶ and in a recent update to their web pages the UK Intersex Association pronounced firm opposition to the term.⁷⁷

Despite a number intersex activists and academics promoting the term DSD,⁷⁸ it is unsurprising that it is not universally accepted. The word ‘disorder’ is a negative one and metaphorically reduces individuals to being in need of ‘correcting’. More acceptable terms of ‘differences of’ or ‘variations of’ sex development were suggested during the consortium meeting,⁷⁹ and supported by experts in the field.⁸⁰ However, the arguments of Alice Dreger, April Herndon and Ellen Feder maintained their support for the term ‘disorder of sex development’.⁸¹ Feder argues that using the word ‘variation’ as opposed to ‘disorder’ ‘does not permit appreciation of the genuine health challenges faced by many individuals with intersex conditions’.⁸² Whilst this is *prima facie* a fair assessment of fact, nevertheless the reverse argument is also true. The term ‘disorder’ does not take into account the fact that many intersexed persons do not need medicalisation. Further, in England the word ‘disorder’ tends to have somewhat sinister overtones, specifically in terms of the mental health of a person.

⁷⁶ OII-UK, ‘Why we do not use “Disorder of Sex Development”’ 12 February 2014 <http://oiuk.org/697/why-we-do-not-use-disorder-of-sex-development/> accessed 24 May 2015.

⁷⁷ UK Intersex Association, ‘Why not “Disorders of Sex Development”?’ <http://www.ukia.co.uk/ukia/dsd.html> accessed 25 August 2014.

⁷⁸ Dreger and Herndon (n70); Ellen K Feder, ‘Imperatives of Normality: From “Intersex” to “Disorders of Sex Development”’ (2009) 15(2) GLQ: A Journal of Lesbian and Gay Studies 134.

⁷⁹ Dreger and Herndon (n70) 211.

⁸⁰ Katrina Karkazis, *Fixing Sex: Intersex, Medical Authority and Lived Experience* (Duke University Press 2008) 259; Elizabeth Reis, ‘Divergence or Disorder? The Politics of Naming Intersex’ (2007) 50 (4) Perspectives in Biology and Medicine 535, 541. Milton Diamond and HG Beh, ‘Variations of Sex Development instead of Disorders of Sex Development’ Letter to the Editor, published in: Archives of Disease in Childhood (26 July 2006) available on the UKIA website <http://www.ukia.co.uk/diamond/variations.html> accessed 25 May 2015.

⁸¹ Catherine Clune-Taylor, ‘From Intersex to DSD: the Disciplining of Sex Development’ (2010) 5 (2) PhaenEx 152, 154.

⁸² Feder (n78).

Although DSD was created to ‘circumvent the fraught history of the terms hermaphrodite and intersex’,⁸³ there remains an international reluctance to agree to any specific nomenclature, and ironically the creation of the term DSD causes as much dissent as the previous terms themselves.⁸⁴ A number of current web help sites have tried to remedy this by referring to the amalgamated term ‘intersex/DSD’, interpreting DSD as *differences* in sex development,⁸⁵ but to no avail. Results of a survey suggest that the term is exceedingly disliked.⁸⁶ Questionnaires were sent to those with Congenital Adrenal Hyperplasia (CAH), asking whether the term DSD received their approval:

A total of 589 responses were received (...). 70.6% had never heard the term DSD. 71.0% disliked or strongly disliked the term DSD. 83.6% stated they did not identify with the term DSD. 76.0% felt that the term DSD has a negative effect on the CAH community.⁸⁷

This is the conclusion reached by the Australian Senate, who used the term ‘intersex’ throughout their recent report.⁸⁸ This renders debating these conditions en masse

⁸³ Ellen K Feder and Katrina K Karkazis, ‘What’s in a Name? The Controversy over “Disorders of Sex Development” ’ (2008) 38 (5) Hastings Center Report 33, 35.

⁸⁴ According to Curtis E Hinkle, Dreger resigned from the consortium because of the backlash she had received. Hinkle describes Dreger as an interloper. He notes her blog ‘Do I sometimes take crap from people in identity rights movements (like the intersex rights movement) for being a supposed interloper? Sure, sometimes. But most people figure out that it’s a good thing to have someone capable helping out.’– Alice Dreger, 14 August 2006’ as quoted rather heatedly by Hinkle. ‘A report from OII, Edited by Curtis E Hinkle, Alice Dreger: Disorders of Sex Development’ September 26 2006 <http://oii-usa.blogspot.co.uk/2006/09/alice-dreger-disorders-of-sex.html> accessed 23 May 2015.

⁸⁵ www.dsdfamilies.org This website refers to both disorder and difference. This indicates a severe level of confusion /acceptability of the term. The NHS website, refers to solely to ‘disorders’ www.nhs.uk/conditions/disorders-sex-development accessed 24 August 2015

⁸⁶ Karen Lin-Su and others, ‘Congenital Adrenal Hyperplasia Patient Perception of ‘Disorders of Sex Development’ Nomenclature’ (2015) 9 International Journal of Pediatric Endocrinology <http://www.ijpeonline.com/content/2015/1/9> accessed 24 May 2015. CAH is just one of several conditions mentioned in this thesis.

⁸⁷ *ibid.*

⁸⁸ In fact they note that the term *disorder*, ‘dangerously pathologises’ intersex individuals. The Senate, Community Affairs References Committee, ‘Involuntary or Coerced Sterilisation of Intersex People in Australia’ (2nd Report, 25 October 2013) 22 <http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Sec_Report/index>accessed 24 March 2015. Quoting Sarah S Topp, ‘Against the Quiet Revolution: The Rhetorical Construction of Intersex Individuals as Disordered’ (2013) 16 (1) Sexualities 180.

somewhat tricky; therefore, in line with current government initiatives,⁸⁹ it is submitted that a more suitable legal interpretation to use would be that of ‘*diversity of sex development*’.⁹⁰ Diversity celebrates rather than condemns those who offer a differing standpoint, and therefore is a more acceptable label.

In the absence of a universally agreed and agreeable nomenclature, this thesis will use the term ‘intersex’ but will also refer to ‘DSD’ (as *diversity of sex development*) and ‘intersex/DSD’ interchangeably.

1.3 Potential Discrimination –Current English Law

Lawyers and lawmakers have a duty to ensure everyone is treated with respect and dignity, in accordance with equality established by law. Wherever possible, the intersexed should be given as much help as is feasible to live their lives to their potential. However, it is clear that in recent times the intersexed have suffered discrimination in a number of environments. The Equality Act 2010 was passed with the aim to end discrimination. Discrimination has been defined as ‘treatment or consideration based on class or category rather than on individual merit; partiality or prejudice’.⁹¹ According to Fernández-Balboa,⁹² discrimination is composed of several facets, the most significant ones being prejudice – ‘an unjustified negative attitude toward others simply because they are members of a different (...) gender’– coupled with stereotyping – ‘the false belief that every person belonging to a group (...) encompasses all the characteristics attributed to that group’.⁹³ Fernández-Balboa

⁸⁹ Home Office, ‘Diversity Strategy 2013-2016 Making the Most of Our Diversity’, 5 August 2013. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/226459/E_D_Strategy_report_v3.PDF accessed 24 May 2014.

⁹⁰ In modern usage ‘diversity’ is a quality to be celebrated not suppressed.

⁹¹ Juan-Miguel Fernández-Balboa, ‘Discrimination: What Do We Know and What Can We Do About It?’ in Robyn L Jones and Kathleen M Armour, *Sociology of Sport* (Pearson 2000) 134, quoting from the American Heritage College Dictionary (1993).

⁹² *ibid*, 136.

⁹³ *ibid*.

rightly pointed out that these groups are socially constructed. In the case of the intersexed, discrimination is heightened because society has not constructed a ‘group’ to which they belong, nor would it be an easy task to do so, as the varying conditions which fall under the penumbra of the term DSD are vast.

Under English law, discrimination can be direct or indirect. Direct discrimination occurs where a person treats the claimant ‘less favourably’ than s/he treats or would treat others,⁹⁴ because the claimant has, or is perceived to have,⁹⁵ a ‘protected characteristic’.⁹⁶ By comparison, indirect discrimination occurs when an apparently neutral and non-discriminatory approach in an organisation’s ‘provision, criterion or practice’⁹⁷ is discriminatory⁹⁸ in relation to those with protected characteristics.⁹⁹ It will be noted that in the healthcare environment, discrimination is more likely to be indirect. Further, Part 3, section 29 of the Equality Act specifically demands that a ‘service-provider’ ‘must not discriminate against a person requiring the service by not providing the person with the service’. Unfortunately, this direct statement is not as transparent as it may appear, and this thesis identifies a number of areas where the

⁹⁴ s13(1) ‘A person (A) discriminates against another (B) if, because of a protected characteristic, A treats B less favourably than A treats or would treat others.’

⁹⁵ s24(1) For the purpose of establishing a contravention of this Act by virtue of section 13(1), it does not matter whether A has the protected characteristic

⁹⁶ s4 specifies that the protected characteristics are, age; disability; gender reassignment; marriage and civil partnership; pregnancy and maternity; race; religion or belief; sex; sexual orientation. Not all of these characteristics apply to every section. Direct discrimination particularly refers to age; disability; gender reassignment; marriage and civil partnership; race; religion or belief; sex; sexual orientation.

⁹⁷ s19 (1) A person (A) discriminates against another (B) if A applies to B a provision, criterion or practice which is discriminatory in relation to a relevant protected characteristic of B’s.

⁹⁸ s19 (2) For the purposes of subsection (1), a provision, criterion or practice is discriminatory in relation to a relevant protected characteristic of B’s if—

- (a) A applies, or would apply, it to persons with whom B does not share the characteristic,
- (b) it puts, or would put, persons with whom B shares the characteristic at a particular disadvantage when compared with persons with whom B does not share it,
- (c) it puts, or would put, B at that disadvantage, and
- (d) A cannot show it to be a proportionate means of achieving a legitimate aim.

⁹⁹ s19 (3) The relevant protected characteristics are: age; disability; gender reassignment; marriage and civil partnership; race; religion or belief; sex; sexual orientation.

intersexed do not receive the service they require.¹⁰⁰ Ironically, at times the intersexed have received treatment that they did not want!¹⁰¹

Indirect discrimination may not be unlawful if it can be shown that there is an 'objective justification' for the policy or practice. This involves demonstrating a 'proportionate means of achieving a legitimate aim'.¹⁰² This may prove to be a defence to potential accusations that aspects of healthcare policy discriminate against the intersexed. However, the more ready defence currently available is that the category of 'intersex' is not afforded any legal protection under the Act. Although the Act identifies 'sex' as a protected characteristic,¹⁰³ this category is only available to a 'man' or 'woman',¹⁰⁴ therefore those who consider themselves to be neither are disadvantaged.¹⁰⁵

1.3.1 Discrimination in Practice

Discrimination occurs if an intersexed person is refused a birth certificate due to genital difference preventing an allocation to either the 'male' or 'female' category. This was alleged to have happened in the Kenyan case of *Richard Muasya v the Hon Attorney General*.¹⁰⁶ Discrimination may occur in the distribution of housing and

¹⁰⁰ In particular newborn bloodspot screening for certain conditions as discussed in chapter seven.

¹⁰¹ In particular enforced genital modification procedures. This is discussed in chapter eight.

¹⁰² s19 (2) (d).

¹⁰³ s11 In relation to the protected characteristic of sex-

(a) a reference to a person who has a particular protected characteristic is a reference to a man or to a woman;

(b) a reference to persons who share a protected characteristic is a reference to persons of the same sex.

¹⁰⁴ *ibid.*

¹⁰⁵ This will not be the case for many intersex/DSD persons, as they have strongly aligned gender and physical personas, but for those who perceive themselves as 'intersexed' there is no legal support currently.

¹⁰⁶ *Richard Muasya v the Hon Attorney General*, High Court of Kenya Petition No 705 of 2007 (2 December 2010). The claimant argued that he was unable to be issued with a birth certificate as he was born with genital difference. The court disagreed and said that on the evidence he could have been registered as male, so no discrimination occurred on those grounds.

prison accommodation,¹⁰⁷ and even a 'trip to the bathroom' can lead to discrimination.¹⁰⁸ Employment often creates fertile ground for discrimination to grow. It is noted that one intersex sex worker was refused healthcare support from local clinics as it offered a service for women sex workers *only*.¹⁰⁹ An American case of sex discrimination also illustrates potential problems faced at work.

In *Wood v C G Studios*,¹¹⁰ the District Court of Pennsylvania decided that the intersexed were not protected by legislation enacted to prevent sex discrimination. In this case the claimant alleged that, contrary to the Pennsylvania Human Relations Act (PHRA), her employer discriminated against her by terminating her contract when it was discovered that she had undergone corrective surgery associated with her intersex condition. However, the Court decided the PHRA was not intended to remedy discrimination against individuals who had undergone gender-corrective surgery.¹¹¹

Greenberg believes this decision results from the fact that the legislation referred to 'males' and 'females', which ruled out those who were 'not part of the traditional binary sexual classification system'.¹¹² Although the ruling seems to have been based on previous case law and was not anti-intersexual per se, it demonstrates the vulnerabilities of minority groups.

¹⁰⁷ *Dion'e Kaeo-Tomaselli v Jennifer Butts Iwalani Souza* Civ. No. 11-00670 LEK/BMK. United States District Court, D. Hawaii. January 31, 2013. Motion for Summary Judgment. Kaeo-Tomaselli alleged that Jennifer Butts (owner) and Iwalani Souza, (manager) of the Pi'ikoi Clean and Sober House for Women ("Pi'ikoi House"), violated the Fair Housing Act ("FHA") of 1968, the Equal Protection Clause of the Fourteenth Amendment, and state law when they allegedly refused her request for accommodation at Pi'ikoi House on August 10, 2010, as she was a 'hermaphrodite'. The claimant was unsuccessful as it was stated that everyone has a right to choose who to live with, and this was not discrimination per se. Further as the claimant was at the time in prison, she had suffered no loss as she was currently in accommodation when her request was refused.

¹⁰⁸ 'My girlfriend (...) never feels safe going into public rest rooms. She can't decide which one to use. She's been kicked out of the ladies room by security guards and fears violence from men if she goes into the men's room.' Thea Hillman, *Intersex (for lack of a better word)* (Manic D Press, 2008) 120.

¹⁰⁹ Sarah-Jane's story in Catherine Harper, *Intersex* (Berg, 2007) 73.

¹¹⁰ *Wood v CG Studios Inc* 660 F Supp 176 (E D Pa 1987).

¹¹¹ *ibid*.

¹¹² Julie A Greenberg, 'Definitional Dilemmas' in Toni Lester (ed), *Gender Nonconformity, Race, and Sexuality* (University of Wisconsin Press, 2003) 119.

1.3.2 Sport

Of all the areas of legal tension, sports display the most literature on direct discrimination of the intersexed.¹¹³ A number of athletes have faced gender questioning if their physique was too ‘masculine’ or if they failed sex chromosome testing.¹¹⁴ The saga first evolved with the Olympic duel, both on and off the track, between two American runners, Stella Walsh and Helen Stephens. When Stephens beat Walsh by a small margin in the 100-metre race during the 1936 Olympics, Walsh accused Stephens of being a man. This led to Stephens undergoing the Olympics’ first gender test, which was purely a ‘crude physical examination’.¹¹⁵ After this test Stephens was pronounced to be ‘female’.¹¹⁶

Over the years, testing became more sophisticated, bringing results which stunned not just the spectators but the athletes themselves. One such unfortunate athlete was the Spanish hurdler Maria Patiño, who it is now known has Complete Androgen Insensitivity Syndrome (CAIS). Her failing of a ‘buccal smear test’¹¹⁷ to prove femininity in 1985 (she has a chromosome configuration of 46 XY –a male arrangement) led to a general sense of shock and disbelief –for Patiño herself as well as others and was initially vilified as a fraud which had a profound effect on her life. She said, ‘I lost friends, fiancé, hope and energy’.¹¹⁸ Patiño took action to clear her name and to change Olympic regulations. Her licence to participate was finally

¹¹³ David McArdle ‘Swallows and Amazons or the Sporting Exceptions to the Gender Recognition Act.’ (2008) 17 (1) Social and Legal Studies 39. In this article, McArdle discusses the role of s19 of the Gender Recognition Act 2004 in its restriction of competition for transsexual athletes.

¹¹⁴ M A Ferguson-Smith and Elizabeth A Ferris, ‘Gender Verification in Sport: the Need for Change?’ (1991) 25 (1) Br J Sp Med 17.

¹¹⁵ Robert Richie, John Reynald and Tim Lewis, ‘Intersex and the Olympic Games’ [2008] J R Soc Med 395, 395.

¹¹⁶ Ironically Walsh was later discovered to sport genital difference, *ibid*.

¹¹⁷ This involves the scraping of epithelial cells from inside the cheek. The cells are stained to reveal if a ‘Barr body’ is present. A Barr body is caused by the inactivation of one of the two X chromosomes in female cells. They appear in approximately 25% of nuclei. (Those with XY chromosomes will not have Barr bodies in any cells, but ironically those who are XXY will. In other words Klinefelter Syndrome men could in theory have passed the Buccal smear test of femininity).

¹¹⁸ Maria Jose Martinez –Patiño ‘Personal Account, A woman Tried and Tested’ (2005) 366 Medicine and Sport S38 [http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736\(05\)67841-5.pdf](http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(05)67841-5.pdf) accessed 23 May 2015.

reinstated in 1988, but by then Patiño had lost her focus on training and failed to qualify for the 1992 Barcelona Olympics. Although Patiño's sporting career ended, her actions have helped other women in her position.

It might have been expected that such news would reach the headlines again in August 2012 when London hosted the 2012 Olympic Games. However, there was very subdued coverage of Caster Semenya, the South African runner who had caused a storm of controversy three years previously when she won the 800-metre race in Berlin 2009. After winning, Semenya would have undergone various tests. It appeared that she had high levels of testosterone, normally associated with male gender. As expected, some accused her of misrepresenting her sex. It was reported, for example, that Elisa Cusma who came sixth in the race stated, '(t)hese kind of people should not run with us. For me, she's not a woman. She's a man!'¹¹⁹ Meanwhile, the *Australian Daily Telegraph* reported that Semenya's confidential test results indicated that although Semenya had the typical phenotype of a female, internally her body contained undescended testes as opposed to ovaries.¹²⁰ Although the International Association of Athletics Federations (IAAF) were quick to say these were not official IAAF statements,¹²¹ the general public were happy to assume they were. It was later reported that she had received treatment for an intersex condition, and was given clearance to participate once more.¹²²

¹¹⁹ Christopher Clarey and Gina Kolata, 'Gold Awarded Amid Dispute Over Runner's Sex' *New York Times* (New York 20 August 2009) http://www.nytimes.com/2009/08/21/sports/21runner.html?pagewanted=all&_r=0 accessed 24 March 2015.

¹²⁰ Anna Peterson, 'But She Doesn't Run Like a Girl. The Ethic of Fair Play and the flexibility of the Binary Conception of Sex' [2010-11] *Tul J Intl & Comp* 315, 316.

¹²¹ *ibid.*

¹²² Simon Hart 'Caster Semenya given all clear after Gender Test Row.' *The Telegraph* (6 July 2010) <http://www.telegraph.co.uk/sport/othersports/athletics/7873240/Caster-Semenya-given-all-clear-after-gender-test-row.html> accessed 24 March 2015. There have been recent rule changes by the International Association of Athletics Federations, so that now, women competitors must have certain testosterone levels, which do not exceed the male threshold. If a high testosterone level is detected, the athlete must have surgery or receive hormone therapy prescribed by an expert IAAF medical panel and submit to regular monitoring. It is likely that Semenya has now met the required hormone level.

In her article,¹²³ Peterson poses the question, ‘Would allowing intersexuals to participate nullify the ethic of fair play?’ She answers that, on the contrary:

the ethic of fair play does not demand that the IOC [International Olympic Committee] or ISF [International Sports Federations] impose discriminatory eligibility requirements on intersex athletes, but, instead, supports the inclusion of athletes who, through hard work and natural ability, have become elite in their respective events.¹²⁴

Interestingly, one of the demands of TIIF is:

To ensure that intersex people are able to participate in competitive sport, at all levels, in accordance with their legal sex. Intersex athletes who have been humiliated or stripped of their titles should receive reparation and reinstatement.¹²⁵

In the light of the above discussion, the Forum is justified in its demand.

Adair suggests¹²⁶ that the case of *Richards v United States Tennis Association*,¹²⁷ in which the Court held that requiring Richards to undertake genetic testing was a violation of New York human rights law, has made New York a ‘safe haven where intersex athletes can compete without fear of sex verification testing’. She suggests that this case is a potential precedent for intersex athletes to use throughout the US. Whether this can be a reality is yet to be seen. The world of sport magnifies difficulties that many with intersex conditions face, namely the lack of awareness from all¹²⁸ and the general disgust from the public at large once such a condition is identified.

¹²³ Peterson (n 120).

¹²⁴ *ibid.*

¹²⁵ TIIF, Appendix A.

¹²⁶ Jessica L Adair, ‘In a League of their Own: The Case for Intersex Athletes’ (2011) 18 Sports Law J 121, 149.

¹²⁷ 400 NYS 2d 267 (Sup Ct 1977) This case involved a male to female transsexual as opposed to an intersexual.

¹²⁸ Including the person themselves.

It is beyond the scope of this thesis to identify every area of discrimination that the intersexed face, but it is clear that discrimination stems primarily from the revered belief in the binary gender system.¹²⁹ It is no wonder, therefore, that healthcare practitioners have attempted to eradicate any sign of intersexuality. Further, as doctors appeared to have been acting in good faith, legal systems were unlikely to step in and challenge them. The problem lies not with doctors per se but with society, as ‘Western societies have required that they (the intersexed) conform to one sex’.¹³⁰

Throughout life, a child diagnosed with an intersex condition is more likely to receive medical attention than a child without such a condition. This ‘interest’ will start at birth if a child presents with genital difference (and even before should an intersex condition be diagnosed prenatally).¹³¹ However, not all conditions manifest themselves at birth. Some will lie dormant until puberty whilst others will never be discovered at all.¹³² Lack of diagnosis can prove more problematic than for those who are identified at an early stage, as it prevents these people from finding answers to the various medical questions that have perplexed them during their lifetime.¹³³

No matter how or when intersex/DSD conditions are diagnosed, from that point onwards, the child and parents are likely to feel vulnerable. English law by its binary conformity has allowed this to happen,¹³⁴ and compounds this misery by its willingness to assume that ‘doctor knows best’ for these children.¹³⁵ Further, lawmakers have yet to wake up to the fact that they have the power to intervene. In

¹²⁹ In computer terms ‘binary’ is a non-discretionary base-2 numeral system, typically using two symbols 0 (zero) and 1 (one), but even then with effort fractions can be transferred into the binary system. One half is represented as (0.1).

¹³⁰ Juan Carlos Jorge and others, ‘Male Gender Identity in an XX Individual with Congenital Adrenal Hyperplasia.’ (2008) 5 J SexMed 12.

¹³¹ As discussed in chapter six.

¹³² This is particularly the case of those with Klinefelter Syndrome. The conditions are discussed in detail in chapter three.

¹³³ Andrew’s Story: The Buck Stops With Me’ NHS National Genetics and Genomics Education Centre <http://www.tellingstories.nhs.uk/index.php/joys-story?id=212> accessed 15 May 2015.

¹³⁴ A detailed discussion of the relationship between the intersexed and society will take place in chapter three.

¹³⁵ *Chester v Afshar* [2004] UKHL 41.

this respect, it might have been hoped that the Equality Act 2010 would help to resolve some of these tensions; unfortunately, with the introduction of the Act, there was still a notable absence of direct inclusion of people with intersex conditions. This absence of protection allows discrimination to remain in all spheres of society.¹³⁶

With this in mind, it will be important for the purpose of this thesis to identify current law that might be utilised to protect the intersexed in a healthcare environment. This in itself will prove problematic as there is a relative paucity of developed legal material medical law in its own right, as it is a relatively new addition to a lawyer's area of practice. Although there have been a number of influential medical cases over the last 200 years, these have usually been considered from a tort, criminal law or even contract law perspective. Medical law as we know it today only came into its own discrete being after the Nuremburg Code was formulated in the wake of the Second World War,¹³⁷ and with the rebirth of medical ethics.

Ethical and legal principles are usually closely related; however, ethical obligations often exceed legal duties. In terms of the healthcare system, '(t)here are few decisions, actions or omissions that do not have an ethical dimension'.¹³⁸ It is therefore important to consider whether medical ethics can assist the intersexed to achieve equality in the healthcare environment.

1.4 Hippocrates –a Code of Ethics

In Western medicine, ethics can be dated back to Classical Greece.¹³⁹ Ethics in its purest terms should not be confused with professional codes of ethics. In this respect, the Hippocratic Oath,¹⁴⁰ named after Hippocrates, is likely to be the most memorable

¹³⁶ This will be discussed in chapter four and in the concluding chapter.

¹³⁷ This is discussed at section 1.6.

¹³⁸ A Gallagher and S Hodge (eds), *Ethics, Law and Professional Issues* (Palgrave Macmillan 2012) 3.

¹³⁹ This refers to a 200 year period, also known as the Hellenic period, from 510-323 BC.

¹⁴⁰ Appendix B.

of all the professional codes of medical ethics that have been devised, as for centuries the Hippocratic Oath has been sworn by legions of young doctors in the Western world upon entering the medical profession.¹⁴¹

One of the most memorable, albeit mistakenly attributed, sections of the oath promises to ‘first do no harm’.¹⁴² Now referred to in modern medical ethics as non-maleficence, this principle has in recent years been designated as one of four fundamental principles of medical ethics,¹⁴³ and is of significant importance around the world in the application of emergency treatment. However, far from ‘doing no harm’, during the last 80 years some doctors have caused unacceptable levels of pain in their ‘patients’ in the name of ‘science’.¹⁴⁴

Although considered of significance today, the Hippocratic Oath vanished from practice after the fall of the Roman Empire, until early modern times.¹⁴⁵ It was not fully re-endorsed until the end of the Second World War, when it was rebranded by the World Medical Association as the Declaration of Geneva.¹⁴⁶ However, not all of the oath’s original pledges have been adhered to,¹⁴⁷ nor is it identical throughout English medical schools, many students being encouraged to devise their own

¹⁴¹ Hippocrates was born on the Greek island of Cos and lived approximately 460-380 BC. A contemporary of Socrates, he was a renowned physician and teacher of medicine and belonged to a guild of doctors known as the Asclepiadae. Although the Hippocratic Oath has been attributed to him, some believe the oath ‘predates his own school’. JK Mason and GT Laurie, *Mason & McCall Smith’s Law and Medical Ethics*. (9th edn, OUP 2013) 3. However, there is evidence that the oath was written during his lifetime, and therefore it is feasible that Hippocrates was indeed the author of the oath, or at least part of it.

¹⁴² Also translated as ‘above all do no harm’, this appears to be a mid-nineteenth century interpretation of the original phrase in the Oath, ‘to abstain from doing harm’. In *Epidemics* part of the Hippocratic Corpus it states that ‘The physician must ... have two special objects in view with regard to disease, namely, to do good or to do no harm’ Steven H Miles, *The Hippocratic Oath and the Ethics of Medicine* (OUP 2004) 144.

¹⁴³ As described by Beauchamp and Childress. Tom L Beauchamp, James F Childress, *Principles of Biomedical Ethics* (7th, OUP 2013). The other principles are autonomy, beneficence and justice.

¹⁴⁴ The most infamous scientist being Josef Mengele. His activities are discussed in section 1.6.

¹⁴⁵ It was not until 1803 that Thomas Percival (1740-1804) published his *Code of Medical Ethics*. This was adapted and adopted in 1847 by the American Medical Association (AMA).the late 18th Century that the first code of medical ethics was adopted by a professional organisation

¹⁴⁶ After the place of its instigation. It is frequently updated. The most recent version was modified in 2006 at Divonne-les-Bains, France. Appendix C.

¹⁴⁷ For example, the Oath forbids doctors to conduct surgery, euthanasia and abortions.

declaration.¹⁴⁸ It appears, therefore, that even within the parameters of a code of ethics the intersexed may be left unprotected.

1.5 Medical Ethics¹⁴⁹

Nowadays, the term ‘bioethics’ is frequently discussed in the field of medicine,¹⁵⁰ and is an all-encompassing term for practical ethics concerning ‘anything in the biosphere or biological sciences’.¹⁵¹ By its nature, medical ethics is therefore a sub-division of bioethics.

Ethics, itself, is a branch of applied moral philosophy.¹⁵² The term ‘ethics’ derives from two Greek words; *ethikos*, meaning habit or pattern of behaviour, and *ethos*, meaning disposition. The word ethics is a generic term which carries a number of meanings, including the study of values and moral reasoning and their application to human conduct, to specific personal behaviour acting in accordance with human ideals or in alignment with conventional norms.¹⁵³ Reference to medical ethics requires a study of the moral principles that govern the practice of medicine by

¹⁴⁸ R Gillon, ‘In Defence of Medical Commitment Ceremonies’ (2002) 28 J Med Ethics 7. Additionally, there is concern as to *when* a medical student should swear the oath, some believing it more appropriate to take the pledge once qualified. RM Veatch, ‘White Coat Ceremonies: a Second Opinion.’ (2002) 28 J Med Ethics 5; Karen Dyer, ‘Raising Our Heads Above the Parapet? Societal Attitudes to Assisted Suicide and Consideration of the Need for Law Reform in England and Wales’ (2009) 21 Denning Law Journal 28.

¹⁴⁹ It is beyond the scope of this thesis to examine the different approaches to bioethics in significant detail. Rather the terms are introduced as they will be discussed in greater detail throughout the thesis. Beauchamp Childress (n 143).

¹⁵⁰ According to the Nuffield Council on Bioethics, ‘bioethics is a branch of applied ethics that deals with moral problems arising from the life sciences’; Nuffield Council on Bioethics, ‘Emerging Biotechnologies’ Consultation Paper, April 2011, 9 http://nuffieldbioethics.org/wp-content/uploads/Maude_Phipps.pdf accessed 24 June 2015.

¹⁵¹ Ian Kerridge, Michael Lowe, Cameron Stewart, *Ethics and the Law for the Health Professions* (4th edn, The Federation Press, Leichhardt, NSW 2013) 4. Kerridge et al. also list ‘nursing ethics’, ‘public health ethics’ psychological ethics’ ‘clinical ethics’ and ‘environmental ethics’ as being part of bioethics. As will be seen these different branches will be touched on during this thesis, but will not be specifically identified as such.

¹⁵² Other branches include logic (the study of thinking and reasoning) epistemology (study of knowledge); metaphysics or ontology (the study of nature and expression of beauty). Ethical doctrines cover a number of academic activities including teaching and research.

¹⁵³ AR Jonsen, *A Short History of Medical Ethics* (OUP 2000) ix.

doctors and other healthcare practitioners. The recent edition of the American Medical Association Code of Medical Ethics states that:

The term 'ethical' is used in opinions of the Council on Ethical and Judicial Affairs to refer to matters involving (1) moral principles or practices and (2) matters of social policy involving issues of morality in the practice of medicine. The term 'unethical' is used to refer to professional conduct which fails to conform to these moral standards or policies.¹⁵⁴

Over the centuries a number of differing philosophies have been employed in a medico-legal context. All aim to improve healthcare; all fail to form agreements with each other.¹⁵⁵ Although ethics 'demands acknowledgement and respect for others',¹⁵⁶ how this occurs depends on the philosophy adopted by the practitioner. There are a number of established medico-ethical approaches, each with strengths and weaknesses. Before the twentieth century the main approaches to medicine were virtue ethics, deontology and consequentialism. These often worked hand in hand with the teachings of Hippocrates.

1.5.1 Virtue Ethics

Dating back to the time of Aristotle (384-322 BC), virtue ethics focuses on the *modus operandi* of a particular action, emphasising that people should do the 'right thing' for the right reasons, in the right way. 'Virtue is a kind of moderation',¹⁵⁷ and the

¹⁵⁴ AMA (American Medical Association) AMA's Code of Medical Ethics Opinion 1.01 – <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion101.page?> accessed 24 June 2015.

¹⁵⁵ It has been said that '(e)thics is pluralistic. Individuals disagree amongst themselves about what is right and what is wrong, and even when they agree, it can be for different reasons.' WMA *Medical Ethics Manual* (2nd edn, 2009) 19.

¹⁵⁶ Kerridge and others (n 154) 10.

¹⁵⁷ Aristotle *Nicomachean Ethics* (F H Peters tr, 5th edn, Keegan Paul, Trench and Töbner & Co, 1893) Book II.6.13.

character of decision makers is all important. Their actions should incorporate aspects of compassion, honesty and dedication.¹⁵⁸

It would appear to be beneficial for patients to be treated by doctors acting with these qualities to the forefront of their minds; however, this approach is often seen as selfish as it aims to increase one's own portfolio of good works or *eudemonia*, (flourishing). Further, it is possible that in believing they are carrying out virtuous deeds, doctors and researchers make errors in not identifying errors that their treatment has produced. If they continue administering inadequate treatment (albeit they believe that they are acting virtuously), then they will not be performing a good service for their patients and will lose the moral high ground.¹⁵⁹ In the history of intersex treatment, such an example has occurred by the continuing use of castration or clitoridectomy, to try to 'normalise' an intersex patient. Surgeons may have believed that they were acting in all virtue on behalf of their patients, but it is unlikely that patients would share the same viewpoint.

1.5.2 Deontology

The philosopher most linked to this branch of ethics is Immanuel Kant (1724-1804). The word deontology derives from the Greek words for duty (*deon*) and science or study (*logos*). In contemporary moral philosophy, deontology is an approach that judges the morality of an action based on that action's adherence to a rule or rules. In relation to medical ethics there is often considerable room for disagreement, particularly in highly sensitive areas such as assisted suicide or abortion. Deontologists hold that some choices cannot be justified by their effects; no matter how morally good their consequences, some choices are simply forbidden. Such would be the case, for example, where a wrongly assigned intersexed person wished to change their sex to the gender of their choosing. If the law did not allow such a process (and in reality English law is not far from being this prescriptive), then no

¹⁵⁸ There is increasing study in this particular branch of ethics. For more detailed discussion see A Gallagher and S Hodge, *Ethics for Professional Life: Virtues for Health and Social Care* (Palgrave Macmillan, 2009); P Singer, *Writings on an Ethical Life* (Fourth Estate, 2001).

¹⁵⁹ This might be said of the works of John Money. This will be discussed in chapter four.

amount of potential benefit for the patient would eradicate the moral wrong of the physicians performing the surgery, and the patient for undergoing it.

As a general rule, any *illegal* action is considered morally reprehensible. Where there is not specific law in place, what makes a choice ‘right’ is its conformity with a moral norm. Such norms are to be simply obeyed; the Right has priority over the Good. If an act is not in accord with the Right, it may not be undertaken, no matter the Good that it might produce. It can be seen that at times a deontological approach can be extremely harsh. Gallagher and Hodge see deontology as posing questions such as ‘What are my duties as a healthcare professional?’¹⁶⁰ However, as the philosophy is multi-dimensional then the question raised could easily be ‘What are my duties as a patient?’ Neither of these questions fit comfortably into a sphere that strays beyond the normalisation of biology. This is particularly the case when an intersex person wants to perfect one of their indeterminate ‘sexes’,¹⁶¹ as they would ultimately have no choice but to ‘bring death’ to their other sex. Immanuel Kant, whilst supporting the notion of autonomy, was firmly against any degree of self-harm. In this vein, he wrote:

To deprive oneself of an integral part or organ (to maim oneself) – for example, to give away or sell a tooth to be transplanted into another’s mouth, or to have oneself castrated in order to get an easier livelihood as a singer, and so forth – are ways of partially murdering oneself. But to have a dead or diseased organ amputated when it endangers one’s life, or to have something cut-off that is a part but not an organ of the body, for example, one’s hair cannot be counted as a crime against one’s person – although cutting one’s hair in order to sell it is not altogether free from blame.¹⁶²

It would be difficult to assess whether an intersex person would be considered to be ‘partially murdering oneself’ should they require surgical removal of part of their

¹⁶⁰ Ann Gallagher and Sue Hodge (eds), *Ethics, Law and Professional Issues* (Palgrave Macmillan 2012) 4.

¹⁶¹ Albeit in reality they may only have one sex.

¹⁶² Immanuel Kant, ‘The Metaphysics of Morals’, (1797) in: Mary J Gregor (ed), *Practical Philosophy* (Cambridge University Press 1996) 353, 547.

body in order to ‘perfect’ their body, if the operation is not strictly a necessity. Likewise, would refusal of such an operation also be considered morally repugnant? It is not surprising that on occasions Kantian philosophy has been described as being ‘too rigid’ and therefore unlikely to support the needs of the intersexed.¹⁶³

1.5.3 Consequentialism

In comparison with deontologists, a consequentialist holds that choices — acts and/or intentions — are to be morally assessed solely by the states of affairs they bring about. As such they must specify initially the states of affairs that are intrinsically valuable (the Good). They then are in a position to assert that whatever choices increase the Good, those are the choices that it is morally right to make. Unfortunately, Consequentialists differ widely in terms of specifying what is Good. Some identify Good with pleasure, happiness, desire or satisfaction, (a hedonistic approach), whereas a utilitarianist belief considers that how the Good is distributed amongst persons (or all sentient beings) is itself partly constitutive of the Good.

Acting for the Good initially seems an admirable aim, but as ‘the end justifies the means’ individual human rights may be sacrificed for the ‘social good’. In terms of treatment of the intersexed, an application of utilitarianism is likely to consider physical alteration of one intersex person to be for the greater good, if that one person is causing a block to societal conformity and consequently societal happiness. This may not be the real ‘good’ for the person themselves.

As traditional approaches to ethics appear to fail the intersexed, another approach must be sought. For this reason medical principlism will be considered.

1.6 Medical Ethics in the Twentieth Century

Although ethics had been part of the medical sphere for centuries, it had to some extent lain dormant until the dawn of the twentieth century, when for all the wrong reasons, the development of medical ethics was a much needed antidote to unethical practice. What caused this docile creature to gnash its teeth was the acknowledgement

¹⁶³ Tamar Schapiro, ‘Kantian Rigorism and Mitigating Circumstances.’ (2006) 117 Ethics 32.

of inhumane experiments carried out on human participants, conducted by proponents of Nazi Germany.

It is known that from 1936 onwards Adolf Hitler (who was interested in euthanasia) was behind the move to ‘put to sleep’ a number of children born with deformities.¹⁶⁴ This would have included children with genital difference. As certain intersex conditions are more prevalent in Jewish families,¹⁶⁵ Hitler would not have hesitated in ordering such deaths –his abhorrence of those of Jewish faith being well documented.¹⁶⁶ Further, after the establishment of Auschwitz-Birkenau, scientific experiments on individuals grew to monstrous proportions with the ‘Angel of Death’ Josef Mengele in charge. Again, many of the research victims were young children. Mengele displayed a particular interest in twins in his quest for knowledge regarding the science of inheritance, and he performed numerous experiments on these children.¹⁶⁷ In addition to twins, Mengele was ‘ “fascinated by all sorts of freaks of nature, (...) dwarfs, hunchbacks, imbeciles of all nations (...) hermaphrodites” – all of them Jews’.¹⁶⁸ Those with genital difference would, no doubt, have faced his experimentation.

In the aftermath of the war, a series of trials took place, at Nuremburg.¹⁶⁹ One of the second wave of trials,¹⁷⁰ *USA v Karl Brandt et al.*,¹⁷¹ prosecuted 20 Nazi physicians and 3 medical administrators for, amongst other things, conducting inhumane

¹⁶⁴ Robert Jay Lifton, *The Nazi Doctors: Medical Killing and the Psychology of Genocide* (Basic Books, 2000) 51.

¹⁶⁵ Notably Congenital Adrenal Hyperplasia.

¹⁶⁶ Lifton (n164).

¹⁶⁷ The arrival in Birkenau of a large number of Hungarian Jews in 1944 increased his pool of twins to approximately 250 individuals. He carried out numerous (enforced) experiments on these children, including blood transfusions between twins, various injections and spinal taps without anaesthesia. These procedures often resulted in paralysis if not death.

¹⁶⁸ Lifton (n164) 360.

¹⁶⁹ The most famous of these was the Trial of the Major War Criminals (22 of the remaining ‘architects’ of Nazi Germany) before the International Military Tribunal.

¹⁷⁰ Nuremberg Military Tribunals under Control Council Law 10, Washington DC.

¹⁷¹ NMT 01 Medical Case – *USA v. Karl Brandt et al.*, also known as the Doctors’ Trial. Brandt was the senior medical official of the German government during World War II.

medical experiments.¹⁷² The defendants stated that their experiments ‘differed little from previous American or German ones,’¹⁷³ and further that no international law or policy differentiated between legal and illegal experimentation. The fear of this argument proving a successful defence led to Andrew Ivy and Leo Alexander¹⁷⁴ delivering a memorandum to the US Counsel for War Crimes,¹⁷⁵ listing six points identifying and defining legitimate research.¹⁷⁶

The War Tribunal concluded from available evidence that the German ‘research’ should not be considered ‘medical experiments’ but crimes. These atrocities were formally denounced on 19 August 1947,¹⁷⁷ with those found guilty sentenced to death or given long prison sentences. Of course, not all Nazi doctors were caught and punished. Mengele, the most infamous of all, managed to escape to South America where it was rumoured that he continued his experiments on twins.¹⁷⁸

¹⁷² There were four counts on their indictment dated 25 October 1946. (See n177 below)

¹⁷³ United States Holocaust Memorial Museum note, ‘Nuremberg Code’
<http://www.ushmm.org/information/exhibitions/online-features/special-focus/doctors-trial/nuremberg-code> accessed 24 May 2015.

¹⁷⁴ Doctors who were working for the prosecution team.

¹⁷⁵ Which was the foundation of what is now referred to as the ‘Nuremberg Code’.

¹⁷⁶ There is some debate as to where this memorandum came from. It has been noted that it bears an ‘uncanny’ resemblance to the German Guidelines for Human Experimentation of 1931, and evidence suggests that the doctors asked to be tried in accordance with this. Ravindra B Ghooi, ‘The Nuremberg Code –A Critique’ (2011) 2 (2) *Perspect Clin Res* 72.

¹⁷⁷ There were four counts on their indictment dated 25 October 1946: 1. conspiracy to commit war crimes and crimes against humanity (The tribunal decided not to charge under this indictment); 2. war crimes (for which 15 were found guilty and 8 acquitted); 3. crimes against humanity (for which 15 were found guilty and 8 acquitted); and 4. membership in a criminal organization (the SS). ‘This was charged against K Brandt, Genzken, Gebhardt, R Brandt, Mrugowsky, Poppendick, Sievers, Brack, Hoven, and Fischer.’ All were found guilty. Harvard Law School Library, ‘Nuremberg Trials Project: A Digital Documentation Collection: Introduction to NMT Case 1 USA v Karl Brandt et al.’ http://nuremberg.law.harvard.edu/php/docs_swi.php?DI=1&text=medical accessed 24 May 2015.

¹⁷⁸ Nick Evans, ‘Nazi angel of death Josef Mengele “created twin town in Brazil”’ *The Telegraph* (London, 21 Jan 2009).
<http://www.telegraph.co.uk/news/worldnews/southamerica/brazil/4307262/Nazi-angel-of-death-Josef-Mengele-created-twin-town-in-Brazil.html> accessed 25 August 2015. Although reports later that year dispelled that as a myth. Brian Handwerk, ‘“Nazi Twins” a Myth: Mengele Not Behind Brazil Boom?’ *National Geographic News* (25 November 2009)
<http://news.nationalgeographic.com/news/2009/11/091125-nazi-twins-brazil-mengele.html> accessed 23 May 2015.

In an effort to stop such atrocities occurring again, the Tribunal delivered a section in their verdict entitled ‘Permissible Medical Experiments’, which enlarged the six-point memorandum to ten principles.¹⁷⁹ These principles have become known as the Nuremberg Code.¹⁸⁰ Stated to be universal, they are part of an international legal code of conduct that today’s scientists are obliged to adhere to. There is a particular emphasis on ‘informed consent’, albeit the term itself was not promoted at the time, and in fact did not readily appear for a further ten years.¹⁸¹

The Nuremberg Trials ‘deeply impressed upon the world that medical intervention on non-consenting human subjects is morally and legally repugnant’,¹⁸² and from that time onwards the majority of medical communities have worked hard to ensure that such situations do not occur again. Unfortunately, there have been numerous lapses of adherence to the Nuremberg Code. This includes American-led research on syphilis in Alabama and Guatemala,¹⁸³ whilst scandals at the Bristol Royal Infirmary and Alder Hey Hospital confirm that the UK was not immune to lapses in clinical

¹⁷⁹ United States Holocaust Memorial Museum note, ‘Nuremberg Code’ <http://www.ushmm.org/information/exhibitions/online-features/special-focus/doctors-trial/nuremberg-code> accessed 24 May 2015.

¹⁸⁰ Appendix D.

¹⁸¹ Beauchamp, Childress, (n143) 121. The issue of informed consent in relation to treatment of the intersexed, will be considered in depth in chapter five.

¹⁸² ISNA ‘Amicus Brief on Intersex Genital Surgery’ 7 February 1998 <http://www.isna.org/node/97> accessed 24 March 2015.

¹⁸³ On 26 July 1972, news broke of a series of experiments carried out by the United States Public Health Service. It emerged that during the previous 40 years, research had been carried out on over 600 black men from Tuskegee, Alabama. These men, mainly poor and uneducated, had one medical condition in common – they all suffered from syphilis. They had no idea that they were research participants. The study, which started in 1932, had been sanctioned by the US Federal Government, and continued to be so, even after treatment for syphilis was discovered in the 1940s. It was not until 1997 that survivors and family members of the study received an official apology by President Clinton on behalf of the U.S. Government. To compound matters, in 2010, a similar study was exposed in Guatemala. An investigative commission was established by the Obama administration and it is now acknowledged that over 1300 Guatemalan soldiers, prisoners, prostitutes and mental patients were infected as part of a study into the effects of penicillin with at least 83 deaths resulting. See Susan Donaldson James, ‘Syphilis Experiments Shock, But So Do Third World Drug Trials’. (ABC World News August 30 2011) <<http://abcnews.go.com/Health/guatemala-syphilis-experiments-shock-us-drug-trials-exploit/story?id=14414902>> accessed 14 March 2015.

ethics.¹⁸⁴ A member of the Bristol Inquiry commented, ‘we have heard from angry and anguished parents who felt that their children’s bodies had been violated without their knowledge or consent and body parts referred to as stolen’.¹⁸⁵ It is unsurprising that in the Human Tissue Act 2004 (passed in response to these scandals) the requirement of ‘consent’ for organ removal is heavily emphasised. However, as will be discussed in chapter five, consent remains largely undefined by legislation, and relies heavily on case law.

Despite the best endeavours of a number of ethicists, doctors and scientists alike have flouted codes of conduct in the search for advancement in medicine and science. Nowhere is this latter statement more apt than in the area of medical treatment for those born with genital difference. During the last 50 years, globally there have been many intersex individuals (and their parents) who have suffered from lapses in medical ethics. A myriad of writings¹⁸⁶ give testament to such events. The predicament has been heightened by the secrecy and shame that has surrounded their lives. The instigator of this treatment was psychologist Dr John Money.

¹⁸⁴ In 1999 in the course of an inquiry that centered initially on Bristol Royal Infirmary’s (BRI) poor success rates for young children undergoing heart operations, evidence emerged that BRI and Alder Hey in Liverpool, were removing various organs from children who had died whilst in their care. These organs had been removed without the knowledge or consent of their parents and families, and it was reported that as many as 2,500 hearts were kept at Alder Hey. These scandals prompted new legislation and it is now illegal to take body parts without consent, which is now embedded in Schedule 1 of the Human Tissue Act 2004. The results of a public inquiry into these hospitals were published on 18 July 2001. This can be accessed via: www.bristol-inquiry.org.uk/final_report/index.htm - 8k. It was found that not only were some 35 deaths avoidable, but the sheer quantity of tissue removed without parental knowledge or consent led to some of the most condemnatory accusations. The discovery of the seemingly routine practice of retaining human material after *post-mortem* did nothing to help assuage the fears of those families who wanted their loved ones and themselves, to be treated with respect after death. The practice of retaining organs appears more widespread than first thought. In 2007, newspapers covered the story of the Sellafield workers whose organs were retained (without family consent) for testing between 1962 and 1992. Christine Buckley & Rajeev Syal, ‘Sellafield Kept Workers’ Body Parts for Research.’ *The Times* (London, 18 April 2007).

¹⁸⁵ Mavis Maclean, ‘Letting go...Parents, Professionals and the Law in the Retention of Human Material after Post Mortem’ in Andrew Bainham, Shelley Day Sclater, Martin Edwards (eds) *Body Lore and Laws*, (Hart Publishing, 2002).

¹⁸⁶ Suzanne Kessler, *Lessons From the Intersexed* (Rutgers University Press 1998); Catherine Harper, *Intersex*, (Berg 2007). Katrina Karkazis, *Fixing Sex: Intersex, Medical Authority and Live Experience* (Duke University Press, 2008); Thea Hillman, *Intersex (for lack of a better word)* (Manic D Press 2008) Iain Moreland (ed), *Intersex and After; GLQ Vol 15; 2* (Duke University Press, 2009); Julie A Greenberg, *Intersexuality and the Law – Why Sex Matters* (NYU Press 2012); Ellen K Feder, *Making Sense of Intersex: Changing Ethical Perspectives in Biomedicine* (Indiana University Press 2014).

1.6.1 John Money

John Money was born in New Zealand in 1921. He studied psychology and education at Victoria University in Wellington, graduating in 1944. After the end of the Second World War he left New Zealand to study in America, and was awarded his PhD from Harvard University in 1952. In 1951, he joined the Johns Hopkins University where he became a professor of medical psychology. He is generally credited with coining the term 'gender identity' and for a significant time his treatment was considered to be the *sine qua non* of treatment for the intersexed.¹⁸⁷

During the 1970s Money's works were quoted by many feminists in support of their arguments that gender difference was not a biological but a social phenomenon,¹⁸⁸ 'determined by post natal forces'.¹⁸⁹ It was also in the 1970s that Tajfel and Turner developed the concept of 'social identity theory'.¹⁹⁰ There are three stages to this: social categorisation, social identification and social comparison. Central to their theory was the premise that we divide the world and those in it into social categories, for example 'men', 'women', 'Christians', 'Buddhists' and so forth. This is known as social categorisation. Once we have put people into boxes we can then separate 'them' (the out-group) from 'us' (the in-group). Further, when we become a 'member' of a particular group, our identity will develop along the group lines (social identification) and our self-esteem improves accordingly. Once we identify, we can then compare (social comparison). It is said that we enhance our self-image at the expense of those we put into the 'out-group'. Likewise, those who believe that they belong to the 'out-group' develop low self-esteem. It is submitted that we are uneasy

¹⁸⁷ This changed after the famous John/Joan case was exploded by David Reimer. This is discussed in chapter four.

¹⁸⁸ The included Suzanne J Kessler Wendy McKenna, *Gender: An Ethnomethodological Approach* (John Wiley & Sons, 1978).

¹⁸⁹ Kate Millet, *Sexual Politics* (1969, First Illinois Paperback 2000) 30.

¹⁹⁰ H Tajfel & JC Turner, 'An Integrative Theory of Intergroup Conflict' in William G Austin & Stephen Worchel (eds), *The Social Psychology of Intergroup Relations* (Brooks-Cole 1979) as quoted by Saul McLeod, 'Social identity Theory' (2008) Simply Psychology <http://www.simplypsychology.org/social-identity-theory.html> accessed 24 July 2015.

with what we cannot successfully categorise. This fear turns into hostility and ridicule.

Adopting this theory, it is easy to understand why those who are ‘intersexed’ are put at a social disadvantage from the day they are born. Further, it is not just the child that is likely to suffer; parents often suffer too, and seek to find an instant remedy to the child’s sex, sometimes rejecting the child if a solution cannot be found.¹⁹¹ It is also comprehensible as to why Money was so successful in promoting his treatment to parents, as it would allow their ‘out-group’ child to be able to join an ‘in-group’.

Whilst social identity theory has stood the test of time, it was later proved that Money’s experiments were not as holistic as advertised. ‘Gender’ is more than a social construct and to artificially enforce a gender on a person opposite to their inherent persona leads to emotional and physical conflict, and ultimately failure.¹⁹² Eventually Money’s Gender Identity Clinic was closed.¹⁹³ In the interim, countless numbers of those with genital difference were forced to yield to this erroneous and damaging treatment.¹⁹⁴ Some countries still follow this treatment protocol. It is no wonder that TIIF demands its cessation.¹⁹⁵

¹⁹¹ Roy tells of the fictional plot of an episode of *ER*, in which a child was given up for adoption when the parents were informed that their child could not be ‘normal’. William G Roy, *Making Societies* (Pine Forge Press 2001) 110. This is not an unrealistic situation and a number of intersex children are given up for adoption. See for example, DSDfamilies, ‘Adopting a child with a DSD’ <http://www.dsdfamilies.org/parents/adopt/index.php> accessed 24 August 2015.

¹⁹² The paradigm story of David Reimer is discussed in chapter four.

¹⁹³ This occurred partly because the new chair of psychiatry at Johns Hopkins, Paul McHugh, was avidly against gender assignment surgery. Terry Goldie, *The Man Who Invented Gender: Engaging the Ideas of John Money* (UBC Press 2014).

¹⁹⁴ William Reiner, notes that 29 children who were castrated and raised as girls, retained masculine characteristics and nearly 50% of them readopted their birth gender. WG Reiner, ‘Psychosexual Development in Genetic Males assigned Female: the Cloacal Exstrophy experience’ (2004) 13 (3) *Child Adolesc Psychiatr Clin N Am* 657; WG Reiner, JP Gearhart, ‘Discordant Sexual Identity in some Genetic Males with Cloacal Exstrophy assigned to Female Sex at Birth’ (2004) 350 (4) *N Engl J Med* 333. It would be incorrect to state that all those treated by Money were unhappy, but a significant number of males, assigned female transitioned back.

¹⁹⁵ Appendix A.

1.7 The Four Principles

At the height of Money's influence a new approach to medical ethics was 'championed'¹⁹⁶ by Beauchamp and Childress. In their 'seminal book',¹⁹⁷ *Principles of Biomedical Ethics*,¹⁹⁸ the authors have attempted to blend the best of ethical stances into four main principles, creating an 'analytical framework of general norms'¹⁹⁹ a way of 'reflecting on one's behaviour towards others'.

Although their framework has been described as the 'classic compromise position'²⁰⁰ their work has proved immensely successful, primarily because it does not offend any moralist who holds tightly onto their chosen viewpoint. That notwithstanding, the individual selections of the specific principles often face intense academic critique.²⁰¹

Beauchamp and Childress identify their 'four clusters' of moral principles to be:

- (1) respect for autonomy (a norm of respecting and supporting autonomous decisions);
- (2) non-maleficence (a norm of avoiding the causation of harm);
- (3) beneficence (a group of norms pertaining to relieving, lessening or preventing harm and providing benefits and balancing benefits against risks and costs); and
- (4) justice (a group of norms for fairly distributing benefits, risks and cost).²⁰²

¹⁹⁶ JK Mason and GT Laurie, *Mason & McCall Smith's Law and Medical Ethics*. (9th edn, OUP 2013) 5.

¹⁹⁷ Margaret Brazier and Emma Cave, *Medicine, Patients and the Law* (5th edn, Penguin 2011) 64.

¹⁹⁸ Beauchamp, Childress, (n143).

¹⁹⁹ *ibid* 13.

²⁰⁰ Shaun D Pattinson, *Medical Law and Ethics* (3rd edn, Sweet & Maxwell 2011) 10.

²⁰¹ *ibid*.

²⁰² Beauchamp, Childress (n 143). Other aspects such as confidentiality and informed consent have also emerged as important considerations in healthcare practice.

1.7.1 Autonomy

‘Autonomy’ derives from the Greek and means ‘self-rule’. Of the four principles, autonomy is generally considered to be the most ‘dominant principle, especially in legal debate’,²⁰³ however, what amounts to autonomy in a medical setting leads to discussion in itself.²⁰⁴ Additionally, there is a danger of regarding autonomy as having a universally understood single meaning²⁰⁵ with attempts to define autonomy unsuccessful,²⁰⁶ although ‘self-determination’ is often considered the most apt term.²⁰⁷

In theory, the principle of autonomy empowers patients by promoting their right to bodily integrity (albeit the right is not an unqualified one).²⁰⁸ Inevitably, there are situations for the intersexed, where neither the right to bodily integrity nor self-determination exists. Indeed, it is sometimes the person’s immediate kin who exerts undue influence on financial or healthcare arrangements.²⁰⁹ For those with intersex conditions resulting in genital difference, it is likely that some families will be very

²⁰³ Brazier and Cave, (n 196) 68.

²⁰⁴ It has been said that ‘the principle of autonomy is the principle of liberty’ Tuija Takal, ‘Concepts of “Person” and “Liberty”, and their implications to our Fading Notions of Autonomy.’ (2007) 33 J Med Ethics 225. This leads one to believe that patients lack autonomy. It would prove challenging to equate being a patient with being at ‘liberty. A number of people I have met during my time as a student or hospital patient, expressed their discontent as being ‘locked-up’ or ‘kept-in.

²⁰⁵ Kay Wheat, ‘The Law’s Treatment of the Suicidal’ (2000) 8 (2) Med L Rev 182.

²⁰⁶ Lars Sandman, ‘On the Autonomy turf. Assessing the value of Autonomy to Patients.’ (2004) 7 Medicine, Health Care and Philosophy 261.

²⁰⁷ Self-determination’ occurs when a person ‘does what she chooses to do (because she chooses to do so) and she chooses to do what she does because she wants to do so,’ *ibid* 262.

²⁰⁸ Jukka Varelius, ‘Health and Autonomy’ (2005) 8 Medicine, Health Care and Philosophy 221.

²⁰⁹ There have been numerous cases where a spouse has been the victim of ‘undue influence’, to the point of signing away her share of the house, with no benefit in return. See in particular Lord Browne-Wilkinson’s judgment in *Barclays Bank v O’Brien* [1994] 1 AC and *Bank of Credit and Commerce International SA v Aboody* [1990] 1 QB 923. Mark Pawlowski and James Brown, *Undue Influence and the Family Home*, (Cavendish Publishers 2002).

A good example of this in the medical arena can be seen in relation to organ donation. Not only do families exhibit good tissue matches, but also faster treatment is a certainty. Many a parent/sibling will declare themselves happy to donate, but it is not unknown for a sibling to be emotionally bullied into donating life-saving tissue. See for example, Guy Patrick, ‘Condemned to Die, by my Sis.’ *The Sun* (London, 24 March 2007).

keen to 'normalise' their child to fit in with their societies. This may mean that a child who might gender orientate as 'female' is allocated as 'male' to best suit the parents' cultural settings; it has been noted, for example, that in India most parents would 'insist on a male sex assignment irrespective of the genotype and the surgical feasibility'.²¹⁰ If this is the situation it is unlikely that the child will be allowed the freedom to change at a later stage in their life. It can be seen that 'autonomy' is in the eyes of the beholder and in certain circumstances it is as much a myth to the intersexed as Hermaphroditos himself. As Professor McLean notes,

(t)he major consequence of being respected as autonomous is that it implies the capacity or liberty to make decisions, free from external control and in the expectation that they will be accepted as valid and binding on others.²¹¹

As will become obvious throughout this thesis, there has been, until recently, a lack of respect for the decisions of intersex/DSD patients.

1.7.2 Non-maleficence

The origins of non-maleficence are somewhat in dispute,²¹² and there is a suggestion that the real author of *primum non nocere* was the English physician Thomas Sydenham (1624-1689).²¹³ Regardless of its origins, non-maleficence holds an important, albeit limited, role in medical ethics. If physicians during the last 50 years had adhered to this principle, then many unnecessary sex rectification operations would not have been carried out on those with an intersex condition.

²¹⁰ Subodh Kumar Das, 'Surgical management of ambiguous genitalia in infants and children: An SGPGI experience', (2003) 19 (2) Indian Journal of Urology 145.
<http://www.indianjurol.com/article.asp?issn=0970-1591;year=2003;volume=19;issue=2;spage=145;epage=151;aulast=Das> accessed 25 March 2015.

²¹¹ Sheila A M McLean, *Autonomy, Consent and the Law* (Routledge-Cavendish, 2010) 40.

²¹² The original command not to do any harm apparently dates back to the *Hippocratic Corpus*, a collection of over 60 treatises of medicine, which was compiled during the fourth century BC. They have been attributed to Hippocrates, but it is extremely unlikely that they were written solely by him, as the writing styles of individual pieces diverge, and yet more significantly, the content often conflicts with itself.

²¹³ Sydenham is also known as the English Hippocrates. Cedric M Smith 'Origin and uses of *primum non nocere* – above all, do no harm!' (2005) 45(4) J Clin Pharmacol 371.

The difficulty with this approach is that it is extremely tricky to do nothing. What might be ‘harm’ may be for the good. For example, women with CAIS often have well defined testes in their abdomen. *Prima facie*, these should not be removed, as to do so is to cause unnecessary trauma to the body. However, if testes are not removed, this may be detrimental to the patient in the long-run, as a higher incidence of cancer has been found in ‘internal’ testes.²¹⁴ It can be seen that non-maleficence alone will not answer all the ethical debates, and only works well when in conjunction with the other principles.

1.7.3 Beneficence

The term beneficence refers to the duty of doctors to act in the ‘best interests’ of their patients. This will necessarily involve considering all the potential options available for treatment, then weighing up the pros and cons of each one. Ultimately the treatment with the best chance of success and/or minimum number of side effects would be considered the ethically correct treatment. However, there are often disadvantages in any treatment plan; therefore in the event of doing any harm there is the presumption that it is being done for the best of reasons. In the past, doctors have been able to force through treatment regimes on the grounds of ‘best interests’, particularly if their patients are under the age of 18, with very little consideration of the patients themselves.²¹⁵

This type of approach, known as paternalism, lies in direct contrast to the principle of autonomy, as it often has involved doctors acting in the ‘best interests’ of their patients, with or without the patients’ consent. Until the last few decades in the UK, medical practice was ‘unquestionably paternalistic’.²¹⁶ Whilst undoubtedly there have been, and remain, excellent doctors who have acted in the best interests of their clients, there have been an equal number who have treated their patients in a high-

²¹⁴ Albeit this would be an extremely rare occurrence before puberty.

²¹⁵ *Re R (a minor) (wardship; medical treatment)* [1992] 1 FLR 190.

²¹⁶ Mason and MacCall Smith (n 195) 9. Medical paternalism sees a doctor, acting in the ‘best interests’ of his patients, with or without that person’s consent.

handed manner, little caring whether their patients understood what was going to happen, or, at times, even bothering trying to explain.²¹⁷

These days, paternalism is not considered an appropriate day-to-day medical principle to adhere to, although it still retains its *effect utile* in circumstances of necessity, such as treating an unconscious patient.²¹⁸ Unfortunately, whilst paternalism ruled, a number of intersex individuals were harshly treated in their ‘best interests’, surgeons being of the mind that ‘a chance to cut is a chance to cure’,²¹⁹ even if the diagnosis had not been established. More fortunately for the intersex children of today, paternalism has for the most part been usurped by the principle of autonomy, but as upholding patients’ autonomy has been relatively new in entering into everyday practice in the UK, some healthcare workers still find the principle difficult to accept, and to apply.

According to Brazier and Cave, beneficence demonstrates that ‘(e)thics demands a higher standard of behaviour than law requires’.²²⁰ To some extent this is true; certainly there are areas where law is absent, and needs to be present, or is present but remains silent on important ethical issues. As will be seen during this thesis, intersex conditions present in society frequently remain absent in law. Whilst this remains the *status quo*, it is imperative that ethical behaviour is promoted to protect this vulnerable minority.

1.7.4 Justice

The final principle is the principle of justice. This refers to a range of issues concerning equitable sharing of both resources and costs to treat each person in accordance with what is morally right and to treat each patient as equal. In terms of medical research involving human subjects the principle refers primarily to distributive justice, which requires the equitable distribution of both the burdens and

²¹⁷ Having worked in a hospital during the 1980s, the author witnessed such experiences first-hand.

²¹⁸ Interview with junior doctor, London 21 September 2013.

²¹⁹ Barron H Lerner, ‘If Biology is Destiny, When Shouldn’t It Be?’ *The New York Times* (New York, 27 May 2003).

²²⁰ Brazier and Cave, (n 196) 66.

benefits of participation in research. In the past, those with an intersex condition have often been the subject of research activities, often without their awareness, and certainly bearing more of the burden than receiving benefits. However, in terms of receiving medical treatment, it is clear that the intersexed have (rightly or wrongly) received a considerable share of available resources.

1.8 Healthcare Law and the Intersexed

During this thesis, it will be demonstrated that past incorrect medicalisation of the intersexed raises questions as to whether such treatment needs to be formalised in a legal framework. To date, English law acts as both a preventative and reactive measure in current healthcare practice. A significant weakness with current English law and international legal systems generally, is that it is difficult to pre-empt advancement in medical science.

This difficulty had been noted as early as 1970 in the Australian case of *Mount Isa Mines Ltd v Pusey*, with Windeyer J noting that ‘(l)aw march(es) with medicine but in the rear and limping a little’.²²¹ Without the knowledge of ‘what is to come’ it is unusual to develop legal provisions to stop future eventualities.²²² In the age of exponential growth of medical inventions,²²³ English law often finds itself staggering behind biological development, not just ‘limping a little’. This has been compounded until fairly recently by a reluctance of lawyers to pass judgment against the medical profession. If the doctors wanted to operate and a patient refused to agree, the courts would sanction it, if it could be said that the patient was not legally competent²²⁴ or mentally competent.²²⁵ It is particularly the plight of minors that needs consideration;

²²¹ *Mount Isa Mines Ltd v Pusey* (1970) 125 CLR at 395 as noted by Ian Kerridge, Michael Lowe, Cameron Stewart, *Ethics and the Law for the Health Professions* (4th, The Federation Press, Leichhardt, NSW 2013) 1094.

²²² *ibid.* One such exception was the haste in which many countries passed legislation banning human cloning, after the success of ‘Dolly the Sheep’.

²²³ There are numerous advances in medical technology that have taken place, then the law has been passed – notably in regard to heart transplants and IVF treatment.

²²⁴ In England this is anyone below the age of 18. S1(8) Family Law Reform Act 1969.

²²⁵ This is discussed in more detail in chapter five.

they have been left vulnerable in many ways –at the whim not only of the doctors but also of their families,²²⁶ without any legal support or redress.²²⁷

During the past ten years, there has been a move away from the wholesale acceptance of medical authority in England and Wales and more support for patients' human rights. Since the coming into force of the Human Rights Act 1998, NHS organisations and local authorities are required to act in accordance with rights afforded by the European Convention on Human Rights (ECHR) as they are 'public authorities'.²²⁸ However, this may still not prove to be adequate protection for a child who has been born with some type of intersex condition.²²⁹ Although it has been estimated that only five per cent of intersex/DSD people feel that they were wrongly assigned at birth,²³⁰ they are still faced with a variety of difficulties.²³¹

Further, should an intersex person feel that they have been wrongly assigned they will be faced with two significant challenges: getting surgeons to 'redo' their bodies into the sex of their choosing, and of more difficulty still, obtaining a birth certificate indicating their 'new' sex instead of that initially chosen by doctors. Unlike transsexuals there is no available route via the Gender Recognition Act 2004, as the

²²⁶ This is considered in chapters seven, eight and nine.

²²⁷ This is considered in chapters five and nine.

²²⁸ s6 (3) (b) Human Rights Act 1998 defines a public body as '*any person certain of whose functions are of a public nature*'. The main articles relevant in medical case law are Article 2 (protection of right to life), Article 3 (prohibition of torture, inhuman or degrading treatment or punishment), Article 5 (right to liberty and security), Article 6 (right to a fair trial), Article 8 (right to respect for private and family life), Article 9 (freedom of thought, conscience and religion).

²²⁹ If the Act is repealed, as the new Government are considering this may make the situation even more problematic.

²³⁰ Stephen Kerry, 'Are you a Boy or a Girl? Contesting the Uncontested: Intersex and Genders, (PhD thesis, University of Newcastle Australia 2005) 254.

²³¹ For example, it has been indicated in a study carried out by Catherine L Minto that of 39 intersexuals raised as women, all 28 who reported being sexually active also reported having some type of sexual difficulty. 18 of these women had undergone some degree of clitoral surgery, and indicated that they often experienced inability to achieve orgasm. Catherine L Minto and others 'The effect of clitoral surgery on sexual outcome in individuals who have intersex conditions with ambiguous genitalia: a cross-sectional study' (2003) 361 (9365) *The Lancet* 1252.

Act specifically excludes those with an intersex condition.²³² Consequently, it is extremely difficult for an intersex person to change their sex on official documentation.²³³

Although currently in the UK standard medical practice is *not* to operate on an intersex child until they become more aware of their gender identities and their bodies, there is legal uncertainty in this regard. Should doctors change their minds (once again) and decide that early gender assignment surgery would best benefit an individual then there is nothing to prevent this happening. However, to pass legislation to prohibit such surgery would in itself be a considerable challenge, and a legal ‘procrustean bed’ approach may ensue.²³⁴ There is no quick fix available in such circumstances.

1.9 Following Chapters

In the following chapters, I aim to identify where the intersexed face discrimination in the healthcare environment and to assess the efficacy of English law in preventing such discrimination. As part of this assessment, it will be pertinent to consider the demands of the TIIF 2013,²³⁵ to identify where such demands apply to English law. It will be important to note that although a situation may arise which initially appears to be discriminatory, the actions taken may be deemed a ‘proportionate means of achieving a legitimate aim’;²³⁶ however, there are occasions, particularly at the

²³² s2 (1) (a) Determination of applicants refers to a person who has ‘gender dysphoria’, as opposed to a person who was wrongly allocated to a sex at birth by the medical profession. Further s 9(2) does not allow for any retrospective alteration of gender. Those with an intersex condition, who feel that they have been wrongly assigned will want the correction to take place in effect from birth. This is discussed in the concluding chapter.

²³³ s9 (2) of the Act does not allow for any retrospective alteration of gender. Those with an intersex condition, who feel that they have been wrongly assigned, will want the correction to take place in effect from birth.

²³⁴ ‘Intersex specialists are busily snipping and trimming infant genitals to fit the Procrustean bed that is our cultural definition of gender.’ Cheryl Chase Letters from Readers, [1993] *The Sciences* July/August, 3. www.isna.org/articles/chase1995 accessed 29 December 2013. Procrustes, a famous host in Greek mythology adjusted his guests to their bed. According to myths, defeating Procrustes was the last of many challenges facing Theseus on his way home from the Trojan War. Ovid VII, 438.

²³⁵ Appendix A.

²³⁶ Equality Act 2010 s19 (2) (d).

embryonic stage, where English law itself clearly discriminates against the intersexed.

Medico-legal conflicts can arise at any point in an intersexed/DSD person's life, but it will vary from person to person as to when precisely these problems occur. For some they may never materialise. The remaining chapters aim to illuminate these tensions, with an attempt, where possible, to offer legal solutions. However, in order to be in a position to assess the law critically it is important to establish the scientific and social backgrounds to this societal dilemma. These will be considered in chapters three and four respectively. Chapter five considers the complexity of informed consent to treatment for those with intersex conditions. As is to be expected, the significant difficulty here lies in the unavailability of detailed literature to help prepare the patient.

In the remaining chapters I discuss a number of situations where it is possible to identify discrimination against the intersexed in the healthcare environment, by investigating both the processes and the legal framework that surrounds them. Chapter six considers the lives of the intersexed pre-birth. Chapters seven and eight debate the impact of birth and the following weeks on intersexed children and their parents. In chapter nine, I investigate the dilemmas a young person with an intersex/DSD condition faces in accessing their medical information. It will be noted that whilst most of the procedures occur as a result of healthcare policy and procedures, these policies are authorised by a higher legal framework. Unless and until society has a change of heart, the best that can be done to support the intersexed is to change the law surrounding these individual issues. In the concluding chapter, I consider whether society needs to take immediate action by altering the laws surrounding gender allocation on documentation, or by altering the Equality Act 2010 to include a category of 'intersex'.

Before addressing any of these issues, it is important to discuss the rationale behind this thesis, firstly by discussing its place amongst other literature in this field and secondly by explaining the methodology employed. Both of these issues are addressed in the following chapter.

Chapter Two: Literature Review and Methodology

2.1 Literature Review

During the last 20 years there has been a surge in literature, both academic and popular,¹ which has aimed to highlight the plight of those with intersex/diversity of sex development (DSD) conditions. This increase has taken place at an exponential rate in the last four years, with several books emerging into print since I embarked on this thesis.² However, with the one notable exception of literature on informed consent to treatment, there remains a limited range of information on the relationship between the intersexed and law.³

Up to now authors have predominantly focused (not undeservingly) on the ‘shame’ and ‘secrecy’ surrounding their own and/or others’ intersex conditions, highlighting the discriminatory treatment they face in society and consequently in hospitals.⁴ The majority of this research has been centred on the lifelong trauma of undergoing unexplained and unnecessary surgery in childhood and adolescence.⁵ Literature has also attempted to address ways to shift the balance away from the patriarchal role of the doctor to ‘creating’ doctors with a more patient-centred approach.⁶ Most of the

¹ In this latter category is Lianne Simon, *Confessions of a Teenage Hermaphrodite* (MuseItUp Publishing 2012).

² These include: Julie A Greenberg, *Intersexuality and the Law – Why Sex Matters* (NYU Press 2012); Geertje Mak, *Doubting Sex: Inscriptions, Bodies and Selves in Nineteenth-century Hermaphrodite Case Histories* (Manchester University Press 2012); Ellen K Feder, *Making Sense of Intersex: Changing Ethical Perspectives in Biomedicine* (Indiana University Press 2014); Megan K DeFranza, *Sex Difference in Christian Theology, Male Female and Intersex in the Image of God* (Wm B Eerdmans Publishing Company 2015).

³ Authors writing on areas of law outside ‘informed consent’ include Greenberg, *ibid*, and Jonathan Herring and P L Chau. Jonathan Herring and P L Chau ‘Assigning Sex and Intersexuals’ (2001) 31 Family Law 762; P L Chau and Jonathan Herring, ‘Defining, Assigning and Designing Sex’ (2002) 16 IJLPF 327; Pak-Lee Chau and Jonathan Herring, ‘Men Women, People: The Definition of Sex’ in Belinda Brooks-Gordon and others (eds) *Sexuality Repositioned: Diversity and the Law* (Hart 2004).

⁴ Suzanne Kessler, *Lessons From the Intersexed* (Rutgers University Press 1998); Michelle Morgan LeFay Holmes (Morgan Holmes), ‘The Doctor will Fix everything: Intersexuality in Contemporary Culture’ (PhD thesis, Concordia University 2000). Catherine Harper, *Intersex*, (Berg 2007); Thea Hillman, *Intersex (for lack of a better word)* (Manic D Press 2008); Iain Moreland (ed), *Intersex and After; GLQ Vol 15; 2* (Duke University Press 2009).

⁵ Katrina Karkazis, *Fixing Sex: Intersex, Medical Authority and Live Experience* (Duke University Press, 2008).

work in the field has been tackled from two angles, namely sociological and medical. Other texts look specifically at the relationship between intersexuality and Christianity.⁷ Several of these works refer in passing to aspects of law, particularly issues of consent to treatment, and the requirement to fit intersexed bodies into a binary system. Seldom though have these works used law as a starting point, nor have they ascertained that law is often used as the excuse for (unnecessary) treatment as opposed to being its cause.⁸ In fact, generally, with a few key exceptions, they do not take account of the legal perspective at all.⁹ Therefore a motivating factor for embarking on this particular research was to seek out (through literature or otherwise) the legal dilemmas surrounding medical treatment of the intersexed.

With this in mind, this thesis aims to complement texts from a variety of genres and to address the gap in current literature in relation to English law. The objectives of this thesis are to investigate and analyse English law in regard to the lives of the intersexed in a healthcare environment; to highlight any inconsistencies or discrimination the intersexed might face from current English law; and finally to offer solutions (where appropriate) to medico-legal dilemmas in relation to treatment of the intersexed. It will be pertinent at this point to demonstrate the variety of literature that can be found, indicating the extent to which the relationship between English law and medical treatment of the intersexed is addressed.

⁶ *ibid.*

⁷ Susannah Cornwall, *Sex and Uncertainty in the Body of Christ: Intersex Conditions and Christian Theology*. (Routledge 2010); Megan K DeFranza, *Sex Difference in Christian Theology, Male Female and Intersex in the Image of God* (Wm B Eerdmans Publishing Company 2015).

⁸ In this respect I refer to the registrations of births using a system of binary sex allocation. Additionally until the recent Marriage (Same Sex Couples) Act 2013, the inability of people registered in the same sex to get married. This Act was passed on 17 July 2013, and according to the Government Equalities Office, the first marriages of same sex couples took place on 29 March 2014, (It will still depend on religious organisations whether to allow them to take place in their establishments.) Government Equalities Office, 'Marriage (Same Sex Couples) Act: A factsheet' (April 2004) https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/306000/140423_M_SSC_Act_factsheet_web_version.pdf accessed 23 May 2015.

⁹ These will be discussed in more detail in the following sections.

2.1.1 Scientific Authorities

Many authoritative journals and books discuss intersex conditions from a scientific perspective,¹⁰ several of which have been incorporated in this thesis. However, the vast majority of these articles are ‘scientific’ in the very broadest sense of the word, so seldom consider the intersex dilemma by taking an approach of treating the whole person, and by their very nature they do not consider legal aspects (albeit some will discuss ethical implications).¹¹ One of the key authors, who has successfully blended a scientific approach with an awareness of societal response, is Professor Milton Diamond. Consequently, his articles have been utilised throughout this thesis.¹²

Of the ‘scientific’ literature that incorporates the views of the intersexed, Daniela Crocetti’s thesis, ‘Medicalizing Gender: From Intersex to DSD, From Laboratory to

¹⁰ This includes the fields of medicine, neuroscience and psychology. A L Ogilvy-Stuart, C E Brain, ‘Early Assessment of Ambiguous Genitalia’ (2004) 89 (5) Arch Dis Child 401; I Hughes ‘Prenatal Treatment of Congenital Adrenal Hyperplasia : Do we have enough evidence?’ (2006) 5 (1) Treat Endocrinol 1; V Pasterski, P Prentice, I A Hughes, ‘Impact of the Consensus Statement and the new DSD Classification System’ (2010) 24 (2) Best Pract Res Clin Endocrinol & Metab 187; E Coleman and others, ‘Standards of Care for the Health of Transsexual, Transgender, and Gender-Nonconforming People, Version 7.’ (2011) 13 International Journal of Transgenderism 165; Stefan White and Andrew Sinclair, ‘The Molecular Basis of Gonadal Development and Disorders of Sex Development’ in John M Hutson Gary L Warne, Sonia R Grover (eds), Disorders of Sex Development (Springer-Verlag 2012); Murray Bartlett, ‘Imaging in DSD’ in John M Hutson, Gary L Warne and Sonia R Groves (eds) *Disorders of Sex Development, An integrated approach* (Springer 2012); to mention but a few.

¹¹ Ian Aaronson, ‘The Investigation and Management of the Infant with Ambiguous Genitalia: a Surgeon’s Perspective’ (2001) 31 Curr Prob Pediat 168; Nancy Ehrenreich and Mark Barr, ‘Intersex Surgery, Female Genital Cutting, and the Selective Condemnation of “Cultural Practices”’ (2005) 40 Harvard Civil Rights – Civil Liberties Law Review 71, 128 http://www.law.harvard.edu/students/orgs/crcl/vol40_1/ehrenreich.pdf accessed 18 April 2015; BA Vanderbrink and others, ‘Does Preoperative Genitography in Congenital Adrenal Hyperplasia Cases Affect Surgical Approach to Feminizing Genitoplasty?’ (2010) 184 (4) J Urol, 1793; PW Speiser, and others, Endocrine Society ‘Congenital Adrenal Hyperplasia due to steroid 21-hydroxylase deficiency: An Endocrine Society Clinical Practice Guideline.’ J Clin Endocrinol Metab, (2010) 95 (9) 4133; Daphna Joel, ‘Male or Female? Brains are Intersex’ (2011) 5 Front Integr Neurosci 57 <http://dx.doi.org/10.3389%2Ffnint.2011.00057><http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3176412> accessed 12 May 2015.

¹² Milton Diamond, ‘A Critical Evaluation of the Ontogeny of Human Sexual Behavior’ (1965) 40 (2) *The Quarterly Review of Biology* 147; Milton Diamond, ‘Pediatric Management of Ambiguous and Traumatized Genitalia’ web version of the National Kidney lecture and publication 17 October, 1998 San Francisco www2.hu-berlin.de/sexology/BIB/DIAM/pediatric_management.htm accessed 17 August 2014; Milton Diamond, and Linda Ann Watson, ‘Androgen Insensitivity Syndrome and Klinefelter’s Syndrome’ (2004) 13 (3) Child Adolesc Psychiatric Clin N Am 623.

Patient Groups',¹³ blends scientific detail with real-life experiences. Her interviews with those who are considered intersexed are illuminating and give colour to other science-based accounts. However, as Crocetti's emphasis is on the medicalisation of conditions, there is little reference to legal dimensions beyond informed consent.

As I note throughout this thesis, a substantial problem facing the intersexed and their parents is the lack of straightforward accessible material on the conditions themselves. This leads to a major tension in English law as it will render 'informed consent' invalid.¹⁴ In this respect, a recent publication from Wisniewski, Chernausek and Kropp, *Disorders of Sex Development*,¹⁵ gives a clear basic introduction to a number of intersex/DSD conditions. The authors reiterate how little information is published in this area. They announce in their preface, 'We decided to write this book because we know that there is not much information about DSD for the general public'. Research undertaken for this thesis indicates that this is a correct statement. Therefore it is hoped that this thesis will provide information in an accessible fashion, not just for the intersexed but for a wider audience.¹⁶

2.1.2 Gender Studies and Sociological Texts

In contrast to Crocetti's thesis, Stephen Kerry's research is orientated towards an exploration of the intersexed in social dimensions through time, and adopts a 'feminist, postmodern and queer framework and qualitative methodological design' in relation to those who are intersexed.¹⁷ This is just one of many sociologically based texts that centre on or allude to the intersexed. Some of these use the example of the intersexed to explore social construct theory in depth. In this regard, Judith

¹³ Daniela Crocetti, 'Medicalizing Gender: From Intersex to DSD, From Laboratory to Patient Groups' (PhD thesis, Università di Bologna 2011).

¹⁴ As discussed in chapter five.

¹⁵ Amy B Wisniewski, Steven D Chernausek, Bradley P Kropp, *Disorders of Sex Development* (The John Hopkins University Press, Baltimore 2012) 1.

¹⁶ Elizabeth Riley and others, 'Recognising the Needs of Gender-variant Children and Their Parents.' (2013) 13 (6) Sex Education: Sexuality, Society and Learning 644.

¹⁷ Stephen Kerry, 'Are you a Boy or a Girl? Contesting the Uncontested: Intersex and Genders, (PhD thesis, University of Newcastle Australia 2005) 250.

Butler is perhaps the most discussed current author. However, whilst she incorporates the intersexed in some of her works,¹⁸ the discussion is very much from a sociological approach. As such these texts provide useful theoretical discourse on societal backdrops to the intersex dilemma, but along with other writers in this field, she does not consider law as a concept in its own right.¹⁹

2.1.3 Medical Ethics

There is an overlap between law and ethics in a medical context, and at times this thesis will address ethical, in addition to legal, dichotomies for the intersexed. It has therefore been necessary to investigate literature on bioethics and the intersexed.²⁰ In biomedical ethics, the leading exponents in this field are Beauchamp and Childress, in their seminal work, *Principles of Biomedical Ethics*.²¹ A recent publication by Ellen Feder²² addresses the relationship between the intersexed and biomedical ethics. This is a useful addition to literature, but does not by its nature address English law.

In addition a number of influential authors in English medical law and ethics have also been considered. These include Mason and Laurie,²³ Sheila Maclean,²⁴ Jonathan Herring and Pak-Lee Chau,²⁵ to mention but a few.²⁶ All of these academic texts

¹⁸ Referred to in some of her texts by the term hermaphrodite. Judith Butler, *Gender Trouble, Feminism and the Subversion of Identity* (Routledge 1999); Judith Butler, *Undoing Gender* (Routledge 2004).

¹⁹ This will be discussed further in chapter four.

²⁰ T Colborn, FS vom Saal, and A M Soto, 'Developmental effects of Endocrine-disrupting Chemicals in Wildlife and Humans' (1993) 101 (5) *Environ Health Perspect* 378; B Eskenazi, A Bradman, and R Castorina, 'Exposures of Children to Organophosphate Pesticides and their Potential Adverse Health Effects' (1999) 107 (3) *Environ Health Perspect* 409.

²¹ Tom L Beauchamp, James E Childress, *Principles of Biomedical Ethics* (7th edn, OUP 2013).

²² Ellen K Feder, *Making Sense of Intersex: Changing Ethical Perspectives in Biomedicine* (Indiana University Press 2014).

²³ J K Mason and G T Laurie, *Mason & McCall Smith's Law & Medical Ethics* (9th edn, OUP 2013).

²⁴ Sheila AM McLean and Laura Williamson, *Impairment and Disability: Law and Ethics at the beginning and end of life* (Routledge-Cavendish 2007); Sheila A M McLean, *Autonomy, Consent and the Law* (Routledge-Cavendish 2010); Sheila McLean and Sarah Elliston (eds) *Regulating Pre-Implantation Genetic Diagnosis, A Comparative and Theoretical Analysis*. (Routledge 2012).

²⁵ Herring and Chau (n3).

and articles have been of significance in considering appropriate legal responses although, with the exception of Herring and Chau's work,²⁷ they do not in themselves particularly focus on intersex people.²⁸

2.1.4 Legal Writing

Coming to this area as a lawyer, I was surprised to find that there was very little literature that investigated this phenomenon from a legal aspect. The easily identifiable exceptions in regard to English law were works by Jonathan Herring and Pak-Lee Chau.²⁹ Further, when embarking on this thesis, there was no international text which focused on legal difficulties that the intersexed might face in the healthcare environment. For example, there were a number of articles written on sex discrimination which touch on the treatment of the intersexed and transgender communities,³⁰ but these are primarily American.³¹ In this respect, it should be noted that some of the intersexed do not wish to be aligned with those who are transgendered, albeit there are significant areas of overlap.³² The Australian

²⁶ Hazel Biggs, *Euthanasia: Death with Dignity and the Law* (Hart Publishing Ltd 2001); Ellie Lee 'The Abortion Debate Today' in Horsey and Biggs (eds) *Human Fertilization and Embryology: Reproducing Regulation* (Routledge-Cavendish 2006); Sally Sheldon and Stephen Wilkinson, 'Termination of Pregnancy for Foetal Disability: Are there Grounds for a Special Exception in Law?' (2001) 9 (2) *Medical Law Review*, 85.

²⁷ *ibid.*

²⁸ In respect of Herring and Chau, the dilemmas they address in regard to marriage may have been ameliorated to some extent by the recent Marriage (Same Sex Couples) Act 2013. This will be discussed in the concluding chapter.

²⁹ *ibid.*

³⁰ Tey Meadow, 'Deep down where the Music Plays: How Parents Account for Childhood Gender Variance' (2011) 14 (6) *Sexualities* 725.

³¹ Chinyere Ezie, 'Deconstructing the Body: Transgender and Intersex Identities and Sex Discrimination – the Need for Strict Scrutiny' [2011] *Colum J Gender & L* 141.

³² 'Whereas individuals who are intersexed might identify as transgender, the opposite is not true. Most people who are part of the transgender movement are not intersexed. To include intersex under the umbrella term, "transgender," overlooks our specific needs which often are medical reform, legal issues concerning which gender we are, health issues specific to intersexed bodies and more importantly, the fact that most intersexed people are not trans.' Curtis E Hinkle And Hida Viloria *Ten Misconceptions about Intersex* (2012) <<http://oii-usa.org/1144/ten-misconceptions-intersex/>> accessed 24 May 2015; E Coleman and others, 'Standards of Care for the Health of Transsexual, Transgender,

academic Karen Gurney frequently blends the two areas in her work.³³ Similar questions arise for both communities, such as the difficulties with marriage, employment and going to prison.³⁴ However, there is an anachronism in terms of the current legal rights of these two definable groups in English law.³⁵ The Equality Act 2010 is significantly more supportive of transgender rights than it is of those who are intersexed. Ironically those who are transgender have difficulties in requesting operations to fit their bodies, whereas those who are intersex have traditionally had difficulties in stopping such operations.³⁶

Inevitably, those writing in the area eventually identified lacunas within current literature and in 2012 Professor Greenberg published *Intersexuality and the Law – Why Sex Matters*.³⁷ Greenberg specifies in her introduction that her book is a ‘first’ in this area of research. She writes:

Although scholars in a variety of disciplines, including medical ethics, history, psychology, sociology, and anthropology, have published books on intersexuality, none has examined the role that the law can play in enhancing the lives of people with an intersex condition.³⁸

and Gender-Nonconforming People, Version 7.’ (2011) 13 International Journal of Transgenderism 165.

³³ Karen Gurney, ‘Twisting the Knife: Discrimination in the Law’ (2004) 9 (2) Deakin Law Review 339; Karen Gurney, ‘Discussing “sex” at work can be a costly business: Translating the science, language and law behind M v A & U [2007] QADT 8’ (2007) 7 (2) QUTLawJl 13.

³⁴ Since 2006 transgender people in Spain have been allowed to request to be placed into a male or female prison based on their external appearance, as opposed to their birth certificate, by virtue of Act 7/2006 on the penitentiary integration of transgender people. Raquel Platero, ‘The Narratives of Transgender Rights Mobilization in Spain’ (2011) 14 (5) Sexualities 597, 602.

³⁵ This will be addressed in the concluding chapter.

³⁶ In this respect some ‘trans’ people are those who might have been born intersexed, and who require operations to redefine them into the gender of their (the patient’s) choosing, as opposed to the gender selected by doctors. ABDessens, FM Slijper, SL Drop ‘Gender Dysphoria and Gender Change in chromosomal females with Congenital Adrenal Hyperplasia’ (2005) 34 Arch Sex Behav 389.

³⁷ Julie A Greenberg, *Intersexuality and the Law – Why Sex Matters* (NYU Press 2012).

³⁸ Ibid, 5.

This agreed with my previous analysis of the literature that I had read at the time.³⁹ As this book is published, it can no longer be claimed that this thesis is a ‘first’ in terms of *international* research. However, having carefully studied the text, it can be concluded that although Greenberg’s book is an extremely useful addition to literature, it is written primarily for an American audience. Further, the aim of the book is to analyse US law.⁴⁰ In this respect, Greenberg’s work does not significantly impact upon the original aim of this thesis, namely to investigate and evaluate current English law and the treatment of the intersexed. Likewise, publications by attorney Anne Tamar-Mattis consider the law from an intersex perspective in the state of California.⁴¹ These papers are very useful for a comparative law approach; however, they do not discuss the UK position and therefore will be persuasive only in their content.

Of all the areas to be addressed, the most potent area for consideration is the role of informed consent in operations on the intersexed, and the lack of judicial authority in this regard. In her book, Greenberg emphasises the lack of established legal systems for the protection of intersex individuals, and attempts to utilise existing legal frameworks in the US, notably disability legislation, as a way to support these minority rights. Greenberg also discusses the few available cases on this subject. Of disappointment is that for the cases mentioned she does not analyse the decisions in

³⁹ Albeit noting that Greenberg had been very active in this field in the US. Julie A Greenberg, ‘When Is a Man a Man, and When Is a Woman a Woman?’ (2000) 52 Fla L Rev 745; Julie A Greenberg, ‘What Do Scalia and Thomas Really Think about Sex? Title VII and Gender Nonconformity Discrimination: Protection for Transsexuals, Intersexuals, Gays and Lesbians’ (2002) 24 T Jefferson L Rev 149; Julie Greenberg, ‘Legal Aspects of Gender Assignment’ (2003) 13 (3) The Endocrinologist 277; Julie A Greenberg, Keynote Address at the Cardozo Women’s Law Journal & Bodies Like Ours Symposium: Intersex Education, Advocacy & The Law (Feb. 23, 2005).

Many of the decided cases used in these papers, explicitly involve transsexuals rather than intersexuals, nevertheless the cases are useful for the purposes of forecasting how courts may possibly deal with intersexuality based on the way they approached and discussed the issue of sex in the context of transsexuality.

⁴⁰ It is important to note that whilst the UK and the US are both common law jurisdictions, there are more differences than similarities in the systems. The US has a different legal culture with differing constitutional rights. This complexity is added to when considering the variations of laws passed in each state.

⁴¹ Anne Tamar-Mattis, ‘Exceptions to the Rule: Curing the Law’s Failure to Protect Intersex Infants’ (2006) 21 Berkeley J Gender L & Just 59; Katrina Karkazis Anne Tamar-Mattis Alexander A Kon, ‘Genital Surgery for Disorders of Sex Development: Implementing a Shared Decision-Making Approach’ (2010) 23 (8) Journal of Pediatric Endocrinology and Metabolism 741; Anne Tamar-Mattis, ‘Sterilization and Minors with Intersex Conditions in California Law’ (2012) 3 Calif L Rev Circuit 126.

great depth, so that it is challenging for anyone reading the book to understand any rationale for the decisions made. This might be due to the fact that Greenberg had made a more comprehensive attempt at this in an earlier work, ‘International Legal Developments Protecting the Autonomy Rights of Sexual Minorities’, which forms a chapter in the influential book *Ethics and Intersex*.⁴² In this chapter, Greenberg is more specific about underlining the importance of the ‘Columbian cases’ and following international jurisprudence.⁴³ However, her bias is naturally towards US interpretations of these cases, and the situation generally in regard to parental consent to treatment on behalf of children, and this does not correlate with the common law situation in England. In this respect then, although Greenberg has made a niche for herself in academia, in terms of English law she lightly refers to it but does not investigate and analyse it in depth.

By comparison, the Parliament of Australia’s Senate Report on ‘Involuntary or Coerced Sterilisation of Intersex People in Australia’⁴⁴ not only analyses its own law, but also incorporates jurisprudence from other jurisdictions. This perhaps is the most comprehensive account of legal provisions to date. However, by its very nature is concerned with Australian as opposed to English law and therefore its existence enhances rather than invalidates this research.

2.1.5 Consent to Treatment

Consent to treatment of an intersex condition (or lack thereof) has been a *leit motif* of many publications in this field.⁴⁵ Of books printed in recent years, several concentrate

⁴² Julie Greenberg ‘International Legal Developments Protecting the Autonomy Rights of Sexual Minorities: Who Should Decide the Appropriate Treatment for an Intersex Child?’ in Sharon Sytsma (ed) *Ethics and Intersex* (Springer 2006) 87.

⁴³ This is discussed in chapters five and seven.

⁴⁴ The Senate, Community Affairs References Committee, ‘Involuntary or Coerced Sterilisation of Intersex People in Australia’ (2nd Report, 25 October 2013). <http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Sec_Report/index> accessed 24 March 2015. Thanks to Dr Caroline Sanders, University of Lancaster for recommending this.

⁴⁵ C Chase, ‘Surgical Progress is Not the answer to Intersexuality’ (1998) 9 J Clin Ethics 385. Kenneth Kipnis and Milton Diamond, ‘Pediatric Ethics and the Surgical Assignment of Sex (1998) 9 (4) J Clin Ethics 398; T Briffa, ‘Intersex Surgery Disregards Children’s Human Rights’ (2004) 428 Nature 695;

on case studies of intersex individuals and pay specific attention to the treatment that they have undergone.

Suzanne Kessler's *Lessons from the Intersex*⁴⁶ focuses on the social construction of intersex individuals. This was considered to be a ground-breaking text when it was published, as for the first time detailed interviews with parents of intersexed children were included alongside doctors who diagnosed and treated them. This provided a different stance on the necessity or otherwise for genital surgeries as for the first time documentary evidence confirmed that some parents are happy for their children to live with atypical genitals, at least until the children are old enough to have a say in the matter.

In her book, Kessler refers back to her earlier work with Wendy McKenna, *Gender: An Ethnomethodological Approach*, published in 1978,⁴⁷ in which the authors critiqued the then familiar sex-gender distinction, arguing that there is no sex, only socially constructed gender. Ethnomethodologists see gender as a practical accomplishment rather than an absolute fact, attributing gender to the actions that are performed and society's views on those performances. This is similar to later postmodern feminist arguments, such as those of Judith Butler. These views will be considered in chapter 4, when the views of society are investigated.

Kessler's book helped to create an avalanche of tales of intersexed dissatisfaction,⁴⁸ and it is not surprising that her book has been incorporated into many current texts, including Katrina Karkazis's text, *Fixing Sex: Intersex, Medical Authority and Live*

Alice Dreger, 'Shifting the Paradigm of Intersex Treatment.' <http://www.isna.org>. ISNA, 1993-2008. Web. 1 Aug. 2013. <<http://www.isna.org/compare>>. accessed 23 May 2015;
C Wiesemann, 'Ethical Guidelines for the Clinical Management of Intersex' (2010) 4 (4-5) Sex Dev DOI: 10.1159/000316232 <http://www.aissg.org/PDFs/Wiesemann-Ethical-Guidelines-2010.pdf> accessed 24 May 2015.

⁴⁶ Kessler (n4).

⁴⁷ Suzanne J Kessler Wendy McKenna, *Gender: An Ethnomethodological Approach* (John Wiley & Sons, 1978).

⁴⁸ WG Reiner, JP Gearhart 'Discordant Sexual Identity in some Genetic Males with Cloacal Exstrophy Assigned to Female Sex at Birth' (2004) 350 (4) New England Journal of Medicine 333; IGLA Europe, '3rd International Intersex Forum Concluded' 02/12/2013 http://www.ilga-europe.org/home/news/latest/intersex_forum_2013 accessed 12 August 2014; OII Australia, 'Public Statement by the Third International Intersex Forum' 1st December 2013 <https://oii.org.au/24241/public-statement-by-the-third-international-intersex-forum/> accessed 24 March 2015.

Experience,⁴⁹ which has been seen as building on Kessler's work. It is a relatively recent account of current intersex activism, looking in particular at treatment protocols. Karkazis's text is comprehensive in that it utilises 53 in-depth interviews: some with intersex individuals, some with their parents, others with doctors. These accounts give a 360 degree view of surgery carried out on the intersexed. However, the interviews were conducted some ten years ago now, and are all US-centric. During this time, medical protocols have changed in the UK,⁵⁰ so to some extent the interviews are of historical interest only. Additionally, due to the difficulty in accessing subjects for interviews (something that has become all too apparent from my own fieldwork), the sample of intersex individuals who were prepared to be interviewed was somewhat lacking in social diversity in that they were 'overwhelmingly white'.⁵¹ Perhaps of even greater concern, Karkazis only interviewed 'one individual who identified as male'. This therefore lacks a balanced view of those with intersex/DSD conditions. This imbalance persists, albeit to a less marked extent, in *Intersex* by Catherine Harper.⁵²

In her work, Professor Harper, tells the stories of a number of intersexed individuals. The book differs from Karkazis' work in that the subjects have a more international dimension. Additionally, Harper pays more attention to the social backgrounds surrounding those whom she has interviewed. *Intersex* is a very useful text. It is easily readable; it blends information on the conditions themselves, presented in a non-medical context to be readily accessible to the general reader, and then focuses in on individual's stories. For an in-depth personal perception of living with an intersex condition, *Intersex (for lack of a better word)* by Thea Hillman⁵³ is a series of thought-provoking writings, some esoteric, some more crystallised, which tell the story of living with her intersex condition, Congenital Adrenal Hyperplasia. However, in terms of the relevance of this thesis, neither Harper nor Karkazis consider the situation from the legal dimension to any significant degree (and Hillman does not address this at all, albeit she touches on the law by default in her

⁴⁹ Karkazis (n 5).

⁵⁰ There has been some corresponding adaptation to treatment protocols in the US.

⁵¹ Karkazis (n 5) 22.

⁵² Catherine Harper *Intersex* (Berg 2007).

⁵³ Thea Hillman, *Intersex (for lack of a better word)* (Manic D Press 2008).

writing). Certainly there is no analysis of current legal frameworks surrounding these investigations.

There are a number of significant additional works that concentrate on this area, written by renowned writers in this field. Of the most use from a research point of view are the San Francisco Human Rights Commission Report⁵⁴ and the follow-up Symposium on Disorders of Sex Development held in San Francisco.⁵⁵ The papers are a mixture of personal and medical accounts and, with the exception of informed consent, there is very little attention paid to law on its own.

Other notable texts in this area include Alice Domurat Dreger's *Intersex in the Age of Ethics*⁵⁶ and *Sexing the Body* by Anne Fausto-Sterling.⁵⁷ Fausto-Sterling tackles the issue by blending biology, sociology and psychology. Again this book focuses on early operations, and looks at the psychological outcomes of children raised as either male or female, often against their natural karyotype. This book is useful in that it presents long-term studies on the intersexed. It is also useful in contextualising intersex in today's society. Having been written as a follow-up to her earlier work 'The Five Sexes',⁵⁸ in which she investigates the history of sexuality and intersexuals from myth to modern day, it is unsurprising that in *Sexing the Body* she attempts to explode the 'myth' of the binary gender system. Interestingly she touches on some of the historical law suits connected with the intersexed, enhanced by some amusing cartoons drawn specifically for this book. However, although she mentions some recent cases involving those with an intersex/DSD condition, she does not consider current law from any jurisdiction to any large extent.

⁵⁴ Human Rights Commission of the City & County of San Francisco, 'A Human Rights Investigation into the Medical "Normalisation" of Intersex People' (April 28, 2005) <http://www.isna.org/files/SFHRC_Intersex_Report.pdf>accessed 24 March 2015.

⁵⁵ PA Lee and others, 'Consensus Statement on Management of Intersex Disorders' (2006) 118 Paediatrics 488.

⁵⁶ Alice Domurat Dreger *Intersex in the Age of Ethics* (Univ Pub Group 1999).

⁵⁷ Anne Fausto-Sterling *Sexing the Body* (Basic Books 2000).

⁵⁸ Anne Fausto-Sterling, 'The Five Sexes: Why Male and Female are Not Enough' [1993] *The Sciences* 20.

In this vein, amongst British authorship is 'Intersex and After',⁵⁹ a collection of articles written from a number of perspectives.⁶⁰ Although interesting to read this does not make much headway into the legal dimensions of the conditions.

No literature review in this field would be complete without mention of John Money's once acclaimed work, *Man and Woman, Boy and Girl*,⁶¹ and its antidote, 'The True Story of John/Joan'.⁶² In the light of this latter work and articles from a variety of sources including socio-legal, gender studies and medical, significant aspects of Money's book have now been largely discredited, and reading the book after studying critical arguments of it is an uncomfortable experience. The book is written in a very authoritarian and convincing manner, to 'transcend several traditional specialties'.⁶³ It demands to be followed, and doctors who wanted to help their intersexed patients did just that. Sadly this blind faith was not justified, and with hindsight it is possible to highlight a number of discrepancies and what appear to be untruths in the text.⁶⁴ Further, it is possible to identify flaws in the arguments presented.

It is clear that Money and Ehrhardt recognised the effects of gender imprinting due to exposure of the fetus to hormones *in utero*, but despite this they convinced all concerned to gender reassign intersex patients before the age of two years, disregarding the pre-birth stage completely. In recent times, the preterm exposure to hormones has been identified as increasingly important in the child's gender and

⁵⁹ Iain Moreland (ed) 'Intersex and After', (2009) 15 (2) GLQ.

⁶⁰ Including writings from intersex activists as well as writings from the medical profession.

⁶¹ John Money and Anke A Ehrhardt, *Man and Woman, Boy and Girl: Gender Identity from Conception to Maturity* (Soft Cover edition, Jason Aronson Inc 1996, Original Publication John Hopkins University, 1973).

⁶² John Colapinto, 'The True story of John/Joan' [1997] *The Rolling Stone* (11 December 1997) 54. www.healthyplace.com/gender/inside-intersexuality/the-true-story-of-john-joan/ accessed 25 May 2015.

⁶³ Money (n 61) preface xv.

⁶⁴ *ibid.* Chapter seven discusses the John/Joan experiment which includes quotes which do not tally with other accounts.

sexuality.⁶⁵ Indeed, that was the situation before Money's 'unorthodox' theory was promoted.

2.1.6 Intersex Organisations

As will be discussed in the methodology, some organisations are of more assistance to both researchers and those with intersex/DSD.⁶⁶ Some websites carry detailed literature from the scientific to human rights approaches. The former Intersex Society of North America (ISNA) website (which is still accessible) contains links to various academic writings.⁶⁷ They also touch on ethical and legal aspects, but they tend to address the former rather than the latter.

2.1.7 Summary

A detailed investigation into global literature has indicated that, with the one exception of informed consent to genital assignment surgery, legal analysis in regard to the intersexed is a relatively scarce commodity. As there is now a myriad of writings on the views of the intersexed on their enforced treatment;⁶⁸ this thesis will only lightly touch on this area.⁶⁹ Instead it will concentrate on analysing the law in relation to specific procedures and treatments that an intersexed person may undergo. In this respect it is hoped that this thesis will add to current literature in the field.

⁶⁵ Celina CC Cohen-Bendahan, Cornelië van de Beek, Sheri A Berenbaum 'Prenatal Sex Hormone effects on Child and Adult sex-typed Behavior: Methods and Findings' (2005) 29 *Neuroscience and Biobehavioral Reviews* 353 http://psych.colorado.edu/~carey/pdfFiles/CAH_Berenbaum01.pdf accessed 24 May 2015.

⁶⁶ In this respect AISSG website is perhaps the most informative and helpful of those currently based in the UK. <http://www.aissg.org/> accessed 24 May 2015.

⁶⁷ Intersex Society of North America <http://www.isna.org/books?from=10> accessed 24 May 2015. As discussed in the introduction, this organisation does not exist in this form any longer, so the publications lists have not been updated. ISNA became Accord Alliance and therefore up-to-date literature can be found on this website. <http://www.accordalliance.org/> accessed 24 May 2015.

⁶⁸ Cheryl Chase Letters from Readers. *The Sciences* [1993] July/August, 3. www.isna.org/articles/chase1995a accessed 29th December 2013.

⁶⁹ References to this will be made in chapters five and eight.

2.2 Methodology

The methodological approach I adopted was designed to seek out and assimilate information concerning any legal discrimination that the intersexed may face in the healthcare environment in England. Further, it was formulated to assist in the analysis of specific aspects of English law which frame the relationship of current medical practice and the intersexed. In this respect, a systematic methodological approach to *legal* analysis was required. However, by its nature, my research also encompassed aspects of health and social science. Therefore, in order to conduct this thesis, I developed a blended methodological approach. I use the term ‘blended’ as opposed to ‘mixed’ because ‘mixed methods research’ has a specific meaning in its approach to utilising both qualitative and quantitative methodologies.⁷⁰ For this thesis, both methods were employed primarily to identify areas for further in-depth doctrinal research, as opposed to being finite in their own right.

2.2.1 Doctrinal Research Analysis

As the identification and analysis of current English legislation and case law were central to my research, the underpinning methodology utilised was that of doctrinal research analysis. In the past, academics from different fields have looked down on the lack of methodology that lawyers employ during their research.⁷¹ This may be due to the fact that lawyers consider doctrinal methodology to be self-explanatory, and have not discussed its application in depth as part of their research findings. Although it is rare to find a detailed methodology section in a pure doctrinal research paper,⁷² it has been said that doctrinal research is as ‘intellectually rigorous’ as scientific research if properly undertaken.⁷³

⁷⁰ Larry B Christensen, R Burke Johnson, Lisa A Turner, *Research Methods, Design, and Analysis* (11th, Pearson, 2011) 380.

⁷¹ Paul Chynoweth, 'Legal Research' in Andrew Knight and Les Ruddock (eds), *Advanced Research Methods in the Built Environment* (Wiley-Blackwell, 2008)

⁷² *ibid* 37.

⁷³ Terry Hutchinson, 'Doctrinal Research Researching the Jury' in Dawn Watkins and Mandy Burton (eds), *Research Methods in Law* (Routledge, 2013) 11.

Doctrinal analysis has been described as the ‘core legal research method’,⁷⁴ to be found in ‘all but the most radical forms of legal research’.⁷⁵ It is best described as a systematic exposition of rules governing a particular legal category, analysis of the relationship between the rules and explanation of the areas of tension.⁷⁶ However, my aim was not just to identify and analyse current English law, but rather to evaluate ‘the adequacy of existing rules’⁷⁷ and to recommend amendments, should this be possible. In this respect doctrinal research is inadequate to build an all-encompassing picture of the effects of law on society (and in particular on the intersexed); therefore it was important to incorporate other methodologies into my research strategy.

2.2.2 Comparative Law Methodology

The paucity of English law which deals directly with intersexed conditions⁷⁸ rendered it necessary to consider whether a comparative law methodology would assist, as in the words of Professor Markesinis, ‘(l)ooking at foreign law can bring a deeper understanding of problems (...) perhaps even unexpected ideas for solving them’.⁷⁹ In his article,⁸⁰ Markesinis explains in some detail the dangers of ‘insularity’, particularly where novel points of law occur and when time and the cost of legal action in the UK might have been reduced, if not eradicated, had lawyers paid

⁷⁴ Terry Hutchinson and Nigel Duncan, ‘Defining and Describing what we do: Doctrinal Legal Research’ (2012) 17 (1) Deakin Law Rev 83, 85.

⁷⁵ Chynoweth (n 71) 31.

⁷⁶ Hutchinson (n 73) 101 quoting the findings of the ‘Pearce Committee’ in 1987.

⁷⁷ *ibid.*

⁷⁸ One exception to this is the case of *W v W (nullity: gender)* [2001] 1 FLR 324, in which an intersexed woman successfully defended a decree of nullity of her marriage under s 11 (c) Matrimonial Causes Act 1973, on the grounds that she was not female when entering the marriage. In contrast to *Corbett v Corbett* [1970] 2 All ER 33, the wife in *W*, although registered as boy at her birth in 1947 and had a male karyotype 46 XY, was thought to suffer from partial androgen insensitivity, being ‘female for the purposes of her marriage to the Applicant.’ [363G] (Charles J).

⁷⁹ Basil Markesinis, ‘Comparative Law – A Subject in Search of an Audience’ (1990) 53 (1) MLR 21.

⁸⁰ *ibid* 4. This was an expanded version of the Shimuzu lecture delivered at the London School of Economics, November 30th 1989.

attention to cases from other jurisdictions.⁸¹ In fact, it has been said that ‘(l)egislators all over the world have found that on many matters good laws cannot be produced without the assistance of comparative law’.⁸²

A number of jurisdictions were initially consulted: the United States, Columbia, New Zealand, Germany and Australia, as well as various countries in Asia. All of these have recorded law in regard to the intersexed. Whilst noting the divergence of legal processes that lie within these countries, for example Germany has a civil code which is ‘very logical’ in its construction⁸³ whereas the majority of countries considered are common law jurisdictions, it was important to consider international jurisprudence to identify whether English law was out of step in respect of its treatment of the intersexed. However, there is a scarcity of case law and legislative measures *internationally*; therefore, to embrace a comparative study with one other jurisdiction would have yielded limited results. Nor would it have been appropriate to adopt a full comparative law methodology for the number of jurisdictions that were consulted, as such a methodology requires:

delv(ing) beyond judicial decisions, doctrinal writings and the black-letter law of code and statute and reach(ing) into the ill-defined region of ‘deeper structures’ where law meets philosophy, sociology and social culture.⁸⁴

In terms of ‘delving’ into social cultures,⁸⁵ it is to be noted that the cultural acceptance of the condition 5-alpha-reductase deficiency (5-ard) in isolated communities,⁸⁶ notably in the Dominican Republic, has allowed these children to obtain a specific social status not currently awarded to such children in the UK or the

⁸¹ *ibid* 3. In particular, the discussion of the tort law case *Dutton v Bognor Regis UDC* [1972] 1 QB 373 and its successors, and the ‘correct’ approach already established in German courts.

⁸² K Zweigert & H Kotz, *An Introduction to Comparative Law* (Tony Weir tr, 3rd edn, OUP 1998) 16.

⁸³ H Patrick Glen, *Legal Traditions of the World* (5th edn, OUP 2014) 153.

⁸⁴ Vernon Valentine Palmer, ‘From Leretholi to Lando: Some Examples of Comparative Law Methodology’ (2004) 24 (2) *Global Jurist Frontiers* 1, 6.

⁸⁵ *ibid*.

⁸⁶ This is discussed in chapter three at 3.5.3.

US.⁸⁷ This acceptance comes from the knowledge and understanding of the condition within the locality.⁸⁸ Whilst noting that ‘there are dangers in assuming that a solution considered right for one country will automatically be appropriate for another’,⁸⁹ it is submitted that English society would benefit from offering a more liberal approach to gender allocation at birth to those children born with genital difference.⁹⁰

It will be seen that during various developmental stages of an intersexed person’s life, different jurisdictions have taken the lead. In terms of case law on informed consent of the intersexed patient, Columbia leads the way,⁹¹ whilst New Zealand is a good model for legislative measures on informed consent in healthcare systems.⁹² When considering gender documentation, recent legislation in both Australia and Germany has highlighted the need for similar reforms in the UK.

Taken as a whole it does not appear that England is out of line with other jurisdictions,⁹³ but neither does that mean that English law is as supportive as it should be. It appears that English law might benefit from considering a more flexible position in regard to traditional binary sex classifications of its citizens.⁹⁴

⁸⁷ This will be discussed in chapter four.

⁸⁸ It is also noted that, a number of native American societies have a gender status known as *berdache*. They ‘occupy an alternative gender role that is a mixture of diverse elements’. Walter L Williams, *The Spirit and the Flesh: Sexual Diversity in American Indian Culture* (Beacon Press, 1986), 344. <http://www.worldpolicy.newschool.edu/wpi/globalrights/sexorient/williams.html> accessed 24 July 2015. These people have a high status within their cultural groups and are therefore awarded full respect. William G Roy, *Making Societies* (Pine Forge Press 2001) 113.

⁸⁹ Michael D Kirby, ‘A Patient’s Right of Access to Medical Records’ (1996) 12 (1) J Contemp Health Care and Policy 93, 93.

⁹⁰ This would include a more flexible system of issuing birth certificates that could be adapted in the light of medical changes as a child develops. This is discussed in the concluding chapter.

⁹¹ These cases are discussed in detail in chapters five and seven.

⁹² As discussed in chapter five.

⁹³ In fact there is some evidence to suggest that the UK has been more supportive of upholding the integrity of the child with genital difference, then in some other jurisdictions.

⁹⁴ As discussed in the concluding chapter.

2.2.3 Empirical Research

According to Brownsword, ‘theoretical work without any empirical content is hollow and that empirical work without supporting theory is shallow’.⁹⁵ As empirical research helps us to ‘build our theoretical understanding of law as a social and political phenomenon’,⁹⁶ it was my intention from the outset to gather first-hand empirical evidence in order to investigate areas of tension between law and society in respect of the intersexed. For this, primarily qualitative research was undertaken. There are several different methodologies that might be employed to achieve this, and for my thesis I adopted a phenomenological approach.

2.2.3.1 Phenomenology

Phenomenology, which has a long-standing history in psychology,⁹⁷ studies the conscious lived experience of a phenomenon from the perspective of the individual, in order to ascertain the meaning of that lived experience. Examinations of lived experiences are necessary for ‘challenging structural or normative assumptions’,⁹⁸ such as legal rules, which are ‘normative in character’.⁹⁹ This approach is deemed particularly suitable for understanding and describing life experiences and is

⁹⁵ Roger Brownsword as quoted by Rob van Gestel, Hans-W Micklitz and Miguel Poiars Maduro, EUI Working Papers, *Methodology in the New Legal World* (European University Institute, Law 2012) 7.

⁹⁶ Hazel Genn, Martin Partington and Sally Wheeler, *Law in the Real World: Improving our Understanding of How Law Works: The Nuffield Inquiry on Empirical Legal Research* (The Nuffield Foundation 2006) www.ucl.ac.uk/laws/socio-legal/empirical/docs/inquiry_report.pdf accessed 2 April 2015.

⁹⁷ Larry B Christensen, R Burke Johnson and Lisa A Turner, *Research Methods, Design, and Analysis* (11th, Pearson, Boston 2011) 368.

⁹⁸ Stan Lester, *An Introduction to Phenomenological Research* (Stan Lester Developments, 1999) www.sld.demon.co.uk/resmethv.pdf accessed 2 April 2014.

⁹⁹ Chynoweth (n 71) 30.

frequently adopted in health and social care studies as being a method to elucidate important aspects of healthcare practice.¹⁰⁰

There are different versions of phenomenology, but according to Denscombe,¹⁰¹ two main types are utilised. The original version belongs to the European school of philosophy, as founded by Edmund Husserl (1859-1938), and adapted by Jean-Paul Sartre and Martin Heidegger. This version investigates the ‘essence of human experience’.¹⁰² By contrast, the North American approach –a derivative of the European version as developed by Alfred Schultz¹⁰³– concentrates on describing ‘*what* is being experienced’ as opposed to describing the essence alone.¹⁰⁴ The aim of my research was not to elucidate the lived experience of those with intersex/DSD conditions *per se*, but to highlight areas of tension in current English law; therefore this second approach was adopted for the purposes of this thesis.

Phenomenology frequently encompasses a narrative inquiry approach, which ‘involves the collection and development of stories’.¹⁰⁵ The advantage of this particular approach, as opposed to other qualitative approaches, is that it requires lower numbers of participants, for the research to be valid. Indeed, it is acknowledged by writers that there is often a difficulty in obtaining suitable participants who have specific experiences of the phenomenon in question.¹⁰⁶

¹⁰⁰ An excellent example of this can be found in the project conducted by Jan Pascal. Jan Pascal, ‘Phenomenology as a Research method for Social work Contexts: Understanding the Lived Experience of Cancer Survival’ (2010) 9 (2) *Currents: New Scholarship in the Human Services* 1.

¹⁰¹ Martin Denscombe, *The Good Research Guide* (4th, OUP 2010) 100.

¹⁰² *ibid* 101.

¹⁰³ Schultz, was born in Vienna in 1899, and whilst an early scholar was influenced by Husserl’s work, and that work of Max Weber. In 1932, Schultz published *Der sinnhafte Aufbau der sozialen Welt* (The Phenomenology of the Social World). The Nazi occupation of Austria led to Schultz emigrating to New York in 1939, where he continued his work.

¹⁰⁴ Denscombe, (n 101) 102.

¹⁰⁵ J Gray ‘Narrative Enquiry’ (1998) an unpublished paper as quoted in Judith Bell, *Doing Your Research Project* (5th, OUP 2010) 19.

¹⁰⁶ Magnus Englander, ‘The Interview: Data Collection in Descriptive Phenomenological Human Scientific Research’ (2012) 43 *Journal of Phenomenological Psychology* 13, 19.

As Pascal points out,¹⁰⁷ there are challenges to be faced in every methodological tradition. One of the difficulties in utilising this methodology for research is balancing the maintenance of purity within the technique –namely, minimal influence from the researcher whilst upholding ethical codes of conduct. Ethical concerns include, amongst others, principles of informed consent, confidentiality and avoidance of deception. Ethical approval was sought and given by the University’s Ethics Committee before interviews were conducted,¹⁰⁸ but in order for such approval to be secured, a questionnaire indicating the content and structure of interviews had to be devised, submitted and approved. This was helpful in many ways, as potential research subjects were happier about answering a pro forma set of questions sent prior to the formal interview than if questions were ‘sprung’ on them in the context of the interview. However, in a pure phenomenological/narrative inquiry approach, no structure would be given to the interviewee; they would simply be allowed to talk. For this reason, the interviewee was always given an opportunity to ‘discuss anything else’, hence allowing them the opportunity to explore their experience without being constrained by the more technical questions posed.

The more substantial difficulty this research faced was that of data sampling and accessing suitable participants. At the outset, I had wanted to make contact with as many intersex/DSD people as possible, preferably from the UK. This was, as anticipated, quite time-consuming. It is understandable that individuals are reluctant to talk on intimate aspects as all too often these people have been interviewed with the goal of writing a sensationalist type of article for newspapers or magazines. Indeed, for one organisation I had to sign a disclaimer that the interview was not to be used in the context of ‘a magazine story’ in case I was attempting to glean information for commercial ends. Likewise, I was careful to stress that I would honour data subjects’ anonymity, as it appears (not just from my own research but others) that an intersex person will not want to discuss their condition openly for the (not unreasonable) fear of being ‘outed’ in the public domain. Perhaps for this reason the majority of individuals who came forward were from academic research backgrounds themselves. This reduced the potential field significantly.

¹⁰⁷ Pascal (n 100) 13.

¹⁰⁸ Appendix E.

In order to seek a balanced view, I also contacted medical specialists in this field. It was not surprising, though a little disappointing, that all those I contacted either referred me to someone else or informed me that they were too busy to participate. For this reason, this thesis has not been able to discuss novel medical thinking within the UK which may be of assistance to the intersexed.

Of most surprise in this respect were the varying responses I received from my initial inquiries to intersex help groups. Some groups were very proactive and kindly promoted my research to their members. In this regard I must mention and give thanks to AISSG, DSD/families and IntersexUK, who assisted in moving my project forward. Some groups (such as the Turner Syndrome Support Society) felt that they could not assist me with my research as they perceived it, as they did not consider themselves to be intersexed (which they are not), but women. In this respect they did not see that they were affected by legal issues.¹⁰⁹ A number of other groups did not even reply to my initial, and follow-up, correspondence. This is not a unique situation as other researchers have been faced with the same quandary.¹¹⁰ Indeed, one of my informants explained that they had ‘drawn a blank’ from a support group when they, as the parent of a DSD child, sought help and so they decided to ‘go it alone’.¹¹¹ This I found to be disappointing. It is one thing for support groups to jealously guard their membership from the probing investigations of researchers, but another to ignore its potential membership. Further, if society is to be educated, it needs to listen to those who are intersexed. If society has no knowledge or understanding of these conditions, how can it be proactive in welcoming these people into its system? It cannot. Law cannot be changed without debate. Parliament is inundated with work and does not have the time to consider issues lacking strong political force or strong public sentiment. If there is no evidence and no witnesses, then there will be no

¹⁰⁹ Email from Turner Syndrome Support Society to author (13 September 2011).

Albeit that within the field of abortion the rights of Turner Syndrome (TS) women are significantly impacted upon, as discussed in chapter six. Further they are the significant benefactors of assisted Reproductive Technology through donor gametes. Of further interest, one of the respondents to my questionnaire to doctors noted that ‘One patient with mosaic TS requested a letter to confirm that she is fit and healthy as a travel insurance company was not keen on offering her Travel Insurance!’ (Clinic correspondent 12). This appears to be discrimination.

¹¹⁰ Kerry (n 17).

¹¹¹ Interview with B, mother of DSD child (Kent, 14 September 2012).

voices heard outside Parliament. This will mean no debate within Westminster, and consequently no legislation in this area.¹¹²

Ultimately, I extended my search for potential interviewees to English speaking countries abroad, including the United States and Ireland. I used the information they gave me to ascertain whether their legal systems have something to offer English law. Eventually, a mixture of face-to-face interviews and email correspondence, and additionally reading first-hand accounts that have been posted on the internet, helped me to identify a number of important issues surrounding the discrimination of those with an intersex condition in the healthcare context.

2.2.3.2 Quantitative Data

At the outset of this research, I appreciated that it would not be possible to analyse legal provisions in depth if I did not also understand the background of my interviewees. For this reason, the methodology incorporates the interdisciplinary perspectives of science and medicine, in as far as they relate to intersex/DSD conditions. In addition to reviewing the literature in the field, I wanted to investigate specific healthcare issues. To this end, I sent questionnaires to all privately funded clinics that specialised in pre-implantation genetic diagnosis (PGD) and fertility treatment.¹¹³ There was a 28 per cent return rate of questionnaires overall. They identified that the majority of intersex conditions mentioned in this thesis had been seen at fertility clinics,¹¹⁴ with the majority of conditions being supported by treatment, often successfully.¹¹⁵

The results of these questionnaires were exciting, if not startling. Albeit the focus was on fertility treatment and detection of intersex fetuses by PGD, the impact of the

¹¹² To this end IntersexUK made an impact with lobbying, but this did not progress as quickly as hoped. With Parliament newly elected, it remains to be seen whether it will be revisited in any immediate future.

¹¹³ There are a limited number of clinics that specialised in PGD. At the time the surveys were sent, some 18 clinics offered this service. Additionally I selected a further 50 clinics (from a range of postcodes) to bring the total number of surveys sent out to 68 in total. (I had received ethical approval to do so). In received 19 answers in total (28%). Of those 19 replies, 4 clinics offered PGD, some 22% of responses from these clinics.

¹¹⁴ Congenital Adrenal Hyperplasia, Complete or Partial Androgen Insensitivity Syndrome, Klinefelter Syndrome Turner Syndrome, Swyer's Syndrome and other Gonadal Dysgenesis, Hypospadias.

¹¹⁵ Donor gametes were often used to assist treatment. The results of these questionnaires will be discussed in chapters six and ten.

responses was significant in that they identified that even within the medical sphere, there is an inconsistent knowledge of intersex/DSD conditions. It was clear from the replies received that some correspondents did not appreciate what the term ‘intersex’ encompassed, and in at least one response, it was clear that there was some confusion between intersex and gender dysphoria. Whilst acknowledging that the two conditions can overlap, I was not expecting this to come to the fore in the context of clinical specialism. To investigate this further, I contacted a number of people who work as healthcare professionals, but *not* in the field of intersex/DSD, and asked them simply what they understood, if anything, by the term intersex/DSD. These professionals included nurses, midwives and sonographers. Their answers confirmed what I had previously discovered in the questionnaires –that when asked directly, the vast majority had not heard of either ‘intersex’ or ‘DSD’.¹¹⁶ I was not surprised to find that there is a lack of knowledge and understanding in those *without* any medical training, but I was surprised that within the medical profession there seemed comparative ignorance of such conditions.¹¹⁷ Here it can be noted that there is much to do to educate all.

2.2.4 Summary

The blended methodological approach I employed assisted in developing an awareness, knowledge and analysis of legal tensions between the intersexed and the healthcare environment. These will be discussed during the remainder of this thesis.

Regardless of any legal changes that should or should not be obligatory to prevent discrimination in English law, it is clear that a significant amount of work is required

¹¹⁶ There was normally a positive response when asked if they understood the term ‘hermaphrodite’ but what this meant they were unaware of. Only one of these interviewees gave a positive response, in that as a midwife she knew of one baby born with genital difference, but the baby was ‘whisked off’ for further investigation, and so she did not know the outcome of this child.

¹¹⁷ Tal Marom, David Itskoviz, Ishay Ostfeld, ‘Intersex Patients in Military Service’ (2008) 173 *Military Medicine* 1132, where a discussion of intersex and Complete Androgen Insensitivity Syndrome (CAIS) suggests that the terms refer to one and the same thing, whereas, CAIS is just one of many conditions.

in order to educate *everyone* about intersex/DSD conditions. Indeed, this is one of the demands of the Third International Intersex Forum.¹¹⁸

In this respect it is appreciated that one of the major obstacles to overcome is the diversity of conditions involved. The ‘science’ of intersex would be easy to discuss if there was only one cause, but there are many, some of which are unknown. Their effects lead to a multiplicity of outcomes. This makes passing any effective and encompassing legislative changes challenging, if not impossible. That is, however, no reason not to attempt it.

In the next chapter, I discuss various intersex conditions from a medical prospective, before considering, in chapter four, the relationship between the intersexed and society. From chapter five onwards, I investigate aspects of English law and consider whether they discriminate against the intersexed. The concluding chapter proposes various recommendations in the light of my research.

¹¹⁸ ‘To raise awareness around intersex issues and the rights of intersex people in society at large.’ TIFF, Appendix A.

Chapter Three: Medical Science and Intersex Conditions

3.1 Introduction

It is not possible to assess whether English law discriminates against the intersexed without considering the nature and effects of various intersex/diversity of sex development (DSD) conditions themselves; therefore this chapter investigates the genetic background to various intersex/DSD conditions. By considering the nature and effect of these conditions, this chapter aims to identify potential areas for discrimination against sufferers. As will be noted, although all DSD conditions have medical implications, some have few, if any, *legal* difficulties for individuals. Conversely, some conditions have wide-ranging effects, transforming not just physical bodies, but also socio-legal identities. These individuals are prone to facing a lifetime of discrimination, therefore it is important to assess whether there is any method of redress in English law.

The diverse nature of these conditions makes classification difficult, but it is generally accepted that such conditions can be subdivided into the following groups: congenital development of ambiguous genitalia (46, XX DSD); congenital disjunction of internal and external sex anatomy (46, XY DSD); incomplete development of sex anatomy sex chromosome DSD; and sex chromosome anomalies.¹ These subdivisions intertwine in respect of *legal* tensions that arise, therefore during this thesis it will be pertinent to rearrange the conditions into groupings that best correspond to potential legal anomalies faced.

This chapter commences by considering the relationships between genetic errors and resulting intersex conditions. I then discuss individual conditions in detail, starting first by considering conditions that arise due to alterations to the *karyotype* (chromosomal arrangement), before turning to conditions occurring as a result of alterations to specific *genes*. Whilst discussing the biological aspect of each

¹ This is the recently revised nomenclature; see Peter A Lee and others, 'Census Statement on Management of Intersex Disorders' (2006) 118 (2) *Pediatrics* 448. <http://pediatrics.aappublications.org/content/118/2/e488.full.pdf+html> accessed 16 April 2015.

condition, related ethical and legal tensions will be indicated. These will be explored in further detail in subsequent chapters.

3.1.1 Scientific Background

Scientists estimate that the human body is composed of approximately ten trillion cells.² Contained inside the nucleus of the vast majority of each of these cells are chromosomes which are complex packets of DNA (deoxyribonucleic acid) mixed with proteins.³ DNA has been described as ‘an organic blueprint or book of recipes’.⁴ Individuals inherit half of their nuclear DNA from their father, and half from their mother.⁵ A person’s complete set of nuclear DNA is called their genome, and this genome contains all the instructions needed to build and maintain the individual that it creates.

In the usual human pattern, there are 23 pairs of chromosomes, 22 pairs of autosomes and one ‘pair’ of sex chromosomes in the body. The sex chromosomes are responsible for deciding whether the new life will be male or female: an XX configuration will traditionally be found in females, XY in males. Each chromosome is composed of a number of shorter segments known as genes. An individual gene carries the code for the synthesis of a specific protein. Scientists have yet to identify the total number of genes in our bodies, but they currently estimate it between 20,000 and 25,000. This figure indicates the significant potential for genetic mutations to

² 1,000,000,000,000 cells (1 trillion is 1000000000000 or a million millions).

³ Some 3cm in length if fully stretched out.

⁴ deCODEme, ‘About Genetics what are Genes?’ (www.decodeme.com/genetic-code) accessed 11 May 2011.

⁵ Although there is a crossover of genetic material from gestational mother to child, and children who are born as a result of egg donation or surrogacy agreements might have extra genes given to them by their gestational mother, in reality this is a very small amount of the total DNA a child will have and is unlikely to have any real effect. Julie Kranka ‘Chimeras, Mosaics, and Other Fun Stuff’ 13 July 2011, <http://genetics.thetech.org/ask/ask420> accessed 24 November 2014.

Additionally humans and other complex organisms also have a small amount of DNA in mitochondria. Mitochondria are the powerhouses of cell-generating, the energy the cell needs to function properly. Everyone’s mitochondrial DNA is inherited from their mothers.

occur in any of us. A slight alteration in the protein recipe accounts for the differences in height and eye colour and so forth. Some of us are born with the potential to grow tall, others to be intelligent, some to run like the wind. This observation is general to us all, and as such does not need further discussion. However, genetic modifications in approximately 1 in 4500 of us lead to alterations in genital anatomy; whereas most of us are recognisably a ‘boy’ or a ‘girl’ at birth, not all of us are.⁶ There are a multitude of causes for this. These will now be investigated.

3.2 Alterations to the Karyotype: Sex Chromosome Anomalies – DSD Associated Conditions

In early embryogenesis, all fetuses appear to have identical genitals, regardless of whether they are male or female. Eight weeks after fertilisation, the fetus will develop male or female genitals, *primarily* due to their genetic make-up (XX or XY). In this respect, the mammalian Y chromosome has been described as ‘a crucial factor for determining sex in mammals’,⁷ as the Y chromosome ‘encodes a testis-determining factor’,⁸ necessary for establishing the male phenotype.⁹ But although the presence of a Y chromosome will *usually* lead to the creation of a male, it is not necessarily so.¹⁰ Moreover, it is not the Y chromosome per se, but rather a specific gene, the SRY gene,¹¹ which resides in the Y chromosome which is responsible. Discovered in 1990, the SRY is just one of a number of genes that play a part in

⁶ V Pasterski, P Prentice, IA Hughes, ‘Impact of the Consensus Statement and the New DSD Classification System’, (2010) 24 (2) *Clinical Endocrinology & Metabolism* 187.

⁷ Scott F Gilbert, *Developmental Biology* (6th, Sinauer Associates, 2000)
<http://www.ncbi.nlm.nih.gov/books/NBK9967/> accessed 24 April 2014.

⁸ *ibid.*

⁹ This organises the potential gonads (*gonadal primordia*) into testes rather than ovaries.

¹⁰ As will be seen there are a number of conditions which present anatomical conditions other than the expected norm. Likewise, there are a number of transgender persons who reversed their phenotype with the aid of surgical intervention.

¹¹ SRY (‘sex-determining region Y’).

gonadal differentiation, but the SRY gene ‘tip(s) the balance in favour of the testis-specific pathway’.¹²

If no Y chromosome is present, the female reproductive system and genitals develop automatically. Once the ovaries are formed they produce oestrogen, which aids in the synthesis of the Müllerian duct into the uterus, oviducts and upper end of the vagina. The presence of the Y chromosome prevents this from happening by creating testes, which in turn synthesise two hormones, the anti-Müllerian duct hormone and testosterone. These prevent the full female physical development.¹³ If one Y chromosome is present, even if surrounded by a number of X chromosomes, for example 49 XXXXY,¹⁴ the phenotype is still likely to be male, albeit this individual may well develop a female gender alignment.

It should be mentioned that in the past, scientific writers have noted the ‘Y-effect’, concluding that the ‘dominant’ Y prevents the default female phenotype. By contrast, more recently, feminist writers have argued that it is not the presence of a ‘dominant’ Y chromosome that creates maleness, but rather that the Y chromosome has a ‘mutant’ element preventing potential gonads developing into ovaries.¹⁵ Regardless of academic debates for or against the power of the Y chromosome, the net effect is the creation of a binary system of sex.

¹² Stefan White and Andrew Sinclair, ‘The Molecular Basis of Gonadal Development and Disorders of Sex Development’ in John M Hutson Gary L Warne, Sonia R Grover (eds), *Disorders of Sex Development* (Springer – Heidelberg, 2012).

¹³ Anti-Müllerian duct hormone (AMH: also referred to as Müllerian-inhibiting substance, MIS) destroys the Müllerian duct, whereas testosterone masculinises the fetus, stimulating the formation of the penis, scrotum, and other portions of the male anatomy, as well as inhibiting the development of the breast primordia. ‘Thus, the body has the female phenotype unless it is changed by the two hormones secreted by the fetal testes.’ Scott F Gilbert, *Developmental Biology* (6th, Sinauer Associates, 2000) <http://www.ncbi.nlm.nih.gov/books/NBK9967/> accessed 24 April 2014.

¹⁴ This arrangement is occasionally found in nature. It is a variety of Klinefelter Syndrome, which is discussed later in this chapter.

¹⁵ Jennifer A Marshall Graves, ‘Human Y Chromosome, Sex Determination and Spermatogenesis – a Feminist View’ (2000) 63 (3) *biolreprod* 667, 675.

Missing or extra chromosomes (either autosomes or sex chromosomes) will cause a divergence from the standard human development and spontaneous abortion often occurs in the early stages of pregnancy.¹⁶ Children with a divergence of sex chromosomes in some or all of the cells will have an intersex/DSD condition. In addition to spontaneous abortions, a number of medically induced abortions take place each year on the grounds of sex chromosome anomalies.¹⁷ In spite of this, many such babies survive and grow up never knowing they have such a condition.¹⁸ This poses the question as to whether it is ever ethical to abort a fetus on such grounds alone. Further, those who do know of their altered karyotype may not perceive themselves as intersexed,¹⁹ and indeed doctors would not regard them as such. However, they are a DSD.²⁰ Consequently, it is submitted that discrimination occurs before birth, via the law on pre-implantation genetic diagnosis (PGD) and abortion. This will be discussed in depth in chapter six. We shall now consider some of these individual conditions in detail.

¹⁶ The most well-known 'extra chromosome condition' is trisomy 21 aka Down's syndrome. This condition has many health and developmental difficulties associated with it, but it does not bring difficulties in terms of gender recognition. Although fertility is reduced overall, both Down's males and females will be able to procreate naturally, often to the horror of their parents and/or carers. Where this occurs there is a high chance of a miscarriage, or if the pregnancy continues, that the child conceived will also be a Down's baby. A number of court cases have seen parents of such a female child seeking to have their daughter sterilised for fear that promiscuous behaviour will lead to an unwanted pregnancy. In Australia this has been outlawed by *Marion's Case, (sterilization of intellectually disabled child) (Department of Health and Community Services v JWB and SMB)* (1992) 175 CLR 218), but in the House of Lords in the case of *F v West Berkshire HA* also known as *Re F (mental patient: sterilisation)* [1990] 2 AC 1, which still is good law, albeit that it was heard before the Human Rights Act 1998 was passed, sterilisation of the mentally disabled is still lawful in England and Wales. This will be discussed in more depth in chapter eight.

¹⁷ The precise number is difficult to identify, as one fetus may well be allocated to several different anomaly groups, but see for example <http://www.swcar.org.uk/data-open/outcome-region-public.html> accessed 5 April 2014.

¹⁸ PA Jacobs, JA Strong 'A case of human intersexuality having a possible XXY determining mechanism' (1959) 163 Nature 302.

¹⁹ Email from Turner Syndrome Support Society to author (13 September 2011). They are very clear that TS women are not intersexed. However, some KS men do identify as intersexed. Email from Stefan Schwarz to author (27 May 2012).

²⁰ It is not unknown for researchers to also link in those with a chromosomal arrangement of XXX also known as trisomy X. These individuals will develop a female phenotype.

3.2.1 Klinefelter Syndrome (KS)

KS is a congenital condition that occurs when a male has extra X chromosomes. According to Diamond and Watson,²¹ KS is the most frequently found sex chromosome disorder, with an estimated 1 in 650 males identified as suffering from this syndrome,²² and is the cause of 1 in 300 spontaneous abortions.²³

The syndrome was first identified in 1942 by Dr Harry Klinefelter Jnr (1912-90), an endocrinologist who worked at Massachusetts General Hospital.²⁴ Klinefelter had developed previous works by Richard Altmann in 1895 and Walther Berblinger in 1934. They all described a series of men who were around six feet tall, had small testes and were unable to produce sperm. These men also had sparse facial and body hair, but by contrast had gynaecomastia.²⁵

The usual karyotype identified with this condition is 47 XXY, but different arrangements are also detected: 47XYY, 48XXXY, 48XXYY, 49XXXXY or mosaic versions e.g. 47XXY/46XY. Additional X chromosomes are the result of a random error during the formation of either egg or sperm. During meiosis (a two-stage cell division for reproduction), the pairs of chromosomes should divide to create units of 23 chromosomes (22 autosomes and one sex chromosome – 22X or 22Y). However, KS occurs because in either gamete the sex chromosomes stay as a pair (22XX, or

²¹ Milton Diamond, and Linda Ann Watson, 'Androgen Insensitivity Syndrome and Klinefelter's Syndrome' (2004) 13 (3) Child Adolesc Psychiatr Clin N Am 623.

²² J Nielsen, M Wohler, 'Sex Chromosome Abnormalities found among 34,910 Newborn Children: results from a 13-year incidence study in Aarhus, Denmark.' (1991) 26 Birth Defects Orig Artic Ser 209. A number of men go through life never knowing that they have KS.

²³ Magdalena Bielanska, Seang Lin Tan and Asangla Ao, 'Fluorescence in-situ hybridization of sex chromosomes in spermatozoa and spare preimplantation embryos of a Klinefelter 46,XY/47,XXY male' (2000) 15 (2) Human Reproduction 440.

²⁴ It was only after the development of chromosomal analysis techniques that the genetic identity of KS was first identified by Dr Patricia Jacobs in 1959. PA Jacobs, JA Strong 'A case of human intersexuality having a possible XXY determining mechanism' (1959) 163 Nature 302.

²⁵ enlarged breasts.

22XY). There is some evidence to suggest that the error is found in equal distribution in eggs and sperm, although it should be noted that statistics indicate that women who have pregnancies after the age of 35 have an increased chance of having a boy with this syndrome.²⁶ For example, the South West Congenital Anomaly Register (SWCAR) indicates that for the period 2003-11 there were 8.6 registered KS births per 10,000²⁷ amongst women aged 20-24, whereas during the same period for mothers aged 35-39 there was an incidence of 31.4 registered KS births per 10,000.²⁸ Some rise in numbers may occur as older mothers are offered more testing for chromosomal anomalies where KS is detected;²⁹ however, corresponding Danish research, whilst also noting that testing occurs more frequently in older mothers, concludes that a higher maternal age will increase the risk of a child having an XXY karyotype.³⁰

Although the vast majority of KS people will present as boys and develop a male gender identity, some individuals will present as female, or develop a female gender identity.³¹ With this exception, there are likely to be few legal difficulties in a healthcare environment for these DSD individuals, but those with KS syndrome may well find themselves on the wrong side of the law. According to Diamond and

²⁶ In recent times evidence has emerged to suggest that men beyond the age of 40 who father children are more likely to have autistic children, but no research has yet been completed in regard to investigating any potential link between older fathers and KS.

²⁷ A registered birth includes both live births and stillbirths.

²⁸ <http://www.swcar.org.uk/data-open/maternal-region-public.html> accessed 25 March 2014. The updated website presents data in percentages and it is noted that over 50% of KS babies are born to women over the age of 35. <http://www.swcar.org.uk/data-open/maternal-region-public.html> accessed 25th May 2015.

²⁹ Additionally older mothers may be more prepared to keep a Klinefelter's fetus especially if they have been trying for a child for a length of time.

³⁰ Anders Bojesen, Svend Juul, and Claus Højbjerg Gravholt, 'Prenatal and Postnatal Prevalence of Klinefelter Syndrome: A National Registry Study' (2003) 88 (2) *Journal of Clinical Endocrinology & Metabolism* 622.

³¹ Kiran Randhawa, 'A woman spent 28 years living as a man until doctors discovered they had got her sex wrong.' *London Evening Standard* (London 12 January 2011). The article discusses a KS individual who is transitioning to a female. (The article erroneously states that the sex was 'wrong' – in this case the individual clearly has gender dysphoria which occurs in many non-KS males!)

Watson,³² social differences occur within each of the separate karyotypes. They intimate that those with an XYY karyotype are more likely to be bullies, whereas individuals with an XXY karyotype are more likely to be bullied.³³ Additionally, there have been concerns that those with an XYY configuration are more likely to commit crimes than non-KS men, a fact borne out by a recent Danish survey. This survey has indicated that both XXY and XYY men appear to have a higher conviction rate for sexual offences, burglary and arson.³⁴ There was no percentage increase in the number of traffic offences committed. The survey suggests that overall there is not a significant statistical deviation, but that the ‘increased risk of conviction among the cases may partly or fully be explained by disadvantageous socioeconomic conditions’,³⁵ due to weaker education profiles.³⁶

In terms of potential legal difficulties in the healthcare context, as mentioned, KS men may be discriminated against before birth if their karyotype is discovered, and an abortion is recommended. At a later stage of their life, KS men may be discriminated against by *not* being tested, being left to live without medical support.³⁷ Finally, some KS men develop a female gender identity and may wish to undergo transgender procedures and change their legal gender. In this respect the English law, by virtue of the Gender Recognition Act 2004, is now supportive of such requests. This will be discussed in chapter eight.

³² Milton Diamond and Linda Watson, ‘Androgen Insensitivity Syndrome and Klinefelter’s Syndrome’ (2004) 13 (3) Child Adolesc Psychiatric Clin N Am 623.

³³ *ibid* citing A Theilgaard. ‘A Psychological Study of the Personalities of XYY and XXY men: Assessment and Discussion’ (1984) 31 (5) Acta Psychiatr Scand 170, 124.

³⁴ Kirstine Stochholm and others, ‘Criminality in Men with Klinefelter’s Syndrome and XYY Syndrome: a Cohort study’ 2012 BMJ Open;2:e000650. doi:[10.1136/bmjopen-2011-000650](https://doi.org/10.1136/bmjopen-2011-000650) accessed 25 March 2014.

³⁵ *ibid*.

³⁶ KS boys are frequently detected during school, due to their poor educational performance. This is discussed in chapter seven.

³⁷ This is discussed in chapter seven.

3.2.2 Turner Syndrome (TS) ³⁸

In 1938 an American endocrinologist Dr Henry Turner investigated seven women patients with similar physical features. These included an increase in skin folds in the neck, short stature, absence of female sexual characteristics and a wide carrying angle of the arms, which could not be straightened fully.³⁹ These physical symptoms occur if there is one sex chromosome missing (either X or Y),⁴⁰ or a partial deletion of one of two X chromosomes, in some or all of the body cells.⁴¹ It is sex specific to females and will affect in the region of 1 in every 2000 female live births worldwide.⁴²

TS embraces a broad spectrum of health difficulties, from major heart defects or kidney failure in some to minor cosmetic issues in others; however, almost all women with TS will have short stature and non-functioning ovaries. As with KS men, TS women face discrimination at very early stages of development and many TS fetuses will be aborted.⁴³ As noted above, these women are not ‘intersexed’ in the classic

³⁸ Turner Syndrome is sometimes known as Ullrich-Turner Syndrome, after the two doctors who independently identified a common link in certain female patients.

³⁹ Now known as Cubitus Valgus. Other symptoms have now been identified. These include lymphoedema of hands and feet, low hairline, low-set ears, short fourth toe and short fingers, high arch palate, hearing problems, myopia (short sightedness), infertility, high blood pressure, kidney and urinary tract problems and osteoporosis (due to lack of oestrogen, a result of ovarian failure). Turner Syndrome Support Society ‘Turner Syndrome: A Guide for Patients & Parents’ <http://tss.org.uk/> accessed 7 April 2014. These characteristics had previously been described by a German paediatrician, Otto Ullrich, in 1930, however, as with Klinefelter Syndrome, it was not until 1959 when the technique for analysing human chromosomes was operative, that it was diagnosed that one of the X chromosomes was missing in TS. Later it was shown that the X chromosome can be missing from just some of the body cells.

⁴⁰ The standard karyotype is 45X, (although it is normally reported as 45XO).

⁴¹ If the X chromosome is missing from only some of the cells (46XX/45XO) this is known as Turner mosaic. The ‘fault’ can come from either a mother’s egg or the father’s sperm, and does not appear to be age related. However, to date researchers are unsure as to how or why this happens.

⁴² As previously mentioned the presence of a Y chromosome results in a male genotype and as discussed later in section 3.3.1, if there is a partial deletion of the Y chromosome then the child will present with mixed gonadal dysgenesis. An embryo without any X chromosomes will abort.

⁴³ For example, 38.7 % of all cases of TS notified to the Anomaly Register for the south-west between 2003-12 were aborted. <<http://www.swcar.org.uk/data-open/outcome-region-public.html>> accessed 25 May 2015. This is discussed in chapter six. If a TS girl is born discrimination may occur on the grounds of her height etc. www.tellingstories.nhs.uk/transcript.asp?id=24 accessed 21 April 2014.

sense, and often resent the fact that they are linked into this category. As one TS woman states:

Some textbooks still describe TS as a form of hermaphroditism when it is certainly not! This often affects the way TS is talked about (for example Germaine Greer says unless you have 2 hermaphroditism X chromosomes (TS women have 1) you are not a proper woman).⁴⁴

As with KS boys, TS girls not diagnosed through antenatal testing are often diagnosed at school, if they struggle academically, notably with maths,⁴⁵ handwriting and spatial awareness.⁴⁶ As TS women usually have non-functioning ovaries, their bodies will not produce growth hormones and oestrogen.⁴⁷ To counteract this, TS girls are given growth hormone injections. Even so, their height is not likely to be more than 155cm. Consequently, TS women may find themselves looked down on both physically and metaphorically throughout life.⁴⁸ The earlier a child is diagnosed, the earlier that treatment can occur. Those TS women who are not identified before they are teenagers are likely to suffer more medical difficulties, and issues with body image and self-esteem, than those identified in early childhood.⁴⁹

3.3 Alterations to the Karyotype: Sex Chromosome DSD⁵⁰

This category encompasses a variety of sex chromosome anomalies, such as 45,X/46,XY (Mixed Gonadal Dysgenesis (MGD) also referred to as True Gonadal Intersex) or 46,XX/46,XY (chimeric ovotesticular DSD). In these conditions, the

⁴⁴ <http://www.tellingstories.nhs.uk/transcript.asp?id=24> accessed 21 April 2015.

⁴⁵ Bruce Pennington, *Diagnosing Learning Disorders* (2nd, The Guildford Press 2009) 244.

⁴⁶ This has been attributed to the loss of a second sex chromosome. Arthur R Jensen, *Genetics and Education* (Methuen & Co Ltd 1972) 204.

⁴⁷ The average height of a TS girl is 140cm.

⁴⁸ <http://www.tellingstories.nhs.uk/stories.asp?id=7> accessed 21 April 2015.

⁴⁹ Oestrogen replacement therapy is often started when the girl is 12 or 13 years old. This helps trigger the growth of breasts, pubic hair, and other sexual characteristics, which can help to promote self-esteem.

⁵⁰ Separated into two groups of 'sex chromosomal anomalies' and 'disorders of gonadal development'.

alteration to the chromosomal arrangement in some or all of the cells creates a mixture of ovarian and testicular tissue.⁵¹ In 90 per cent of all cases genital difference occurs, in a variety of gradations from male to female, both externally and internally. Occasionally only a hint of the condition is shown in the form of hypospadias⁵² or clitoromegaly.⁵³ Identifying the ‘correct’ sex of these children is difficult, and children with these conditions are likely to face discrimination throughout their lives.

For most people with true gonadal intersex, the underlying cause is unknown, although research into animals presents evidence indicating that intersex conditions have been caused by exposure to common agricultural pesticides⁵⁴ or effluent from various sewage purification plants into rivers.⁵⁵ Evidence produced for the study of intersexuality in the European roach, *Rutilus rutilus*, has been described as having ‘multiple complementary lines of evidence’, and is therefore particularly convincing in this respect.⁵⁶

Although studies involving human populations are not so advanced, evidence suggests that women exposed to pesticides during pregnancy are more prone to miscarriages or stillbirths due to congenital abnormalities in their babies.⁵⁷

⁵¹ A person may have one ovary and one testis, or the individual may present with both tissue types in the same gonad. (This is known as an ovotestis).

⁵² This is where the urethral meatus is not at the tip of the glans of the penis, but on the underneath side.

⁵³ The medical term for an enlarged clitoris.

⁵⁴ KA McCoy and others ‘Agriculture Alters Gonadal Form and Function in *Bufomarinus*’ (2008) 116 *Environmental Health Perspectives* 1526.

See also Marla Cone, ‘Hermaphrodite Frogs linked to Pesticide Use’ *Los Angeles Times* (Los Angeles, 2 March 2005) articles.latimes.com/2005/mar/02/nation/na-frogs2 accessed 4 April 2015, which indicates a direct causal link between pesticides and intersexuality in frogs. It would, of course, be unethical to carry out direct research in humans to see if a similar effect has occurred; however, results from other surveys are suggestive!

⁵⁵ S Jobling and others, ‘Altered Sexual Maturation and Gamete Production in Wild Roach (*Rutilus rutilus*) Living in Rivers That Receive Treated Sewage Effluents’ (2002) 66 *Bio Reprod* 272. The condition appears to be the result of oestrogen effects on a genetic male roach, rather than the reverse.

⁵⁶ JC Wolf, ‘Letter to the Editor: The case for Intersex Intervention’ (2011) 30 (6) *Environmental Toxicology and Chemistry* 1233, 1234.

Additionally, a significant causal link between exposure to pesticides and congenital abnormalities (some urogenital) has been reported.⁵⁸ Although beyond the scope of this thesis, it is clear that legal rules surrounding the use and distribution of pesticides need to be analysed to see whether there are enough safeguards in place in terms of long-term health effects on all animal life.

3.3.1 Mixed Gonadal Dysgenesis (MGD)

MGD, the second most common cause of ambiguous genitalia in newborns, is usually caused by a spontaneous genetic error.⁵⁹ The most usual karyotype identified is 45XO/46XY.⁶⁰ The number of babies presenting with this condition is difficult to assess, but a significant number of these fetuses will have been aborted if detected at an early stage.⁶¹ This may be unnecessary as statistics indicate that 90 per cent of boys with 45X/46XY have normal male genitalia⁶² and will be able to lead a 'normal life', albeit fertility treatment may be needed at a later stage.⁶³ Of the remaining ten per cent, half of these will develop external female anatomy. This is known as Swyer's Syndrome.⁶⁴ Only the remaining five per cent of children with

⁵⁷ 'Investigation of stillbirths and neonatal deaths in California reported that maternal occupational exposure to pesticides was associated with more than a doubling of the risk of stillbirth due to congenital anomalies.' LM Pastore, I Hertz-Picciotto, JJ Beaumont 'Risk of stillbirth from occupational and residential exposures' (1997) 54 *Occup Environ Med* 511.

⁵⁸ M Sanborn and others, 'Non-Cancer health effects of Pesticides' (2007) 53 *Canadian Family Physician*, <http://www.preventcancer.ca/wp-content/uploads/2009/08/sanborn.pdf> accessed 25 March 2014. The effects of pesticides on penile structures are discussed additionally under the subheading of hypospadias at 4.6.3.

⁵⁹ MGD is the condition also referred to as true gonadal intersex, and used to be considered true hermaphroditism.

⁶⁰ This is the virilised form of TS. In complete TS, it is never known whether the child was originally destined to be 46XX or 46XY. However, as discussed above, as soon as a Y chromosome is present, albeit in limited amounts, the genitals will start to form in the male form.

⁶¹ xyTurners – Genetic Mosaics Support Group www.xyxo.org accessed 24 April 2012.

⁶² http://www.rarechromo.org/information/Chromosome_Y/45X%2046XY%20including%20Y%20chromosome%20rearrangements%20FTNW.pdf 5. accessed 2 April 2014.

⁶³ *ibid*, 8.

⁶⁴ Internally there will be streak gonads.

MGD present with ambiguous genitalia. This small minority of children will face the most enormous legal difficulties.

True MGD babies are likely to have internal gonads, one of which will be a defined ovary or more usually testis, but the other will be a 'streak gonad' which is mixed tissue. Sometimes there will be an ovotestis – which potentially has both types of functioning tissue in it. If a streak gonad is present, the genitalia will fail to be fully defined, although the external genitalia will *usually* be male in appearance.⁶⁵ The vast majority of these babies will *also* have a uterus, vagina and fallopian tubes.⁶⁶ At one stage, the majority of these children would have been assigned female, but modern medicine has brought about 'a paradigm shift in the management of children with MGD', with the majority of these babies now raised successfully as males.⁶⁷

It will be apparent that gonadal dysgenesis will raise a number of legal issues. One issue that will face the parents and child is whether to agree to the removal of streak gonads. It has been estimated that 20-30 per cent of children with pure gonadal dysgenesis and 15-20 per cent of children with MGD will develop cancer in the streak gonads during the first two decades of life.⁶⁸ In the past, the 'scare factor' of cancer was used as an excuse to de-masculinise an intersex child and allocate a female sex.⁶⁹ It is clear that parents need substantial legal and ethical support when making such an important decision on behalf of their child.⁷⁰

⁶⁵ Albeit that hypospadias might be present. N Johal and others, 'Urological Outcomes of 45XO/46XY Mixed Gonadal Dysgenesis.' (2007) 3 (1) Journal of Pediatric Urology) S28.

⁶⁶ Ajay Anand, Narmada and others, 'Mixed Gonadal Dysgenesis with Normal Karyotype : A Rare Case Report' (2010) 53 (2) Indian J Pathol and Microbiol 313.

⁶⁷ N Johal (n 65).

⁶⁸ GB Chavhan and others 'Imaging of Ambiguous Genitalia: Classification and Diagnostic Approach' (2008) 28 Radiographics, 1891.

⁶⁹ This will be discussed in chapters five and eight.

⁷⁰ Although not specifically referred to by its name, this condition will be encapsulated by the term 'intersex' throughout the remainder of this thesis.

3.4 Genetic Modifications: Congenital Development of Ambiguous Genitalia (46 XX DSD)

Of all the intersex/DSD conditions currently known, those referred to as 46 XX DSD require the most in-depth investigation. This is partly because some of these conditions give rise to true medical emergencies, but more strikingly because this group has frequently challenged the gender binary system. All too often in the past, these children have faced a series of genital reconstruction surgeries. Ethical and legal tensions will occur throughout life: at embryonic stage, when tested to see if the embryo has the condition; during pregnancy, facing detection and subsequent abortion; at birth in terms of gender assignment; and throughout life as a subject for genital/gender reassignment.

Previously referred to as virilised female or female pseudo-hermaphrodite, a person with 46 XX DSD will have a typical female karyotype⁷¹ and female internal reproductive organs but their external genitals may appear to be male at birth. This presentation occurs when the fetus is exposed to excess male hormones *in utero* and as a result the labia fuse⁷² and the clitoris enlarges – often resembling a penis. There are several possible causes for this: some are hereditary genetic conditions, some are spontaneous genetic ‘errors’ and some are not linked to genes at all. Virilisation can occur if the mother is taking anabolic steroids or the contraceptive pill during early pregnancy. If the mother has an ovarian or adrenal tumour, that too will increase the testosterone levels in the blood.⁷³

According to Reiner and Reiner,⁷⁴ the cause of XX DSD is ‘nearly always’ Congenital Adrenal Hyperplasia (CAH). CAH can occur in both boys and girls, and

⁷¹ chromosomal arrangement 46XX.

⁷² Labia are the folds of skin of the external female genitals.

⁷³ AL Olgivy-Stuart, ‘Assessing Endocrine Functions in the newborn baby’ M B Ranke and P E Mullis (eds) *Diagnostics of Endocrine Function in Children and Adolescents* (4thedn Karger Publishers 2011) 412.

⁷⁴ William G Reiner and D Townsend Reiner, ‘Thoughts on the Nature of Identity: How Disorders of Sex Development Inform Clinical Research about Gender Identity Disorders’ (2012) 59 (3) *Journal of*

is significantly, but not exclusively, a hereditary condition. Described as the most common genetic endocrine disorder,⁷⁵ CAH is the most frequently occurring condition resulting in the birth of a child with ambiguous genitalia, and the only category of intersex conditions that leads to a *true* medical emergency. Further, this condition has a significant impact on gender orientation. The excess of testosterone in the female body often leads to the development of a male persona. A number of CAH females transition as males in later life. This social impact has medical implications. In the past a number of CAH females have received corrective surgery in order to make them ‘socially acceptable’ as females, as opposed to fulfilling their medical needs. The medical situation is starting to change, but there are many intersexed persons bearing the scars of enforced and unnecessary operations.⁷⁶

Those who do not undergo genital surgery may still face endless medical intervention. Specialist help is often needed in terms of fertility treatment, even for those who have the milder versions of CAH.⁷⁷ Only in this way can CAH patients earn their badge of honour as a true member of that sex.⁷⁸ As will be apparent, looking after a CAH child will bring considerable difficulties to parents, in both medical and in legal terms.

Homosexuality 434, published in Jack Drescher and William Byne, *Treating Transgender Children and Adolescents* (Routledge, 2013) 146.

⁷⁵ Wiebke Arlt, and the United Kingdom Congenital Adrenal Hyperplasia Adult Study Executive (CaHASE), ‘Health Status of Adults with Congenital Adrenal Hyperplasia: A Cohort Study of 203 Patients’ (2010) 95 (11) *J Clin Endocrinol Metab* 5110, 11.

⁷⁶ This will be addressed in chapter eight.

⁷⁷ Maud Bidet and others, ‘Fertility in Women with Non Classical Congenital Adrenal Hyperplasia due to 21-Hydroxylase Deficiency’ (2010) 95(3) *J Clin Endocrinol Metab* 1182 <http://press.endocrine.org/doi/full/10.1210/jc.2009-1383> accessed 24 June 2015.

⁷⁸ For, according to various historical sources, only when we procreate as ‘man’ or ‘woman’ can we truly be considered to ‘own’ that sex. ‘You shall be blessed above all peoples; there shall not be a male or female barren among you or among your livestock’ Deuteronomy 7:14. ‘The LORD will give you prosperity in the land he swore to your ancestors to give you, blessing you with many children, numerous livestock, and abundant crops’ Deuteronomy 28:11. This was of course, primarily considered to be a *female* fertility issue, as evidenced in various bible stories, ‘He maketh the barren woman to keep house and to be a joyful mother of children. Praise ye the LORD.’ Psalm 113:9.

3.4.1 Congenital Adrenal Hyperplasia (CAH)

CAH is the blanket term given to a group of inherited disorders which cause the adrenal glands to malfunction. Hyperplasia is the medical term for an abnormal increase in the number of cells that make up specific tissue. In CAH patients the adrenal glands are unnaturally large – hence the name of the condition. CAH conditions are autosomal recessive,⁷⁹ meaning that both parents of the child will either be a CAH sufferer or carrier of a faulty gene. As these conditions are caused by genetic errors they can never be cured completely, but they can be ‘corrected’ with the right balance of drugs.

The role of the adrenal glands is to produce steroids, a group of hormones including cortisol, aldosterone and androgens. Each hormone has a specific role to play and any alternation to the production of these hormones has a significant impact on a person’s body.

Cortisol, also known as the stress hormone, helps to control and maintain the body’s blood pressure, blood sugar levels and general heart function. In times of stress or illness cortisol is needed to assist in recovery. If the body’s cortisol level drops significantly, the patient will suffer an *adrenal crisis* resulting in the lowering of their blood pressure. In severe cases this causes shock and ultimately death.

Aldosterone maintains the balance of water and salts (sodium and potassium) in the body. Aldosterone ensures that the kidneys conserve salt if there is too little salt in the diet or salt has been lost through sweating. Should there be too much sodium present, and then aldosterone production will be reduced to allow sodium salts to be removed from the body via urine production.

Androgens, including testosterone, are needed for normal development and growth. Androgens are produced in both males and females, but if a female fetus is over exposed to androgens *in utero*, then her genitals are likely to appear male rather than

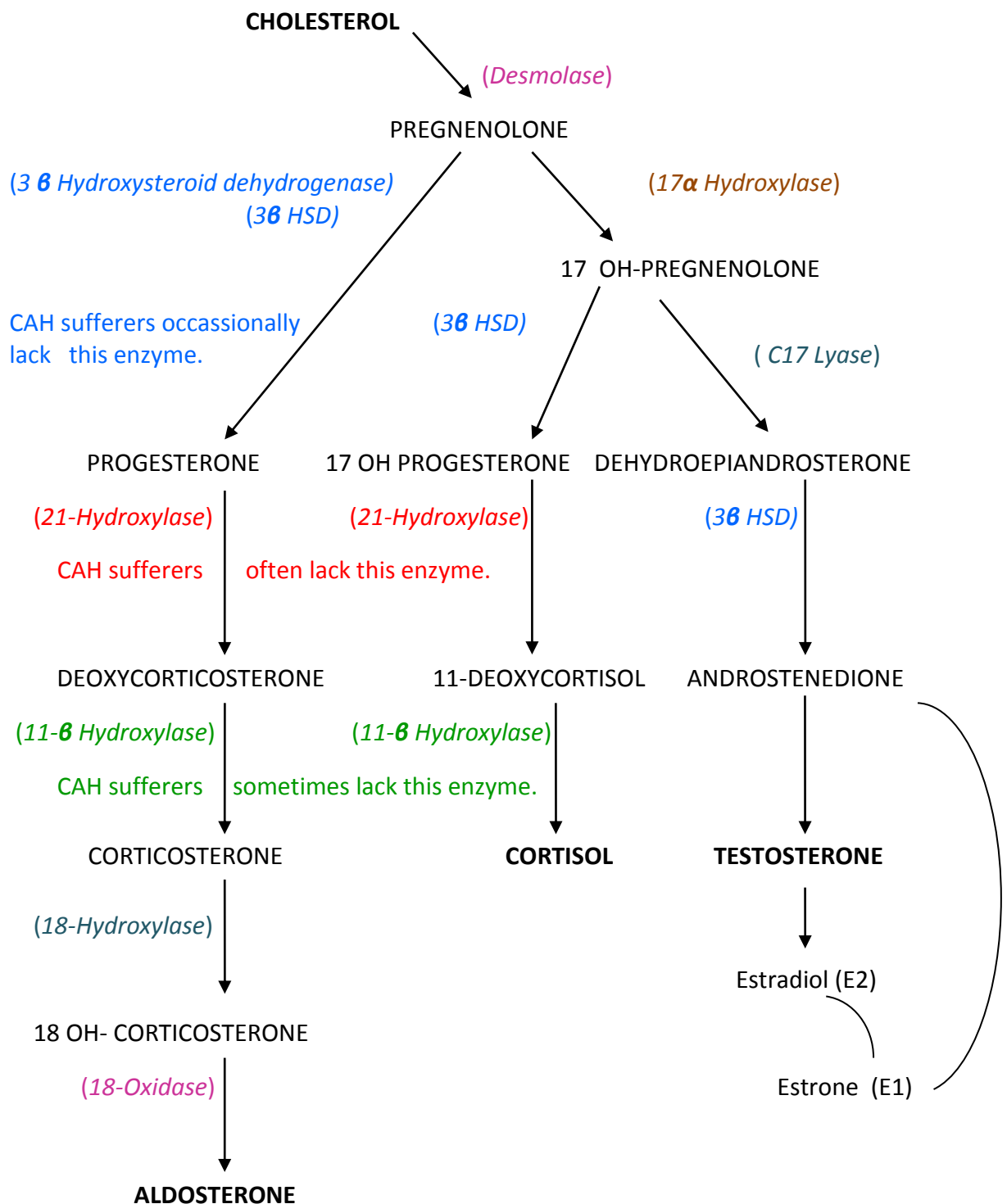
⁷⁹ Autosome denotes a chromosome which is not a sex chromosome.

female at birth. Androgens are influential during puberty, and should a child produce too many androgens at an early age then precocious (early) puberty will occur.

All of the above hormones are manufactured from cholesterol. In order to produce the right substance, a number of chemical reactions need to take place which facilitate the use of enzymes.⁸⁰ If, as a result of a faulty gene, a specific enzyme has not been produced, or not produced in sufficient quantities, then the chain of reactions will be broken, with severe biological effects for the individual concerned. This is best demonstrated by considering a chart of the chemical reactions involved in the process, and the various points where genetic errors create a child with CAH.

⁸⁰ Enzymes are protein compounds which act as catalysts for the various chemical reactions in our bodies. Enzymes are not changed by the reaction as such, but the presence of an enzyme starts and speeds up the whole chemical process. Enzymes work by reducing the activation energy which is the minimum energy required to start a chemical reaction. Reactions using catalysts can be several millions times faster than those of comparable uncatalyzed reactions. Each chemical process requires a reaction-specific enzyme. Often a series of enzymes will be needed to convert one substance into another for use in the body.

Figure 3: **Chemical (Enzymatic) Pathway: Production of Hormones from Cholesterol** ⁸¹



⁸¹ This diagram is based on others, in particular that devised by Michael A Deaton, John E Glorioso and David McLean, 'Congenital Adrenal Hyperplasia: Not Really a Zebra' (1999) 59 (5) American Family Physician 1190. (Enzymes in italics).

3.4.1.1 Grades of Severity

There are various grades of severity of CAH, depending on the reduction of synthesis for the chemicals involved. There are two forms of the condition – one is Classic CAH, and the other is known as Non-Classical CAH (sometimes referred to as late onset CAH). Classic CAH is further subdivided into two categories: salt-wasting (SW) CAH and virilising CAH.

The most severe category is Classic SW CAH. It has been estimated that this condition occurs in approximately 1 in every 12,000 births.⁸² In the UK, recent statistics suggest the incidence is 1 in every 18,000 births;⁸³ however, the prevalence in Wales is slightly less than 1 in every 12,000 births.⁸⁴ If a child has Classic CAH, then he or she will produce little, if any, aldosterone. With no natural regulator to maintain the salt levels in the body, the baby's body lets salts into the urine stream, the body believing (erroneously) that they are not needed. Consequently, the baby's supply of sodium and glucose is rapidly depleted, causing dehydration and very low blood pressure. This is known as an *adrenal crisis*. Should a baby suffer from this doctors will need to act fast to save the baby's life. As will be discussed in chapter seven, boys are more at risk than girls of an unexpected adrenal crisis during the first month after birth.

Individuals with Classic SW CAH have mutations in their CYP21A2 gene, resulting in enzyme activity of less than one per cent of the normal range.⁸⁵ By comparison, in

⁸² Wiebke Arlt (n 75) 11.

⁸³ Javaria Mona Khalid and others, 'Incidence and Clinical Features of Congenital Adrenal Hyperplasia in Great Britain' (2012) 97 (2) Arch Dis Child 101, 106.

⁸⁴ 'The prevalence rate in Wales is 0.84 per 10,000 live births. (1:11,900 live births)' Congenital Anomaly Register and Information Service Wales, <http://www.caris.wales.nhs.uk/metabolic#CAH> accessed 23 March 2015.

⁸⁵ S Peter, and others 'Congenital Adrenal Hyperplasia in the Bahamas due to 21-hydroxylase deficiency.' (2006) 55 (2) West Indian Med J http://caribbean.scielo.org/scielo.php?pid=S0043-31442006000200009&script=sci_arttext accessed 24 March 2015.

classic virilising CAH, one to five per cent of normal enzyme activity occurs.⁸⁶ Virilising CAH is not normally detected until around two years of age.⁸⁷

In non-classical CAH conditions, the enzyme activity has been estimated to be in the range of 50-80 per cent of the normal enzyme activity. Therefore a reasonable amount of steroids is produced and the salt balance is likely to be normal. However, under stressful conditions, including illness and physical trauma, these people can also lose salt. Girls born with these less severe types of CAH may have partially fused labia and an enlarged clitoris, depending on the enzyme activity. By comparison, boys do not show any initial signs and it is not until these boys suddenly grow tall and their genitals show signs of developing at an early age (approximately 5 years old), that CAH will be detected.

There are widely varying statistics regarding late onset CAH. Some surveys have estimated that there will be an incidence of between 1:1000 and 1:2000 births with a less severe form, with an increase in certain ethnic groups up to two per cent of the population.⁸⁸ The prevalence of both classic and non-classical forms varies in different ethnic populations; for example, the milder form has been identified more frequently in Ashkenazi Jews (where some statistics have reported an even higher incidence of CAH of 1 in 27 births),⁸⁹ in Hispanic, Slavic and Italian populations,⁹⁰ and in the Philippines (1 in 7000 births).⁹¹ In comparison, a high incidence of Classic

⁸⁶ *ibid.*

⁸⁷ Dóra Török, Gudrun Eckhardt and János Sólyom, 'Twenty years' experience in Rapid Identification of Congenital Adrenal Hyperplasia in Hungary' (2003) 162 (12) *Eur J Pediatr* 844.

⁸⁸ CM Trapp, SE Oberfield 'Recommendations for Treatment of Nonclassic Congenital Adrenal Hyperplasia (NCCAH): an update' (2012) 77(4) *Steroids* 342-6. <<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3638754/>> accessed 24 March 2015.

⁸⁹ R Bhanji and others, 'Profile of Children with Congenital Adrenal Hyperplasia – a Hospital Study' [2004] *Journal of Pakistan Medical Association* www.jpma.org.pk/full_article_text.php?article_id=486 accessed 11 April 2014.

⁹⁰ A Balsamo and others, 'CYP21 analysis and phenotype/genotype relationship in the screened population of the Italian Emilia-Romagna Region' (2000) 53 *ClinEndocrinol* 117, 122.

⁹¹ Deborah P Merke, Stefan R Bornstein, 'Congenital Adrenal Hyperplasia' (2005) 365 (9477) *The Lancet* 2125, 25.

CAH has been noted on the French island of La Reunion near Madagascar⁹² (1 in 2100 births) and certain areas of Western Alaska, where the incidence in the Yupik Eskimos has been reported as high as 1 in every 280 births.⁹³

Further, it has been estimated that globally 1 in 60 people are carriers for the genetic mutation,⁹⁴ therefore in a closed community the chance of inheriting this condition will significantly increase. In Pakistan, a study indicated that in over 50 per cent of cases of children born with CAH there was some degree of consanguinity in the parents.⁹⁵

3.4.1.2 CAH due to 21-Hydroxylase Deficiency

The most common variety of CAH is a deficiency of enzyme 21-Hydroxylase.⁹⁶ This is caused by mutations of a specific gene labelled CYP21A2, which is located on the short arm of the sixth chromosome. As a result of the various mutations, the DNA sequence for CYP21A2 can be altered in 14 different ways, many of which leave the enzyme impaired but not totally inactive.⁹⁷ It has been estimated that up to 95 per

⁹² Michael A Deaton (n 81) S Peter (n 85).

⁹³ S Peter (n 85) This journal also notes that In 2001 an Endocrine clinic was established in the Bahamas. Results obtained during the first two years of study indicated that in the Bahamas, the incidence of Classic CAH was one birth per 10,000, making it one of the highest incidences in a population. However, on talking to a colleague from the Bahamas, in reality this is a most conflated picture. It appears that this clinic was set up as a centre for drug trials that could not take place legally in the United States. Therefore the seemingly large proportion of intersex people, were actually not native to the islands at all, but rather part of experimental trials.

⁹⁴ Wendy A. Conlon, Raymond G. Fenwick, 'The Basics of Genetic Testing for CAH and How it May Benefit You and Your Family', [2004] www.caresfoundation.org/productcart/pc/news_letter/... - Cached last accessed 13 October 2013.

⁹⁵ R Bhanji (n 89). The law in regard to close family relationships is of need of reconsideration, but beyond the scope of this thesis. For a discussion of the requirements to disclose to children that they are the product of donor eggs or sperm, and the consequent need to identify potential siblings. K Dyer, 'The Need to Re-evaluate Incest in the age of Assisted Reproductive Techniques.' (2012) 42 (September), Fam Law, 1144.

⁹⁶ Other variations include Lipoid adrenal hyperplasia, Aldosterone synthase deficiency, 3 β -hydroxysteroid dehydrogenase deficiency, 11 β -hydroxylase deficiency, 17 α -hydroxylase deficiency.

⁹⁷ S Peter (n 85).

cent of patients with CAH have some type of CYP21A2 gene mutation.⁹⁸ As can be seen from the preceding diagram, without an adequate supply of 21-Hydroxylase, the chemical reactions during the production of aldosterone *and* cortisol will not take place, or if they occur at all then the overall production is very low. The body senses this low production and sends a message to the brain indicating that more cortisol and aldosterone are needed. Consequently, the brain sends signals to the adrenal glands to work harder.⁹⁹ In a person *without* CAH the adrenal glands produce even amounts of the steroids, but for those *with* CAH, the constant push to produce aldosterone and cortisol creates a surge in the production of androgens which are free to circulate the body.¹⁰⁰

As the body is constantly over exposed to androgens, the physical structure will alter, becoming more masculinised. In boys, the surge of testosterone will cause early sexual development, whereas in females the excess testosterone can cause incorrect genital development before birth. In adults, milder forms of CAH will cause excessive body hair, irregular periods and spots.

Some CAH girls will be *incorrectly* diagnosed as ‘male’ at birth – but not all. It is not only the physicality that is affected by the surge in androgens, but also the gender alignment. There are a number of CAH ‘females’ who develop a male identity during puberty as their bodies become more virilised with age.¹⁰¹ This is particularly the case for girls who have virilising CAH. In a Dutch study conducted on women with CAH, it was discovered that although the majority of these girls develop a female identity, some 5.2 per cent of cohort had ‘serious problems’ with their gender identity. The authors report that this percentage is higher than the normal ratio of

⁹⁸ Michael A Deaton (n 81) The authors suggest to 90%, but in Wiebke Arlt (n 75) the figure of 95% is given.

⁹⁹ This ‘negative feedback’ process is a typical bio-mechanism found throughout the human body.

¹⁰⁰ The gene mutation affecting aldosterone and cortisol production does not play a part in the production of androgens, consequently despite the shortage of cortisol, androgens will be produced in a normal amount.

¹⁰¹ Juan Carlos Jorge and others, ‘Male Gender Identity in an XX Individual with Congenital Adrenal Hyperplasia’ (2008) 5 J Sex Med 122.

genetic females who elect to become female-to-male transsexuals.¹⁰² Some CAH ‘women’ opt to change their registered gender.¹⁰³

3.4.1.3 CAH due to 11 β -Hydroxylase Deficiency and 3 β -dehydrogenase.

Although the vast majority of CAH cases are caused by a deficiency of 21-Hydroxylase, in certain populations (notably Moroccan Jews)¹⁰⁴ mild CAH has been identified as occurring as a result of mutations in a different gene, found on chromosome 8. This gene is responsible for the production of 11 β -Hydroxylase, which is needed to complete the production of both cortisol and aldosterone. As with 21-Hydroxylase, the degree of severity can range from severe to mild.

Other enzyme inactivity has been discovered in CAH individuals, namely 17-Hydroxylase, 3 β -Hydroxysteroid dehydrogenase and desmolase.¹⁰⁵ With 3 β -dehydrogenase, the ‘absent’ enzyme is required at the start of many of the chemical processes, therefore there will be a reduction in all the necessary chemicals produced. As a deficiency in these enzymes also affects testosterone production, it is more likely to lead to a situation where a male child presents with female genitalia, rather than girls presenting as virilised. Therefore, in a reversal of fortunes, a girl with this variation may not be diagnosed initially, whereas early detection in boys will be assisted by a presentation with hypospadias and /or a very small penis.

For doctors, it is important to establish which type of CAH is present in their patient. One potential way to identify the enzyme affected is to take blood pressure measures. Patients with 11 β -Hydroxylase can produce deoxycortisol (unlike those with 21-

¹⁰² AB Dessens, FM Slijper, SL Drop ‘Gender Dysphoria and Gender Change in chromosomal females with Congenital Adrenal Hyperplasia’ (2005) 34 Arch Sex Behav 389.

¹⁰³ There are several such cases internationally. The case of Jennifer/Jeff Cagandahan of the Philippines is one example. After feeling uncomfortable all through her life with a female gender assignment, Jennifer discovered that she had virilising CAH, and eventually changed her identity to male. A petition to the court in the Philippines allowed Jennifer to become Jeff on all legal documentation. *Republic of the Philippines, Petitioner, VS Jennifer B Cagandahan, Respondent*. [G.R. No. 166676, September 12, 2008]. Jennifer/Jeff’s story www.clanchildhealth.org accessed 22 May 2012.

¹⁰⁴ Michael A Deaton (n 81).

¹⁰⁵ These variations are extremely rare.

Hydroxylase deficiency), but this product cannot be synthesised into cortisol in their bodies and consequently there is a build-up of excess amounts of deoxycortisol in the body. The excess of deoxycortisol is known to elevate blood pressure. Blood pressure readings might therefore be of some use in determining which enzyme is affected, and consequently help in the overall medication of the patient.

If a child has been diagnosed with CAH they will be ‘managed’ using a multidisciplinary team. This is likely to include a paediatric endocrinologist, gynaecologist and psychologist, and may occasionally include an ethicist. Lawyers are not specifically mentioned. In the publication produced by the Consortium on the Management of Disorders of Sex Development, the Team Composition is as follows: ‘Child Psychology/Psychiatry, Genetics and Genetic Counseling, Gynecology, Nursing, Pediatric Endocrinology, Pediatric Urology, Social Work and *others as needed.*’¹⁰⁶ Further in the same document, it mentions that ‘the team may also need to consult with a clinical ethicist, especially when opinions differ regarding what constitutes the child’s best interests’.¹⁰⁷ Note the word ‘need’ as opposed to ‘want’, the impression being that anyone from a legal calling should not be incorporated unless there is no other option. Further, whereas the roles of medical ethicist and medical lawyer may well overlap, they are not identical in practice, and it might be that parents are left unprepared for any ‘legal’ as opposed to ‘ethical’ issues that might arise at a later stage.

Recently the Society for Endocrinology has revised its guidelines for managing intersex conditions. Again a lawyer is not considered nor is an ethicist. They state that to supervise such conditions requires a multidisciplinary team, which should include ‘(a)s a minimum standard, (...) specialists in endocrinology, surgery and/or urology, clinical psychology/psychiatry, radiology, nursing and neonatology’.¹⁰⁸ Whilst a

¹⁰⁶ Consortium on the Management of Disorders of Sex Development ‘Clinical Guidelines for the Management of Disorders of Sex Development in Childhood’, (2006) <http://www.dsdguidelines.org/files/clinical.pdf> accessed 24 March 2015. My italics.

¹⁰⁷ *ibid.*

¹⁰⁸ S Faisal Ahmed and others, ‘Society for Endocrinology UK Guidance on the Initial Evaluation of an Infant or an Adolescent with a Suspected Disorder of Sex Development (Revised 2015)’ Clinical

multidisciplinary team is essential, it is of some concern that there is no minimum requirement for ‘ethicist’ or ‘legal representative’.

Therefore, although the physical child may be treated, the action appears to be mainly medical in dimension. If this is the case, then there appears to be a need for more consideration of the child’s role in a binary system, and here a legal input may well prove useful, particularly as the CAH adult faces compromised fertility. It is submitted that there should be non-clinical personnel amongst the team to look at the overall socio-legal effect of treatment. Due to the potential for discrimination that this condition brings, CAH will be discussed extensively throughout the remainder of this thesis.

3.5 Genetic Modifications: Congenital Disjunction of Internal and External Sex Anatomy (46 XY DSD)

Previously labelled as male pseudo-hermaphrodite, children born with 46 XY DSD are under virilised males and the individual may physically appear to be ‘female’ or be born with genital difference. Regardless of the external appearance, it is usual to find testes inside the body (although this is not always the case). If the testes are not formed properly, the body will not develop along traditional male lines. On occasions the testes are fully formed, but various body cells do not recognise testosterone, and so secondary sexual characteristics do not form. A question often raised with doctors is, ‘If our child has XY genes why doesn’t that make him a boy?’

¹⁰⁹ There are a number of possible causes, put broadly into three main subdivisions.

3.5.1 XY Gonadal (Testicular) Dysgenesis

Male external genitals are only formed if there is an appropriate balance and timing between male and female hormones. There are many causes associated with

Endocrinology, 13 August 2015.DOI: 10.1111/cen.12857
<http://onlinelibrary.wiley.com/doi/10.1111/cen.12857/full> accessed 14 August 2015.

¹⁰⁹ A typical question asked by parents of those with AIS. See William G Reiner and others ‘Partial Androgen Insensitivity Syndrome’ (2005) 7 VirtualMentor 11.

chemical imbalances, but predominantly faulty or absent enzymes are to blame. As a result, testosterone will not be produced, or if it is produced the quantity will be insufficient for normal body development.

3.5.2 Androgen Insensitivity Syndrome (AIS)¹¹⁰

AIS is predominantly a hereditary condition, although it can occur spontaneously. As the name suggests, the condition causes the body to be insensitive to androgens and this consequently affects sexual development before birth and also during puberty.

AIS is caused by mutations in the *AR* gene which is found on the long arm of the X chromosome. This gene provides instructions for making a protein androgen receptor. Androgen receptors permit cells to respond to androgens, allowing the body to develop as 'male'. Androgens have other functions in both males and females, such as regulating hair growth and promoting sex drive. Mutations in the *AR* gene prevent androgen receptors from working properly, which makes cells less responsive to androgens, the net effect of which will vary from person to person. Over 600 different mutations in the *AR* gene have been identified,¹¹¹ each having a different end effect.¹¹²

In a fetus with AIS, the testes will start to develop. These produce the Müllerian inhibiting hormone (MIH) and testosterone. The MIH causes the fetal Müllerian ducts to subside, and as a result the uterus, fallopian tubes, cervix and upper vagina will not be developed. However, to develop a *male* phenotype, androgens need to be absorbed by various cells. As the fetus is insensitive to androgens, the Wolffian structures (epididymis, vas deferens and seminal vesicles) are not formed and ultimately the testes are unable to descend.

¹¹⁰ Formerly known as testicular feminisation.

¹¹¹ Genetics Home Reference, ghr.nlm.nih.gov/gene/AR accessed 24 March 2014. The website also adds 'Most of these mutations are changes in single DNA building blocks (base pairs). Other mutations insert or delete multiple base pairs in the gene or affect how the gene is processed into a protein.'

¹¹² Whereas sometimes this will cause the androgen receptor protein to be extremely short in length, at other times the protein will not be able to bind to either the androgens or the cellular DNA at all, making the cells less responsive to these hormones or unable to use these hormones at all.

AIS occur in varying degrees which affect the body accordingly. Some children have Complete Androgen Insensitivity Syndrome (CAIS), whereas others have Partial Androgen Insensitivity Syndrome (PAIS). However, all these children share the same male karyotype (46, XY).¹¹³ With the exception of the sporting world,¹¹⁴ children with PAIS are more likely to be victims of legal anomalies than those with CAIS, as those with CAIS normally have a well-developed match between their phenotype (female) and their sexual and gender orientation.

3.5.2.1 Complete Androgen Insensitivity Syndrome (CAIS)

CAIS occurs when cells in the forming fetus are unable to receive androgens at all. The result of this condition is that the baby will be genetically male (46XY) but will have a typical female exterior appearance at birth. They will present with normal labia, a clitoris and a vagina, and will be assigned as ‘girl’ when born. This is an uncontroversial decision, as the child’s gender alignment will nearly always be female.¹¹⁵ However, as previously discussed, ovaries will only be formed in the absence of a Y chromosome, and inside a CAIS woman, undescended testes can be detected in the pelvis or abdomen. CAIS women will be diagnosed in early childhood if they suffer a hernia in the abdomen or groin area. Under surgical exploration this turns out to be a testicle.¹¹⁶ This early diagnosis can cause significant anxiety. Not only is the diagnosis of CAIS a shock to parents, but on top of this news, parents may be told that these undescended testes may become cancerous later in life. Reports of the incidence of cancerous growth have been said to be overestimated, but in the past this has put parents under pressure and has led to a

¹¹³ There are also some female karyotype (46 XX) conditions with similarities to AIS: Mayer Rokitansky Kuster Hauser (MRKH) Syndrome, Müllerian dysgenesis, vaginal atresia.

¹¹⁴ As discussed in detail in chapter one.

¹¹⁵ Interviewed by Karkazis, one paediatric endocrinologist stated, that the only condition which had a firm diagnosis was Complete Androgen Insensitivity Syndrome (CAIS). Karkazis carried out her interviews between 2000 and 2002. Katrina Karkazis, *Fixing Sex* (Duke University Press 2008) 93.

¹¹⁶ There are various stories posted on the internet regarding the discovery of testes in daughters. See for example ‘The Lady Lump Diaries’ entry for September 2010, http://www.dsdfamilies.org/parents/experience_advice/diary.php accessed 12 November 2013.

number of unnecessary procedures, sometimes without parental consent.¹¹⁷ This in effect has made the operations unlawful, although very few of these have ever been challenged.¹¹⁸ Here we see an example of where the intersexed have been unprotected from unnecessary physical interference, to their detriment.

During puberty the testes produce testosterone. As testosterone is very similar in chemical structure to oestrogen, some of the testosterone converts or ‘aromatises’ to oestrogen in the bloodstream.¹¹⁹ As a result, these girls may develop breasts, although other secondary characteristics, for example body hair, will not develop. CAIS girls will not menstruate as they do not have female internal reproductive organs; consequently, many CAIS girls are first diagnosed after an initial referral for amenorrhoea. Unsurprisingly, many CAIS women and their families find infertility the main source of sadness of living with this condition. As one woman states,¹²⁰

The year I was in fifth grade, I saw a television commercial for tampons. Like most 10-year-olds, I'd never heard of a tampon. But when I asked my mom what one was, she started crying.

During the past 30 years there has been a shift from ignorance to acceptance. Originally such a diagnosis would be hidden from patients, but nowadays there is an open approach, which has a beneficial effect on AIS sufferers.¹²¹ Not only is this likely to improve the CAIS woman’s self-esteem, but it will also enable her to learn of remedies for infertility through adoption or surrogacy.

¹¹⁷ Anne Fausto-Sterling, *Sexing the Body* (Basic Books 2000) 92.

¹¹⁸ This is discussed in chapter eight.

¹¹⁹ This can be identified by the diagram on page 93.

¹²⁰ Interview, ‘I’m a Woman with Male Chromosomes’ *Marie Claire* (London, 9 August 2010) <http://www.marieclaire.com/sex-love/relationship-issues/woman-with-male-chromosomes?src=rss> accessed 24 June 2013.

¹²¹ Wellcome Trust, ‘What it’s like for me: Androgen Insensitivity Syndrome’ online interview http://genome.wellcome.ac.uk/doc_WTX059581.html accessed 12 April 2015. The need for disclosure of information will be considered in chapter nine.

3.5.2.2. Partial Androgen Insensitivity Syndrome (PAIS)

The partial and mild forms of AIS occur when body cells are partially sensitive to the effects of androgens. People with PAIS (also called Reifenstein Syndrome) exhibit a spectrum of genital arrangements. Sometimes, where androgen sensitivity is weak, their phenotype will be female. Conversely, those who are only mildly affected will have a male phenotype. Although born with male sex characteristics, PAIS boys are often infertile and tend to experience breast enlargement at puberty. Others with PAIS will present at birth with mildly virilised female external genitalia. This might be an enlarged clitoris, or mildly undervirilised male external genitalia, for example a small penis or hypospadias.

To help their development, it is recommended that children with PAIS take hormone supplements. Girls with PAIS who have had their testes removed will need to take oestrogen to encourage female development during puberty and maintain secondary sexual characteristics in adulthood. Boys with PAIS may need to take androgens to encourage certain male characteristics, such as the growth of facial hair and the deepening of their voice. This depends on being certain as to their gender alignment. Some PAIS people have been given endless medication supporting the wrong gender balance in them. Meanwhile, others who needed to receive treatment were given none, and only at a later stage in their life have they been able to access medical care to support their desired gender assignment.¹²² Once again we see that the intersex face discrimination in their healthcare.

3.5.3 5-alpha-reductase deficiency (5-ard)¹²³

5-ard is caused by mutations to the *SRD5A2* gene,¹²⁴ located on the short arm of autosome 2. In the region of 50 mutations of the *SRD5A2* gene have been

¹²² Lex explains about taking hormone therapy for the first time at 34. www.nhs.uk/conditions/Androgen-insensitivity-syndrome accessed 24 March 2014.

¹²³ 5-alpha-reductase is an enzyme.

¹²⁴ The official name of this gene is steroid-5-alpha-reductase, alpha polypeptide 2 (3-oxo-5 alpha-steroid delta 4-dehydrogenase alpha 2). There are two isoenzymes; 5ARD is due to the absence of type 2.

identified.¹²⁵ As with CAH, 5-ard is a hereditary autosomal recessive condition, therefore it occurs in close communities, notably in Papua New Guinea, Turkey,¹²⁶ Egypt and the Dominican Republic, where consanguineous marriages are more frequent.¹²⁷ There are a number of international communities, the most well-known perhaps being that of the ‘Guevedoces’;¹²⁸ they were first brought to scientific attention in the 1970s when an expedition led by Dr Julianne Imperato-McGinley, an endocrinologist at Cornell Medical College US, travelled to Salinas, a remote village in the Dominican Republic, where it was rumoured that some ‘girls’ turned into men at puberty. These children were known locally as ‘guevedoces’ or ‘machihembras’.¹²⁹ It was far from being a mythical story, and a number of individuals were recorded by the expedition. It was discovered subsequently by the team that these men (some two per cent of the population) all had the same medical condition, namely a deficiency in the production of the enzyme 5-alpha-reductase. Most guevedoces were found to be descendants of a single common ancestor, Altagracia Carrusco.¹³⁰

Another isolated community can be found in the Taurus Mountains in southern Turkey. The condition has been identified in men there for the last seven generations.¹³¹ Nowadays these boys are detected early and grow up with a male name and a male identity. In the past these children were not so lucky. Known at

¹²⁵ Genetics Home Reference ghr.nlm.nih.gov/gene/SRD5A2 accessed 5 July 2013.

¹²⁶ Selcuk Can Yuan-Shan Zhu and others, ‘The Identification of 5a-Reductase and 17b-Hydroxysteroid Dehydrogenase-3 gene Defects in Male Pseudohermaphrodites from a Turkish Kindred’ [1998] *Journal of Clinical Endocrinology and Metabolism* 560. Various gene mutations were discovered in this community.

¹²⁷ *ibid*; P Canto and others, ‘Mutations of the 5alpha-reductase Type 2 gene in eight Mexican patients from six different pedigrees with 5alpha-reductase-2 deficiency’ (2003) 46(2) *Clinical Endocrinology* 155; PB Adiyaman and others, ‘5 alpha steroid reductase deficiency in Turkey.’ (2006) 3 (3) *Pediatr Endocrinol Rev* 462.

¹²⁸ which translates as ‘penis at 12 years’.

¹²⁹ meaning ‘first woman, then man’.

¹³⁰ Andrew Siegel ‘The Guevedoces: How An Intersex Genetic Defect Led To A Blockbuster Class Of Medicines’ February 12 2012 <http://healthdoc13.wordpress.com/tag/guevedoces/> accessed 4 March 2014.

¹³¹ Selcuk Can Yuan-Shan Zhu (n 112).

puberty as kiz-oglan (girl-boy) they were not considered to be ‘complete’ men, and therefore did not receive the full benefits that a male in such a society would expect. In Papua New Guinea, men with 5-ard come from the Sambian tribe, who live in the eastern highlands. The Sambian name for these men is kwolu-aatmwol (female thing-transforming-into-male thing) or turnim man (expected to become a man). It appears that the Sambians are much less comfortable with their intersex progeny than the communities in Turkey or the Dominican Republic.

Men with this condition lack the enzyme needed to convert testosterone to dihydrotestosterone (DHT).¹³² As with the previously described conditions, 5-ard occurs in varying degrees. Some 5-ard babies have normal male genitalia, some have normal female genitalia, and many have ambiguous genitalia. However, most of these children develop external male genitalia, and a male gender, during puberty. This has been a source of conflict with medical opinion. If a child is castrated in early life in the erroneous belief that a female gender can be sustained, it is easy to identify that the sufferer will experience trauma in later life.

3.5.3.1 5-ard – its developmental effect

During early stage growth, the urogenital tract will form in the fetus. DHT ‘mediates virilisation’¹³³ of the majority of the male urogenital tract. In order for full sexual maturation to occur in the male fetus, testosterone has to be converted into DHT, which has a more potent effect on cells than testosterone, by binding itself to androgen receptors in genital tissues. However, due to the shortage of 5-alpha-reductase,¹³⁴ not enough DHT is produced. The end result is that, although the child has male internal sexual organs, the external male sexual organs are incompletely developed and the baby presents with ‘female’ genitalia, or with ambiguous genitalia. If there has been a reasonable amount of DHT produced, the baby will appear as an ‘undeveloped’ male, often with a ‘micropenis’ or hypospadias. The testes are

¹³² It is possible that girl can inherit this pattern, but it will not affect her sexual development.

¹³³ Elizabeth P Jenkins and others, ‘Genetic and Pharmacological Evidence for More Than One Human Steroid 5 a-Reductase’ (1992) 89 J Clin Invest 293, 293.

¹³⁴ Specifically the 5-alpha-reductase type 2 isoenzyme.

usually found in the inguinal canal or scrotum but it is not unusual for cryptorchidism to occur, and for the testes to remain in the abdomen.

Due to their initial external appearance, children with 5-ard are often raised as girls. Additionally, many of these children in the US will often receive treatment to feminise them,¹³⁵ so that it may be impossible for the transformation to male to take place. However, despite a usually female appearance during childhood, puberty will change that. The testes will descend into the scrotum, and a functioning penis will develop. Other secondary sexual characteristics will occur; the voice will become more resonant and there will be a growth spurt with muscle development. However, body hair remains relatively sparse, and the prostate remains small for the rest of the person's life.

It has been estimated that approximately half of the children living as girls in childhood will adopt a male gender in adolescence or early adulthood, particularly if they have been exposed to normal testosterone levels.¹³⁶ Therefore careful assessments of several factors are needed before gender assignment is completed: physical structures, fertility potential,¹³⁷ the need for lifelong hormone replacement therapy, and the geographical cultural environment of the family.

In the Dominican Republic, where the condition is accepted, the vast majority of these children take on a male gender. In select cultures with a high prevalence of 5-ard, such as the Dominican Republic, gender role change is an 'accepted part of culture',¹³⁸ but internationally, particularly in the US, there are reports of children being physically realigned female at an early stage.¹³⁹

¹³⁵ Martha Rosenthal, *Human Sexuality: From Cells to Society* (Wadsworth, Cengage Learning, 2013) 119.

¹³⁶ Lih-Mei Liao and others, 'Determinant factors of Gender Identity: A Commentary' (2012) 8 *Jpurol* 597, 98.

¹³⁷ Not all men with this condition are sterile, although difficulties with fertility are likely to occur.

¹³⁸ Jill E Emerick '5-Alpha-Reductase Deficiency Treatment and Management' Medscape, <http://emedicine.medscape.com/article/924291-treatment> accessed 24 March 2014.

¹³⁹ Karkazis (n 114) 122.

3.5.3.2 17-beta hydroxysteroid dehydrogenase 3 deficiency (17bHSD3)

The deficiency of the enzyme 17bHSD3 leads to a similar condition to 5-ard in XY children, one which is often mistaken for AIS.¹⁴⁰ As with 5-ard, 17bHSD is an autosomal recessive condition caused by mutations in the *HSD17B3* gene which is located on the long arm of chromosome 9. If the enzyme 17bHSD3 is not produced in sufficient quantities, there will be reduced production of both testosterone and DHT. Therefore, as with 5-ard, the child will present with female, ambiguous or poorly developed male external genitalia, albeit the child has an XY configuration and has internal male genitalia; likewise, puberty will alter the exterior physicality to make it more markedly male.¹⁴¹ However, unlike 5-ard, this condition also leads to breast enlargement in sufferers, as androstenedione can aromatise into oestrogen (which will feminise the body) if it is in abundance.¹⁴²

Researchers have estimated that this condition occurs in approximately 1 in 147,000 newborns. However, notably the condition is identified in 1:200 to 1:300 people in the close Arab population in Gaza.¹⁴³

3.6 Incomplete Development of Sex Anatomy

The umbrella term DSD includes those conditions which occur when a child has a type of genital agenesis.¹⁴⁴ Such conditions include vaginal agenesis, gonadal agenesis¹⁴⁵ and Mayer-Rokitansky-Küster-Hauser (MRKH) syndrome.¹⁴⁶ Previously

¹⁴⁰ A study in the Netherlands found that 12 out of 18 sufferers of 17bHSD3-deficiency had received the initial diagnosis of AIS. AL Boehmer and others, '17Beta-hydroxysteroid dehydrogenase-3 deficiency: diagnosis, phenotypic variability, population genetics, and worldwide distribution of ancient and de novo mutations' (1999) 84 (12) J Clin Endocrinol Metab 4713.

¹⁴¹ This is because conversion of androstenedione to testosterone increases in a number of body tissues through processes which utilise other enzymes.

¹⁴² See the diagram for CAH above on page 93.

¹⁴³ This is presumably due to the 'reduced gene pool' that occurs in close communities.

¹⁴⁴ Part of their genital tract is missing.

¹⁴⁵ Some boys present with congenital anorchia, or vanishing testes syndrome. In this situation, boys may present with ambiguous genitalia, or they might present with a 'normal' penis and scrotum but no testicles in the scrotum. On further testing it will become obvious that the testes are 'lost'. If the testes

those with penile agenesis may have been re-gendered as female, but these days persuasive medical authority would prevent this from happening. As sufferers from these conditions normally have an aligned karyotype and genotype, they will require the least amount of legal adjustments, and therefore will not be discussed in depth in the remaining chapters.

3.6.1 Hypospadias

Approximately 1 in 300 male babies is born with some degree of hypospadias. The term hypospadias refers to three separate aspects of penile structure, but primarily where the urethral opening in the penis does not lie at the top of the glans, but in various positions at the back of the glans or further down the underside of shaft.¹⁴⁷ In severe cases, the opening will be located at the base of the penis by the scrotum. Additionally the boys may have bunched-up foreskin, either at the front or the back of the penis, and may also have ‘chordee’, which results in the penis curving downwards. As this will make erections difficult in later life, therapeutic surgery is

are lost when the fetus is between eight and ten weeks’ gestation, the baby will have ambiguous genitalia. However, if the baby appears to have normal male genitals, then the testes will have ‘disappeared’ between 12 and 14 weeks gestation. A male gender is indicated in these circumstances.

¹⁴⁶ MRKH syndrome, which affects approximately 1 in 4,500 newborn girls, is a disorder which causes the vagina and uterus to be underdeveloped or absent. Women with MRKH have a female chromosome pattern (46 XX) and normally functioning ovaries; however, without a uterus, a girl will not menstruate. The condition is usually diagnosed around the age of 16, when a girl will be investigated for primary amenorrhea. Women with MRKH syndrome may also have abnormalities in other parts of the body. They are particularly at risk of unilateral renal agenesis, and will therefore undergo various tests once their condition is discovered. Other medical complications include skeletal abnormalities, hearing loss or heart defects. MRUK support website, <http://www.mrkh.org.uk/mrkh.html> accessed 24 March 2013. It appears that, to date, scientists have not been able to identify why this condition occurs although, in some families, the condition appears to have an autosomal dominant pattern of inheritance. (Autosomal dominant inheritance means that one copy of the altered gene in each cell is typically sufficient to cause the disorder, although no genes have yet to be associated with MRKH syndrome). With the exception of access to appropriate healthcare, and the law surrounding surrogacy and adoption, there are likely to be few legal concerns for those with this condition. In the future, MRKH syndrome may become a category for PGD or abortion, should a specific gene be identified as the causal link. However, for the purpose of this thesis, this will not be considered further.

¹⁴⁷ If the urethral opening occurs on the topside of the shaft this is referred to as epispadias.

normally carried out on the boys at some stage in their early infancy, with varying degrees of success,¹⁴⁸ but for some this leads to a loss of sensitivity.¹⁴⁹

For some children, an initial diagnosis of hypospadias can lead to the discovery of an underlying intersex condition,¹⁵⁰ although this is not usually the case. As a condition on its own, it is unlikely to cause gender identity issues, although it is known that boys can have emotional difficulties when they discover they are ‘different’ to their friends. This quite often occurs; for example, if the boy has to sit down to pass urine, as opposed to standing up like his peer group. Additionally, men with hypospadias may have difficulties forming sexual relationships due to a poor self-image. Should they find themselves in a relationship, it will usually be possible for these men to father children, although assisted reproductive techniques (ART) may be required, particularly if the urethral opening is at the base of the shaft.¹⁵¹ However, it has been estimated that potentially one per cent of men with hypospadias will also have unilateral or bilateral cryptorchidism (undescended testes). Where this is the case, a more severe disorder is likely to be present, such as gonadal dysgenesis, discussed above.¹⁵²

In recent years there have been concerns that the occurrence of hypospadias is increasing.¹⁵³ Research from Atlanta indicates that the incidence of hypospadias

¹⁴⁸ Usually before the age of two. Whilst noting that ‘genital surgery in infancy remains controversial’, Sharma and Gupta note that many adult patients agree that the best time for such procedures is during infancy. Shilpa Sharma and Devendra K Gupta, ‘Male Genitoplasty for Intersex Disorders’ [2008] *Advances in Urology* doi:10.1155/2008/685897, 5.

¹⁴⁹ Iain Moreland’s account of his unsuccessful surgery, Iain Moreland, ‘What can queer theory do for intersex?’ in Iain Moreland (ed), *Intersex and After* (Duke University Press 2009).

¹⁵⁰ N Yordam and others, ‘True Hermaphroditism: Clinical Features, Genetic Variants and Gonadal Histology’ (2001) 14(4) *J Pediatr Endocrinol Metab* 421.

¹⁵¹ As research findings from my survey indicate, a significant number of men with hypospadias use ART as a means to father children. Appendix E.

¹⁵² SY Tong, K Donaldson, JM Hutson, ‘When is Hypospadias not Hypospadias?’ (1996) 164(3) *Med J Aust*; 153.

¹⁵³ Natasha Nassar, Carol Bower, and Andrew Barker, ‘Increasing prevalence of hypospadias in Western Australia, 1980-2000’ (2007) 92 (7) *Arch Dis Child* 580.

doubled between 1968 and 1993,¹⁵⁴ and some European countries generally have reported rises.¹⁵⁵ It is likely that some increase in incidences is due to a change in diagnostic techniques. For example, in the past when a man had the urethral opening on the glans itself, albeit not at the top, that would not have been noted, whereas today it seems generally that it will be recorded as an incidence of hypospadias, often as a surprise to the man himself who 'had not previously been aware of any penile deformity'.¹⁵⁶ Along with several 'true' intersex conditions, hypospadias has a genetic link,¹⁵⁷ although the precise etiology has not yet been discovered.¹⁵⁸

Scientists have tried to identify why there has been an increase in hypospadias, and have pinpointed exposure to hormones as one possible cause. Originally there were suggestions that this was due to the production of oral contraceptive pills, but it was decided that this could not lead to such a significant rise in incidence. More recently, it was thought that vegetarian women who ate a large proportion of soya products were more likely to have a boy with hypospadias.¹⁵⁹ This is because soya products have high levels of phyto-oestrogens which act in a similar way to female sex hormones. However, further studies have suggested that it is not the soya itself that is responsible, but rather how that soya is grown. The effect on the child now appears to be caused by specific endocrine-disrupting chemicals in the environment, which are often composite materials of pesticides used in farming. The studies carried out

¹⁵⁴ As reported by Jean Robinson, 'Research Roundup' (1998) 10 (1) AIMS Journal.

¹⁵⁵ Although Finland appears to have a comparatively low incidence of hypospadias; Helen Dolk, 'Epidemiology of Hypospadias' in Ahmed T Hadidi, AAF Azmy (eds), *Hypospadias Surgery-an illustrated guide* (Springer 2004) 54.

¹⁵⁶ *ibid*, 51.

¹⁵⁷ www.lpch.org/diseasehealthinfo/healthlibrary/hrnewborn/hsp.html accessed 18 April 2014.

¹⁵⁸ Tine H Schnack and others, 'Familial Aggregation of Hypospadias: A Cohort Study' (2008) 167 (3) *Am J Epidemiol* 251. It has been suggested that improved fertility treatment for men with hypospadias is likely to lead to a rise in this condition as affected men will be able to pass on their genetic defect to their sons, although this may not be the reality.

¹⁵⁹ K North, J Golding, THE ALSPAC STUDY TEAM, 'A maternal vegetarian diet in pregnancy is associated with hypospadias' (2000) 85 *BJU International* 107.

in California¹⁶⁰ indicate the difference in the progeny of mice given organically grown food and those given food produced with artificially manufactured pesticides. As mentioned above, as pesticides seem to affect fertility and formation, the question arises as to whether the law should look afresh at or revisit its take on lawful chemical production.¹⁶¹

3.6.2 Cloacal Exstrophy

In approximately 1 in 400,000 births a child will be born with a severe congenital malformation of the pelvis known as cloacal exstrophy. Children with this condition are born with many of their internal organs left on the outside of the body. This is not an intersex condition as such, but due to the extreme physical rearrangement of the genital area, testing and treatment of this condition may be consistent with true intersex conditions. Although the general risk of having a child with cloacal exstrophy is small, it has been noted that the familial recurrence figure is large.¹⁶²

Cloacal exstrophy occurs more often in males than females. In girls, the clitoris is usually split into two segments, and there is likely to be more than one vaginal opening. In boys, the penis is ‘usually flat and short with the exposed inner surface of the urethra on top’,¹⁶³ although sometimes the penis is split into two halves. Understandably these children need urgent medical treatment for this life-threatening condition;¹⁶⁴ however, in the urgency of the situation (and following John Money’s

¹⁶⁰ ML Vilela and others, ‘Endocrine disruptors and Hypospadias: role of Genistein and the fungicide Vinclozolin’ (2007) 70 (3) Urology 618.

¹⁶¹ It is highly probable that the full extent of side effects will remain unknown for decades to come. For example, consider the various discussions of the effects of DDT, now banned as a widespread insecticide. T Colborn, F S vom Saal, and A M Soto, ‘Developmental effects of Endocrine-disrupting Chemicals in Wildlife and Humans’ (1993) 101 (5) Environ Health Perspect 378; B Eskenazi, A Bradman, and R Castorina, ‘Exposures of Children to Organophosphate Pesticides and their potential Adverse Health Effects’ (1999) 107 (3) Environ Health Perspect 409.

¹⁶² If the parents of a child with cloacal exstrophy have a second child, there will be a 1 in 100 chance that this child is born with the same condition.
http://www.pediatricurologybook.com/bladder_exstrophy.html accessed 18 April 2014.

¹⁶³ Boston Children’s Hospital www.childrenshospital.org/az/Site2187/mainpageS2187P0.html accessed 18 April 2014.

¹⁶⁴ M McHoney and others, ‘Cloacalexstrophy: Morbidity associated with Abnormalities of the Gastrointestinal tract and spine’ (2004) 39 (8) J Pediatr Surg 1209.

work), many boys with cloacal exstrophy have been sexually modified during these operations to be brought up as girls. In contradiction to this, recent evidence indicates that a male child is likely to form a male identity, regardless of whether a penis is present or not, and therefore all sex reassignment of these children should be prohibited.¹⁶⁵

Although not an intersex condition, this condition has been incorporated into this thesis as it acts as a ‘control’ in regard to the assignation of truly intersex children to a specific gender. The effect of significant virilising hormones on the brain of the fetus during pregnancy seems to be a major factor in gender identity regardless of the karyotype of the child. The evidence this group brings suggests that demarcation of gender identity should be taken very slowly, and certainly no irreversible operations should be considered without detailed evidence.

3.7 Summary

Although a range of intersex/DSD conditions has been discussed in this chapter, it does not hold itself out to be a foolproof compendium of every intersex condition found today. Indeed, it would not be possible to write such a chapter, primarily because there are many children with genital difference who live, and will continue to live, without a diagnosis for their condition, regardless of healthcare awareness and facilities in their communities.¹⁶⁶ However, in terms of *legal* issues, the unique physical condition an individual may have is likely to mirror a number of other conditions in the same physiological bracket, e.g. virilised females or inadequately virilised males.

The conditions mentioned above will be considered at various stages in this thesis, predominantly where the most ethical or legal tensions are likely to occur. For some

¹⁶⁵ WG Reiner, JP Gearhart ‘Discordant Sexual Identity in some Genetic Males with Cloacal Exstrophy Assigned to Female Sex at Birth.’ (2004) 350 (4) *New England Journal of Medicine* 333.

¹⁶⁶ Even conditions that are recognised are not entirely understood, and research is constantly elucidating new discoveries. Nina Kossack and others, ‘Mutations in a Novel, Cryptic Exon of the Luteinizing Hormone/Chorionic Gonadotropin Receptor Gene Cause Male Pseudohermaphroditism’ (2008) 5 (4) *PLoS Medicine* e88.

children with MGD or PAIS, the most likely legal and ethical tensions will occur at birth and in early childhood, whereas for those with CAIS, their problems may only begin at puberty. Likewise, those children with KS, TS or CAH may find themselves discriminated against before they have even been implanted. It is this primitive stage of development that will be investigated first in part II of this thesis. Before considering current legal tensions, it will be important to consider society's role in formalising a backdrop to various medico-legal scenarios. For this reason, the following chapter is dedicated to considering social dimensions and gender studies, including social construction theory.

Chapter Four: Society, the Intersexed and the Law – a Historical Prospective

4.1 Introduction

There is a well-known Japanese proverb, 出る杭は打たれる, *Deru kugi wa utareru*, which translates as ‘the protruding nail will be hammered’.¹ This proverb encapsulates the social difficulties that intersexed people face in English society today. It has been said that meeting someone of ambiguous gender² is a ‘disquieting experience’.³ Consequently, those with non-binary gender appearance are ‘stigmatised as deviant’⁴ and receive ‘particularly negative reactions’.⁵

As Casey notes,

We can treat other people in ways which diminish our sense of them as persons like ourselves. Some of the things we do can amount to a withdrawal of recognition of others as persons.⁶

In this chapter, I comment on what, from an outsider’s point of view, appears to be the primary challenge of being intersexed, namely confronting and encouraging the adaptation of the established binary system to allow those with ambiguous gender to

¹ David Galef, *Japanese Proverbs: Wit and Wisdom* (3rd edn, Tuttle Publishing, 2012) 61. There are different versions of this proverb: 出る杭は打たれる (*deru kugi wa utareru*) – ‘A nail that sticks out will be hammered’ and 出る杭は打たれる (*deru kui wa utareru*) – ‘A stake that sticks out will be hammered.’ As well as being a proverb to support the consistency of social behaviour, as used in this chapter, these proverbs have also been used to explain leadership situations, where those who lead are often under attack from their subordinates. <http://www.quora.com/Japanese-language/What-do-you-think-about-the-Japanese-proverb-The-nail-that-sticks-out-shall-be-hammered-down> accessed 5 May 2014.

² Regardless as to whether the gender can actually be considered ambiguous, or is the result of a personification of ambiguity.

³ William G Roy, *Making Societies* (Pine Forge Press 2001) 112.

⁴ *ibid* (113).

⁵ Michael A Hogg, ‘Social Categorisation, Depersonalization, and Group Behavior’ in Marilyn B Brewer and Miles Hewstone (eds), *Self and Social Identity* (Blackwell 2004) 214.

⁶ John Casey, *Pagan Virtue* (OUP 1990) 9.

belong to a society where they are ‘understood, accepted and respected and able to participate fully in all aspects of (it)’,⁷ rather than ‘hammered’ into binary ‘normality’.

English law, notably in the field of medical law, tends to be reactive as opposed to proactive,⁸ and current English law reflects attitudes held in society at the time that the law was made. Both judges and politicians can be persuaded by the views of society of the time,⁹ but more particularly the views of the specialists in their fields. It has been common, for example, for judges to rely on the views of doctors where issues of medical treatment are under trial.¹⁰ This has often been at the expense of patients.¹¹ Parliamentary lobbying can and has changed aspects of law, but in the absence of any vocal opposition lawmakers will assume that the law as it stands is a fair reflection of societal views. Even when faced with significant demands, Parliament may not always react.¹² Only recently have the intersexed become vocal in their demands for non-gender-specific passports, and there was only a lukewarm

⁷ <http://intersexuk.org/vision-mission-statement> last accessed 21 May 2013.

⁸ A good example of this is the Surrogacy Arrangements Act 1985, which was passed in a rushed response to the ‘Baby Cotton’ case 1985 (involving surrogate mother Kim Cotton who had been paid £6,500 to carry a child through surrogacy). The Act prohibited commercially-arranged surrogacy and advertising about surrogacy. Likewise the Human Fertilisation and Embryology Act 1990 was passed in response to medical advancements in the treatment for infertility, which had resulted in the birth of the first ‘test tube’ baby, Louise Brown, in 1978.

⁹ The marital rape case of *R v R* [1991] UKHL 12 is a good example of this. The House of Lords noted the views of Court of Appeal *R v R* [1991] 2 WLR 1065 (Lord Lane) CJ [1074]. ‘This is not the creation of a new offence, it is the removal of a common law fiction which has become anachronistic and offensive and we consider that it is our duty having reached that conclusion to act upon it.’

¹⁰ In clinical negligence, for example, the *Bolam* test states, ‘he is not guilty of negligence if he has acted in accordance with a practice accepted as proper by a responsible body of medical men skilled in that particular art (...) as long as you accept that what the defendants did was in accordance with a practice accepted by responsible persons’ *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582 (McNair J) [587]. This has been qualified in recent years, for example in *Bolitho v City and Hackney Health Authority* [1998] AC 232, it was stated that ‘if, in a rare case, it can be demonstrated that the professional opinion is not capable of withstanding logical analysis, the judge is entitled to hold that the body of opinion is not reasonable or responsible.’ [243] (Lord Browne-Wilkinson).

¹¹ A number of women and children have experienced over-patriarchal approaches to their healthcare. This will be discussed in chapter five.

¹² A good example can be seen in the repeated attempt to introduce legislation to legalise attempted suicide. A number of such bills have failed to be passed, for example Lord Joffe’s Assisted Dying for the Terminally Ill Bill in 2006, and more recently Lord Falconer’s Bill, despite the fact that surveys suggest that over 70% of the population would favour such legislation. A YouGov/Daily Telegraph survey in 2010 found that 75% thought the law should allow ‘some people, such as doctors and/or close relatives to assist a suicide in particular circumstances’. http://iis.yougov.co.uk/extranets/ygarchives/content/pdf/Euthanasia_28-Jan-2010.pdf accessed 5 May 2014.

response from MPs in the last Parliament.¹³ Further, and more significantly, the Equality Act 2010 does not allot a category for the ‘intersexed’.

This chapter comprises four sections. The first section will consider the socio-legal treatment of intersex/diversity of sex development (DSD) people throughout history. In this regard, a small selection of case studies will be used to illustrate how the intersexed have fared at the hands of law and society. The second section of this chapter will consider aspects of medical management (or mismanagement) of intersex patients, and considers why medical ‘experiments’ were allowed to occur. The third section will look at the socio-theoretical backdrop to intersex conditions. The final part of this chapter will consider the current need for gender allocation in today’s society, and will discuss the contemporaneous tensions that the intersexed face with current English law in this respect. An amendment to the Equality Act 2010 will be advanced.

4.2 The Views of Society

Current English society can be considered the happy accident of centuries of invasions from the continent. Arguably the most influential was the Roman invasion commencing in 55 BC. Rome itself was founded much earlier, c750 BC. These original Romans have been recorded as considering intersex babies to be ‘monsters’, and these monsters were ‘piteously eliminated’¹⁴ in purifying ceremonies.¹⁵ However, this attitude had changed by the time of Pliny the Elder (23-79 AD) and the intersexed were allowed to live and even marry.¹⁶ Why the change of heart? The Roman Empire was notorious for not only expanding its boundaries, but also acquiring ideas that it came across. Having conquered Greek colonies in Southern

¹³ Early day motion 907: Legal Recognition for those who do not associate with a particular gender (No 2) <http://www.parliament.uk/edm/2013-14/907> accessed 24 May 2015. There were 40 supporting signatories by 5 May 2014. As this Parliament has subsequently been dissolved, no further action will be taken.

¹⁴ Luc Brisson, *Sexual Ambivalence; Androgyny and Hermaphroditism in Greco-Roman Antiquity* (Janet Lloyd tr, University of California Press 2002) 2.

¹⁵ Peggy T Cohen-Kettenis, Friedmann Pfafflin, *Transgenderism and Intersexuality in Childhood and Adolescence* (Sage 2003) 155.

¹⁶ Anne Fausto-Sterling, *Sexing the Body* (Basic Books 2000) 33.

Italy by 275 BC, and finally defeating the State of Corinth and its allies at the Battle of Corinth in 146 BC,¹⁷ the Romans embraced Greek culture. The Romans adopted and adapted the Greek Pantheon of Gods and Goddesses to be their own.¹⁸ In this respect, Hermes (renamed Mercury) and Aphrodite (Venus) were prominent figures in Roman mythology. Hermaphroditos was also imported into this mythology as a minor deity. Hence, temporarily at least, intersex children were elevated from 'monster' to 'progeny of the gods'.¹⁹

By the sixth century AD, the Roman Empire, which still influenced Britain, was under the leadership of Justinian I.²⁰ At this point, the choice of sex rearing of intersex children seems to have been based on the predominant genitalia,²¹ a practice which carried on until the twentieth century. For the majority of this time, society seemed to be quite nonchalant about the intersexed. Difficulties only appear to have occurred when society believed that an individual was being fraudulent in his or her activities, or when there was a direct conflict of laws, for example if a marriage was lawful.²²

During medieval times it was the responsibility of the father to declare the sex of the child at the time of baptism.²³ As baptisms took place during early infancy, it is unsurprising that mistakes were made.²⁴ This led to social difficulties regarding the

¹⁷ This was the start of the new era known as Roman Greece.

¹⁸ Kathleen N Daly, *Greek and Roman Mythology A-Z* (Marian Rengel (rev) 3rd edn, Chelsea House, 2009) 114. They worshipped the same gods and goddesses but gave them different names.

¹⁹ Although as will be seen later, intersex individuals were considered to be monsters by some in Western societies up to the 17th Century.

²⁰ Justinian was the Roman Emperor from 527-565 AD.

²¹ 'The question has been raised to which sex shall we assign an hermaphrodite? And I am of the opinion that its sex should be determined from that which predominates in it.' The Enactments of Justinian. *Ulpianus, on Sabinus, Book I*. SP Scott, *The Civil Law*, II, Cincinnati, 1932 http://droitromain.upmf-grenoble.fr/Anglica/D1_Scott.htm#V accessed 28 April 2014.

²² In different cultures, specific rules were established to incorporate a hermaphrodite child into society. For example, in Judaism, the Talmud and Tosefta 'list extensive regulations' for those of indeterminate sex. Fausto-Sterling (n 16).

²³ Peggy T Cohen-Kettenis, (n 15).

²⁴ An example can be seen from France, when Andre de Laurens, a physician, quoted a tale of a baby born in Saint-Denis, a northern suburb of Paris, who was christened a girl, only for it to be discovered

rites of marriage and the legitimacy of the same,²⁵ as by medieval times the premise of sex alignment, and consequently lawful marriage, was not just based on anatomical appearance but also sexual functioning. The writings of Peter the Chanter, a Parisian theologian,²⁶ highlight such issues in his explanation of ecclesiastical policy regarding the intersexed at that time:

The church allows a hermaphrodite – that is, someone with the organs of both sexes, capable of either active or passive functions – to use the organ by which (s)he is most aroused or the one to which (s)he is most susceptible. If (s)he is more active, (s)he may wed as a man, but if (s)he is more passive, (s)he may marry as a woman. If, however, (s)he should fail with one organ, the use of the other can never be permitted, but (s)he must be perpetually celibate to avoid any similarity to the role inversion of sodomy which is detested by God.²⁷

This clear emphasis on sexual performance and fertility remains a *leit motif* in the treatment of the intersexed today, and was the root issue in several European court actions that took place.

Green recounts two such medico-legal cases from the medieval period.²⁸ One concerns a woman from Bern in the early fourteenth century. Her marriage to a man was dissolved because ‘she could not have sex with him as a woman’.²⁹ Ultimately she was able to undergo surgery to be able to live and marry as a man. A similar story emerges from Catalonia of a woman who was said to have ‘a male penis and testicles like a man’. Her husband was granted a divorce.³⁰

later that ‘she’ was a ‘he’. Cathy McClive, ‘Masculinity on Trial: Penises, Hermaphrodites and the Uncertain Male Body in Early France.’ (2009) 68 (1) Hist Workshop J 45, 49.

²⁵ Monica H Green, ‘Caring for Gendered Bodies’ in Judith Bennett and Ruth Mazo Karras (eds), *Oxford Handbook of Women and Gender in Medieval Europe* (OUP 2013) 355.

²⁶ He died in 1197.

²⁷ Peter the Chanter, *De vitio sodomitico* as quoted by Cary J Nederman and Jacqui True, ‘The Third Sex: The Idea of the Hermaphrodite in Twelfth-century Europe’ (1996) 6 (4) *Journal of the History of Sexuality* 497, 510.

²⁸ Green (n 25).

²⁹ *ibid.*

³⁰ *ibid.*

There are a number of Spanish accounts of masculinised women. The comparative abundance of literature goes hand in hand with current statistical data regarding Congenital Adrenal Hyperplasia (CAH). As discussed in chapter three, CAH often results in gender ambiguity at birth or leads to ‘masculinised women’ at a later stage of life. Although there is no diagnosis for these historical women, their symptoms and physical characteristics resonate with those who have the condition today. As the incidence rate of CAH is ten to twenty times higher in women whose ethnic origins are Hispanic, as compared with the majority of their European counterparts,³¹ it is not surprising that there are more accounts of ‘hermaphrodites’ in Spain than are documented in England during this time.³²

One such example is ‘Estefanía’. Estefanía³³ was born in 1496 in Valdaracete, a village to the south-east of Madrid. At an early age, Estefanía impressed everyone with her ‘ability to play ball with such skill and will, that in her time no boy could equal her’.³⁴ Eventually travelling to Granada, she was required by the Chancery Court to undergo testing by local midwives. As they were unable to identify her predominant sex, she was declared a hermaphrodite, and ‘following established law’,³⁵ she was given the choice of sex to live in. Estefanía became ‘Esteban’, married a woman and made a living as a fencing instructor.³⁶

³¹ ‘The disease frequency is estimated at 0.1% of the general population but it occurs in 1–2% of Hispanics and Yugoslavs and 3–4% of Ashkenazi (Eastern European) Jews.’ Perrin C White and Phillis W Speiser, ‘Congenital Adrenal Hyperplasia due to 21-Hydroxylase Deficiency’ (2000) 21(3) Endocrine Reviews 245, 245.

³² There are in the region of twenty such cases from Spain (predominantly from the region of Castile) from 1530 to 1792. This figure would include some cases of ‘transvestism’. See Francisco Vazquez Garcia and Richard Cleminson, ‘Subjectivities in Transition: Gender and Sexual Identities in cases of ‘Sex-Change’ and ‘Hermaphroditism’ in Spain c 1500-1800’ [2010] Hist Sci xlviii 1, 4, <http://rodin.uca.es/xmlui/bitstream/handle/10498/14518/ArtHistoryofScience.pdf?sequence=1> accessed 5 April 2015.

³³ Also referred to as Estebania. The story was written down in 1580 as point 44 in the *Relaciones topograficas de Felipe II* as a notable event in the local area. This was a document to be sent to Philip II of Spain, (1527-1598) so that Philip could acquire an in-depth knowledge of his country. (Philip had previously been married to Mary I of England, until her death in 1558). Francisco Vazquez Garcia *ibid*, 3.

³⁴ Francois Soyer, *Ambiguous Gender in Early Modern Spain and Portugal* (Brill 2012) 54.

³⁵ Garcia (n32).

³⁶ Soyer (n 34). The majority of the Spanish stories focus on ‘masculinised women’, for example the soldier–nun Catalina de Erausco (1592-1650), as known as Francisco de Loyola, who escaped from a

However, tales of ‘military women’ were not exclusive to Spain, and the Italian story of Daniel Burghammer, and the abrupt end to his marriage, is perhaps the most exceptional of all.³⁷

Notaries recorded Daniel’s story on 26 March 1601. Daniel was christened as a boy and was an apprentice blacksmith in his youth until he joined various armies. He was at the time of the event a mercenary soldier. In 1601, he was stationed in Piadena, where he lived with his wife of seven years. The couple had been unable to have children together. Imagine his wife’s surprise when, one evening, Daniel complained of ‘great pains in his belly and felt something stirring therein’,³⁸ only to find out that her husband had given birth to a daughter one hour later. This caused uproar, and Daniel was investigated. He admitted that he had always been both male and female, and that on one occasion he had slept with a Spanish soldier during his recent duties in the Netherlands. He had managed to conceal all this from his wife, until the arrival of his daughter.

Rather than the child being rejected, her birth was deemed to be a miracle, and when the baby was christened Elisabeth, the town celebrated in style. Moreover, there were many neighbouring towns who wished to adopt Elisabeth as she was considered to be a good omen. The journal noted that Daniel ‘breastfed his infant from the right

convent, travelled to the New World and killed one of her brothers in a battle. She was allegedly given permission by the Pope to wear men’s clothes. Catalina de Erausco, *Lieutenant Nun: Memoir of a Basque Transvestite in the New World* (Michele Stepto and Gabriel Stepto (trs), Beacon Press, 1996) xiv. Another such person is Helena de Céspedes. Whilst living in Toledo, de Céspedes was summoned by the Inquisition to answer charges of sodomy and witchcraft. However, as ‘sodomy’ fell under the remit of civil law in Castile, she escaped the Inquisition, and ultimately escaped the charges and the associated death penalty. Garcia (n 32) 4.

³⁷ Reported in several journal articles including Duane E Jeffery, ‘Intersexes in Humans: an Introductory exploration’ *Dialogue-A Journal of Mormon Thought* https://www.dialoguejournal.com/wp-content/uploads/sbi/articles/Dialogue_V12N03_111.pdf accessed 10 May 2014.

³⁸ Taken from George T Matthews (ed) *The Fugger Newsletters* (1959, 1970). This story could be considered by some to be as mythological as Hermaphroditos himself if it was not for the fact that anatomically speaking this would be consistent with a virilised female chromosome 46 XX. <http://www.crossmyt.com/hc/gen/weirdest.html> accessed 10 May 2014.

breast'.³⁹ The record also noted that '(t)he couple, however, are to be divorced by the clergy'.⁴⁰

Records suggest that court cases were more likely to occur when an intersex 'female' elected to be 'male'. This is likely to be due to the fact that the 'hermaphrodite' would automatically achieve a higher degree of social standing if they were classed as male, as '(m)an was at the top and woman at the bottom of the same scale of values'.⁴¹ Under eighteenth century English law 'male hermaphrodites' would be able to own property and to vote.⁴² Indeed, in various, and some might argue all, societies today there are more privileges to those who are male, with the result that a number of children presenting with a female karyotype will be designated male,⁴³ or will

³⁹ Recorded by Pierre de L'Estoiles quoted by McClive (n 24) 51.

⁴⁰ *The Fugger Newsletters* (n 38).

⁴¹ Toril Moi, *Sex, Gender and the Body* (OUP 2005) 10.

⁴² The American case of Levi Suydam from Salisbury, Connecticut illustrates this point. In 1843, Suydam, with the support of his favoured Whig party, petitioned to be acknowledged as a free man and property owner and thus to be able to vote in local elections later that year. His petition was challenged by the opposition party, especially as the Whigs won the seat by a majority of one! Although the court accepted that Suydam owned enough land, it was said 'that he was more a female than a male and that he partook in both sexes'. Although the judgment initially went in his favour, a later more robust examination identified Suydam as more female than male and therefore he was considered to be an imposter, and a voting fraudster. Elizabeth Reis, 'Impossible Hermaphrodites: Intersex in America, 1620-1960' (2005) 92 (2) *The Journal of American History* 411, 431.

By comparison, the life of the Chevalier/Chevalière d'Eon, should be noted. The chevalier, after a life of espionage, was considered to be the first openly transvestite in the modern world when it was pronounced that 'he' was in fact a 'she'. At the time the claims made were that she was a hermaphrodite and was aligned male to inherit 'his' father's estates. However, this change of sex has been described as a 'politically expedient act, as opposed to an issue of finding himself'. By all accounts the Chevalière d'Eon took no pains to adopt feminine traits in deportment or conversation, quite often enjoying vulgar conversation (something the gentler sex was not allowed to do). When he died there was a clamouring to verify his sex, and his autopsy revealed that he was male. Stephen Brogan, 'A "Monster of Metamorphosis": Reassessing the Chevalier/Chevalière d'Eon's Change of Gender' in Simon Burrows, Russell Goulbourne, Jonathan Conlin, Valerie Mainz (eds) *Chevalier d'Eon and his Worlds: Gender, Espionage and Politics in the Eighteenth Century*. (Continuum Books, 2010) 81.

⁴³ 'In our study, wrong gender assignment to genotypic females is noted and in some of them male sex was maintained due to late presentation and development of male gender identity at diagnosis (5 cases, 17.2%). It is a result of lack of awareness, failure to diagnosis, false social beliefs, religious dogmas, pressure from relatives and society in this part of the world.' Aysha H Khan and others, 'Ethnic disparity in 21-hydroxylase gene mutations identified in Pakistani Congenital Adrenal Hyperplasia Patients' (2011) 11 (5) *BMC Endocr Disord* <http://dx.doi.org/10.1186%2F1472-6823-11-5> accessed 25 May 2015.

decide to be male if they are given that choice.⁴⁴ It is therefore unsurprising that in the past European courts dealt with ‘fraudsters’.

One such fraudster was Anne/Jean-Baptist Grandjean.⁴⁵ Born in Grenoble in 1732, Grandjean lived as a girl until the age of 14, when she started to find women attractive. Lest ‘Anne’ be castigated as homosexual, her local priest advised her to change to live as a man, which she did. Jean-Baptiste moved to Lyon, where he met Francoise Lambert and married her.⁴⁶ After three years of childless marriage, Francoise reported Jean-Baptiste to the authorities when she was informed by another woman that her husband was not a ‘proper man’. By the eighteenth century in France, it was a fraudulent action to marry if the individual knew (be they intersex or not) that s/he was impotent. Consequently, Jean-Baptiste was sent to trial, accused of ‘profaning the sanctity of marriage’.⁴⁷ At his trial, Jean-Baptiste’s physique was assessed, but the lack of semen production meant that he could not satisfactorily prove his masculinity to the court. He was found guilty, and his appeal to the Dauphine Court was unsuccessful. His ‘sentence’ was to spend the rest of his life as a woman, and he was banned from making intimate contact with other females.

The earlier case of Marie/Marin (Martin) Lemarcis led to a series of trials in Normandy in 1601. Marin spent his life as a girl, Marie, until, at the age of 20, he threw off his feminine persona, rebranded himself as Marin and became engaged to a fellow servant, Jeanne LeFevre, who was a widow with three children. When the two tried to arrange their marriage the law became involved. Marie/Marin was accused of:

⁴⁴ In an article dated from 1948, the author writes a case report of a 16-year-old Chinese female, Miss LB who displayed masculine physical characteristics. It was reported that the patient was extremely anxious to become a boy. ‘The male sex is regarded, (...) so much above the female, that this patient will accept the hardships which no doubt will accompany him throughout his life with gratitude and satisfaction.’ David D Kulcsar, ‘Intersexuality (with report of a case)’ (1948) 59 *Canad. M A J* 144, 148.

⁴⁵ Vermeil, *Mémoire pour Anne Grandjean, connu sous le nom de Jean-Baptiste Grandjean accuse & appellant*. (Louis Cellot, MDCC LXV) 4.

⁴⁶ Michel Foucault, ‘Abnormal. Lectures at the College de France 1974-5’ Valerio Marchetti and Antonella Salomoni (eds) (Graham Burchell (tr), Verso 2003) 71.
http://monoskop.org/images/9/9b/Foucault_Michel_Abnormal_Lectures_at_the_College_de_France_1974_1975_2003.pdf accessed 23 March 2015.

⁴⁷ The case was told throughout Europe through the writings of Arnaud, ‘Dissertation sur les hermaphrodites’ in *Memoires de Chirurgie vol 1* (London/Paris 1768).

Offending God and Justice in calling himself a man, since we found no such signs, but on the contrary all the signs of girlhood, not only the feminine formation of the parts, but also the flowers or menses which are only accustomed to appear to girls and to women.⁴⁸

Marin was initially condemned to be burnt at the stake for acts of sodomy and cross-dressing,⁴⁹ and Jeanne was to be flogged, but because the death penalty had been evoked, the defendant had a right of appeal to the Rouen Court (Parlement de Rouen). On appeal, Jacques Duval, a doctor, testified that on examination he had discovered a functioning penis, which could ejaculate semen. This was backed up by Jeanne informing physicians that Marin was as virile a man as her late husband. The doctors commented that this woman had not been duped by inexperience, as may have happened in other cases. Although Marin was saved from the gallows, Parlement decreed that 'he' be made to wear women's clothes until he reached 25,⁵⁰ and therefore he was not allowed to marry Jeanne.⁵¹

Michel Foucault⁵² sees this case as interesting not just because there was a duel between two renowned physicians, Duval and Riolan,⁵³ but because this case indicates that there was a *clinical* attempt to identify the 'true sex' of an intersex individual. It should be noted that at this time, medico-legal writers formulated ideas within the context of a religious framework which often referred to canon law. Those

⁴⁸ McClive (n 24) 53.

⁴⁹ Thomas Laqueur, *Making Sex: Body and Gender from Greeks to Freud* (Harvard University Press 1990), 136. Such treatment befell Joan of Arc, who was ultimately executed for no other reason than the spurious excuse of her inhabiting male clothes. Without the ability to use DNA tests, it is impossible to discover whether Joan of Arc was a woman with Complete Androgen Insensitivity Syndrome, as has been suggested. Regardless of this, there are many accounts of Joan's last days, but the theme remains the same. It is clear that Joan's death was highly desirable but she handled herself very well during her trial, and it was only when she was threatened with torture that she 'admitted' that she had invented her voices from the saints. The central argument against her appears to be the wearing of male clothes, which she said she did for protection. Having agreed to wear female clothes, which were then taken away from her in prison, she was forced into wearing a man's clothes again. This gave her prosecutors the cue they needed to act. She was treated as a relapsed heretic, the penalty for which was to be burnt at the stake. Ronald Sutherland Gower, *Joan of Arc* (The Echo Library, 2006) 116.

⁵⁰ The age of majority in France at the time.

⁵¹ McClive (n 24) 56.

⁵² Foucault, (n 46) 69.

⁵³ who believed in 'monsters'.

who held fast to the religious aspects of this framework would argue that Marin was a monster, because a person comprised of two sexes *must* be a monster. This belief in ‘monsters’ would remain for at least another century,⁵⁴ as can be seen in an English case from 1719.⁵⁵ In this case, Katherine Jones was on trial for bigamy, having entered into a marriage ceremony with Constantine Boone whilst still being married to John Nowland. At the trial, Jones said that she had not married another *man* but a ‘Monster’.⁵⁶ Boone appeared in court, where it was accepted after hearing evidence that she was a hermaphrodite and that ‘the Woman was more predominant in her than the Man’.⁵⁷ Jones was acquitted.⁵⁸

These cases are indicative of the desire to allocate a hermaphrodite to one or other of the traditional sexes. This regularisation increased over time and the nineteenth century saw movements to make the binary adherence of sex ever more sacrosanct. Under King William IV, the Births and Deaths Registration Act 1836 and the Marriage Act 1836 were passed. Prior to this time, the registration of such events was the domain of church authorities. This was the first time that such events had fallen under the control of civil authorities, and society demanded more information about these events than was previously asked for. This civil interest expanded with the 1841 census.⁵⁹ For this census, each householder was required to complete information on the names, ages, sexes, occupations and places of birth of everyone living at the

⁵⁴ See Joseph Jacob Plenck, *Elementa medicinae et Chirurgiae forensis* (Elements of Forensic Medicine and Surgery) 1781, 120. For further discussion, Garcia (n 32) 12.

⁵⁵ *Old Bailey Proceedings Online*, September 1719, trial of Katherine Jones, alias Nowland (t17190903-50). <http://www.oldbaileyonline.org/browse.jsp?ref=t17190903-50> accessed 28 April 2014.

⁵⁶ *ibid*

⁵⁷ *ibid*

⁵⁸ The same situation would result in a different outcome now. As a result of the Marriage (Same Sex Couples) Act 2013, it would be possible to marry either a man or a woman, but not at the same time by virtue of Section 57 Offences Against the Persons Act 1861.

⁵⁹ Although there had been previous censuses in 1801, 1811, 1821 and 1831, very little remains of them. Furthermore, these earlier censuses only recorded a head count and demanded no personal information. The 1841 census, which remains intact, is therefore considered the start of the modern census, albeit some of the information is naturally incorrect, such as recording a person’s age or indeed name. ‘The ages of people over 15 years old were usually rounded down to the nearest 5 years. For example, someone who was actually 24 years would have their age listed as 20, and someone who was actually 27 years old would have their age listed as 25.’ <http://search.ancestry.co.uk/search/db.aspx?dbid=8978> accessed 5 May 2014.

address. With the increase in record keeping came a more fervent desire to compartmentalise individuals into specific categories, be it sex, age or occupation. It was also at this time that medical opinion sought to regularise hermaphrodites into one of two sexes, rather than allowing them to remain in their own class. This rigid recorded system of binary sex remains with us today and pervades all aspects of our lives.

One of the most well-known stories of hermaphrodites of this time is that of Herculine Adélaïde Barbin, who was born in France in 1838.⁶⁰ Having been brought up as female, and known by her circle of friends as Alexina or Alexine, Barbin received a charity scholarship to study in a convent school, where her intellectual attributes shone. In 1857 Barbin became an assistant teacher in a girl's school. Here, Barbin fell in love with another teacher Sara, and they started an affair. This relationship carried on until Barbin became ill one night, and a doctor was summoned. The doctor was shocked by his discoveries but said nothing. Eventually, after Barbin confessed to his Bishop, another doctor was summoned and Barbin was identified as a male pseudo-hermaphrodite. He was later decreed a man by French law, but he was never happy in his new role. Feeling a sense of uselessness, and being unable to cope outside the convent, he fell into depression and committed suicide in 1868. His memoirs were found in his room.

4.3 The Views of Scientists

According to Toril Moi,⁶¹ from ancient times through the Middle Ages, the view of 'scientists' was that there was only one 'sex', with female genitalia being an inverted version of the superior male design. Consequently, anatomical differences were

⁶⁰ Michael Foucault discovered the memoirs, and has since reproduced them. Michael Foucault, *Herculine Barbin (Being the Recently Discovered Memoirs of a Nineteenth-century French Hermaphrodite)* (Richard McDougall (tr), Pantheon Books, 1980).

⁶¹ Toril Moi, *Sex, Gender and the Body* (OUP 2005) 10.

considered ‘hierarchical as opposed to complementary’,⁶² and ‘rigidly differentiated’.⁶³

Medieval medicine considered the intersexed in terms of divine messages – they were monsters ‘demanding interpretation’.⁶⁴ In earlier times, these ‘monsters’ were seen as objects of wonder, but by the seventeenth century, in France, hermaphrodites had taken on the role of scientific subject matter.⁶⁵

By the eighteenth century the ‘two-sex’ model of biology came into being, which ‘encapsulated anatomical, biological, legal and social differences between men and women’.⁶⁶ In terms of medical intervention, the policy towards hermaphrodites was relatively liberal in England at this time. Advice issued by James Parsons in 1741 was that the child should be baptised in the predominant sex, ‘but if the Sexes seem equal, the choice is left to the hermaphrodite.’⁶⁷ Reis points out⁶⁸ that this approach contrasts with more recent medical opinion which favoured doctors making the choice of sex, mainly based on anatomy, rather than allowing the choice to come from the intersex persons themselves.⁶⁹ This comparatively mild treatment was to alter in the following century with the emergence of the new scientists of the late Victorian era.

⁶² *ibid*

⁶³ Garcia (n 32) 4.

⁶⁴ Jenny C Mann, ‘How to Look at a Hermaphrodite in Early Modern England’ (2006) 46 (1) *SEL* 67, 69.

⁶⁵ Studies included Jacob Rueff’s *De Conceptu et Generatione Hominis* (1554) (translated in London 1637); Ambroise Paré’s *Des Monstres et Prodiges* (1573) (translated in London 1634). Later texts included Jacques Duval’s *Traité des hermaphrodites* (1612), Jean Riolan’s *Discours sur les Hermaphrodits* (1614) and Gaspard Bauhin’s *De Hermaphroditum* (1614) as noted in Mann, *ibid*.

⁶⁶ Garcia (n 32) 1.

⁶⁷ James Parsons, ‘A Mechanical and Critical Enquiry in the Nature of Hermaphrodites’, as quoted by Reis; Elizabeth Reis, ‘Impossible Hermaphrodites: Intersex in America, 1620-1960’ (2005) 92 (2) *The Journal of American History* 411, 419.

⁶⁸ *ibid*.

⁶⁹ Cohen-Kettenis (n15) 156.

During the nineteenth century, scientists across Europe developed a profound interest in individuals with ambiguous genitalia. In 1833, Isidore Geoffroy Saint-Hilaire presented his classification system of hermaphrodites in France. His system considered whether the sexual organs were ‘concordant within an individual’,⁷⁰ by considering ‘normal’ sexual development and then comparing a patient’s abnormality in relation to it. Around this time in England there developed a distinction between ‘true’ hermaphrodites and ‘spurious’ hermaphrodites. This was based on a fairly broad classification devised by Sir James Young Simpson, which was published in 1839. Simpson noted that

the spurious comprehending such malformations of the genital organs of one sex as make these organs approximate in appearance and form to those of the opposite sexual type; and the order, again of true hermaphroditism, including under it all cases in which there is an actual mixture or blending together, upon the same individual, of more or fewer of both the male and female organs.⁷¹

Applying Simpson’s classification, a number of intersexed persons counted as ‘true’ hermaphrodites. This ‘fairly liberal’⁷² approach was not to last out the century.

The 1870s saw a new growth in intersex investigation generally, and hermaphrodites frequently become public spectacles. Katharina/Karl Hohmann was one such exhibition model.⁷³ Such experiments continued for decades. In 1876, a German pathologist, Klebs, instigated a hermaphrodite taxonomy based purely on whether a patient had testes or ovaries, and tissue analysis of the same. The label ‘spurious’ hermaphrodite was altered into the term ‘pseudo-hermaphrodite’ to present, in scientists’ opinion, a more accurate description of an individual who has the gonads (ovaries or testicles) of one sex but whose external genitalia primarily or fully

⁷⁰ Katrina Karkazis, *Fixing Sex: Intersex, Medical Authority and Lived Experience* (Duke University Press, 2008) 35.

⁷¹ Sir James Young Simpson’s classification system, as in Todd’s *Cyclopaedia of Anatomy and Physiology* [1839], as quoted by Alice Domurat Dreger, ‘The Fate of the Hermaphrodite in Victorian Medicine’ (1995) 38 (3) *Victorian Studies* 335, 358.

⁷² *ibid*, 359.

⁷³ Gertie Mak ‘Hermaphrodites on Show. The case of Katharina/Karl Hohmann and its Use in Nineteenth-century Medical Science’ (2012) 25 (1) *Soc Hist Med* 65. doi: 10.1093/shm/hkr050.

resemble the opposite sex. This term was to remain in medical taxonomy until 2006, when calls to change this unpalatable term by the individuals concerned were honoured by the published census statement.⁷⁴

By 1890s England there was a desire for a new hermaphrodite taxonomy. It was delivered by Blacker and Lawrence in 1896.⁷⁵ The upshot of the new criteria, according to Dreger,⁷⁶ was the refuting of the number of ‘true’ intersex cases that had occurred in earlier times, and inhibition of new cases of ‘true’ hermaphrodites being identified. This, it is suggested, led to the reduction of a hermaphrodite’s social status – something to be expunged from records and replaced with a definitive ‘male’ or ‘female’. Dreger believes that this was to ensure that ‘normal’ sexual relationships occurred as opposed to homosexual ones,⁷⁷ and that medics found this to be a ‘necessity of social order’.⁷⁸ Hence in the new taxonomy the binary system of sex was firmly re-established – a process that was to continue for the next century.

At the turn of the twentieth century, scientific discoveries indicated that hereditary traits were passed through chromosome acquisition, and that sex was established via the acquisition of one of two ‘sex chromosomes’. This binary system of sex chromosomes helped to ensure that the ‘two-sex’ binary system in general was firmly embedded in society by the end of the Edwardian era. Writing in 1913, Heape specified that ‘Male and Female are essentially different throughout...(They are) complimentary, in no sense the same, in no sense equal to one another; the accurate adjustment of society depends on proper observation of this fact.’⁷⁹

⁷⁴ PA Lee and others, ‘Consensus Statement on Management of Intersex Disorders’ (2006) 118 (2) *Paediatrics* 488.

⁷⁵ Published in *Transactions of the Obstetrical Society of London* as discussed in Alice Domurat Dreger (n 67) 61.

⁷⁶ *ibid.*

⁷⁷ *ibid.*, 39.

⁷⁸ *ibid.* Translating French medical practitioners T Tuffier and A Lapointe ‘L’hermaphroditisme. Ses variétés et ses conséquences pour la pratique médicale (l’après un cas personnel)’ [1911] *Revue de gynécologie et de chirurgie abdominale* 17 209-68.

⁷⁹ Laqueur, (n 49), 220 quoting Walter Heape, *Sex Antagonism* (London, 1913) 23.

This perceived inequality led to a desire for societal reform. Whilst early twentieth scientists were advocating two sexes, women were campaigning for equality of sexes. A long-term and still waging battle, some small inroads were made at the turn of the last century in the UK with the suffrage movement ‘burning to get the vote’, both metaphorically and literally.⁸⁰ In the United States, a parallel movement saw the introduction of compulsory education laws in 1912, which led to an increase in the educated female as a whole. This ‘first-wave feminism’⁸¹ was centred on obtaining legal rights. However, despite radical action from some, the suffrage movement appears to have had limited impact on society and it took two World Wars for the balance to shift.

As Karkazis notes, despite a number of scientific investigations and theories internationally, no single strategy ‘emerged for understanding and dealing with intersexuality in the West, either socially or medically’.⁸² By the 1950s, New Zealander John Money saw this lacuna and attempted an ambitious programme to produce a unifying treatment protocol. This dramatic regime affected treatment of the intersexed throughout the world for over half a century, and still retains a hold on medical thought in various communities today.

4.3.1 The Legacy of John Money

Although treatment of intersex patients had been carried out at the Johns Hopkins University in Baltimore since the turn of the twentieth century, under the guidance of Hugh Hampton Young, it was not until the 1950s that a team of medical specialists, including Money, developed what is now known as the ‘optimum gender of rearing’ system for treating intersexed children. This system emphasised that gender was a matter of nurture rather than nature. The idea was to gender assign (or reassign) the child at an early stage in life, via surgical, hormonal and psychological treatments, so that the children would grow up to be both a believing and believable girl or boy. Money pronounced that any child could be made a ‘real’ girl or boy if their bodies

⁸⁰ ‘Burning to get the vote’ was the message left by suffragettes in March 1913 when they fire-bombed a small station in Buckinghamshire. Colin Cartwright, *Burning to get the Vote, the women’s suffrage movement in central Buckinghamshire 1904-1914* (University of Buckingham Press 2012).

⁸¹ A phrase coined in the 1970s.

⁸² Karkazis (n 70) 46.

were adapted and their ‘matching’ gender roles enforced from this point. This had to occur before 18-24 months of age, at which point the so-called ‘gender-gate’ would firmly close.

It is said the Johns Hopkins team initially prescribed that children should be told the truth about their intersex histories, but in practice this did not happen, and in later life many patients were left confused and disorientated about their bodies, gender and sexuality. According to the Intersex Society of North America (ISNA) website, ‘medical textbooks frequently gave doctors advice about how to *lie* to patients with intersex’.⁸³ Doctors believed that intersex children would develop better without the ‘terrible knowledge’ of their history, and so silence ensued.

The most familiar story associated with Money is that of David Reimer who was born an identical twin boy on 22 August 1965 in Winnipeg, Canada. Reimer was not born with an intersex condition, but at seven months old it was identified that David (then called Bruce) and his twin brother appeared to be suffering from phimosis,⁸⁴ and a circumcision was recommended for both of them.⁸⁵

It is common knowledge that Reimer’s operation was unsuccessful. Rather than cutting the prepuce (foreskin) with a scalpel, as is the more traditional practice, the doctor decided to use electrical equipment to ‘burn off’ the foreskin. Unfortunately, the equipment malfunctioned several times, ultimately burning off David’s penis during the last attempt.

⁸³ ISNA, ‘What’s wrong with the way intersex has traditionally been treated?’ <http://www.isna.org/faq/concealment> accessed 9 September 2015.

⁸⁴ The medical name for a tight foreskin; it frequently makes urination difficult and can lead to a life-threatening condition from adolescence onwards.

⁸⁵ Today, in the UK, it would be extremely unlikely that a diagnosis of phimosis would lead to surgery on such young children; however, in the 1960s circumcision was a routine operation in the US, UK and Commonwealth countries. The procedure is still routine in the US, albeit the national rate of newborn circumcision in the US dropped by 10% overall, from 64.5% to 58.3%, in 1979-2010. Maria Owings, Sayeedha Uddin, and Sonja Williams, Division of Health Care Statistics, Centers for Disease Control and Prevention. ‘Trends in Circumcision for Male Newborns in US Hospitals: 1979–2010’ http://www.cdc.gov/nchs/data/hestat/circumcision_2013/circumcision_2013.htm/ accessed 24 April 2014.

Some months later, David's parents saw a television programme which featured Money in a debate about sex change operations on transsexuals. In this programme, Money advanced his theories that nurture rather than nature was the cause of gender alignment, and given the right time frame a 'boy' could happily adjust as a 'girl'. Janet Reimer wrote to Dr Money immediately. He responded swiftly and invited them to come and visit him in Baltimore, Maryland. Following Money's advice, David's parents agreed to have him reassigned as a girl, and at 21 months, Bruce's testicles were removed. On leaving the hospital his parents were told not to say a word to anyone about the operations, particularly not Bruce, who was renamed Brenda.

Although Money had carried out such experiments on intersex children, he had not carried out his controversial theories on a non-intersex child. Here was a perfect opportunity to carry out such an experiment with an identical twin boy to act as a control. Brenda's parents took her for regular check-ups with Money and, in an effort to promote his research, Money published his experiment when Brenda was five, using the pseudonyms Joan/John to conceal her identity.⁸⁶ Money claimed that Brenda turned out to be a 'real' girl with a female gender identity. The case became an overnight success. Classified as a landmark in science, it defied all the other science emerging at the time that hypothesised that hormones received during pregnancy shape us, not just in how we look but in our gender identity.

However, the reality was somewhat different. Brenda, and Brenda's twin brother, had countless experiments conducted on them by Money's team. Money frequently took photographs of Brenda and her brother naked and showed Brenda graphic photographs of women giving birth, in order to encourage her to undergo vagina reconstruction.⁸⁷ Brenda felt traumatised and became suicidal. Eventually her parents told her the truth and overnight Brenda re-invented himself as David. The world at large knew nothing of this for nearly 30 years. Both brothers had endured considerable emotional distress and ultimately, during the last decade, both twins committed suicide.

⁸⁶ David Reimer 'The Boy who lived as a Girl' CBC News Online May 10 2004. <https://myportal.bsd405.org/personal/perezl/Shared%20Documents/CBC%20News%20Indepth%20%20David%20Reimer.htm> accessed 12 May 2015.

⁸⁷ *ibid.*

Some scientists, including Money's ex-students, have expressed their opinions that Money had a genuine interest in his patients and that he was acting in the best interests of his patients. This may be so, but his research fostered the erroneous belief globally that gender identity is *all* about nurture, and nature is irrelevant. This does not appear to be the case.⁸⁸

It is now understood that Money's results from the John/Joan experiment were fabricated, but at the time they were accepted as the truth. Money used the 'success' story to promote his research and consequently his career. The results produced were so convincing that his approach to the treatment of the intersexed was used consistently worldwide. Money's treatment may have been discredited after Reimer's story emerged but it was too late to stop countless similar operations taking place in the US, UK and globally. There are many stories told by the intersexed of enduring unnecessary genital surgery,⁸⁹ and although in the UK, at least, 'routine' intersex operations have diminished, Money's approach is still used today in many countries.

One of the earliest challenges to Money was undertaken by a junior doctor, Milton Diamond. In a Skype interview,⁹⁰ Professor Diamond clearly states that when he first took on Money's ideas in the 1960s, 'Money was the big guru, and I [Diamond] was a graduate student.'⁹¹ Diamond was required to pick a theme in order to apply for a research grant, and he wrote a critique of Money's theories stating that he believed that Money's ideas were wrong. Diamond eventually published his argument in *The*

⁸⁸ This is discussed in section 4.4.3.

⁸⁹ Suzanne Kessler, *Lessons From the Intersexed* (Rutgers University Press 1998); Catherine Harper, *Intersex*, (Berg 2007); Thea Hillman, *Intersex (for lack of a better word)* (Manic D Press 2008); Katrina Karkazis, *Fixing Sex: Intersex, Medical Authority and Live Experience* (Duke University Press, 2008). Iain Moreland (ed), *Intersex and After; GLQ Vol 15; 2* (Duke University Press 2009); Julie A Greenberg, *Intersexuality and the Law – Why Sex Matters* (NYU Press 2012); Ellen K Feder, *Making Sense of Intersex: Changing Ethical Perspectives in Biomedicine* (Indiana University Press 2014).

⁹⁰ Interview with Dr Milton Diamond: research.cristanwilliams.com
<https://www.youtube.com/watch?v=IKqU1IxEDxk> accessed 24 July 2015.

⁹¹ *ibid.*

Quarterly Review of Biology,⁹² which was, and remains, a ‘premier review journal in biology’.⁹³

Diamond explained that he saw its publication as an ‘intellectual achievement as a student’,⁹⁴ but Money took it as a *personal* attack rather than an intellectual critique. When the two finally met at a conference in Dubrovnik, a scene erupted, because, according to Diamond, Money had not been able to separate personal from professional.⁹⁵

The Money: Diamond ‘rivalry’ indicates that Money’s work was not fully evaluated with adequate control measures. Money appears to have forced his theories onto others without taking all necessary ethical considerations on board, allegedly writing defamatory comments about anyone who criticised his work.⁹⁶ The John/Joan ‘deception’⁹⁷ was ultimately proof positive of this lack of systematic analysis; however, his work led to a seismic shift in activities towards enforced operations on the intersex, the aftershocks of which have been felt in the UK for over 50 years .

Diamond was not the only scientist to question Money’s theories. In the 1990s, paediatric urologist William Reiner argued against Money’s theory of gender identity development, believing in a ‘strong inborn bias for gender identity and sexual development’.⁹⁸ Reiner has a firm belief in the relationship between androgen exposure *in utero* and the gender at birth.⁹⁹ This argument is not without its critics,¹⁰⁰

⁹² Milton Diamond, ‘A Critical Evaluation of the Ontogeny of Human Sexual Behavior’ (1965) 40 (2) *The Quarterly Review of Biology* 147.

⁹³ ‘According to the 2013 science edition of *Journal Citation Reports*, the *QRB* is ranked tenth out of 83 journals and given an impact factor of 5.059 in the category of biology.’ <http://www.press.uchicago.edu/ucp/journals/journal/qrb.html> accessed 24 May 2015.

⁹⁴ Interview with Dr Milton Diamond (n 90).

⁹⁵ *ibid.*

⁹⁶ *ibid.*

⁹⁷ *ibid.*

⁹⁸ Karkazis, (n 70) 77.

⁹⁹ WG Reiner, ‘Psychosexual Development in Genetic Males assigned Female: the Cloacal Exstrophy experience’ (2004) 13 (3) *Child Adolesc Psychiatr Clin N Am* 657; WG Reiner, JP Gearhart ‘Discordant Sexual Identity in some Genetic Males with Cloacal Exstrophy Assigned to Female Sex at Birth.’ (2004) 350 (4) *New England Journal of Medicine* 333.

¹⁰⁰ Karkazis, (n 70) 79.

but Reiner's work on cloacal exstrophy produces some of the most convincing arguments against Money's treatment paradigm.¹⁰¹ Although often born without a recognisable penis, boys with this condition will usually gender orientate male, even if they have been reassigned female at birth, hence falsifying Money's results.

It is curious that one man's research was allowed to play such a dominant role in international medical treatment without further analysis. In this respect, it is submitted that Money was 'successful' not solely due to his 'persuasive' methods and personality, but due to general ignorance of the role of gender on the persona. Early social constructivists, eager to obtain evidence to back up their theories, also promoted his 'successes'. 'Gender Studies' are relatively recent phenomena and such studies did not fully develop until after the 'Money paradigm treatment' had been established. Although some attention was paid to gender development in the 1950s, it was not until the 1960s, according to Spence,¹⁰² that the watershed in terms of gender studies occurred, and particularly during the late 1960s when 'gender skyrocketed from a minor topic to one of psychology's most popular'.¹⁰³ Additionally, it was only in the 1970s that social psychologists fully developed strategies to counteract social discrimination,¹⁰⁴ thus promoting opportunities to 'know outgroup members as individual persons'.¹⁰⁵

Fifty years ago an intersex child was squeezed into a binary system of sex and society, amidst shame and secrecy. The desire for intersex conformity enabled Money to promote his research, and well-intentioned medical practitioners followed Money's lead to give what they believed to be the best medical treatment. From her

¹⁰¹ The condition is discussed in chapter three at 3.6.4.

¹⁰² Janet T Spence, 'Women, Men, and Society: Plus Ça Change, Plus C'est La Meme Chose' in Stuart Oskamp and Mark Costanzo (eds), *Gender issues in Contemporary Society* (Sage Publications, 1993) 4.

¹⁰³ *ibid.*

¹⁰⁴ This evolved from social identify theory and social categorisation. Marilynn B Brewer and Samuel L Gaertner, 'Toward Reduction of Prejudice' in Marilynn B Brewer and Miles Hewstone (eds), *Self and Social Identity* (Blackwell 2004) 299.

¹⁰⁵ This is known as 'decategorisation' *ibid* 304.

research in the 1990s,¹⁰⁶ Kessler identified that all the specialist surgeons interviewed were following the Money theory of gender:

‘I think we [physicians] have been raised in the Money theory’ one endocrinologist said. Another claimed, ‘We always approach the problem in a similar way and it’s been dictated, to a large extent, by the work of John Money and Anke Ehrhardt because they are the only people who have published, at least in medical literature, any data, any guidelines.’¹⁰⁷

Money, himself, was extremely scathing of writers who challenged the binary sex system. He is reported as writing, ‘(i)t simply does not make sense to talk of a third sex, or of a fourth or fifth, when the phylogenetic scheme of things is two sexes...To advocate medical non-intervention is irresponsible.’¹⁰⁸

It can be seen that a mixture of individual charisma and societal ignorance can lead to devastating results. The lack of balanced gender studies in a masculine society assisted Money to rise to fame, and the rise of gender studies helped in his downfall.

4.4 Gender Studies and the Intersexed

With the recent growth of gender studies, literature has teased apart the elements of ‘sex’ or ‘phenotype’, ‘sexuality’ and ‘gender’ as separate aspects of one persona. For the majority of us, our physical body will be used by society to allot us to one of two binary ‘sexes’. In the past, society has failed, and indeed continues to fail, a number of us by assuming that if our bodies fall neatly into a ‘male’ or ‘female’ category, other aspects of our persona, namely our sexuality (the physical desire for another), will fall into line with the expected heterosexual norm. This is clearly not the case. A more drastic complication occurs when our physicality does not match with our gender alignment (how the individual perceives their own role in society). This leads

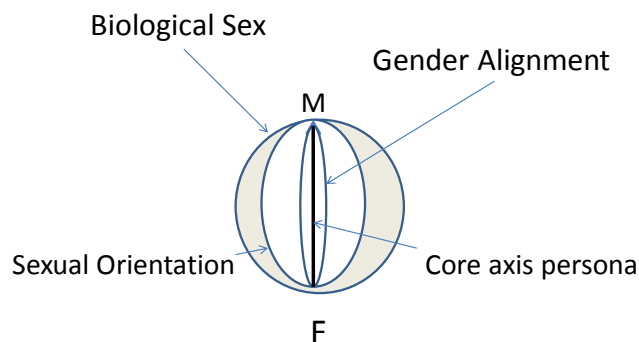
¹⁰⁶ Suzanne J Kessler, *Lessons from the Intersexed* (Rutgers University Press 1998) 15.

¹⁰⁷ *ibid.*

¹⁰⁸ John Money, *Sex Errors of the Body: Dilemmas, Education, Counseling*. (The Johns Hopkins Press 1968), as quoted by Suzanne J Kessler (n 106) 121.

to ‘in group favouritism’,¹⁰⁹ or more pertinently leads to the potential for ‘negative intergroup schema’.¹¹⁰

Figure 4: **Diagrammatic Representation of the Three Aspects of Persona.**¹¹¹



If the three ‘personas’ are all female or all male in orientation the sphere will be weighted at one ‘polar’ end and therefore will be ‘stable’ for the purposes of society. However, if one of the personas is at variance with the two other aspects, the sphere will destabilise, causing much anxiety for both the person and the society that surrounds him or her. This will be particularly the case if the *biological sex* is not weighted at one ‘pole’ but finds itself positioned halfway along the central axis, as occurs in those who are born with genital difference.

Each of these aspects can shift, and in some people all of these aspects might find themselves away from the polar regions, or indeed seated at opposite poles. As gender orientation does not depend on physical sex and sexuality far less so, physicians need to consider and balance all three components when allocating an intersex child to a specific gender.

¹⁰⁹ Marilynn B Brewer and Samuel L Gaertner, ‘Toward Reduction of Prejudice’ in Marilynn B Brewer and Miles Hewstone (eds), *Self and Social Identity* (Blackwell 2004) 303.

¹¹⁰ *ibid* 304.

¹¹¹ Author’s diagram.

4.4.1 Sexuality

Sexuality appears to be the most elastic persona component. There are many non-intersexed individuals who do meet the requirements of heteronormativity.¹¹² According to Schilt and Westbrook, 'the hierarchical gender system that privileges masculinity also privileges heterosexuality. Its maintenance rests on the cultural devaluation of femininity and homosexuality.'¹¹³ Catharine MacKinnon considers that 'sexuality is the linchpin of gender inequality'.¹¹⁴

Society still retains a sense of dislike of homosexuality. This may prove challenging for the intersexed as certain conditions predispose the sufferer to be attracted to his or her own sex.¹¹⁵ The intersexed who are not homosexual (in that their bodies are not 'perfectly' male or female) may well find themselves the victims of homophobic attacks. Adopting roles which do not conform to 'the norm' gives rise to potential discrimination, to the point of endangering life. This is particularly the case if an individual 'poses' in the opposite gender to their genitals.

Westbrook's investigation into the reports of murders of transgender people demonstrates how transgender women are frequently the victims of hate crime.¹¹⁶ This particularly manifests after a casual sexual encounter between a cisgender man and a transwoman. Feeling 'duped' and sometimes 'raped', some cisgender men are reported as flying into a rage on 'discovery of the truth of the woman's original physical state'.¹¹⁷ According to Amnesty International, from 2008 to 2012 there were 1083 reported killings of trans people globally, with research indicating that the

¹¹² A 'philosophy' that promotes heterosexuality as the normal or preferred sexual orientation.

¹¹³ Kristen Schilt, Laurel Westbrook, 'Doing Gender, Doing Heteronormativity "Gender normals," Transgender people, and the social maintenance of Heterosexuality' (2009) 23 *Gender & Society* 440.

¹¹⁴ Catharine MacKinnon, 'Feminism, Marxism, Method and The State: An Agenda for Theory' (1982) 7 (3) *Signs: Journal of Women in Culture and Society* 515, 533.

¹¹⁵ There appears to be a higher incidence of lesbianism charted for women with Congenital Adrenal Hyperplasia than for those without, and additionally a higher incidence of male gender identity in such women. Juan Carlos Jorge and others, 'Male Gender Identity in an XX Individual with Congenital Adrenal Hyperplasia.' (2008) 5 *J Sex Med* 122.

¹¹⁶ Kristen Schilt, Laurel Westbrook (n 113).

¹¹⁷ *ibid* 459. Although it appears that the attacks seem to be most likely to occur where the transgender woman has not completed all operations, so might still have a penis, for example.

number of deaths rises each year.¹¹⁸ Following through on this analogy, intersexed women may also face violence in sexual relationships with cisgender men, should the man feel duped. This would appear to vindicate the efforts of physicians to ‘perfect’ intersexed bodies.¹¹⁹

4.4.2 Sex and Gender

Although these two terms are quite often interposed, in reality ‘sex’ refers to specific biological formation whereas ‘gender’ refers to more fluid social attributes. Although in the majority of individuals a female ‘sex’ will generate a female ‘gender’, and likewise male sex to male gender, this is not necessarily the case. Biological sex does not have a definitive relationship with gender; in fact, far from providing a solid foundation ‘for the cultural category of gender, (biological sex) constantly threatens to subvert it’.¹²⁰ Nowhere is this more obvious than in the bodies of those born with ambiguous genitalia. In terms of intersex gender alignment, since the time of Money there has been persistent questioning of whether our gender is the result of nature or nurture. Money was clearly in favour of the ‘nurture’ argument, but not so everyone. Supporting Money’s theories were those academics who researched under the premise that gender is a social construct. This approach to gender studies views gender not just as a feature of the individual but as something that is ‘perpetually recreated’ during interactions which take place within a society organised by fixed binary structures,¹²¹ and sees that ‘(g)ender is an inequality of power, a social status based on who is permitted to do what to whom’.¹²² In later years these views have

¹¹⁸ ‘Europe has still a long way to go to combat violence against transgender people’ 20 November 2012 www.amnesty.org/en/news/europe-has-still-long-way-go-combat-violence-against-transgender-people-2012-11-20 accessed 23 August 2015.

¹¹⁹ By comparison, there were no reports of a cisgendered woman reacting violently to the discovery of her sexual partner being a transman, and this suggests that an intersex man need not fear his female partner in this respect. *ibid.*

¹²⁰ Laqueur (n 49) 124.

¹²¹ Regine Gildemeister, ‘Gender Studies’ in Uwe Flick, Ernst von Kardoff and Ines Steinke (eds), *A Companion to Qualitative Research* (Sage Publications, 2004) 125.

¹²² Catharine A MacKinnon, *Feminism unmodified: Discourses on Life and Law* (Harvard University Press 1987) 8.

come under attack from poststructuralist authors such as Judith Butler, who challenge and reject the binary oppositions upheld by constructionists. As Butler notes,

If gender is the cultural meanings that the sexed body assumes, then a gender cannot be said to follow from a sex in any one way. Taken to its logical limit, the sex/gender distinction suggests a radical discontinuity between sexed bodies and culturally constructed genders. Assuming for the moment the stability of binary sex, it does not follow that the construction of 'men' will accrue exclusively to the bodies of males or that 'women' will interpret only female bodies. Further, even if the sexes appear to be unproblematically binary in their morphology and constitution (which will become a question), there is no reason to assume that genders ought also to remain as two.¹²³

Whilst physical bodies might be predetermined before birth, gender identification is more mutable; indeed, '(g)ender differences – cognitive, behavioural or otherwise – are observable in every known culture in any historical period'.¹²⁴ Herring and Chau consider that we only find our 'true sense of self and identity' when we interact with society.¹²⁵ Is social interaction the *causa sine qua non* of our gender identities? Gender studies have attempted to answer this.

4.4.3 The Rise of Gender Studies and the Fall of Money

During the aftermath of the Second World War, psychology had grown in its variance of studies, and the mid-1960s saw the introduction of new personality tests developed to assess 'gender'. One such set of tests evolved around the so-called bipolar masculinity–femininity scales. The undercurrent of these scales appears to have been based on the somewhat flawed 'Heapean' assumption of a psychological binary difference between male and female.¹²⁶

A further erroneous presumption pervaded these early personality tests. They assumed that 'normal' men and women would align themselves to the appropriate

¹²³ Judith Butler, *Gender Trouble/Feminism and the Subversion of Identity* (Routledge 1999) 10.

¹²⁴ Lih-Mei Liao and others, 'Determinant factors of Gender Identity: A Commentary' (2012) 8 *Jpurol* 597, 98.

¹²⁵ Jonathan Herring and P L Chau, 'My Body, Your Body, Our Bodies' (2007) 15 *Med Law Rev* 34.

¹²⁶ A Constantinople, 'Masculinity–Femininity: An exception to the famous dictum?' (1973) 80 *Psychological Bulletin* 389.

end of the gender spectrum. It was 'indicative of maladjustment'¹²⁷ should anyone wish to deviate from the 'correct' gender alignment, and further it was not to be encouraged as it would 'disrupt cultural expectations that gender identity is an immutable derivation of biology'.¹²⁸

Therefore the aim of these studies was to encourage and produce a male polar-orientated man, and a female polar-orientated woman. Achievement of this structure was deemed to be good not just for the individual but for society as a whole, and woe betide anyone who could not align themselves to societal norms. This is ironic as the test evolved during times of significant advances the Civil Rights movement, and the rise of second-wave feminism. It appears that only *large* minority groups could be heard at the time – a problem that remains the same for the intersexed today.¹²⁹ These tests show just how underdeveloped gender studies were.

By and large, literature in this area at the time was comparatively sparse. According to Diamond, the term gender had no significant usage before the late 1960s and came into being to categorise 'those aspects of life that were more easily attributed or understood to be of social rather than biological origin'.¹³⁰ Indeed, Professor Diamond credits John Money with raising gender awareness in this area in the late 1950s, albeit he disagreed with Money's interpretation of a sex neutral starting point.¹³¹ The answer may lie in the fact that before this time men, who were the primarily activists in psychology and its development, may not have questioned stereotypical gender roles, believing in the 'two-sex' theory firmly embedded by biologists, which matched general 'common sense' understandings. Female philosophers sought to redress this imbalance.

¹²⁷ Spence (n 102) 4.

¹²⁸ Schilt, Westbrook (n 113) 441.

¹²⁹ Cheryl Chase was unsuccessful in aligning herself and other victims of unnecessary operations, with those who rallied in support of ending female genital mutilation. Peter Hegarty in conversation with Cheryl Chase, 'Intersex Activism, feminism and Psychology: Opening a Dialogue on Theory, Research and Clinical Practice' (2000) 10(1) *Feminism & Psychology* 117, 123.

¹³⁰ Milton Diamond, 'Sex and Gender : Same or Different?' (2000) 10 (1) *Feminism & Psychology* Volume 46.

¹³¹ Milton Diamond, 'A Critical Evaluation of the Ontogeny of Human Sexual Behaviour.' (1965) 40 (2) *The Quarterly Review of Biology* 147.

Although not considered to be a philosopher at the time,¹³² Simone de Beauvoir's book *The Second Sex*¹³³ has since been demarked as the start of second-wave feminism.¹³⁴ In this work, de Beauvoir comments on the exclusion of women from social theories, and on the treatment of women throughout history generally (as opposed to a work on gender differentiation). In fact, the term 'sex' as opposed to 'gender' is used throughout the work. Her famous remark, '(o)ne is not born, but rather becomes, a woman',¹³⁵ has led to a variety of interpretations which were the bases for writings in subsequent years. The quote has been used to support the argument that one 'acquires' their internal gender persona as a result of socialisation, which builds on a framework laid down by internal and external biological features.

During the 1970s de Beauvoir's arguments were to some extent dismissed by feminist writers such as Carole Pateman, who during this time expounded on their philosophy that political and social gender theory was based on the 'male'. Catherine MacKinnon argued that this essence reduced effective action for equality, stating that as 'gender is socially constructed as difference epistemologically',¹³⁶ men and women can never be equal, and therefore to aim for equality is contradictory to reality.

Since that time, a number of de Beauvoir supporters, including Toril Moi,¹³⁷ have emerged promoting de Beauvoir's work. Judith Butler adds that de Beauvoir had a significant role in the debate concerning women and 'gender asymmetry'.¹³⁸ Elizabeth Spelman praised de Beauvoir for identifying the difference between sex and gender. She notes,

¹³² '...there are those who have gradually won the right to be admitted into the philosophical fold. Simone de Beauvoir is one of these belatedly acknowledged philosophers.' Stanford Encyclopedia of Philosophy plato.stanford.edu/entries/beauvoir/ accessed 13 May 2014.

¹³³ First published in 1949.

¹³⁴ Also known as the Feminist Movement. This was a period of feminist activity primarily from the 1960s to the early 1990s.

¹³⁵ Simone de Beauvoir, *The Second Sex* reprinted (Vintage, London 1997) 295.

¹³⁶ Catharine A MacKinnon (n 114) 32.

¹³⁷ Toril Moi, *Sex, Gender and the Body (The Student Edition of What is a Woman?)* (OUP 2005).

¹³⁸ Judith Butler, *Gender Trouble* (Routledge 1990) 17.

It is one thing to be biologically female, and quite another to be shaped by one's culture into a 'woman' – a female with feminine qualities, someone who does the kinds of things 'women' not 'men' do, someone who has the kinds of thoughts and feelings that make doing these things seem an easy expression of one's feminine nature.¹³⁹

In the 1970s, writers of social constructionist theories actively supported Money's work, as it gave credence to their own. The 'successful' Janet/John experiment provided practical evidence for their research.

As Kessler writes,¹⁴⁰

When Money's theory was first introduced, it impressed people in the field of psychology as very radical. Gender was not only a social construction in theory, it could literally be constructed through human intervention.

(...)

(M)y interest in the [Janet/John] case is not whether it supports a biological or social theory of gender development but why gender theorists (including McKenna and myself) were so eager to embrace Money's theory of gender plasticity.

(...)

For whatever reason, gender researchers were blinded to a number of unexamined and deeply conservative assumptions embedded in Money's argument; (...) Social constructivists (...) should have been more critical of Money's theory for putting so much emphasis on the genitals as evidence of gender.

In 1987, West and Zimmerman published an article entitled 'Doing Gender'.¹⁴¹ This piece has been described as a 'conceptual contribution to social thought'.¹⁴² Its primary contribution is that it reassesses the role of gender in relation to social interaction. The authors see doing gender as 'creating differences between girls and

¹³⁹ Elizabeth V Spelman, *Inessential Woman* (Beacon Press 1988) 124

¹⁴⁰ Kessler (n 100) 6-7.

¹⁴¹ Candice West and Don H Zimmerman, 'Doing Gender' (1987) 1 (2) *Gender & Society* 125.

¹⁴² Barbara J Risman, 'From Doing to Undoing: Gender as We Know it' *Gender & Society* Vol 23 No1 February 2009, 81-4.

boys and women and men, differences that are not natural, essential or biological',¹⁴³ and see these differences as being constructed and maintained to 'reinforce the "essentialness" of gender'.¹⁴⁴ Throughout the piece they promote the idea that gender acquisition is not a product of being born to a specified pathway, but rather that we behave in certain ways when in specific situations: 'it is something that one *does*, and does recurrently, in interaction with others'.¹⁴⁵ Interestingly, the authors do not believe that gender is a role or a display; they intimate that gender works at a deeper level. Without our awareness, we are gender chameleons, behaving in a male/female way in one society that we would not do in another.

It has been recognised that boys more than girls are more likely to criticise peers for engaging in gender-atypical behaviour,¹⁴⁶ therefore those who are intersexed may well 'play gender' to a more radical degree for fear of bullying. As gender orientation usually forms around the age of six,¹⁴⁷ this can lead to difficulties throughout school years for those who are intersexed or those with gender identity disorder.

In adulthood our daily interactions at work socialise us further into a male/female divide,¹⁴⁸ and the field of employment has frequently enforced rules of gender, to the point of discrimination. Employers often fail to recognise 'gender qualities' that

¹⁴³ West, Zimmerman (n 141) 137.

¹⁴⁴ *ibid.*

¹⁴⁵ *ibid* 140.

¹⁴⁶ Lih-Mei Liao (n 124) 99.

¹⁴⁷ Natacha Kennedy and Mark Hellen, 'Transgenderchildren: more than a Theoretical Challenge' (2010) 7 (2) *Graduate Journal of Social Science* 27, 28. In this article the authors ask participants when they first believed that their gender identity was at odds with their physical sex. Their data produced a 'clear spike at age 5 years, representing the modal average with the mean average of 7.9 years'.

www.mermaids.org.uk. (A website for parents of gender dysphoric children) also highlight this as the time when the majority of children feel at odds with their supposed sex.

¹⁴⁸ Fiona M Wilson, *Organizational Behaviour and Gender* (2nd, Ashgate 2003) 180.

women bring to the workplace and women are still denied equal financial rewards.¹⁴⁹ However, research has also shown that in some organisations where females exhibit ‘masculine’ attributes, such as being aggressively hardworking and ruthlessly ambitious, these women may not be considered for promotion because they are not ‘feminine enough’.¹⁵⁰

According to West and Fenstermaker,¹⁵¹ the development of feminist theory was hindered as ‘new conceptualisations of the bases of gender inequality still rest on old conceptualisations of gender’.¹⁵² For example, feminist writers would state that, ‘(w)omen and men are divided by gender, made into the sexes as we know them, by the social requirements of heterosexuality, which institutionalizes male sexual dominance and female sexual submission’.¹⁵³ Scott writes that this ‘had perpetuated rather than challenged the essentialised male/female binary structures of traditional history’.¹⁵⁴ This was partially redressed by the arrival of poststructuralist theories of identity which, although a ‘critical interrogation of the exclusionary operations by which “positions” are established’¹⁵⁵ rather than positions in themselves, ‘came to

¹⁴⁹ ‘The gender pay gap (i.e. the difference between men’s and women’s earnings as a percentage of men’s earnings) based on median gross hourly earnings (excluding overtime) for full-time employees increased to 10.0% from 9.5% in 2012.’ Equal Pay Portal <http://www.equalpayportal.co.uk/statistics/> accessed 2 May 2014. According to the Chartered Management Institute, the average UK salary for a male manager currently £10,071 more than that of a female manager. <http://www.managers.org.uk/news/equal-pay-women-still-57-years-away> accessed 2 May 2014. Although equal pay legislation has been in force since 1975, Britain has one of the worst male/female pay divides in Europe. In the UK, on average, women are paid 79% of their male counterparts. Katie Allen, ‘Equal pay for women not likely till 2067, says research’ *The Guardian* (London 19 August 2010).

¹⁵⁰ Susan T Fiske and Laura E Stevens ‘What’s so special about Gender Stereotyping and Discrimination’ in Stuart Oskamp and Mark Costanzo (eds) *Gender issues in Contemporary Society* (Sage Publications 1993) 173.

¹⁵¹ Candace West, Sarah Fenstermaker, ‘Doing Difference’ (1995) 9 (1) *Gender & Society* 8, 15.

¹⁵² *ibid.*

¹⁵³ Catharine MacKinnon, ‘Feminism, Marxism, Method and The State: An Agenda for Theory’ (1982) 7 (3) *Signs: Journal of Women in Culture and Society* 515, referring also to Ellen Morgan, *The Erotization of Male Dominance/Female Submission* (Know Inc. 1975); Adrienne Rich, ‘Compulsory Heterosexuality and Lesbian Existence’, (1980) 5 (4) *Signs: Journal of Women in Culture and Society* 631.

¹⁵⁴ Joan Wallach Scott, ‘Gender: A useful category of historical analysis’ in Sue Morgan (ed), *The Feminist History Reader* (Routledge 2006) 133.

¹⁵⁵ Judith Butler and Joan W Scott (eds), *Feminists Theorise the Political* (Routledge 1992) xiv.

fuel a particular hostility towards the concept of gender'.¹⁵⁶ Post-structuralists argued that 'even orthodox formations of the sex/gender distinction accepted gender as "a multiple interpretation" of sex and thus could not be said to follow directly from it'.¹⁵⁷

Judith Butler is renowned for her desire to see the removal of gender difference in society. Butler has argued in favour of practices which allow us to choose our gender or a gender variant. Medical skills now mean that individuals can change their physical sex, and do so successfully, but if by becoming pure in the new sexual body means that new body can produce children, then this is not truly successful. As much as one may try to deny it, there are still fundamental differences between the male and female body – namely the ability to spontaneously procreate.

According to Mary Evans, the dichotomy of Judith Butler's work is that whilst she appears to see a reduction in both gender difference and gendered social differentiation, she inadvertently speaks for it as 'without gender difference there is no resistance, because there is no difference to resist'.¹⁵⁸ Until medical technology reaches such a stage of advancement,¹⁵⁹ it is clear that only 'females' can develop ova and only 'males' can produce sperm. Both are needed to create a child. So far the sexes are equal. The inequality appears at the next distinction, in that only the female body can be the 'greenhouse' to grow the embryo and give birth to a child. Further, once that child is born, only females can lactate to feed their babies. True, this last stage is not an issue in contemporary society, as many babies are now bottle fed, with or without their mother's milk. However, we cannot get away from the fact that a

¹⁵⁶ Sue Morgan (ed), *The Feminist History Reader* (Routledge 2006) 12.

¹⁵⁷ Judith Butler, *Gender Trouble* (Routledge 1990) 6.

¹⁵⁸ Mary Evans, *Gender and Social Theory* (OUP 2003) 61.

¹⁵⁹ There have been reports from America that scientists have found a successful technique which will mean that ultimately skin cells can be turned into sperm, therefore it might be possible in the future to self-impregnate. The fears of 'cloning' have so far stopped any significant forward movement with this technique. Rosa Silverman, 'Scientists Create Sperm from Skin Sample' *The Telegraph* (London, 29 August 2012); Linda Wijlaars, 'Sperm precursor cells grown from skin sample' [3rd September 2012] BioNews (3 September 2012) http://www.bionews.org.uk/page_170881.asp accessed 14 January 2015.

‘female’ is one who carries the child inside for nine months.¹⁶⁰ As Evans says, ‘the gender experience of human beings across history and across cultures is that motherhood, however differently constructed, is a condition experienced by women rather than men’.¹⁶¹ According to Anne Fausto-Sterling, if doctors investigate an intersex child and discover a mixture of male and female sex organs, ‘(m)ost doctors declare the child a girl, despite the penis, because of her potential to give birth’.¹⁶²

If ‘gender is a construction that doesn’t necessarily follow from anatomy’,¹⁶³ but is ‘accomplished in interaction with others’,¹⁶⁴ parents play a pivotal role in gender imprinting in early days,¹⁶⁵ seemingly becoming more ‘traditional’ in their approach to gender-training after the birth of their first child.¹⁶⁶ Money cast parents in the role of gender enforcer if the child was chosen to be a girl, as all that had to be done was for her mother to tell her she was a girl. He firmly advocated ‘you do it, you do it, and you do it; then you become it’.¹⁶⁷ This was easier said than done.

Individual children do show differences in development, but significant differences appear to lie *within a sex* rather than dividing the sexes. According to Jacklin and Baker writing in 1993,¹⁶⁸ in early childhood there have only been two identifiable

¹⁶⁰ There have been stories of men giving birth, but invariably these will be female-to-male transsexuals, most famously Thomas Beatie, who retained his uterus and decided to stop taking drugs in order to allow pregnancy to occur.

Tom Leonard, ‘Pregnant man Thomas Beatie gives birth to baby girl’ The Telegraph (London 3 July 2008) <http://www.telegraph.co.uk/news/worldnews/northamerica/usa/2242666/Pregnant-man-Thomas-Beatie-gives-birth-to-baby-girl.html> accessed 24 March 2015.

Andrew Dagnell, ‘The world’s first pregnant man: “I want more kids – if my new girlfriend can’t get pregnant, then I will!”’ The Mirror, (London, 2 September 2012). <http://www.mirror.co.uk/news/uk-news/worlds-first-pregnant-man-i-want-1296196> accessed 24 March 2015.

¹⁶¹ Mary Evans, *Gender and Social Theory* (Open University Press 2003) 61.

¹⁶² Anne Fausto-Sterling (n 16) 5.

¹⁶³ Milton Diamond, (n 90) commenting on the work of Kessler & McKenna.

¹⁶⁴ Candace West & Sarah Fenstermaker, (n 143) 21.

¹⁶⁵ Lih-Mei Liao (n 124) 600.

¹⁶⁶ SL Katz-Wise, H A Priess, J S Hyde, ‘Gender-role attitudes and behavior across the transition to parenthood.’ (2010) 46 (1) Dev Psychol 18.

¹⁶⁷ The words of a coerced pornography model, as cited by Catharine MacKinnon, (n114) 39.

¹⁶⁸ Carol Nagy Jacklin, Laura A Baker ‘Early Gender Development’ Stuart Oskamp and Mark Costanzo (eds) *Gender issues in Contemporary Society* (Sage Publications 1993).

differences between ‘boys’ and ‘girls’, namely that boys are more aggressive than girls, and girls develop more sophisticated language at an earlier stage.¹⁶⁹

Scientists have argued that ‘there is a genetic basis for gender’,¹⁷⁰ and that our gender identity is created by circulating hormones during pregnancy.¹⁷¹ In this case it would be difficult to ‘un-gender’ the gendered infant. Indeed, the Consortium on the Management of Disorders of Sex Development note that if an intersex child presents with normal testes, the starting point will be to assume that the brain has been masculinised.¹⁷² They add that evidence shows that if these children are assigned as girls, then a significant percentage will transition to boys at a later stage in life.¹⁷³ As Karkazis notes, hormonal theories appeal to clinicians who treat the intersexed because they are ‘grasping for something definitive to guide them’.¹⁷⁴ Hormones can be identified and measured at an early age; gender orientation cannot.¹⁷⁵

¹⁶⁹ In an educational context during primarily schooling, researchers indicate that girls are *more likely* struggle with maths, whereas writing is the main area of concern for boys. Increasing these skills is often the focus of the equality aims that various schools promote. Amy Devine and others, ‘Gender differences in mathematics anxiety and the relation to mathematics performance while controlling for test anxiety’ [2012] *Behavioural and Brain Functions* 8:33, along there appears to be no gender difference in mathematical ability per se Maths Anxiety is higher amongst girls than boys. ‘What is the research evidence on writing?’ [2012] Research Report DFE-RR238, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/183399/DFE-RR238.pdf accessed 23rd April 2014.

In order meet the general equality duty, there are two specific duties that schools in England are required to carry out. These are to publish information to demonstrate how they are complying with the equality duty, and to publish one or more specific and measurable equality objectives. Equality and Human Rights Commission, ‘Public sector equality duty guidance for schools in England’ [2011] http://www.equalityhumanrights.com/uploaded_files/pdfs/public_sector_equality_duty_guidance_for_schools_in_england_final.pdf accessed 2 May 2014.

¹⁷⁰ Richie Gupta and Anil Muraka, ‘Treating transsexuals in India: History, prerequisites for Surgery and Legal Issues’ (2009) 42 (2) *Indian J Plast Surg* 26, 28.

¹⁷¹ W Davies LS Wilkinson, ‘It is not all hormones: Alternative Explanations for Sexual Differentiation of the Brain’ (2006) 1126 (1) *Brain Res* 36.

¹⁷² Consortium on the Management of Disorders of Sex Development, *Clinical Guidelines for the Management of Disorders of Sex Development in Childhood* (Accord Alliance 2008) 6.

¹⁷³ *ibid.*

¹⁷⁴ Karkazis (n 70) 93.

¹⁷⁵ *ibid.*

Research into transsexual adults has identified differences in aspects of the brain when compared to non-transsexuals. Kruijver and others¹⁷⁶ studied whether a difference in gender identity was brought about by a difference in the central part of the bed nucleus of the stria terminalis (BSTc) in the brain. They reported that regardless of sexual orientation there was a difference in the number of somatostatin (SOM) neurons found in the BSTc. They discovered that males have nearly twice as many SOM neurons as females, and further noted that transsexuals have the number of SOM neurons that correlate with the sex of choosing, rather than their birth sex. Their conclusion was that gender identity disorder might result from this 'neurological switch'.¹⁷⁷ In a separate study,¹⁷⁸ it was hypothesised that male gender identity might be partly mediated through the androgen receptor, whilst other studies suggested that gender identity could be isolated by studying the subcortical grey matter in the right hemisphere of the brain.¹⁷⁹

These studies suggest that biology does have an impact on our gender, but it is unlikely that biology alone is responsible. It is submitted that both biology and society will always play a role in defining one's gender.¹⁸⁰

¹⁷⁶ Frank P M Kruijver and others, 'Male-to-Female Transsexuals Have Female Neuron Numbers in a Limbic Nucleus' (2000) 85 (5) *Journal of Clinical Endocrinology & Metabolism* 2034, 37. <http://press.endocrine.org/doi/full/10.1210/jcem.85.5.6564> accessed 24 March 2015.

¹⁷⁷ *ibid.* This leads the authors to conclude that the present findings of somatostatin neuronal sex differences in the BSTc and its sex reversal in the transsexual brain clearly support the paradigm that in transsexuals sexual differentiation of the brain and genitals may go in opposite directions and point to a neurobiological basis of gender identity disorder.

¹⁷⁸ Lauren Hare and others, 'Androgen Receptor Repeat Length Polymorphism Associated with Male-to-Female Transsexualism' (2009) 65 (1) *Biological Psychiatry* 93. 'A significant association was identified between transsexualism and the AR allele, with transsexuals having longer AR repeat lengths than non-transsexual male control subjects ($p = .04$).'

¹⁷⁹ 'FTMs showed evidence of subcortical gray matter masculinization, while MTFs showed evidence of CTh feminization. In both types of transsexuals, the differences with respect to their biological sex are located in the right hemisphere.' Leire Zubiaurre-Elorza and others (2012) *Cereb Cortex* (2012) doi: 10.1093/cercor/bhs267 First published online: August 31, 2012. Further it should be noted that the 'inability of binary (male/female) gender categories to adequately describe gender identity is more common in people with DSD who possess a Y chromosome'. P Lee and others, 'Advances in Diagnosis and Care of persons with DSD over the Last Decade.' (2014) 19 *International Journal of Pediatric Endocrinology* <http://www.ijpeonline.com/content/2014/1/19> accessed 24 May 2015.

¹⁸⁰ This is the view of F Conte and M Grumbach, 'Diagnosis and Management of Ambiguous External Genitalia' (2003) 13 (3) *Endocrinologist* 260. The authors are firmly of the view that gender identity is created from both genetic make-up and environmental interactions.

4.5 Gender Allocation and Legal Support – Concluding Thoughts

Current UK society relies on the sex binary system, demanding knowledge of our sex at an early stage of our lives.¹⁸¹ The registration of a birth is purely the starting point of a life of binary distinctions. As “‘anatomy” and “sex” are not without cultural framing’,¹⁸² most societies require ‘males’ and ‘females’ to conform to a discrete behavioural framework. This ‘differentiated socialisation’¹⁸³ is constantly re-enforced throughout life ‘by direct and indirect, intended and unintended messages from families, peers, schools and increasingly, the mass media’.¹⁸⁴ The deep sense of accountability can overwhelm us all. If we cannot be accountable for our ‘correctly gendered’ actions then we may find ourselves punished for our subversive behaviour and ostracised.

For the vast majority of us, society is essential for our survival. We will need to undertake paid employment; consequently, individuals will adapt their social roles or persona to procure the desired work. Additionally, the vast majority of us need companionship. A significant amount of a general practitioner’s contact time is spent talking to patients suffering with depression and anxiety, which is frequently caused by loneliness or social isolation.¹⁸⁵

Until fairly recently cultural groups such as those with disabilities, transsexuals and homosexuals were left unprotected by law. In recent years the rights of these minority groups have been recognised and to some degree protected by Parliament. Such legislation has been consolidated by the Equality Act 2010. Unfortunately, although the Act makes provisions for the protected characteristics of ‘sex’ and ‘gender reassignment’,¹⁸⁶ neither of these characteristics encompasses the physical

¹⁸¹ Birth registration. There is a very limited timeframe 42 days and it is extremely difficult alter such registrations, even when made erroneously. This will be discussed in detail in chapter ten.

¹⁸² Judith Butler, *Undoing Gender* (Routledge 2004) 10.

¹⁸³ Lih-Mei Liao (n124) 99.

¹⁸⁴ *ibid.*

¹⁸⁵ Karen Windle, Jennifer Francis, and Caroline Coomber, ‘Preventing Loneliness and Social isolation: interventions and outcomes.’ Social care Institute for Excellence. Research Briefing 39 www.scie.org.uk/publications/briefings/files/briefing39.pdf accessed 30 April 2012.

¹⁸⁶ Equality Act 2010, Part 2, Chapter 1, Section 4.

structure of every intersex condition. The introduction to the Act, dated 8 April 2010, states that this is:

An Act to make provision to require Ministers of the Crown (...) to have regard to the desirability of reducing socio-economic inequalities; to reform and harmonise equality law and restate the greater part of the enactments relating to discrimination and harassment related to certain personal characteristics; (...); to prohibit victimisation in certain circumstances; to require the exercise of certain functions to be with regard to the need to eliminate discrimination and other prohibited conduct; to enable duties to be imposed in relation to the exercise of public procurement functions; to increase equality of opportunity; (...)

For the intersexed this fails significantly, primarily because ‘intersex’ is not mentioned in the Act at all. Currently section 11 of the Act states that

In relation to the protected characteristic of sex—

- (a) a reference to a person who has a particular protected characteristic is a reference to a man or to a woman;
- (b) a reference to persons who share a protected characteristic is a reference to persons of the same sex.

It is abundantly clear that this section is not equitable for the intersexed. What is required is a ‘minor’ amendment with the addition of the word ‘intersexed’ in section 11 (a) to read:

a reference to a person who has a particular protected characteristic is a reference to a man, a woman or a person who is intersexed.¹⁸⁷

I note ‘minor’ amendment but of course from a societal point of view this would be an immense change in societal thinking. It is envisaged that such a ‘minor’ amendment would require a significant number of hours of debate in Parliament. Nevertheless, it is submitted that debate is precisely what needs to occur, even if no amendment is passed. Only by raising awareness of the intersex as a specific gender will Parliament assist the intersexed to be sheltered from unnecessary discrimination.

¹⁸⁷ Or similar wording that meets the approval of the intersex community.

The lack of legal protection of the intersexed is not an English problem but an international problem. According to a report produced by the European Commission,¹⁸⁸ by 2011 the only legislation that had been passed in Europe which specifically mentioned ‘intersex’ was the Offences (Aggravation by Prejudice) (Scotland) Act 2009. Further, even in this Act, intersexuality, which is covered by virtue of section 2 (8), is incorporated under the heading ‘transgender identity’, rather than owning its own category.¹⁸⁹ Only in recent months has Europe seen a more progressive stance taken by Governments. On the 1 April 2015, Malta adopted the Gender Identity, Gender Expression and Sex Characteristics Act.¹⁹⁰

One of the potential reasons for the lack of legal protection in the Equality Act might be due to the confusion over the differences between transgender persons and the intersexed. It appears to have been assumed that in legislating on behalf of transgender persons, the intersexed were also covered.¹⁹¹ Further, even if Parliament had *thought* that it had covered the intersexed, the wording of the Act clearly indicates a lack of understanding in this respect. The protected characteristic of ‘sex’ states that this is ‘a reference to a man or a woman’.¹⁹² Some intersex people do not identify as a ‘man’ or a ‘woman’ and are happy to be ‘intersexed’. As T states,¹⁹³

¹⁸⁸ Silvan Agius and Christa Tobler, *Trans and Intersex People Discrimination on the Grounds of Sex, Gender Identity and Gender Expression* (European Commission Directorate-general for Justice, 2011) 84. http://www.coe.int/t/dg4/lgbt/Source/trans_and_intersex_people_EC_EN.pdf accessed 24 May 2014.

¹⁸⁹ s2(8) In this section, reference to transgender identity is reference to—

(a) transvestism, transsexualism, intersexuality or having, by virtue of the Gender Recognition Act 2004 (c. 7), changed gender, or

(b) any other gender identity that is not standard male or female gender identity.

The more recent Irish Gender Recognition Act 2015, does not make specific arrangements for those who are intersexed. It mentions in s14 (4) (B) (i) (D) ‘the child has transitioned or is transitioning (...)’. This suggests that the original gender assigned was accurate at the time.

¹⁹⁰ This is discussed in the concluding chapter.

¹⁹¹ See Letter (5 Nov 2010), from Lynne Featherstone MP, Minister for Equalities, to Keith Taylor MP explaining that it was believed that the Act did cover intersex individuals, albeit in an opaque fashion. <http://www.keithtaylormep.org.uk/wp-content/uploads/file/Response%20to%20equality%20for%20Intersex%20people.pdf> accessed 24 March 2012.

¹⁹² Equality Act 2010, Part 2, Chapter 1, S 11 Sex.

¹⁹³ Email from Correspondent T to author (30 July 2012) (anonymity preserved).

Some countries are now moving to accept gender neutral recognition, Australian Passports and forms, Sweden adopting a gender neutral pronoun, but it is very slow. My status as 'intersex' is not recognised outside of medical circles: to the world in general I am female. But I am not. I am intersex. I am male, and female; both and neither. I don't have a problem with that. Others do.

The vast majority of us will consider at some point in our lives how much we wish to conform to the society we live in, and how much we want others to do the same. It is submitted that all healthcare professionals have this in mind when they treat intersex children. As Karkazis notes,¹⁹⁴ a number of the clinicians she interviewed felt under 'intense pressure from parents' to identify the sex of their intersexed baby, one clinician noting the pressure to do so 'within a week'.¹⁹⁵ For this reason, doctors have been able, or indeed have been forced, to specify the child's gender and perform 'gender-making' procedures without the necessary consolidated evidence. As Roen writes,

a queer reading of such surgical practices would suggest that the binary framework is a fantasy that can never be fully attained and that, as long as surgeons seek to (re)produce the reality of binary sexes, they inevitably keep producing queer embodied subjects.¹⁹⁶

By allocating gender, clinicians were imposing society's social norms on individuals. A significant number of intersex adults have been grateful for their early treatment, but it was not always right for every child, as becoming the 'whole person', if allocated to the wrong gender, is far from reality for some people.

As the law currently stands, the intersexed have two choices. Firstly they can hide behind a facade of 'perfect binary sex' and deny their intersexed selves. This would give social acceptability, but may leave them in danger of being emotionally alone if they cannot discuss their true persona with a potential life partner. The second option

¹⁹⁴ Karkazis (n 70) 98.

¹⁹⁵ *ibid.*

¹⁹⁶ Katrina Roen, 'But We Have to Do Something: Surgical "Correction" of Atypical Genitalia' (2008) 14 (1) *Body & Society* 47, 48.

is to risk exposure and to speak out on behalf of themselves and others. As Cheryl Chase (now Bo Laurent) has so keenly demonstrated, the more people are prepared to come forward, the less isolated they will be. However, until society becomes more flexible in its thinking,¹⁹⁷ intersex children may find themselves undergoing unnecessary treatment in order to conform to societal norms. This treatment can start at the moment of conception and can last until death. This makes it all the more imperative that English law supports them, and they are encompassed within the Equality Act.

The remaining chapters of this thesis consider the role of the intersexed as patients in the current healthcare environment. It will be noted that at discrete times, which vary from condition to condition, the intersexed will face discrimination throughout their lives. A considerable tension results from the lack of available information on conditions. As such, consent, an essential part of medical treatment, is unlikely to fully explore all the needs of the intersexed. Therefore, before considering medical treatment in depth, it is essential to investigate the nature and role of consent to treatment in the lives of the intersexed. This will be addressed in the following chapter.

¹⁹⁷ With the adoption of gender-free passports or similar, as current lobbyists demand, (n 8) Early day motion 907, Legal recognition for those who do not associate with a particular gender (No. 2).

Chapter Five: ‘Informed’ Consent and the Intersexed: Myths and Realities

5.1 Introduction

In order for a medical procedure to take place lawfully, practitioners must obtain valid informed consent. Consent in relation to medical treatment has been described as a ‘vexed topic’,¹ and ‘informed consent’ has in the past been considered something of a ‘fairy story, (as) what happens in reality bears little relationship to the expectations that the law superimposes on medical practice’.² As will be seen in the remaining chapters of this thesis, the lack of information available on intersex conditions will continue to create a discord between law and practice for the intersexed patient, and therefore for them or their proxies, informed consent has been, and remains, somewhat a myth.

This chapter investigates the inconsistencies of current English law in relation to ‘informed consent’ to medical treatment in general and medical treatment of the intersexed specifically. In addition to being a study in its own right, this chapter acts as a precursor to the subsequent chapters which aim to highlight discrimination that the intersexed may face during specific medical procedures. In the first part of this chapter I aim to identify the potential discrimination that faces the intersexed in regard to the concept of consent. In the second part of this chapter I attempt to seek remedies to reduce discrimination.

This chapter commences by considering the nature of consent in English law, starting with an adult’s ability to consent to treatment. It then considers parental authority to consent on behalf of children. Parents will usually have the legal right to consent on

¹ Rob Heywood, Ann MacAskill and Kevin Williams, ‘Informed Consent in Hospital Practice: Health Professionals’ Perspectives and Legal Reflections’ (2010) 18 (2) *Med Law Rev* 152, 152.

² Michael A Jones, ‘Informed Consent And Other Fairy Stories’ (1999) 7 (2) *Med Law Rev* 103, 129.

behalf of their children,³ but there are significant tensions as to when this right ends. By virtue of section 1 of the Family Law Reform Act 1969, a child is any person under the age of 18. It might be thought that until a child reaches the age of majority, those with parental responsibility have the legal right to consent to, or to refuse, medical treatment on behalf of their child. This is not the case. Children are given the statutory right to consent to medical treatment at the age of 16, or younger by virtue of the ruling in *Gillick v West Norfolk and Wisbech Health Authority*⁴ if they are considered to be ‘mature minors’. However, a minor cannot legally refuse treatment considered to be in their ‘best interests’ until they reach the age of majority.⁵ This is particularly acute for an intersexed child as by the time they reach adulthood, they are likely to have faced a myriad of invasive procedures, including gender reassignment, with no legal right to refuse. Nor does current English law allow *demands* for treatment to rectify the original surgery, even if possible.⁶

The remaining sections of the chapter investigate how English law might be adapted to better support the intersexed patient by considering international jurisprudence on informed consent and medical treatment of the intersexed.

5.2 The Nature of Consent

Consent is the lynchpin in the parent–doctor–child relationship in regard to any treatment for intersex/DSD conditions. Before birth parental consent is essential for antenatal diagnostic testing; at birth consent is central to genetic testing and newborn

³ Not every parent would have ‘parental responsibility’. Birth mothers always have parental responsibility (unless the child has subsequently been adopted). A father *usually* has parental responsibility (a) if he is married to the child’s birth mother at the time of the birth, (b) if he is named on the birth certificate (since 1 December 2003), or (c) has been given a parental responsibility order from court. The rise of surrogate births has complicated this issue further. In this case parental orders can be obtained if the criteria of s54 of the Human Fertilisation and Embryology Act 2008 are met.

⁴ [1986] AC 112. The age when a minor becomes a ‘mature minor’ will vary. The starting age here would be 12. Below this age parents will be relied upon to consent to treatment for their children. This is discussed in section 5.4.1

⁵ Albeit doctors generally try to honour the wishes of a young person. This is discussed in section 5.4.1.

⁶ *R (Burke) v GMC* [2005] 3 FCR 169.

screening programmes. Consent remains an essential feature of medical treatment throughout childhood and is vital for surgical procedures.

In the past, ‘normalising’ operations were frequently carried out on infants and young children, and they still are ‘a significant component of care’ for those born with genital difference.⁷ Such procedures are rarely straightforward. Operations include the performance of an orchiectomy,⁸ penectomy,⁹ clitoridectomy,¹⁰ or vaginoplasty¹¹ which frequently uses segments of the patient’s bowels. Twenty years ago, a clitoridectomy would have been routinely performed on a girl with an enlarged clitoris as a result of Congenital Adrenal Hyperplasia (CAH), whilst a penectomy was performed if doctors decided that a penis was too small (in the doctors’ opinion) for the child to live successfully as a male. That child was then ‘modified’ to become female. Castration would be accompanied by orchiectomy and vaginoplasty.

Although the timbre of current medical treatment in the UK has subdued gender rearrangement for children on the grounds of penile/clitoral size alone, those with Partial Androgen Insensitivity Syndrome may undergo surgical castration should a female gender be assigned. Likewise, a girl with severe masculinisation as a result of CAH will usually undergo a partial clitoridectomy and neovaginoplasty. Construction or reconstruction of the vulvo-vaginal area is not a single procedure, but will require repeated surgical interventions over a number of years. Until recently, the views of intersex/DSD adults who expressed dissatisfaction with their surgery were ‘taken as a political statement (with no) weight as clinical evidence’.¹² Of late, specialists have listened to patients’ concerns, but this practice is not universal. Needless to say, a number of intersex adults remain frustrated, in many ways.

⁷ Ellen K Feder, *Making Sense of Intersex: Changing Ethical Perspectives in Biomedicine* (Indiana University Press 2014) 43.

⁸ The removal of one or both of the testes.

⁹ Castration.

¹⁰ Total or partial removal of the clitoris.

¹¹ Cosmetic reconstruction of a vagina.

¹² Katrina Roen, ‘“But We Have to Do Something”: Surgical “Correction” of Atypical Genitalia’ (2008) 14 (1) *Body & Society* 47, 48.

5.2.1 'Informed Consent'?

For any medical procedure to take place lawfully consent must be obtained from the patient. The request for consent sees medical practitioners providing information to patients, or their representatives,¹³ in exchange for permission to proceed with the planned treatment. In theory, consent is only valid if patients are fully informed; therefore doctors are required to ensure that patients understand the overall purpose and nature of the procedure, and to warn of any potential risks that might occur. Information should also be given regarding the likelihood of the treatment's success and on any alternative treatments available.

According to Professor McLean, in English law consent is not 'informed' but rather obtained with the assistance of information.¹⁴ This, she notes,¹⁵ is in contrast to the American system of 'informed consent' which is 'predicated on a patient's right to self-determination',¹⁶ and aims to 'expand the liability of doctors'.¹⁷ For this reason, the term *consent* as opposed to *informed consent* will be employed throughout the remainder of this chapter. For many patients, but particularly the intersexed, the difficulties lie with receiving adequate information rather than giving consent.

¹³ Henceforth the term 'patients' will also refer to those with authority to act on behalf of the patient, i.e. those with parental authority in the case of a minor, or those with the power of attorney in the case of the mentally incapacitated.

¹⁴ Sheila AM McLean, *Autonomy, Consent and the Law* (Routledge-Cavendish 2010) 41. Australian authors also consider that 'consent' as opposed to 'informed consent' is a more accurate description of Australian law. Ian Kerridge, Michael Lowe, and Cameron Stewart, *Ethics and Law for Healthcare Professionals* (4th edn, Federation Press 2013) 329.

¹⁵ McLean, *ibid*, 40. Strictly speaking there is no one 'American system' as states vary in their approach.

¹⁶ Alisdair Maclean, 'The Doctrine of Informed Consent: does it exist and has it Crossed the Atlantic?' [2004] LS 386, 396.

¹⁷ The original term of informed consent appears to have been derived from the case of *Salgo v Leland Stanford Jr University Board of Trustees* (1957) 154 Cal App 2d 560, 317 P 2d 170. (Martin Salgo woke up from an aortography to find that he was paralysed. He had not been informed of the risk of this occurrence. The non-disclosure was deemed to be an action in its own right.) The more familiar *Canterbury v Spence* (1972) 464 F 2d 772, developed the concept within an action for negligence. This places the emphasis on doctors to inform patients of *any* risks associated with treatment.

5.2.2 Consent and English Law

Consent has been described as the ‘legal expression of the right of rational, freethinking, self-interested, isolated, autonomous individuals to bodily integrity and self-determination’;¹⁸ in fact, the ‘cornerstone of medical practice’.¹⁹ However, it lies ‘surprisingly uneasily in the medico-legal ambience of the United Kingdom’.²⁰ The concept of competence (both legal and mental capacity) is central to achieving consent. If a patient is not deemed competent at the relevant time consent can never be valid.

Consent has two roles in medical law, firstly to enhance treatment and secondly to protect doctors from needless litigation. In particular, consent is a defence to the tort of trespass to the person.²¹ This principle is extended to criminal law, which builds upon the minor offences against the person of assault and battery, and adds more significant offences such as ‘wounding with intent’.²² Although the controversial policy decision in *R v Brown*²³ ruled that consent is no defence to injuries that constitute ‘actual bodily harm’²⁴ or ‘grievous bodily harm’,²⁵ an exception will be made for necessary medical treatment, for example surgical intervention, where the premise of the incision is to improve the patient’s health.²⁶

¹⁸ Jo Bridgeman, ‘Because We Care? The Medical Treatment of Children’ in Sally Sheldon and Michael Thomson (eds), *Feminist Perspectives on Health Care Law* (Cavendish Publishing 1998) 97.

¹⁹ MY Rathor and others, ‘Informed Consent: A Socio-Legal Study’ (2011) 66(5) *Med J Malaysia* 423, 426 www.e-mjm.org/2011/v66n5/Informed_Consent.pdf accessed 28 August 2014.

²⁰ JK Mason and GT Laurie, *Law & Medical Ethics* (9th edn, OUP 2013) 71.

²¹ Valid consent will not protect from civil or even criminal action, if a doctor is negligent in his work.

²² ss 18 and 20 Offences Against the Person Act 1861 (OAPA 1861). S18 (wounding with intent) carries a potential life sentence.

²³ *R v Brown* [1994] 1 AC 212.

²⁴ s 47 OAPA 1861. This has been defined by case law to mean ‘more than merely transient or trifling’ *R v Donovan* [1934] 2 KB 498 at 509 (Swift J).

²⁵ ss 18 and 20 OAPA 1861. This has been defined by case law to mean ‘really serious harm’ *DPP v Smith* [1961] AC 290, HL; *R v Cunningham* [1982] AC 566, HL; *R v Brown* [1994] 1 AC 212.

The established ethical principle regarding a competent adult patient's right to 'bodily integrity and self-determination'²⁷ was set out nearly one hundred years ago by Mr Justice Cardozo in the United States case of *Schloendorff v Society of New York Hospital*.²⁸ He said:

Every human being of adult years and sound mind has the right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault(...).²⁹

This ruling has been endorsed in English law by *Re F (mental patient: sterilisation)*.³⁰ The common law system in the United Kingdom and abroad not only endorses the necessity of consent but also 'jealously protects'³¹ the rights of any competent adult who wishes to refuse medical treatment, whether the reasons for the same are 'rational, irrational, unknown or even non-existent',³² or even, as in *Re B (adult refusal of medical treatment)*,³³ where death is the likely outcome. Therefore a competent adult has the legal right to consent to, or refuse, any medical procedure that is offered.³⁴

Consent is the patient's 'voluntary and continuing permission' to receive a particular treatment or diagnostic test.³⁵ As it 'is a process, not simply a form to fill in',³⁶ the

²⁶ To make an incision in the body with a scalpel would amount to a wounding offence, s18 Offences Against the Person Act 1861 (with or without consent), if the procedure was not authorised.

²⁷ Jo Bridgeman (n 18) 97.

²⁸ 105 NE 92 (NY, 1914).

²⁹ Technically this would not be an 'assault' but a 'battery', but the term 'assault' is often used synonymously in such circumstances.

³⁰ [1990] 2 AC 1 HL at 55.

³¹ Natasha Cica, 'Euthanasia-the Australian Law in an International Context; Research Paper 3: Part 1 Passive Voluntary Euthanasia' (Dept of the Parliamentary Library 1996-7). http://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/pubs/rp/RP9697/97rp3 accessed 24 March 2013.

³² *Re T (adult) (refusal of treatment)* [1992] 4 All ER 649 at 653 (Lord Donaldson).

³³ *Sub nom Ms B v An NHS Hospital Trust* [2002] EWHC 429 (Fam).

³⁴ As previously mentioned, this right does not extend to *demanding* specific treatment, *R (Burke) v GMC* [2005] 3 FCR 169.

essential criterion of consent is the *manner* of its attainment, rather than its final form.³⁷ However, for more intricate procedures such as surgical investigations, it is usual to obtain written consent from the patient.³⁸

In the past, doctors have been known to place too much emphasis on obtaining a signature on the paperwork, albeit a signature ‘merely serves of evidence of consent’,³⁹ and have not given sufficient time to explaining relevant information.⁴⁰ This is not valid consent. Further, if consent is obtained only after coercion or undue pressure from *any* source, consent will not be voluntary and its legal effect will be nil.

Consent *should* evolve from a doctor–patient discussion regarding all aspects of the proposed testing or treatment. The only valid exception to this occurs when healthcare workers need to administer emergency treatment to an unconscious adult or a child. If this situation occurs, healthcare workers will be immune from prosecution if they can raise the defence of necessity. Until *Re F (mental patient: sterilisation)*⁴¹ was decided, English law was somewhat silent on the point. *Re F*

³⁵ ‘Consent is the voluntary and continuing permission of the patient to receive a particular treatment based on an adequate knowledge of the purpose, nature and likely risks of the treatment including the likelihood of its success and any alternatives to it. Permission given under any unfair or undue pressure is not consent.’ (Department of Health 1993). <<http://www.dhsspsni.gov.uk/gmgr-glossary-a-c>>accessed 1 June 2015.

³⁶ Douglas ST Green, C Ronald MacKenzie, ‘Nuances of Informed Consent: The Paradigm of Regional Anesthesia’ (2007) 3 HSSJ 115, 118. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2504103/> accessed 24 August 2014.

³⁷ The only treatment that requires written consent in treatment pursuant to the Human Fertilisation and Embryology Acts 1990 & 2008, and the Human Tissue Act 2004.

³⁸ The General Medical Council specify that, ‘You should also get written consent from a patient if: a) the investigation or treatment is complex or involves significant risks, b) there may be significant consequences for the patient’s employment, or social or personal life, c) providing clinical care is not the primary purpose of the investigation or treatment, d) the treatment is part of a research programme or is an innovative treatment designed specifically for their benefit.’ GMC, ‘Consent: Patients and Doctors and Making Decisions together’ (2008), Consent Guidance: Expressions of Consent, 21. http://www.gmc-uk.org/guidance/ethical_guidance/consent_guidance_expressions_of_consent.asp accessed 24 May 2015.

³⁹ Department of Health, *Reference Guide to Consent for Examination or Treatment* (2nd, 2009) 16. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/138296/dh_103653_1.pdf accessed 24 May 2014.

⁴⁰ British Medical Association ‘Consent to Treatment: Doctors’ and Patients’ Concerns’ (2001).

changed this by referring to American cases, including *Pratt v Davis*.⁴² This case noted that:

Emergencies arise, and (...) it is sometimes found that some action must be taken immediately for the preservation of the life or health of the patient, where it is impracticable to obtain the consent of the ailing (...). In such event, the surgeon may lawfully, and it is his duty to, perform such operation as good surgery demands, without such consent.⁴³

Therefore a doctor will be able to raise the defence of necessity in a life and death situation. But if a patient has consented to operation X, doctors cannot lawfully perform operation Y at the same time unless there is a medical emergency. Two useful Canadian cases confirm the difference in acceptable exceptions and non-necessity.⁴⁴ Interestingly, these procedures are akin to some of the operations those with an intersex condition may face.

In *Marshall v Curry*,⁴⁵ the claimant sought damages for battery when his left testicle was removed during a hernia operation. In this case the claim was unsuccessful.⁴⁶ The Nova Scotia Supreme Court found that there had been neither consent nor implied permission, adding that ‘it is not useful to strain the law by establishing consent by fictions’.⁴⁷ However, the surgeon was able to persuade the Court that he had acted in the best interests of the patient, as the testicle was diseased, and could have caused significant detrimental harm to the claimant had there been a delay in its removal. Chisholm CJ noted that ‘it is the surgeon's duty to act in order to save the

⁴¹ Also known as *F v West Berkshire HA* [1990] 2 AC 1 HL at 55 (Lord Brandon)

⁴² *Pratt v Davis* (1906) 224 Ill 300.

⁴³ *ibid*, 309 (Scott CJ), as quoted in *F v West Berkshire HA* (1989) 86 (10) LSG 42.

⁴⁴ Both cases were quoted in *F v West Berkshire HA* (1989) 86 (10) LSG 42.

⁴⁵ [1933] 3 DLR 260, 60 Can CC136.

⁴⁶ The doctor was no doubt aided as technically the action was barred under the Statute of Limitations.

⁴⁷ *Marshall v Curry* (1933) 3 DLR 260, 275.

life or preserve the health of the patient; and that in the honest execution of that duty he should not be exposed to legal liability'.⁴⁸

By comparison, in *Murray v McMurchy*⁴⁹ the claimant was successful in an action in battery. In this case, the doctor had performed a caesarean section on the claimant. When he noticed that her uterus contained fibroids, he tied her fallopian tubes to inhibit any further pregnancy which he believed would have been detrimental to the patient. This procedure was not agreed in advance and served no immediate medical necessity. In the opinion of the court, the procedure should have been postponed until the patient's consent was obtained.⁵⁰ The English case of *Devi v West Midlands Regional Health Authority*⁵¹ provides a more extreme example. Here, the claimant needed a rupture in her uterus to be repaired after the birth of her fourth child. The surgeon (one presumes) acting in the patient's best interests, did not repair the uterus but removed it.⁵² The Court confirmed that this was not a medical necessity at that time, and the claimant succeeded in her action.⁵³ As will be noted in chapter eight, the intersexed frequently complain of such enforced sterilisations.

Protection from lawsuits aside, a patient's consent is essential to a treatment's success. Patients are more likely to 'co-operate fully with the agreed management of their conditions', not only making treatment easier to administer, but more successful, if they have felt empowered by decision making.⁵⁴ This is particularly

⁴⁸ *ibid.*

⁴⁹ [1949] 2 DLR 442.

⁵⁰ Pregnancies are allowed to go ahead with fibroids, albeit that they are more carefully monitored as there is a higher risk of miscarriage.

⁵¹ [1980] CLY 687.

⁵² *Wells v Van Nort* (100 Ohio St. 101) 1919. The Supreme Court of Ohio considered a case where the claimant came around from an appendectomy, only to find that, without her prior consent, the surgeon had also removed her fallopian tubes as they were 'diseased'. The Court found for the claimant.

⁵³ In the past there have been a number of similar gynaecological operations carried out on the intersexed, without valid consent, as discussed in chapter eight.

⁵⁴ General Medical Council 'Seeking Patients' Consent, The Ethical Considerations.' (1998) 2, http://www.gmc-uk.org/Seeking_patients_consent_The_ethical_considerations.pdf_25417085.pdf accessed 22 May 2014. This was withdrawn in 2008, and replaced by General Medical Council 'Consent guidance: patients and doctors making decisions together' (2008).

relevant to minors whose views have long gone unheard.⁵⁵ Whereas younger children tend to be more compliant, the more mature minor will often have decided thoughts as to what is in his or her best interests, regardless of realities.

5.2.2.1 Disclosure

The well-known American case of *Canterbury v Spence*⁵⁶ developed the concept of informed consent within an action for negligence in the US, placing the obligation on doctors to inform patients of any risks associated with treatment that patients would wish to be informed of, whether the information was requested or not.⁵⁷ This approach has not been accepted by English law. By contrast, the original position taken by the House of Lords in *Sidaway v Bethlem Royal Hospital*⁵⁸ indicated that it was not always necessary to give the patient information of *all* relevant risks, particularly if the patient would be too concerned to proceed with the treatment. However, this approach was criticised for running the risk of enhancing medical paternalism at the expense of patient autonomy.⁵⁹ This position has since been modified.

The Australian case of *Rogers v Whittaker*⁶⁰ demanded that doctors share information when specifically requested by the patient themselves regardless of how remote the odds of side effects might be.⁶¹ This case was confirmed in English law by

⁵⁵ See for example, *Re L (medical treatment: Gillick Competence)* [1998] 2 FLR 810 and *Re E (a minor) (wardship: medical treatment)* [1993] 1 FLR 386.

⁵⁶ 1972, 464 F 2d 772.

⁵⁷ In this case the risk was estimated to be in the region of 1%.

⁵⁸ [1985] AC 871.

⁵⁹ Hazel Biggs, *Euthanasia: Death with Dignity and the Law* (Hart Publishing Ltd 2001) 77.

⁶⁰ [1992] 109 ALR 625; (1992) 175 CLR 479.

⁶¹ In this case, Whitaker, who had suffered from virtual blindness in her right eye, was informed by Rogers that an operation on this eye would stand a good chance of improving her sight. Whitaker questioned Rogers regarding any contra-indications to the operations, but was not informed of the risk of sympathetic ophthalmia, which had an estimated risk factor of 1:14000. As this occurrence happened, the Court found that she was entitled to compensation as she had *specifically* requested information on side effects, and received no information of any contra-indications.

the House of Lords decision in *Chester v Afshar*,⁶² in which a surgeon was found negligent for not alerting the claimant to a two per cent risk of spinal damage. Lord Steyn stated:

In modern law medical paternalism no longer rules and a patient has a *prima facie* right to be informed by a surgeon of a small, but well established, risk of serious injury as a result of surgery.⁶³

The decision, ‘which raised a few eyebrows’,⁶⁴ appears to have ‘reinforced the basic concept that doctors’ duties flow from patients’ rights, not the other way around’.⁶⁵ However, this case is confined to situations where a patient *asks* for information; it does not cover situations where the patient does not know what questions to raise in the first place. The difficulty for most, if not all, of the parents of intersexed children will be that they do not know what they need to find out. As one clinician noted,

Intersexuality is complicated even if you have medical training. This is where we get into arguments (...). We talk about chromosomes, and some families don’t have a clue of what you’re talking about. You try and describe it in ways that they can understand, but to explain in any deep fashion is impossible. This is where informed consent breaks down sometimes.⁶⁶

Professor O’Neill believes that it is not difficult to give patients control over the amount of information that they wish to receive.⁶⁷ This might be the case when dealing with a well-known disease, but where a patient or their proxy has to learn the

⁶²[2004] UKHL 41; [2005] 1 AC 134; [2004]; 4 All ER 587; [2004] 3 WLR 927.

⁶³ [2004] UKHL 41 (Lord Steyn) [16].

⁶⁴ Sheila AM McLean, *Autonomy, Consent and the Law* (Routledge-Cavendish, Abingdon 2010) 82.

⁶⁵ *ibid.*

⁶⁶ Katrina Karkazis, *Fixing Sex: Intersex, Medical Authority and Live Experience* (Duke University Press 2008) 128.

⁶⁷ O O’Neill, ‘Some Limits of Informed Consent’ (2003) 29 J Med Ethics 4, 6.

language of a previously unheard of condition it will be much harder to tease out essential from non-essential information. Further, although there appears to be a ‘general willingness’ to share information with patients, research has suggested that there remains uncertainty about precisely what to disclose and when.⁶⁸ This, if it is submitted, is even more likely to be the position with intersex conditions.⁶⁹

Even if patients, or their representatives, *do* know the right questions to ask, healthcare professionals at hand may not know the right *answers*.⁷⁰ If a child with genital difference is born in a remote hospital, it is possible that healthcare professionals will not have access to up-to-date information.⁷¹ Even when specialists are available there will be difficulties. A discussion on the timing of ‘cosmetic’ genital surgery raises more questions than can at present be answered; for example, it is impossible to inform patients/parents if it is better for a vaginoplasty to take place at 6 months, 6 years or 16 years, as medical opinion is divided on the matter.⁷²

Yet more difficulties occur with some conditions in identifying the ‘correct’ gender of rearing. Clinicians will struggle to predict with certainty whether a child with 5-alpha-reductase will develop a male gender identity in puberty as the surrounding data is ‘strikingly complex’.⁷³ If doctors do not know the answer, how can they impart information to parents? Faced with an information vacuum, parents often pass

⁶⁸ Heywood (n1) 53. The recent decision of *Montgomery v Lanarkshire Health Board* [2015] UKSC 11 requires that doctors to give such information that a ‘reasonable person in the patient’s position’ would attach importance to, but here a ‘reasonable person’ is likely to lack knowledge in this respect.

⁶⁹ This issue will be addressed in chapter nine.

⁷⁰ As has been discussed previously, several ‘peripheral healthcare workers’ do not understand the term intersex or DSD, and have no solid grasp of the questions put to them in a working context. Only specialists in the area are likely to know, and they are unlikely to be at hand in the initial stages of consultation.

⁷¹ Karkazis (n 66) 125.

⁷² Professor Creighton and her colleagues have been vociferous in campaigning for a delay in surgical procedures, but without research data it has been impossible to verify if this is the best approach. Julie A Greenberg, *Intersexuality and the Law* (New York University Press 2012) 140.

⁷³ Kenneth J Zucker, ‘Gender Identity and Intersexuality’ in Sharon E Sytsma (ed), *Ethics and Intersex* (Springer, 2006) 172.

any decision making back to the doctors.⁷⁴ In this respect, it can be seen that ‘informed consent’ is a myth in regard to the treatment of the intersexed.

5.3 The Legal Meaning of ‘Capacity’

In England and Wales, there are two main categories of incapacity to be considered, *legal* incapacity⁷⁵ and *mental* incapacity. Although ethical guidelines state that doctors must work on the presumption that every adult has capacity to consent to, or refuse, treatment unless proved otherwise,⁷⁶ patients’ capacity has often been challenged. A High Court decision, *Re C (adult: refusal of treatment)*,⁷⁷ established the common law test for adult capacity. The test has since been consolidated in section (3) sub-section (1) of the Mental Capacity Act 2005 (MCA 2005), which states:

(...) a person is unable to make a decision for himself if he is unable—

- (a) to understand the information relevant to the decision,
- (b) to retain that information,
- (c) to use or weigh that information as part of the process of making the decision, or
- (d) to communicate his decision (whether by talking, using sign language or any other means).

This statutory test does not require a specific means of transfer of information, nor does it require that a person retains the information indefinitely.⁷⁸ Where competence

⁷⁴ Karkazis (n 66) 123.

⁷⁵ Those under the age of 18. This will be examined in more depth later in the chapter.

⁷⁶ British Medical Association ‘Consent to Treatment: Doctors’ and Patients’ Concerns’. (Nov 2001)

⁷⁷ [1994] 1 WLR 290, where a Broadmoor detainee was held competent to refuse a life-saving operation.

⁷⁸ s3 (2) A person is not to be regarded as unable to understand the information relevant to a decision if he is able to understand an explanation of it given to him in a way that is appropriate to his circumstances (using simple language, visual aids or any other means).

(3) The fact that a person is able to retain the information relevant to a decision for a short period only does not prevent him from being regarded as able to make the decision.

cannot be established, healthcare providers have an obligation to consider the ‘best interests’ of the patient, as provided for by section 4 of the MCA 2005.⁷⁹

A weakness with this system is that within the hospital environment capacity depends on the nature of the proposed treatment. The level of capacity a patient must demonstrate changes from treatment to treatment, and from location to location within the hospital setting.⁸⁰ Therefore, if the treatment is a matter of life and death, the patient will be required to demonstrate greater ‘capacity’ than for routine procedures. This is particularly difficult in emergency situations, as the availability of time for informed discussion is severely curtailed and patients may feel pressurised into ‘consenting’ to a procedure that they did not fully understand, or really agree to.⁸¹ Further, doctors have been known to usurp patient autonomy by utilising mental health legislation to sanction unwanted treatment if consent is not forthcoming. This is particularly noticeable in the field of obstetrics, and is relevant to the treatment of those with intersex/DSD conditions, being one of the first points of tension between parent and doctor. The origin of this dilemma can be found in the case of *Re T (adult) (refusal of treatment)*⁸² when Lord Donaldson said:

An adult patient who (...) suffers from no mental incapacity has an absolute right to choose whether to consent to medical treatment, to refuse it or to choose one rather than another of the treatments being offered. The only possible qualification is a case in which the choice may lead to the death of a viable fetus.⁸³

⁷⁹ The Act provides a non-exhaustive checklist of factors that decision makers must work through in deciding what is in a person’s best interests, including consideration of any advance directives made by the patients. In addition, people involved in caring for the person lacking capacity should be consulted.

⁸⁰ Rita M Struhkamp, ‘Patient Autonomy: A View from the Kitchen’ (2005) 8 *Medicine, Health Care and Philosophy* 105.

⁸¹ An example of this is during labour, where some midwives have been known to cajole a woman, including me, into taking unwanted pain relief, more for the nurse’s comfort than the patient’s, to the detriment of both mother and baby. (As discussed later in this chapter).
<http://www.midwiferytoday.com/articles/drugsinlabour.asp> accessed 12 May 2014.
<https://www.birthinginternational.com/articles/midwifery/48-the-pain-of-labour-a-feminist-issue> accessed 12 May 2014.

⁸² [1992] 4 All ER 649; [1992] 3 WLR 782; (1992) 9 BMLR 46, CA .

⁸³ [1992] 4 All ER 649 at 652-3.

Within three months of *Re T*, the judgment of *Re S (adult: refusal of medical treatment)*⁸⁴ was delivered by the High Court, after a health authority applied for a declaration to carry out an emergency caesarean section on a woman who refused consent for religious reasons. The then President of the High Court, Sir Stephen Brown, agreed the declaration, but gave no substantive legal reasoning for it, merely acknowledging that the fundamental question appeared to have been left open by Lord Donaldson in *Re T*.⁸⁵ The controversy surrounding this case is that in agreeing the declaration the legal precedent was then set.

A turning point occurred in *Re MB (an adult: medical treatment)*⁸⁶ when the Court of Appeal ‘ruled adamantly’ that every competent adult was entitled to refuse a procedure, even though this might lead to fetal death or brain damage.⁸⁷ But even with this precedent established, medics made sure that pregnant women were given the treatment that they (the doctors) wanted, rather than that desired by the woman herself. A vivid example of this can be seen in *St George's Healthcare NHS Trust v S*,⁸⁸ when a competent patient was certified under the Mental Health Act 1983 in order to dispense with any need for her consent to a caesarean section. Not only did the operation violate S’s personal autonomy, it led to the temporary rejection of her child and a successful action of trespass against the NHS trust. A very forceful ruling by Butler-Sloss LJ left no doubt in anyone’s mind that this type of treatment was unacceptable.⁸⁹ This treatment, although an extreme event, was not an isolated

⁸⁴ [1992] 4 All ER 671; [1992] 3 WLR 806.

⁸⁵ *ibid*, albeit his lordship noted the American authority, *Re AC* (1990) 573 A 2d 1235, 1240, 1246-1248, 1252. This is controversial and has been pointed out as ‘bizarre’ and a ‘misreading’ of the case. Emily Jackson, ‘Ethics and British Abortion Law’ pro choice forum <http://www.prochoiceforum.org.uk/al9.php> accessed 24 April 2015.

⁸⁶ *Re MB (an adult: medical treatment)* [1997] 2 FCR 541.

⁸⁷ JK Mason and GT Laurie (n 20) 90.

⁸⁸ *St. George's Healthcare NHS Trust v S; Regina v. Collins and Others, Ex parte S* [1999] Fam 26.

⁸⁹ ‘(W)hile pregnancy increases the personal responsibilities of a woman it does not diminish her entitlement to decide whether or not to undergo medical treatment. (...) She is entitled not to be forced to submit to an invasion of her body against her will (...) Her right is not reduced or diminished merely because her decision to exercise it may appear morally repugnant.’ *ibid* [50] (Butler-Sloss LJ).

incident. Many women have felt that their personal autonomy has been infringed during labour.

Since then, the House Of Commons Health Committee has strongly recommended that women ‘should not be subject to any undue influence in childbirth decisions’.⁹⁰ However, even today women are ‘being led to believe that they have no choice about what is done to them during the birth of their baby’.⁹¹ This is in direct contrast to professional guidance publications. For example, guidance published by the Nursing and Midwifery Council (NMC) notes that:

Nurses and midwives have three over-riding professional responsibilities with regard to obtaining consent:

To make the care of people their first concern and ensure they gain consent before they begin any treatment or care.

Ensure that the process of establishing consent is rigorous, transparent and demonstrates a clear level of professional accountability.

Accurately record all discussions and decisions relating to obtaining consent.⁹²

Similar guidance has been issued by the National Institute for Health and Care Excellence (NICE) who instruct healthcare practitioners to ‘offer evidence-based information and support to enable them to make informed decisions about childbirth’.⁹³ However, the lack of autonomy for expectant mothers remains, particularly in regard to the right to give birth at home, primarily due to the fear of something going wrong.⁹⁴ If women feel disempowered during labour there is a

⁹⁰ Department of Health, ‘Government Response To House Of Commons Health Committee Report On Provision Of Maternity Services – Fourth Report Session 2002–03’ (Cm 6140, 2004) 21.

⁹¹ Debbie Chippington Derrick, ‘Consent – a commonly understood concept?’ (2012) 24 (3) AIMS Journal, www.aims.org.uk/?Journal/Vol24No3/editorial.htm accessed 24 May 2014.

⁹² NMC *Guidance on Consent* (2012) <http://www.nmc-uk.org/Nurses-and-midwives/Regulation-in-practice/Regulation-in-Practice-Topics/consent/> accessed 24 May 2014.

⁹³ <http://pathways.nice.org.uk/pathways/caesarean-section#content=view-node%3Anodes-information-and-consent> accessed 24 May 2014.

significant risk of mid to severe long-term health problems for both mother and child.⁹⁵ It is not unusual for a woman to contemplate or even commit suicide as a result.⁹⁶

For a variety of reasons, a mother of a neonate will not be as capable of giving valid consent during labour and post-birth as she would have been in the latter stages of her pregnancy.⁹⁷ Not only will a new mother have to deal with any lack of autonomy during the birth, but additionally a mixture of hormone disruption and sleep deprivation after birth will cloud decision making. As Professor O'Neill writes, '(e)ven in the maturity of our faculties we may find it quite taxing to give informed consent to complex medical treatment when feeling lousy'.⁹⁸

The experiences of women make it clear that 'routine maternity care' is forced upon women without valid consent. This situation is potentially problematic for *every* mother of a neonate, regardless of the health status of her newborn baby, but adding

⁹⁴ In other countries home births have been criminalised. In *Ternovsky v Hungary*, (Ref no 67545/09) decision 14.12.2010 heard at the European Court of Human Rights, the applicant complained of being denied the opportunity of a home birth, as midwives and other healthcare workers were in danger of being prosecuted if they assisted her. The Court found in the applicant's favour, that the absence of specific and comprehensive legislation regarding home births left health providers vulnerable to prosecution. Consequently there had been a violation of Article 8 of the ECHR, the right of respect for private and family life. A bill was later passed in the Republic of Hungary to legalise homebirth as of 1 May 2011, but midwives are still under threat of prosecution. The sentencing of Dr Ágnes Geréb to two years' imprisonment, with a 10-year ban from practising her profession, shocked a number of civil rights workers and international midwives. 'The Verdict is More Severe in the Case of Ágnes Geréb' www.szuleteshaz.hu 12 February 2012.

⁹⁵ Previous research has identified that boys who have a mother suffering from depression are prone to hyperactivity, and are less emotionally secure. Jean Robinson, 'Research Review: Long-term effects of postnatal depression' (1998) 10 (1) AIMS Journal www.aims.org.uk accessed 10 September 2014 discussing results from D Sinclair and L Murray 'Effects of Postnatal Depression on Children's Adjustment to School' (1998) 172 Br J Psychiatry 58.

⁹⁶ Jean Robinson, 'Post-traumatic stress disorder: AIMS' voice at the RCOG' (2002) 14 (4) AIMS Journal www.aims.org.uk accessed 10 September 2014. According to the author, 'the single largest cause of maternal death during the first year after childbirth is suicide'. She argues that post natal depression is often a result of post-traumatic stress disorder, an iatrogenic illness, 'mainly due to the way women are treated' (during childbirth and after in hospital).

⁹⁷ Louise Moody and others, 'Parental Views on the Provision of Informed Consent for Expanded Newborn Screening' Applied Research Centre Health & Lifestyles Interventions, Coventry University, www.coventry.ac.uk/.../ICBM%202010%20Moody%20v2.pptx last accessed 21 July 2012.

⁹⁸ O O'Neill, 'Some Limits of Informed Consent' (2003) 29 J Med Ethics Vol 4, 4.

to this the trauma of discovering that her child has no ascertainable gender, she may find herself swept away by the tide of ‘supportive’ healthcare. It is not unknown for healthcare providers to ‘bully’ parents into agreeing to procedures that they did not want for their *non-intersex* children.⁹⁹ This does not assist any of the parties concerned. Research has indicated that maternal stress during infancy ‘may increase the susceptibility of the infant’s hypothalamic-pituitary-adrenal system to later stress exposure’.¹⁰⁰ The parent of a child with ambiguous genitalia is likely to be *extremely* stressed. Despite detailed guidance issued by a number of organisations,¹⁰¹ it appears that medical practitioners are still not fully engaged in the process of consent, and more work needs to be done to support all parents, particularly those of an intersex/DSD child.

To summarise, in respect of adults those who are intersexed are given the same legal right by current English law as the non-intersexed to consent to or refuse medical treatment. In theory there should be no discrimination. However, problems do occur in practice in the distribution of relevant information. If the intersexed patient is not fully informed then technically any consent given will be invalid. Therefore the intersexed do face discrimination as a result of medical practice. This is a matter of hospital policy compounded by insufficient training. As will be seen, this trend is intensified when considering the plight of intersexed children.

5.4 Children and Consent

According to Professor Greenberg, in the US medical decisions taken by parents on behalf of their children are ‘generally accorded great deference to protect family

⁹⁹ Threatening legal action, if they (the parents) do not agree to the plan that doctors have decided is in the child’s best interest. Interview with J (London 4 August 2012). In this respect, the story of Ashya King made headline news when his parents were put in jail in Spain, after disagreeing about a course of medical treatment proposed by Southampton General Hospital. BBC News, ‘Brain tumour boy Ashya King free of cancer, parents say’ (23 March 2015) <http://www.bbc.co.uk/news/uk-england-32013634>.

¹⁰⁰ Elizabeth A Gurian and others, ‘Expanded Newborn Screening for Biochemical Disorders: The Effect of a False-Positive Result.’ (2006) 117 (6) *Pediatrics* 1915, 19.

¹⁰¹ Including the General Medical Council. General Medical Council, ‘Consent guidance: patients and doctors making decisions together’ http://www.gmc-uk.org/guidance/ethical_guidance/consent_guidance_index.asp accessed 22 May 2014.

privacy and parental authority’,¹⁰² but the law is not so deferential to parents in England. Parents usually have the right to consent to medical treatment on behalf of their children, but this is not an unqualified right. Firstly, parents of neonates will have to prove that they have both mental and legal capacity. In this respect the United Kingdom has one of the highest number of births per 1000 to women aged 15-17 in the European Union, with the estimated number of conceptions to women aged under 18 in 2011 being 31,051.¹⁰³ Consequently, a child-parent may find themselves unable to consent on behalf of their children, even if ‘Gillick competent’.¹⁰⁴ If the parent is deemed to be withholding consent unreasonably, or lacks competence to consent, then doctors will seek judicial endorsement to perform the specific treatment. This lack of parental authority can be dated back to the cases of *R v Leonard Arthur*,¹⁰⁵ when a medical professional was acquitted of the attempted murder of a neonate with Down’s syndrome, and the following case *Re B (a minor) (wardship: medical treatment)*,¹⁰⁶ in which the court supported the doctors’ decision to operate when parents of a Down’s syndrome baby refused to consent to a life-saving operation.¹⁰⁷ This latter case was extremely unpopular as it gave *too* much

¹⁰² Julie A Greenberg ‘International Legal Developments Protecting the Autonomy Rights of Sexual minorities, Who should determine the Appropriate treatment for an Intersex Infant?’ in Sharon E Sysma (Ed), *Ethics and Intersex* (Springer 2006) 91.

¹⁰³ ‘The United Kingdom has one of the highest number of births per 1,000 women aged 15-17 in the European Union. For 2011 births, only Romania, Bulgaria, Slovakia, Hungary and Malta had higher birth rates for women aged 15-17 than the United Kingdom.’ Office for National Statistics, ‘Teenage pregnancies at lowest level since records began’ Release date: 22 February 2011 <http://www.ons.gov.uk/ons/rel/vsob1/conception-statistics--england-and-wales/2011/sty-conception-estimates-2011.html> accessed 24 May 2015.

¹⁰⁴ Discussed at 5.4.1.

¹⁰⁵ (1981) 12 BMLR 1. Dr Arthur was an experienced paediatrician who acquiesced with parental rejection of a seriously ill neonate with Down’s syndrome. Dr Arthur wrote in his notes, ‘parents do not wish the baby to survive. Nursing care only.’ The nursing care only regime included tranquilisers to suppress the appetite. The baby died 69 hours later. He was originally charged with murder, but during the trial the defence provided sufficient evidence that the child was in a critical condition before Dr Arthur’s ‘prescription’, and may not have survived even if intervention had taken place. As a result the charge was reduced to attempted murder.

¹⁰⁶ [1981] 1 WLR 1421.

¹⁰⁷ Her life expectancy was estimated to be between 20-30 years should the operation were to be carried out. In the end ‘B’ lived about six years.

authority to the doctors. Then followed several cases where parents were forced to sit back whilst hospitals treated children without their consent. Possibly some procedures for intersex children fell into the latter category at this point in time, as it corresponded with the ‘John Money heyday’.¹⁰⁸

In *Re J (a minor) (wardship: medical treatment)*,¹⁰⁹ Lord Donaldson MR noted that the ‘inevitable and desirable result is (...) a joint decision of the doctors and the courts or parents’;¹¹⁰ only rarely has the court supported parents in the face of opposition from doctors. *Re T (a minor) (wardship: medical treatment)*¹¹¹ was one such example in which parents were allowed to refuse a liver transplant for their young son.¹¹²

Here, the Court of Appeal took time to examine a number of past decisions, including that of *Re Z (a minor) (identification: restrictions on publication)*¹¹³ where Sir Thomas Bingham MR said:

I would for my part accept without reservation that the decision of a devoted and responsible parent should be treated with respect. It should certainly not be disregarded or lightly set aside. But the role of the court is to exercise an independent and objective judgment. (...) Its judgment may of course be wrong. So may that of the parent. But once the jurisdiction of the court is invoked its clear duty is to reach and express the best judgment it can.

¹⁰⁸ As discussed in chapter four.

¹⁰⁹ [1990] 3 All ER 930.

¹¹⁰ *ibid* 934.

¹¹¹ [1997] 1 All ER 906; [1997] 1 WLR 242.

¹¹² This case involved an infant who had been born with a serious liver defect. The family gave consent to an operation, which was carried out on the child when he was three and a half weeks old, but it was unsuccessful. Doctors came to the opinion that only a liver transplant would prolong his life, but the parents were unhappy with this method of treatment. Even if the operation had been successful at the time, liver transplants do not usually have the longevity that other transplants have, and so this was not necessarily the end of treatment, merely the start of a life time of immunosuppressant medication and possible future transplants. The parents were experienced healthcare practitioners (which was of significance to the court), and they felt that in the best interests of their son they would take him abroad, and nurse him for the remainder of his life.

¹¹³ [1997] Fam 1, 32.

Building on these words Roch LJ stated that:

If the proper stance for parents is that, whenever there is a treatment which may prolong the life of their child, then that treatment should be accepted, a decision not to accept that treatment would be unreasonable. *But in my opinion that cannot be and will not be the answer in every case. Nor are such decisions to be taken solely with medical factors in mind.*¹¹⁴

This last section of the judgment is significant. Finally there appears to be some recognition that parents do not have to accept every treatment proposed for their children. This is of particular significance for the DSD community. Genital difference is often viewed as a medical emergency and for the most part it is not. If a court is prepared to let a child die, as in *Re T*, then surely the court must be prepared to support parents who do not want to rush into genital normalisation.

With the evolution of medical ethics and patient rights in general, and the enactment of the Human Rights Act 1998, the scales of consent have started to tip in favour of a parent once more.¹¹⁵ For the treatment of young intersex patients, it is clear that a dialogue must take place between parents and consultants before any non-reversible surgery occurs.

5.4.1 Mature Minors and Medical Treatment

The most significant tension surrounding patient consent and refusal occurs in relation to ‘mature minors’. In this respect current law is unsatisfactory and in need of legislative reform. The current situation was established over 50 years ago, as an

¹¹⁴ *Re T* [1997] 1 WLR 242, 256 (my italics).

¹¹⁵ A good example of this can be seen in the case of *David Glass v UK* (2004) 39 EHRR (European Court of Human Rights), a case where a mother challenged her son’s treatment by medical staff. This included the use of diamorphine in the treatment regime, and the putting up of a ‘Do Not Resuscitate’ sign on David’s bed without permission from the family. Here the ECHR held, inter alia, that there had been a violation of Article 8 of the Convention: that a decision to ‘impose treatment gave rise to an interference with her son’s right to respect for his private life, and in particular, his right to physical integrity’ (2004) 39 EHRR [70].

inadvertent consequence of *The Report of the Committee on the Age of Majority*¹¹⁶ and the resulting Family Law Reform Act 1969 (FLRA 1969) which reduced the age of majority from 21 to 18.

Although the report was primarily concerned with the age of majority, it also considered several peripheral matters relating to age, including the appropriate statutory age for deeming minors capable of giving valid consent to medical treatment. The Committee noted that ‘(t)he question of consent to medical treatment was not one which we had expected to consider, but so many witnesses begged us to clear up the law on this point that we felt bound to deal with it’.¹¹⁷ At this time, the majority of children left school and were in work by the age of 16 so this was not an unreasonable request. Unfortunately, the subsequent legislation left a lacuna. Section 8 of the FLRA 1969 stipulates that a minor of 16 years of age can consent to medical and dental treatment, ‘as *it would be if he were of full age*’; however, the age when a minor might *refuse* medical treatment is *not* addressed in the legislation.

Currently, anyone below the age of 18 is a ‘minor’ in the eyes of the law. However, this in itself is a contentious issue. The development of a child’s reasoning ability is often at variance with the preconceptions of parents, the medical profession or the courts. Some may argue that the designated age of majority is nothing more than an artificial legal barrier and not a true reflection of the rights and abilities of young people today. For example, a ‘child’ of 16 can work and have sex and s/he can get married with parental consent. A ‘child’ of 17 can drive a car. These activities need maturity and thought. In more recent legislation, the Domestic Violence, Crime and Victims Act 2004¹¹⁸ refers to a ‘vulnerable *adult*’¹¹⁹ as meaning anyone between the ages of 16 and 17, as well as the more accepted understanding of those with mental incapacity. The guidance notes indicate that this is because a 16- or 17-year-old

¹¹⁶ The Latey Committee, *Report of the Committee on the Age of Majority* (Cmnd 3342, 1967).

¹¹⁷ *ibid* [474].

¹¹⁸ Recently modified by Domestic Violence, Crime and Victims (Amendment) Act 2012 as of 2 July 2012.

¹¹⁹ My italics.

might be vulnerable, albeit they are no longer considered a ‘child’,¹²⁰ as section 5 (6) of the 2004 Act clearly states that a child is someone under the age of 16!¹²¹ Hence the law is confused and needs reorganising in this respect.

In terms of minors under 16, the situation is yet more complicated. Some minors will be mentally ‘competent’ before they are teenagers, whereas others will never be competent. In terms of physical growth, a child with CAH will be a physically mature minor at an early age, and this will affect their intellectual and emotional development.¹²² Girls with CAH are often given the choice of surgery during adolescence, and doctors will wish to ensure they have the patient’s full consent if the procedure is to be successful.

The seminal case of *Gillick v West Norfolk and Wisbech Health Authority*¹²³ attempted to smooth out some of these difficulties by allowing mature minors the right to consent to treatment providing they are deemed ‘competent’. Their lordships took pains to state that there was nothing in section 8 of the FLRA 1969 to rule that children under 16 could *not* give valid consent; in fact, they suggested that it would be ‘verging on the absurd’¹²⁴ should a competent minor not be able to do so. Lord Frazer devised criteria to ascertain whether a young person possesses sufficient

¹²⁰ <http://www.justice.gov.uk/downloads/legislation/bills-acts/circulars/moj/circular-03-12-dvcv-act.pdf> note 29.

¹²¹ s5 (6) In this section—

“act” includes a course of conduct and also includes omission;

“child” means a person under the age of 16;

“serious” harm means harm that amounts to grievous bodily harm for the purposes of the Offences against the Person Act 1861 (c. 100);

“vulnerable adult” means a person aged 16 or over whose ability to protect himself from violence, abuse or neglect is significantly impaired through physical or mental disability or illness, through old age or otherwise.

This is just one of many idiosyncrasies with current law. Consider the age of criminal and tortious liability for children in England. If a child can be convicted of a criminal offence at the age of 10, it does seem odd that they cannot make decisions about their healthcare.

¹²² This will be discussed in chapter eight.

¹²³ *Gillick v West Norfolk and Wisbech Health Authority* [1986] AC 112 This considered the right of a child under 16 to receive contraceptive advice and treatment.

¹²⁴ *ibid* [B] (Lord Frazer) 169.

understanding,¹²⁵ namely that the patient must understand the advice given and be unshaken in attempts to persuade her to inform her parents and that it must be in the patient's 'best interests', either physically or mentally, to receive treatment.

The *Gillick* case was a delight to activists who had been ardently supporting children's rights. The 'remarkably enlightened'¹²⁶ judgment emphasised the perceived change in the role of parents, although the test of competence for mature minors is a rigorous one. In the words of Professor Freeman, 'few adults are *Gillick*-competent if competence hinges upon abilities to fully understand what is involved in a decision'.¹²⁷ It appears that mature minors have to prove a higher level of competence than when they reach the age of 18.

In other jurisdictions,¹²⁸ this judgment was embraced and extended to include the right to refuse consent, as 'consent would be completely pointless if it did not protect a patient's right to refuse treatment'.¹²⁹ Unfortunately this position was seriously undermined by subsequent judicial reasoning in England and Wales, in the case of *Re R (a minor) (wardship: medical treatment)*¹³⁰ which appeared to 'strike at the very core of the *Gillick* principle'¹³¹ and was 'in direct conflict'¹³² with the statutory

¹²⁵ These are known as the 'Frazer Guidelines'. Although specifically devised for the purpose of contraceptive care, the guidelines are used as a starting point for other treatment.

¹²⁶ Jane Fortin, *Children's Rights and the Developing Law* (2nd Edn, Butterworths 2001) 83.

¹²⁷ Michael Freeman 'The Next Children's Act?' [1998] 28 Fam Law 341.

¹²⁸ Including Scotland, South Africa and some Australian states. However, as Trowse notes, Australian courts can still override a *Gillick* competent child. Pip Trowse, 'Refusal of Medical Treatment: a Child's Prerogative?' (2010) 10 (2) QUTLLJJ 191.

¹²⁹ Medical Protection Society SA 'Consent to Medical Treatment in South Africa: An MPS Guide.' (2012) 32. <http://www.medicalprotection.org/docs/default-source/pdfs/Booklet-PDFs/sa-booklets/consent-to-medical-treatment-in-south-africa---an-mps-guide.pdf?sfvrsn=4> accessed 24 March 2015.

¹³⁰ *Re R (a minor) (wardship: medical treatment)* [1992] 1 FLR 190. *Re R*, saw the first real test of *Gillick*. It concerned a 15-year-old girl with a history of abuse and subsequent mental health issues. At times she appeared '*Gillick* competent', at other times not. The Court of Appeal determined that the fluctuating nature of her illness made her incompetent to consent overall. The Court also stated that regardless of the issue of competence, it was able to override the girl's decision by exercising its wardship jurisdiction.

¹³¹ Gillian Douglas, 'The Retreat from *Gillick*' (1992) 55 MLR 569, 571.

provisions of the Children Act 1989,¹³³ and even more so in *Re W (a minor) (medical treatment: court's jurisdiction)*.¹³⁴

In *Re W*, the judges were asked to consider the treatment of an anorexic girl *over* the age of 16. Their lordships referred to the Latey Committee Report,¹³⁵ which noted that all the professional bodies consulted had agreed that patients aged between 16 and 18 should be able to give consent to treatment, and all but one advised that effective refusal be allowed.¹³⁶ Lord Donaldson concluded that when, having received this advice, the committee recommended 'that (...) consent of young persons aged 16 (...) shall be valid (...)', without mentioning refusal,¹³⁷ it was because the committee did not support it. Neither, in his opinion, did Parliament. His lordship added that he was 'quite unable to accept that Parliament, in adopting somewhat more prolix language, was intending to achieve a result which differed from that recommended by the committee'.¹³⁸ His lordship pronounced that neither section 8 of the FLRA 1969 nor the *Gillick* principle gave a 16-year-old an absolute right of veto over medical treatment. Confirming his decision in *Re R*, he held that courts and those in *loco parentis* could override a competent child's refusal, 'destroying in one foul judgment, any meaningful role for older children in decisions relating to their medical treatment'.¹³⁹

¹³² Andrew Bainham 'The Judge and the Competent Minor' (1992) 108 LQR 195, 196.

¹³³ Children Act 1989 incorporated some of the *Gillick* spirit, by allowing children to refuse agree to or refuse a medical examination provided s/he has 'sufficient understanding to make an informed decision' (ss 38(6), 43 (8), 44 (7)).

¹³⁴ [1992] 4 All ER 627; [1992] 3 WLR 758; [1993] FAM 64;

¹³⁵ The Latey Committee, *The Report of the Committee on the Age of Majority* (Cmnd 3342, 1967).

¹³⁶ [1992] 4 All ER 627, 634.

¹³⁷ *ibid.*

¹³⁸ *ibid.*

¹³⁹ *Bridgeman* (n 18) 103.

The judgment in *Re W* attracted widespread academic criticism; nevertheless this decision remains an authority today.¹⁴⁰ Consequently, no matter what procedure is being offered, no minor has the legal right to refuse medical treatment,¹⁴¹ nor can parents refuse on behalf of their mature minor¹⁴² if the court is prepared to sanction a procedure.¹⁴³

Currently, English law does not protect an adolescent's right to 'own' their medical treatment. Whilst flouting children's rights in general, this can be said to discriminate against children with genital difference as parents have often consented on their behalf to gender-altering medication, in the face of the child's opposition.¹⁴⁴ A change in medical thinking in regard to the treatment of those with a DSD has to some extent come to the assistance of those who do not wish to undergo such treatment, but there still remains a lacuna in the law. Hence, there is significant potential for discrimination to occur for those who are intersexed. In this respect, it is

¹⁴⁰ This debate has been brought to life again recently. Stephen Gilmore, Jonathan Herring, 'Children's Refusal of Medical Treatment: Could *Re W* be Distinguished?' (2011) 41 (7) Fam Law 715; Emma Cave and Julie Wallbank, 'Minors' Capacity to Refuse Treatment: A Reply to Gilmore and Herring' (2012) 20 (3) Med L Rev 423; Stephen Gilmore, Jonathan Herring, 'Children's Refusal Of Treatment: The Debate Continues' (2012) 42 (8) Fam Law 925.

¹⁴¹ Albeit in practice a young person's refusal will be listened to. C Dyer, 'Trust decides against legal action to force girl to receive heart transplant' (2008) BMJ 337:a2526, which discussed the case of Hannah Jones who refused a heart transplant. (Ironically, she changed her mind a year later, and in doing so potentially gave excellent ammunition to those who believe that children should not be able to consent to life-saving treatment.)

¹⁴² *Re E, (a minor) (wardship: medical treatment)* ¹⁴² minor who was nearly 16 years old, refused a blood transfusion needed for his treatment of leukaemia. He was a Jehovah's Witness and believed it to be contrary to his faith. His family supported his refusal; however, the court did not. Ward J. stated that the boy had 'insufficient understanding of the pain he has yet to suffer'¹⁴² and that as his welfare was the 'paramount consideration', the treatment would be ordered. In this case there is evidence that he may have had '*sufficient understanding*', as when he reached 18 he exercised his right of refusal and consequently died.

¹⁴³ Further, current Department of Health Guidance recommends that even with parents' consent, a court declaration would be the 'prudent' approach to take if a mature minor refuses treatment. Department of Health, *Reference Guide to Consent for Examination or Treatment* (2nd, 2009) 34. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/138296/dh_103653_1.pdf accessed 24 May 2014.

¹⁴⁴ In *W v W* [2001] 1 FLR 324 [327] it was documented that W was held down by her stepfather whilst testosterone was administered and subsequently ran away from home to avoid undergoing breast reduction procedures.

important to consider jurisprudence from other countries to assess whether English law could be improved by adopting a different approach to informed consent.

5.5 Treatment of the Intersexed – International Jurisprudence

To date, there has been no specific legal action regarding informed consent and medical treatment of intersex/DSD people in the UK, and very few cases globally.¹⁴⁵ The notable exceptions are three cases in Columbia which considered the lawfulness of medical procedures for three differently aged children, one case in Australia, and two cases in Germany which sought compensation several years after surgery had taken place.¹⁴⁶ There is currently a case ongoing in the US.¹⁴⁷

5.5.1 The Colombian Decisions

In the 1990s the Constitutional Court of Colombia heard and decided on a trilogy of cases involving various genital operations on minors. The first case heard by the Constitutional Court was an appeal against Sentencia No T-477/95, more commonly known as the *Gonzalez* case.¹⁴⁸ This case has very similar facts to the story of David Reimer as the subject of the judgment was born ‘male’ as opposed to ‘intersexed’.

The background to this case starts in March 1981, when parents rushed their six-month-old baby boy into the local hospital. The initial story told was that the parents had locked the little boy in a room with their small dog, only to return to find that the

¹⁴⁵ Additionally there are cases which an intersexed person has won the right to change their registered sex on their birth certificate. These are considered in chapter ten.

¹⁴⁶ Silvan Agius & Christa Tobler, *Trans and Intersex people Discrimination on the grounds of sex, gender identity and gender expression* (European Commission Directorate-general for Justice, 2011) 84. http://www.coe.int/t/dg4/lgbt/Source/trans_and_intersex_people_EC_EN.pdf.

¹⁴⁷ As of 11 September 2015.

¹⁴⁸ Sentencia No T-477/95 handed down from the Superior Tribunal of Antioquia, on February 24, 1995. The case (in Spanish) can be accessed through the Intersex Society of North America (ISNA) website. <http://www.isna.org/node/516> accessed 22 May 2014. See also the ISNA Amicus Brief, dated 7 February 1998, presented to the Court prior to the proceedings. It is now accessible directly <http://www.corteconstitucional.gov.co/relatoria/1995/t-477-95.htm> accessed 28 August 2015.

dog had blood on his snout and that the boy's penis and testicles had been severed.¹⁴⁹ This story was never truly accepted and in reality it is believed that this was a 'botched circumcision'.¹⁵⁰ However, having been faced with a castrated boy, the hospital recommended a sex change operation so that an inadequate 'he' could become a fulfilled 'she'. Such operations had been carried out in the hospital since 1975, doctors there having been heavily influenced by the John/Joan story. One doctor informed the Colombian Court that:

(...) by the expressed characteristics, this child was condemned to a person with sexual ambiguity and knowing that a child's sexual identity starts from the year and a half to two years from now, it is logical to think that it was necessary to make a decision on the reallocation of their sex.¹⁵¹

Faced with this information the parents agreed to the operation, which was performed on 21 April 1981.¹⁵²

From September 1981 until 28 July 1986, the child was placed in the House of the Child God, a hostel of nuns. Here the child was educated as a female, with a marked lack of success. It was obvious by the way that the child stood to urinate, and how 'she' deported herself in certain activities, that this was not a 'she' but a 'he'.¹⁵³ Meanwhile, the parents had told everyone that their child had died.

In July 1987 the court renamed the child, designating a feminine name, reported as 'XX'.¹⁵⁴ This was followed by a second operation on 7 April 1987 to ensure that XX's body had a 'female phenotype'.¹⁵⁵ Unsurprisingly, XX's personality matched

¹⁴⁹ 'sangre en el hocico y el niño tenía cercenados el pene y los testículos' [1.1] No T-477/95 (my translation).

¹⁵⁰ As also happened to David Reimer.

¹⁵¹ [1.3]

¹⁵² [1.3]

¹⁵³ [1.3] 'No obstante las rígidas reglas, a las religiosas les causaba extrañeza que el infante "tenía comportamientos de varón en la postura para la micción y en algunos juegos. " ' (my translation).

¹⁵⁴ [1.4]

¹⁵⁵ [1.6]

neither the name nor the new body given, and when the child discovered that ‘she’ was actually born a ‘he’, XX sued the doctors for the enforced operation and demanded to have the treatment reversed. When asked by the Court why XX wished to become a man the answer was, ‘I decided to be a man, because I was born a man.’¹⁵⁶ This was backed up by a specialist who said that ‘I believe that in this case, society failed.’¹⁵⁷

Ultimately, on appeal ¹⁵⁸ the Court held that regardless of the age of the child concerned, and regardless of whether the child’s parents had consented to such operations on behalf of the child, doctors could not lawfully change a child’s gender without the consent of the child themselves. This, the Court noted, was a constitutional guarantee. The free development of one’s own personality implies a right to define one’s own sexual identity; therefore the Court found that the initial operations had violated the child’s fundamental rights.

As the facts were self-contained, this might have been the sole case to come before the Court. However, after this ruling some surgeons who treated intersex patients would not proceed with similar operations for fear of prosecution. Consequently, parents of two children came forward to request that the Court sanctioned such operations as were thought necessary. There was an added complication as one of the children concerned (a two-year-old girl) had been operated on only three days before the hearing. The Columbian Constitutional Court heard both of these cases on appeal.

In *Sentencia No SU-337/99 Ramos* the Court heard evidence concerning an eight-year-old girl who was diagnosed with PAIS. *Ramos* had always been brought up as a

¹⁵⁶ ‘Yo decidí ser un hombre, porque hombre era yo desde chiquitico. Yo decidí ser hombre, porque uno es hombre como nació.’ [1.8] (my translation).

¹⁵⁷ [1.7] ‘Creo que en este caso hubo una falla de la sociedad’ (my translation).

¹⁵⁸ The initial ruling of the Court of First Instance (subsequently overruled) ordered the hospital to form an interdisciplinary group whose aim would be to replace the boy’s penis if possible, and to pay him compensation. This decision was annulled for technical reasons on 20 April 1995, primarily as to whether valid consent had ever been obtained, the issue of guardianship being somewhat unclear throughout the child’s life. The case was reopened on 23 May 1995.

girl and had appeared to have a female persona. It was not until the age of three when a suspicion arose that her genitalia was not quite as expected, that her condition was diagnosed. The Court of First Instance found that some aspects of her behaviour were those of a female, but others more akin to a male. The Court concluded that ‘every person should have the right to develop his or her own gender identity as a part of the development of his or her personality’.¹⁵⁹ The Court agreed with the trial judges’ verdict to refuse to sanction the operation, indicating that such operations should only be carried out with the child’s own informed consent.

The strength of the *Ramos* decision was diluted by the court’s next decision in *Cruz*.¹⁶⁰ In this case the subject was a girl who appears to have had CAH.¹⁶¹ The family wanted her enlarged clitoris/penis removed, or reduced. The trial court sanctioned the operation with the proviso that valid consent had been given. By the time the case came before the Constitutional Court *Cruz* had undergone surgery; nevertheless the Court heard the appeal in order to set a precedent for future treatment.

The Court, whilst relying heavily on its previous judgment in *Ramos*, limited its ruling, stipulating that to prevent comprising parental autonomy, autonomy could only be awarded to children over the age of five as children under this age had not developed their gender identities. The Court also noted that parents alone should not be allowed to choose, but the consent must be in tandem with doctors’ opinions, and subsequently issued good practice procedures, including the need for complete information to be given to parents.¹⁶² Finally, the Court specified that authorisation for such procedures must be given on several occasions over a reasonable time period

¹⁵⁹ Kate Haas, ‘Who will Make Room for the intersexed?’ (2004) 30 (1) AJLM 41, 48 (quoting from the decision, which can be accessed directly. <http://www.corteconstitucional.gov.co/relatoria/1999/su337-99.htm> accessed 10 September 2015.

¹⁶⁰ (T-551/99) <http://www.corteconstitucional.gov.co/relatoria/1999/t-551-99.htm> accessed 10 September 2015.

¹⁶¹ *ibid* [2]

¹⁶² This was to include information on the dangers of current treatments, the existence of other procedures, and the possibility of delaying surgeries and giving adequate psychological support to the children.

to ensure the parents have enough time to truly understand the situation.¹⁶³ On the facts, the Court found that the parents did not give valid informed consent, as they had not fully understood the procedure, nor were they informed of any alternative treatments.

It is submitted that this last opinion confused rather than clarified Columbian law, and would therefore not be a good model to adopt in English law. By choosing the age of five, the Court inadvertently put children significantly at risk. Research suggests that gender identities are not fixed until five,¹⁶⁴ and for that very reason, it is even more important that neither families nor doctors should consent to non-medically necessary, irreversible operations on such young children. Only the child can truly know whether they wish to be a boy or a girl. In this respect the jurisprudence of Columbia is useful, but, it is submitted, has a limited role to play for those intersexed in England who may require legal support.

5.5.2 Other Cases

The first case of an intersexed person successfully suing her former surgeon for non-consensual treatment occurred in Germany in 2008. Christine Völling was originally raised as a boy, 'Thomas'. When she was 17, she underwent an appendectomy. During this operation, it was discovered by the surgeon that 'he' had a uterus, fallopian tubes and ovaries, and the surgeon removed these without waiting to discuss the findings with his patient. Völling had always believed that she was female rather than male. The Kölner Landgericht (Cologne District Court) found that the doctor had 'culpably violated her health and self-determination'.¹⁶⁵ The surgeon was found

¹⁶³ As interpreted by Julie A Greenberg, *Intersexuality and the Law* (New York University Press 2012) 37, who quotes from her translation of this case.

¹⁶⁴ Albeit a child might be aware of his/her gender at the age of two. Mermaids, 'What is Gender Dysphoria' <http://www.mermaidsuk.org.uk/index.php/what-is-gender-dysphoria> accessed 12 May 2015.

¹⁶⁵ Case 25 0 179/07, as reported by Silvan Agius & Christa Tobler, *Trans and Intersex people Discrimination on the grounds of sex, gender identity and gender expression* (European Commission Directorate-general for Justice, 2011) 84. http://www.coe.int/t/dg4/lgbt/Source/trans_and_intersex_people_EC_EN.pdf

guilty of unlawful intervention, and in 2009 was ordered to pay 100,000 Euros in compensation.¹⁶⁶

Although this is an interesting case, jurisprudentially this does not enhance the rights of intersex patients per se, as the premise, lack of valid informed consent, is very similar to that of *Devi v West Midlands Regional Health Authority*,¹⁶⁷ as discussed above. However, an ongoing American case of ‘MC’ may have a more significant impact should it finally be resolved in the claimant’s favour.

In 2013, the South Carolina Federal Court denied a motion by the Department of Social Services to dismiss a case brought by Southern Poverty Law Center on behalf of MC, an eight-year-old boy, and his adoptive parents. MC was born with an intersex condition. An operation was sanctioned by the South Carolina Department of Social Services to convert the child into a girl when he was 16 months old, without considering if it was in the best interests of the child.¹⁶⁸ In April 2014, the 5th Judicial Circuit Court decided in favour of MC, allowing the case to continue after the Department of Social Services applied for a further motion to delay the case.

‘The court’s decision moves MC a step closer to justice,’ said Kristi Graunke, Southern Poverty Law Center senior supervising attorney. ‘This ruling holds doctors accountable when they recommend such drastic and irreversible procedures for infants but fail to ensure caregivers are fully informed about the risks and options.’¹⁶⁹

¹⁶⁶ Zwischengeschlecht.org, ‘Christiane Völling: Hermaphrodite wins damage claim over removal of reproductive organs’ Aug 12, 2009 <http://zwischeneschlecht.org/pages/Hermaphrodite-wins-damage-claim> accessed 24 May 2014.

¹⁶⁷ [1980] CLY 687

¹⁶⁸ Mindy Townsend ‘Choosing Kids’ Genitalia May Be Unconstitutional, Court Says.’ August 26, 2013. <http://www.care2.com/causes/choosing-kids-genitalia-may-be-unconstitutional-court-says.html> Salon, ‘Sex-assignment surgery on a child ruled unconstitutional’ Saturday, Aug 24, 2013 http://www.salon.com/2013/08/24/judge_deems_sex_assignment_surgery_on_a_child_violation_of_constitution_partner/ accessed 24 May 2014.

¹⁶⁹ Circumstitions News, South Carolina: ‘Intersex child castration case to proceed’ Monday, April 14, 2014 <http://circumstitionsnews.blogspot.co.uk/2014/04/south-carolina-intersex-child.html> and ‘Malpractice Trial after Intersexed Infant Castration’ Wednesday August 19 2015 <http://circumstitionsnews.blogspot.co.uk/2015/08/south-carolina-malpractice-trial-after.html> accessed 24 August 2015.

A further motion to dismiss the case, filed by all the doctors and hospitals named in the action was denied at the end of August 2013.¹⁷⁰ The adoptive parents filed both federal and state law suits initially. The court eventually dismissed their federal law suit, but as of writing, the state law suit is still progressing will potentially be heard by a jury in November 2015. Should MC win the case, this is likely to spark a wave of similar actions in the US.

5.6 Legislative Measures – A Comparison with Other Jurisdictions

A survey of current English law indicates that there is an absence of suitable legislative provisions in regard to informed consent for medical treatment. Professor Maclean sees consent as being ‘inherently political’ so any system will be open to criticism, something he sees as strength rather than a weakness.¹⁷¹ One of his concerns is that if we have legislation it may be poorly drafted. This is not an unreasonable concern in the light of various Acts from recent times, with ‘some of the most convoluted offences in decades’¹⁷² being passed recently. Further, although he believes that current provisions are not perfect, they do at least provide ‘a sufficient degree of fair protection’.¹⁷³ I would argue that this point is debatable, particularly where insufficient information undermines the principle of consent. Therefore a look at different jurisdictions may be of benefit in this regard.

In terms of the treatment for adults, a good model to consider is that from New Zealand. New Zealand’s law evolved from English law, but in terms of medical law it has been more proactive in introducing healthcare legislation, such as the ‘no-fault’ liability system, and more recently by ‘wholeheartedly’ embracing the concept of

¹⁷⁰ News Report, WYFF4.com ‘State Sued over ‘hermaphrodite’ child’s sex surgery’ September 11 2013.
<http://www.wyff4.com/news/local-news/greenville-news/State-sued-over-hermaphrodite-child-s-sex-surgery/21891906> accessed 24 May 2014.

¹⁷¹ Alisdair MacLean, *Autonomy, Informed Consent & Medical Law, a Relational Challenge* (2009 Cambridge Law, Medicine and Ethics) 260.

¹⁷² David Ormerod & Rudi Fortson, ‘The Serious Crime Act 2007, the Part 2 offences’ [2009] Crim LR 389 A frank discussion on the relatively recent startling example of poor legislation, as can be found in Part 2 of the Serious Crime Act 2007.

¹⁷³ Alisdair MacLean (n 172) 268.

informed consent, which has now been codified.¹⁷⁴ The framework for this comes from the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumers' Rights 1996.¹⁷⁵ The Code includes three 'rights' that are the building blocks for informed consent: the right to effective communication;¹⁷⁶ the right to be fully informed;¹⁷⁷ and the right to consent by a competent person.¹⁷⁸ All of these rights are written in broad terms, but clearly reflect the spirit of informed consent. For example, Right 6, the right to be fully informed, tells us that:

1) Every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, would expect to receive, including -

a) An explanation of his or her condition; and

b) An explanation of the options available, including an assessment of the expected risks, side effects, benefits, and costs of each option; (...)

It appears that since New Zealand has codified the process there is significantly less court action as a result.¹⁷⁹ One exception is *B v Medical Council of New Zealand*,¹⁸⁰

¹⁷⁴ Joanna Manning, 'Informed Consent to Medical Treatment: The Common Law and New Zealand's Code of Patients' Rights' (2004) 12 (2) Med Law Rev 181, 182.

¹⁷⁵ Appendix F. The Code became law on 1 July 1996. It has been reviewed three times to date (1999, 2004, 2009). According to the Health and Disability Commissioner's website, one change was made in June 2004, to substitute a new version of Right 7(10). <http://www.hdc.org.nz/the-act--code/the-code-of-rights>

A recent review was carried out on the Code by Anthony Hill, the Health and Disability Commissioner. His report was submitted to the Minister of Health in June 2014. Anthony Hill, 'A Review of the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumers' Rights' (June 2014)

<http://www.hdc.org.nz/media/268443/act%20and%20code%20review%202014%20-%20report%20to%20minister.pdf> accessed 24 August 2015.

¹⁷⁶ Right 5 Right to Effective Communication.

¹⁷⁷ Right 6 Right to be Fully Informed.

¹⁷⁸ Right 7 Right to Make an Informed Choice and Give Informed Consent.

¹⁷⁹ Although this is likely to be due to the New Zealand policy of no-fault liability rather than the Code by itself, it does appear that there is a more organised system of redress. It is unlikely that England would adopt a no-fault liability system, although Scotland is considering such a move, but regardless, a structure charter of patient rights would be of assistance in today's healthcare system. According to Joanna Manning (n 173) 182, the standard of disclosure on that required by its antipodean counterpart in *Rogers v Whittaker*.

in which the High Court stressed the importance of assessing the quality of the information imparted from the standpoint of the *patient*, not the doctor. The Court noted that the giving of inadequate information will almost always fall into the category of professional misconduct.¹⁸¹ If this approach was adopted in English law, it would assist the intersexed by ensuring that, before any irreversible procedures take place, doctors always impart adequate ‘consumer friendly’ information.

Further, Right 7(7) states that every consumer has the right to refuse services and to withdraw consent to services. This position was established by the New Zealand Bill of Rights Act 1990. By virtue of section 11 the Bill stipulates that ‘everyone has the right to refuse to undergo any medical treatment’. However, guidance on the Bill also refers to ‘competence’.¹⁸² As with English law there are three categories in which a patient is not considered to be competent to give consent, namely emergency situations or by reason of age or mental capacity. The guidance goes further by adding that ‘every person of diminished competence has the right to grant informed consent to or to refuse treatment to the extent appropriate to the person's level of competence’.¹⁸³ This allows ‘consent’ a greater level of protection than perhaps is seen in English law.

By virtue of section 4 (1) of the Age of Majority Act 1970, (NZ),¹⁸⁴ in New Zealand a ‘child’ is anyone under the age of 20.¹⁸⁵ However, for medical treatment, section 36

¹⁸⁰ [2005] HC 3 NZLR 810.

¹⁸¹ Should consumers be unhappy with their treatment, the code sets out the complaints procedure.

¹⁸² Ministry of Justice New Zealand, The Guidelines on the New Zealand Bill of Rights Act 1990: A Guide to the Rights and Freedoms in the Bill of Rights Act for the Public Sector – Published November 2004. <http://www.justice.govt.nz/publications/global-publications/t/the-guidelines-on-the-new-zealand-bill-of-rights-act-1990-a-guide-to-the-rights-and-freedoms-in-the-bill-of-rights-act-for-the-public-sector/part-iii-rights-and-freedoms-affirmed-by-the-bill-of-rights-act-2#section11> accessed 24 May 2014.

¹⁸³ *ibid*

¹⁸⁴ s4(1) For all the purposes of the law of New Zealand a person shall attain full age on attaining the age of 20 years.

¹⁸⁵ There is currently a proposed members’ bill in the House of Representatives ‘Age of Majority (Attainment at 18 Years) Amendment Bill’, which was introduced in March 2015.

of the Care of Children Act 2004¹⁸⁶ specifies that a child has the full rights of consent to treatment as an adult on obtaining the age of 16. This right is extended to younger children by presumption of competence as contained in Right 7 (2) of the Code, within limitations.¹⁸⁷ The New Zealand *guidance* specifies that although a child may not have the reasoning ability of an adult, nevertheless a child may still be able to make an informed choice, to the extent of his or her level of competence. (There is no lower age threshold.) In this respect, New Zealand has adopted the *Gillick* principle, and minors can consent to treatment if they meet the *Gillick* criteria for the specific procedure at hand.¹⁸⁸

5.6.1 Young Children

An examination of English case law and personal experiences indicates that true ‘informed consent’ is at its most vulnerable from healthcare workers when birth is imminent or has just occurred. This is particularly important in the area of neonatal testing.¹⁸⁹ Here, New Zealand leads by example. According to the Newborn Metabolic Screening website in New Zealand,¹⁹⁰ nearly all neonates are tested for congenital conditions. This website is very clear and informative, and indicates the steps in newborn screening with clarity, including the purpose of the tests and the process of informed consent. This is precisely the type of information that is needed

¹⁸⁶ s36 Consent to procedures generally

(1) A consent, or refusal to consent, to any of the following, if given by a child of or over the age of 16 years, has effect as if the child were of full age:

(a) any donation of blood by the child:

(b) any medical, surgical, or dental treatment or procedure (including a blood transfusion, which, in this section, has the meaning given to it by section 37 (1) to be carried out on the child for the child’s benefit by a person professionally qualified to carry it out.

¹⁸⁷ 7 (2) Every consumer must be presumed competent to make an informed choice and give informed consent, unless there are reasonable grounds for believing that the consumer is not competent. <http://www.hdc.org.nz/education/presentations/the-informed-consent-process-and-the-application-of-the-code-to-children>

¹⁸⁸ New Zealand also pays respect to the United Nations Convention on the Rights of the Child, which also requires that children be actively involved in the process of making decisions about their medical treatment. However, where the child’s view appears not to be in their best interest, parental views or those of a court appointed guardian are likely to be considered.

¹⁸⁹ Newborn screening in England will be discussed in chapter seven.

¹⁹⁰ www.nsu.govt.nz/newborn-metabolic-screening.aspx accessed 24 March 2014.

in England, whether there is statutory protection or not. It is one thing to legislate for informed consent, another to enact it. Even if the law is in place its aims will not be achieved if a suitable practice is not adopted.

The Columbian cases indicate the volatility of a young child's right to bodily integrity. Some procedures need to occur straight away, but many operations which are performed on the intersexed could be postponed until adolescence. For example, in girls with Complete Androgen Insensitivity Syndrome (CAIS), an orchiectomy is usually recommended to prevent testicular cancer. This used to occur at an early age, but the Intersex Society of North America (ISNA) has strongly recommended for a number of years that surgery is left until the girl can decide for herself, as testicular cancer is rare.¹⁹¹ ISNA also advocate that vaginoplasty surgery, which has frequently been performed on Androgen Insensitivity Syndrome (AIS) infants, should not be carried out until the child is older and has 'opportunity to speak with adult AIS women about their sexual experience and about surgery in order to make a fully informed decision'.¹⁹²

Currently there is insufficient data on the advantages or disadvantages of performing early surgery, therefore the medical profession cannot proffer the foundation for consent. For this reason, it is essential that guidelines are issued instructing how to proceed in the absence of information.¹⁹³ It appears that no matter how precise the details of informed consent specified by Parliament are, the process will always be limited by the medical knowledge of the day. For this reason it is important that the views of the child concerned are taken account of, but legislating in this area for very young children is likely to prove a difficult task. In this respect, it is submitted that in line with the New Zealand code there is no finite lower age of consent to medical

¹⁹¹ ISNA, Androgen Insensitivity Syndrome (AIS) <http://www.isna.org/faq/conditions/ais> accessed 21 August 2015.

¹⁹² *ibid.*

¹⁹³ The irony of the situation here is that in the 1980s, doctors, following Money's footsteps, *could* inform patients in all good faith that the early genital surgery was for the advantage of the children concerned, as that was the accepted belief at that time.

treatment, but that all children are considered to be competent unless it can be proved otherwise.¹⁹⁴

5.6.2 Mature Minors

It has been previously noted that in contrast to England, New Zealand has enshrined the young person's right to refuse treatment at 16 years of age.¹⁹⁵ Other jurisdictions have been equally generous in safeguarding the autonomy of young people, albeit a majority of jurisdictions are less direct on refusal of treatment.

In Scotland, minors are supported by section 2(4) of the Age of Legal Capacity (Scotland) Act 1991, which allows any child under the age of 16 to consent to treatment providing they understand it.¹⁹⁶ This section embeds the *Gillick* decision in legislation, and allows 'competent' children to consent to treatment. However, there still remains the uncertainty regarding refusal. Although the Scottish case of *Re Houston (Applicant)*¹⁹⁷ saw Sheriff McGown interpreting consent 'to include refusal', the lack of explicit statutory recognition in this regard leaves matters in a problematic state. In theory a competent child is also allowed to withhold consent, but depending on the circumstances this might be overridden by parents. This lack of certainty does not make for an ideal solution for the intersexed.

In the US, states will vary, but as a result of *Re EG (a minor)*,¹⁹⁸ a case involving a Jehovah's witness and her desire to refuse a blood transfusion, the Illinois Supreme

¹⁹⁴ By virtue of s14 of the recent Gender Identity, Gender Expression and Sex Characteristics Act 2015 (Malta) forbids genital assignment surgery on children- without their express consent. This will be discussed in depth in chapter eight.

¹⁹⁵ s36 of the Care of Children Act 2004 NZ.

¹⁹⁶ Age of Legal Capacity 1991(Scotland) s2(4) 'A person under the age of 16 years shall have legal capacity to consent on his [her] own behalf to any surgical, medical or dental procedure or treatment where, in the opinion of a qualified medical practitioner attending him (her), he (she) is capable of understanding the nature and possible consequences of the procedure or treatment.'

¹⁹⁷ (1996) 32 BMLR 93

¹⁹⁸ *Re EG (a minor)* 133 Ill 2d 98, 549 NE 2d 322(1989).

Court has recognised a common law ‘mature minor doctrine’, allowing a judge to adjudicate that a minor is mature enough to consent to or refuse medical treatment where the evidence is clear and convincing that the minor is mature enough to ‘appreciate the consequences of her actions and to exercise the judgment of an adult’.¹⁹⁹

In a similar case, *AC v Manitoba (Director of Child and Family Services)*,²⁰⁰ the majority of the Supreme Court of Canada ruled that children under the age of 16 can make decisions about their own medical treatment, even if they involve life and death situations. The Court stated that:

adolescents clearly have an interest in exercising their capacity for autonomous choice to the extent that their maturity allows. And society has a corresponding interest in nurturing children’s potential for autonomy by according weight to their choices in a manner that is reflective of their evolving maturity.²⁰¹

Yet other jurisdictions have a more organised approach to medical consent. For example, in South Australia the Consent to Medical Treatment Palliative Care Act 1995 (SA)²⁰² gives a person of 16 years the statutory right to consent to or refuse medical treatment, whilst a more liberal approach can be found in South Africa

¹⁹⁹ *ibid.*

²⁰⁰ *AC v Manitoba (Director of Child and Family Services)*, 2009 SCC 30, [2009] 2 SCR 181. This considered the refusal of blood by a 14-year-old Jehovah’s Witness (AC). By virtue of the *Manitoba Child and Family Services Act*, the court may authorise treatment that it considers to be in the child’s best interests. Section 25(9) of the Act presumes that the best interests of a child 16 or over will be in accordance with the child’s wishes, unless they are incompetent, but there is no such legal presumption for children under the age of 16. By the time this case reached the Supreme Court, AC had received her blood transfusion (which proved successful); nevertheless, the court decided in AC’s favour.

²⁰¹ *ibid* [105].

²⁰² South Australia Consent to Medical Treatment and Palliative Care Act 1995. Part 1 sets out objectives of the Act. Objective (i) states, to allow persons of or over the age of 16 years to decide freely for themselves on an informed basis whether or not to undergo medical treatment. Further Part 2, Division 1, (6) Legal competence to consent to medical treatment, confirms that once the age of 16 is reached, then the patient’s wishes are to be given full accord with those of an adult. This does not apply to the making of advanced directives. The *Gillick* principle is encapsulated in division 4, (12).

where Section 129 of the Children's Act 2005 allows minors to consent to treatment when they reach the age of 12 and have sufficient maturity to understand the treatment offered.²⁰³ In South Africa 'consent' automatically incorporates 'refusal'. In December 2009, the Law Reform Commission of Ireland published its consultation paper on 'Children and the Law: Medical Treatment'. The consultation period lasted four months and the results were collated. Their conclusions were published in July 2011.²⁰⁴ The report's key recommendations, incorporated into a draft bill, are that '16 and 17-year-olds should be presumed (...) to have to consent to, and refuse healthcare and treatment.'²⁰⁵ An additional recommendation states that 'a person who is between 14 and 16 may consent to and refuse health care treatment where it is established that he or she has the maturity and understanding to appreciate the nature and consequences of the specific health care and treatment decision'.²⁰⁶ This refusal would not extend to life and death situations, in which case a High Court declaration would be needed. Further, the bill indicates that parents will also be involved in decision making for those under the age of 16.²⁰⁷ These provisions, if enacted, are similar to the English law but with one crucial difference – the right of refusal of treatment for all but life and death situations is enshrined in the legislation.²⁰⁸

With all the above jurisdictions, there appears to be the desire to allow a mechanism for young people to refuse treatment. This is much needed in English law. With the arrival of the Human Rights Act 1998, one would have thought that a more holistic

²⁰³ If surgery is needed that consent must be verified by their parent or guardian; however, there is no lower legal age to consent to an abortion by virtue of s5 of Act No 92 of 1996: Choice on Termination of Pregnancy Act 1996. Additionally, by virtue of s5 (3) a minor is not required to obtain parental approval. This last aspect does appear to be a part of English law now as a result of *R (on the application of Axon) v Secretary of State for Health*. [2006] All ER (D) 148.

²⁰⁴ Law Reform Commission Report: Children and the Law Medical Treatment (LRC 103-2011) July 2011
<http://www.lawreform.ie/fileupload/consultation%20papers/cpChildrenandtheLawMedicalTreatment.pdf>.

²⁰⁵ *ibid* s7 Draft Bill 153 report.

²⁰⁶ *ibid* s10 (2) Draft Bill 155 report.

²⁰⁷ *ibid* s10 (3) Draft Bill 156 report.

²⁰⁸ To date this has not occurred, nor as of October 2014, had the draft bill been presented to the Irish parliament. <http://www.lawreform.ie/publications/table-of-implementation-of-law-reform-commission-recommendations.171.html> accessed 24 August 2015.

view to the ‘mature minor’ in English law would be promoted, but according to Fortin,²⁰⁹ the courts have responded in ‘an extraordinary haphazard manner when dealing with children’s cases’. However, some judges have been more encompassing of children’s demands, for children have ‘individual minds and wills, views and emotions, which should command serious attention’.²¹⁰ The difficulty with this is that this approach seems to be aimed at promoting children’s rights above parents’ rights. In *R (on the application of Axon) v Secretary of State for Health*,²¹¹ the case gave weight to a young person’s decision by deciding that Article 8 of the European Convention on Human Rights (ECHR) prevented a parent from retaining a right to parental authority for medical decisions if the young person was deemed to be competent. It gave little autonomy to a child to refuse treatment proposed by doctors. The impression is that courts will support doctors first and foremost, and then whoever agrees with them second. This is of concern.

The protection of a great number of individuals should not be left in the hands of one or two judges, no matter how competent they are. It is unacceptable that any ‘child’ of some 17 years does not have the legal right to refuse a medical procedure – even on the eve of their eighteenth birthday. Therefore, it is submitted, the English Parliament needs to redress the lacuna left by section 8 of the FLRA 1969, and incorporate refusal alongside consent as a minimum requirement. In the words of His Honour Judge Tyrer, if young people are asked to ‘respect the law’, then ‘the law must respect them and their wishes(...)’²¹² For those with an intersex condition, the law must not only respect them but protect them.

²⁰⁹ J Fortin, ‘Accommodating Children’s Rights in a Post Human Rights Act Era’ (2006) 69 (3) MLR 299.

²¹⁰ *Re S (a minor) (independent representation)* [1993] 2 FLR 437, 448.

²¹¹ [2006] EWCA 37 (Admin).

²¹² *Re S (contact: children’s views)* [2002] 1 FLR 1156, 1171.

5.7 Conclusion

From the above discussions it can be seen that for those who have an intersex/DSD condition, informed consent for medical treatment remains a myth. The underlying difficulty for adults is the lack of clear and believable information. In this regard, it will be noted in the following chapter that women may be recommended an abortion if their child-to-be is diagnosed with a DSD, without being fully informed of that condition. Further, as discussed in chapter 8, a mother whose child presents with genital ambiguities at birth may find herself ignored in the consent process in the rush to treat the child. The situation remains particularly acute when considering the rights of the intersex child, as *no* child's right to refuse treatment has the full protection of English law. This is particularly sensitive for those with genital ambiguities, as many irreversible procedures occur at an early age, often for no benefit of the child themselves.²¹³

Would the intersexed be better protected if there was a structured code for informed consent, such as the New Zealand model? It is suggested that as distribution of information would be an essential part of the statutory scheme, the intersexed would receive more protection. Currently in England there is an inconsistency in the quality of information given to patients. This is true for all patients, not just the intersexed, but as general knowledge on this subject is sparse, it is even more essential that those involved have access to detailed accurate information delivered in a manner that they can understand.

In regard to mature minors, the law has long since needed clarification, and it is submitted that a minor amendment to s8(2) of the Family Law Reform Act 1969, to incorporate refusal of consent for 16-year-olds, is the least that should be done. In terms of non-reversible procedures, the legal age of refusal of treatment should

²¹³ For example parents have been known to consent to a clitoridectomy purely because they were embarrassed by the size, not for any other medical reasons. This will be considered in more detail in chapter eight.

ideally be lower, to accommodate the wishes of those whose bodies are under the knife.²¹⁴

In the remainder of this thesis, I concentrate on specific ‘stages’ of the intersexed person’s life, to investigate whether those with intersex/DSD conditions face discrimination in specific medical procedures. The following chapter considers the plight of the intersexed child-to-be. As will be noted, this stage is fraught with potential discrimination.

²¹⁴ The mechanisms for this will be discussed in chapter eight.

PART TWO

Seven Ages of Man, Seven Stages for Discrimination¹

¹ The 'Seven Ages of Man' is the subject of a monologue in Act II Scene VII of William Shakespeare's comedy *As You Like It*, which begins with the famous line 'All the world's a stage...'. During this monologue, the melancholy Jaques muses on what he considers to be the seven stages of a man's life, namely infancy, childhood, the lover, the soldier, justice, old age, and finally oblivion, 'Sans teeth, sans eyes, sans taste, sans everything.' For the purposes of this thesis, the stages will consist of pre-conception, implantation, *in utero*, birth, infancy, adolescence, adulthood.

Chapter Six: Discrimination Before Birth; Assisted Reductive Techniques, Pre-implantation Genetic Diagnosis and Abortion

6.1 Introduction

The aim of this chapter is to investigate potential discrimination that intersexed persons may face *before* birth in a medico-legal context in England today, by considering current English law in respect of pre-implantation genetic diagnosis (PGD) and the current law on abortion. Such discrimination was highlighted (on a global as opposed to national basis) by the Third International Intersex Forum (TIIF), which demanded the cessation of all unfavourable medical intervention on the intersexed before birth.¹ It is therefore essential to see if this discrimination occurs in English law and, if so, whether such discrimination can be justified. In this respect there is an overlap with academic writing in the field of disability rights, which debates the ‘eugenics’ of PGD and abortion law generally.² Whilst noting that intersex conditions are not specifically disabilities,³ some intersex conditions give rise to physical difficulties, whilst others may be perceived as a disability, ‘primarily to do with the society in which we live’.⁴

This chapter comprises two sections. The first section will discuss assisted reproductive techniques (ART) and PGD and evaluates the current legal provisions in regard to these activities. The current law in this area is regulated by the Human Fertilisation and Embryology Act 1990 as amended (HFEA 1990) and the Human Fertilisation and Embryology Act 2008 (HFEA 2008). All treatments are

¹ Notably the detection of such conditions before implantation, and the use of prenatal screening for the detection and subsequent abortion of intersexed fetuses after implantation. The full demands issued by TIIF are listed in Appendix A.

² Tom Shakespeare, *Disability Rights & Wrongs Revisited* (2nd, Routledge 2014).

³ Sometimes an indeterminate sex is an indicator of a significant disability which is not specifically an intersex condition, such as occurs with trisomy 21.

⁴ Shakespeare (n2) 196.

independently regulated by the Human Fertilisation and Embryology Authority (HFEA).

The second section will consider antenatal testing and abortion, and the legal parameters of the latter. Since developments in ART and PGD have instigated the creation of numerous legal provisions, this chapter commences by investigating current medical techniques employed to overcome infertility, indicating where the intersexed might benefit from such treatment, before considering the current law that regulates them. It should be noted that whilst the majority of intersex/DSD conditions are caused by random genetic mutations,⁵ other conditions are hereditary.⁶ This poses concerns for sufferers (and carriers) of such conditions should they wish to become parents. This is an important ethical debate. Although it applies to anyone with a hereditary condition, not just the intersexed, it will affect the minds of intersexed parents if they decide to ‘screen out’ a child with their condition via PGD.⁷

6.2 Assisted Reductive Techniques (ART)

Although pregnancy occurs easily for some women (whether they wish it to or not), other women invest a significant amount of money, time and energy to conceive.⁸ The advance of medical science has created opportunities for pregnancies that would not have occurred naturally, by selecting the best available sperm and ova to create embryos.⁹ These techniques, although (usually) of general application to ensure the best chance of pregnancy, can be utilised to stop faulty genes being passed to any

⁵ Mixed Gonadal Dysgenesis is caused by a random genetic mutation.

⁶ CAH is an autosomal recessive condition. Where both parents carry the gene mutation (albeit they are not sufferers themselves) in a natural conception there will be a 1:4 (25%) chance of the child inheriting the condition outright, 1:2 (50%) of being a carrier and only 1:4 (25%) of being free of the gene mutation.

⁷ This is discussed in section 6.4.

⁸ According the Society for Assisted Reproductive Techniques (SART) patients have noted that undergoing IVF is ‘more stressful than or almost as stressful as any other major life event, such as the death of a family member or separation or divorce’. Society for Assisted Reproductive Techniques (SART), ‘Preparing for IVF: Emotional Considerations’
<<http://www.sart.org/detail.aspx?id=1902>>accessed 30 April 2015.

⁹ Embryologists are responsible for selecting the best sperm and embryos for treatment.

future children. This can be achieved, for example, by sorting out 'good' sperm from 'bad', such as occurs during fluorescence in situ hybridization (FISH).

6.2.1 Fluorescence in situ hybridization (FISH)

FISH, pioneered in the 1980s, uses biomechanical fluorescent probes which are designed to attach to specific parts of a chromosome. The success at binding to the chromosome, or otherwise, indicates whether a specific condition is present or absent. FISH has been used to 'deselect' sperm indicating the Klinefelter Syndrome (KS) chromosome configuration (46XXY) when treating KS men.¹⁰

It can be argued that FISH leads to direct discrimination against those with KS. However, as the intention is to achieve fertility, it can be said to be in the patients' best interests if it achieves that goal. FISH is not used in standard treatment but primarily with PGD, although it should be noted that because FISH is limited in its application, assessment of all 23 chromosomes is now undertaken using three separate techniques.¹¹

6.2.2 Intrauterine Insemination (IUI)

IUI is the process whereby a prepared sample of sperm is injected directly into the uterus at the time of ovulation in a woman's cycle.¹² IUI may be recommended where the male partner can create sperm but is physically unable to transfer it,¹³ or where donor sperm is required.¹⁴

¹⁰ Takuya Akashi and others, 'Birth after Intracytoplasmic Sperm Injection of ejaculated Spermatozoa from a man with Mosaic Klinefelter's Syndrome' (2005) 7 (2) Asian J Androl 217.

¹¹ The three techniques are Array Comparative Genomic Hybridization (aCGH), Single nucleotide polymorphism microarrays (SNP) and Quantitative real time polymerase chain reaction (qPCR). <http://www.advancedfertility.com/pgs-ivf-genetic-testing.htm> accessed 10 November 2014.

¹² Ovulation may occur as part of a natural cycle or be stimulated with fertility drugs. IUI removes the first obstacle to conception by allowing sperm to cross the cervix. As part of the process of IUI the sperm provider's sample is 'washed' and then filtered using special techniques, to remove the weakest sperm. For IUI to work, the fallopian tubes must be open. This is normally investigated before the procedure takes place, via a laparoscopy, where a micro-camera is inserted to check for blockages, or a hysterosalpingogram. Here radiographic contrast (dye) is injected into the uterus through the vagina and cervix.

In the results of the survey carried out for this thesis, IUI was a traditional method employed to assist those with intersex/DSD conditions, or their partners, where donor sperm was required. This might be where the male partner had KS¹⁵ or Partial Androgen Insensitivity Syndrome (PAIS),¹⁶ or in a same sex couple where one of the partners had Congenital Adrenal Hyperplasia (CAH).¹⁷ It was also used for those with hypospadias, providing their sperm count was sufficient.¹⁸

IUI has the advantage of being the cheapest method of ART available, currently costing in the region of £1500 per cycle with donor sperm.¹⁹ However, it will not be deemed suitable for men with low sperm counts.²⁰ Even with a good sperm sample this technique only carries a 15 per cent chance of pregnancy.²¹

¹³ As might be the case for those with hypospadias or micropenis.

¹⁴ This technique has also been used frequently in the past for single women and lesbian couples. However, these days, the current view is that it is better to go for direct IVF treatment, as the pregnancy success rates are higher.

¹⁵ 13 out of 19 clinics (68%) had KS men as clients. 7 out of 13 clinics (54%) had treated KS men with donor sperm. Those who had some degree of fertility were offered IVF/ICSI as a more suitable treatment. Questionnaire and results are to be found in Appendix E.

¹⁶ 4 out of 19 clinics (21%) had CAIS or PAIS clients. One was treated with donor sperm. Appendix E

¹⁷ 6 out of 19 clinics (32%) had CAH clients. One was treated with donor sperm. Appendix E

¹⁸ 7 out of 19 clinics (37%) had patients with hypospadias. 3 out of the 7 had treatment using their own sperm and IUI, a further 3 had IVF/ICSI. (One cancelled their treatment.) Appendix E

¹⁹ The basic cost of IUI treatment varies from £500-£1000. NHS, 'Artificial Insemination' <http://www.nhs.uk/conditions/Artificial-insemination/Pages/Introduction.aspx> accessed 24 July 2015.

²⁰ The 'acceptable' sperm count is 20 million spermatozoa per millilitres mL. Those with a lower sperm count (oligozoospermia) can father children naturally. Men with sperm counts below one million have fathered children. However, some men have cryptozoospermia (severe oligozoospermia): this is a count lower than 100,000 sperm/mL in two consecutive semen analyses. For these men, sperm retrieval will be required if pregnancy is desired.

²¹ For example, the current recorded rates of pregnancy on one site is 16 % for those women who are under 35, which dropped to 1% for patients between the ages of 43 and 44, and 0% for women over the age of 44. Babycentre 'Fertility Treatment: Intrauterine Insemination' <http://www.babycentre.co.uk/preconception/fertilitytreatments/iui/#ixzz2DhLl6MfP> accessed 20 April 2015.

6.2.3 In Vitro Fertilisation (IVF)

IVF is a more invasive procedure for a woman than IUI, and significantly more expensive. The basic cost is in the region of £3500 per cycle, but this will increase depending on the number of drugs that are prescribed. A significant portion of this fee pays for egg retrieval, which takes place in a sterile environment usually under general anaesthetic.²² Additional costs occur if donor eggs are required,²³ and this increases the price to around £7000 a cycle.²⁴ However, by using donor eggs clinics successfully overcome infertility in those with Turner Syndrome (TS)²⁵ and Swyer's Syndrome.²⁶ In this respect the cost of one cycle seems a very reasonable figure.

Once the eggs are retrieved, the sperm will be added to them in one of two ways. Under the traditional IVF methods, the clean sample of sperm is added to the collected eggs in a Petri dish, left overnight and assessed the next day to see if fertilisation has occurred. However, for unknown reasons, some sperm do not appear to be capable of penetrating the eggs, therefore allowing for random fertilisation leaves a potential chance that none of the eggs will be fertilised. Consequently, to

²² At the start of the cycle, the woman will need to 'down regulate', which in effect 'switches off' her pituitary gland so that she is put into suspended menopause. This can be achieved either by the patient injecting herself on a daily basis, or by using nasal sprays. Once down regulation is achieved, she will be required to inject with differing levels and types of gonadotrophins (fertility hormones). The vast majority of these injections will be self-administered by the woman in her own home. The developing egg follicles will be scanned on a regular basis until the follicles grow to an approximate size of 16 mm, at which point the woman will self-inject human chorionic gonadotropin (hCG), which is a stimulus for ovulation to occur. A typical cycle aims to develop approximately 12 eggs, but the numbers that are obtained vary wildly from 0 to 24+. If the woman appears to be producing too many follicles, then she will be at risk of a condition known as ovarian hyper stimulation syndrome (OHSS), which is a potentially fatal condition. If this occurs, the treatment cycle will be stopped. This is unlikely to occur in an intersexed patient, as the difficulty is likely to be generating any follicles at all.

²³ This treatment is only possible where the woman has a fully formed uterus, and as such is not applicable to women with CAIS.

²⁴ Some patients may be able to receive NHS funding for their treatment, but this will vary from location to location. A slight alteration to one's postcode can have a devastating financial impact on receiving free treatment. It is clear that for those who do have to pay for fertility treatment, there will be discrimination between those who can and those who cannot afford the fees.

²⁵ 15 out of 19 clinics (79%) saw women with TS. All but 1 of these women received donor gametes (93%).

²⁶ 7 out of 19 clinics (37%) treated those with Swyer's Syndrome. Out of these 7, 6 received donor gametes.

avoid disappointment, couples are encouraged to pay an additional fee (in the region of £1000) for Intra-cytoplasmic Sperm Injection (ICSI). If the male partner has a low sperm count ICSI will always be recommended.

6.2.4 Intra-cytoplasmic Sperm Injection (ICSI)

ICSI is the procedure in which a single sperm is carefully selected, and then injected directly into the egg. ICSI was first used in 1992, and since then over 2.5 million babies have been born using this technique.²⁷ ICSI can be recommended for a number of situations where the sperm is not optimal. Typically, this might be low sperm count, or a high percentage of abnormal sperm. It will also be used where a man has limited sperm presence in the semen and requires surgical retrieval.²⁸ The use of ICSI has proved to be very successful for KS men, who need such treatment.²⁹

6.3 Embryo Monitoring

As part of the IVF process, embryologists monitor the embryos regularly. Once the sperm is added to the eggs, the eggs will be checked to see if there has been successful fertilisation. If fertilisation has been established, 24-36 hours after the addition of sperm, embryologists will examine and grade the developing embryos.³⁰

²⁷ André Van Steirteghem, 'Celebrating ICSI's Twentieth Anniversary and the Birth of more than 2.5 Million Children—the 'How, Why, When And Where' (2012) 27 (1) Hum Reprod 1.

²⁸ This technique might also be used for those with severe forms of hypospadias.

²⁹ GD Palermo and others, 'Births after Intracytoplasmic Injection of Sperm obtained by Testicular Extraction from men with Nonmosaic Klinefelter's Syndrome.' (1998) 338(9) N Engl J Med 588; F Lanfranco and others, 'Klinefelter's Syndrome' (2004) 364 (9430) The Lancet 273; JD Schiff and others, 'Success of Testicular Sperm Extraction (corrected) and Intracytoplasmic Sperm Injection in men with Klinefelter Syndrome' (2005) 90 (11) J Clin Endocrinol Metab 6263.

³⁰ Embryo grading is based on two factors: the number of cells developed in a specific time, and the fragmentation of those cells. A grade one embryo is a 'perfect embryo'. Such an embryo would have the right number of cells (eg eight cells in three days) with no fragmentation of those cells. Grade one embryos are rare, and most treatment involves the use of grade two embryos, which are of very good quality but perhaps showing minor fragmentation, or a slightly slower growth. These embryos will also be considered suitable for storage in liquid nitrogen. Fresh grade three embryos might be used in treatment if there are no better quality embryos available, but are unlikely to be frozen for future treatment. This may depend on the individual clinics, but the majority specified that they do not freeze embryos below grade two. This is because testing over time has indicated that higher grade embryos are better at surviving the freezing/thawing process.

Only high quality embryos will be transferred to the mother-to-be or stored for future use. Embryos can be transferred at the cleavage stage³¹ or the blastocyst stage.³²

6.4 Ethical Concerns with ART

With the exception of FISH, none of the above techniques give rise to any specific discrimination of the intersexed as an embryo. Nevertheless there are ethical concerns which shall now be considered.

KS men who have some degree of fertility are likely to produce a mixture of sperm, some with the XXY configuration and some with the XY configuration. With this in mind it will be considered whether the technique of FISH used to select XY sperm is discriminatory. *Prima facie*, this appears to be the case, but it is suggested that it is ethically acceptable to use such procedures, as this occurs *before* conception and therefore the process does not interfere with the integrity of the embryos. Moreover, some research indicates that only 46 XY cells can undergo meiosis.³³ Therefore to actively select sperm with the 47XXY configuration is ethically *unacceptable*, as these sperm are less likely to create viable embryos, whereas sperm with a normal karyotype are more likely to lead to successful pregnancies.³⁴

In regard to ART as a whole, Steinbock reports that when IVF was a relatively new technique, it received criticism on the grounds that it 'was immoral to run the risk of producing a congenitally abnormal baby',³⁵ and indeed studies have indicated that

³¹ An embryo of 2-3 days often transferred during a cycle of IVF.

³² An embryo of 5-6 days. This embryo has developed to the point where the *zona pellucida* has 'dissolved' so that the embryo is ready to attach to the lining of the uterus.(This 'dissolving' or lysis is known as zona hatching.)

³³ Marianne Bergère and others, 'Biopsied Testis Cells of four 47,XXY patients: fluorescence in-situ hybridization and ICSI results' (2002) 17 (1) Hum Reprod 32.

³⁴ V Poulakis and others, 'Birth of two infants with Normal Karyotype after Intracytoplasmic Injection of sperm obtained by testicular extraction from two men with Nonmosaic Klinefelter's Syndrome' (2001) 76 (5) Fertility & Sterility 1060; S Komori and others, 'Birth of healthy neonates after Intracytoplasmic Injection of Ejaculated or Testicular Spermatozoa from men with Nonmosaic Klinefelter's Syndrome: a report of 2 cases' (2004) 49 (2) J Reprod Med 126.

about 50 per cent of embryos from IVF are chromosomally abnormal.³⁶ In terms of developing pregnancies, most studies to date indicate that fears of significant abnormality in the resulting child are generally unfounded,³⁷ although one study has suggested that there is risk ‘in the order of 30-40 *per cent* of some birth defect in ART babies’.³⁸ Personal experience has confirmed that these risks are not always mentioned to would-be parents, but it is submitted that these statistics are unlikely to prevent would-be parents using ART in order to pursue their dreams of having a family.

Fausto-Sterling had previously suggested that increased use of IVF may lead to the birth of more intersex people,³⁹ but this does not appear to be the case. A brief summary of information received from clinics that took part in the survey conducted for this thesis ⁴⁰suggests that the IVF process does not, in itself, increase the rate of intersex/DSD births. When asked if they had been aware of any child born with an intersex condition, only 4 out of 19 clinics indicated that one child had been born with a DSD, with all but one of the children having TS.⁴¹ Further, one clinic noted statistically that the TS baby was one of 2000 cycles that the clinic had carried out.

³⁵ Bonnie Steinbock, *Life Before Birth The Moral and Legal Status of Embryos and Fetuses* (OUP 1992) 200.

³⁶ Although embryos with genetic abnormalities are unlikely to lead to a successful pregnancy. Indeed it is noted that 70% of such embryos will lead to a miscarriage should implantation occur. Advanced Fertility Center of Chicago ‘Preimplantation Genetic Screening’ <http://www.advancedfertility.com/pgs-ivf-genetic-testing.htm> accessed 24 May 2015.

³⁷ Although there is gradual evidence of slight risks increasing see Michael J Davies and others, ‘Reproductive Technologies and the Risk of Birth Defects’ (2012) 366 N Engl J Med 1803 May 10, 2012 DOI: 10.1056/NEJMoA1008095.

³⁸ Although the article does not differentiate specific types of ART used. Michèle Hansen and others, ‘Assisted Reproductive Technologies and the Risk of Birth Defects—a Systematic Review’ (2005) 20 (2) Hum Reprod 328, 335. More conservative estimates suggest that there is an increased chance of a child developing leukaemia and other conditions if ICSI is used as opposed to IVF alone. Davies (n 37) although the research also pointed that that if ICSI was used, freezing the embryos first reduced the risk to that of normal values.

³⁹ Anne Fausto-Sterling, *Sexing the Body* (Basic Books 2000) 54. She recalls a story where a child was born after an XX and XY embryo were merged to form a ‘chimera’. The child was predominantly male with an additional ovary.

⁴⁰ As discussed in chapter two.

⁴¹ The other child was not followed up by the clinic.

This is comparable with the average background birth rate of TS women, which has been estimated at one in 2000 live female births.⁴² It may well be the case, as ART advances, that there will be fewer intersex children born in the future.

So far there is no discrimination between the intersexed and non-intersexed embryo, as selection will be based on the grade of the embryo not its genome. ART appears to be ethically acceptable and supportive of the intersexed. However, on occasions, PGD will take place on a newly formed embryo to discover if it carries a specific inherited condition.⁴³ By testing *before* implantation, it is hoped to avoid a selective abortion at a later stage should the fetus prove to have a genetic malformation. Although this procedure does not take place routinely, it is important to analyse the law in this area, as PGD, currently allowed under English law, does directly discriminate against the intersexed.⁴⁴

6.5 Pre-implantation Genetic Diagnosis (PGD)

Embryos that are to undergo PGD will be formed using the ICSI procedures.⁴⁵ They will be allowed to grow until four to eight embryonic cells (blastomeres) are present. The first stage for testing is to remove one to two of these cells. This is achieved by

⁴² Estimates vary, but Gravholt and Stochholm note that 50 per 100,000 females are TS females. Claus Højbjerg Gravholt and Kirstine Stochholm, 'The Epidemiology of Turner Syndrome' (2006) 1298 International Congress Series 139, 140. This is confirmed by the NHS, 'Turner Syndrome' <http://www.nhs.uk/Conditions/Turners-syndrome/Pages/Introduction.aspx> accessed 24 May 2015. Further, research conducted on fetal free DNA maternal blood testing, which involved 6123 patients, 40 (0.7%) were detected as carrying a fetus with TS (45,X). This works out to a ratio of 1: 143, a significantly higher incidence. This can account for the potential for a spontaneous abortion to occur after the testing time (usually 8 weeks). Oxford Health Plans, LLC, 'Fetal Aneuploidy Testing Using Cell-Free Fetal Nucleic Acids in Maternal Blood' Clinical Policy (Effective 07/01/2015) https://www.oxhp.com/secure/policy/noninvasive_prenatal_diagnosis_fetal_aneuploidy_715.pdf, 9 accessed 24 July 2015, quoting statistics from T Futch and others, 'Initial Clinical Laboratory Experience in Non Invasive Prenatal Testing for Fetal Aneuploidy from Maternal Plasma DNA Samples' (2013) 33 (6) Prenat Diagn 569.

⁴³ PGD is also referred to by some clinics as Pre-implantation Genetic Screening (PGS), but throughout this thesis the term PGD will be used.

⁴⁴ Of those clinics who responded to the questionnaire, all noted that PGD was only carried out on 'rare occasions' and one clinic only offered single gene detection, as opposed to widespread screening.

⁴⁵ S Desmyttere and others, 'Neonatal follow-up of 995 consecutively born children after embryo biopsy for PGD' (2012) 27 (1) Hum Reprod 288.

making a small hole in the *zona pellucida* (the embryo's protective external 'coat') and using an acidic substance or laser to detach one cell from the rest. This process, in itself, could be considered unethical, as the harm to the embryo may outweigh the good. As this is a relatively new technique, there is a lack of long-term research on the potential detrimental effects of removing cells at an early stage. Studies have indicated that removal of two cells from the embryo will be unfavourable to the chances of pregnancy occurring,⁴⁶ but scientists have commented there is evidence to suggest that removal of a single cell is not harmful at this early stage.⁴⁷ In fact, frozen embryos are implanted even if they have lost up to 50 per cent of their cells during the thaw process.⁴⁸ However, this results in lower birth rates if PGD is used.⁴⁹ According to the Parliamentary Office of Science and Technology (POST), the success rate of cycles with PGD 'is similar' to IVF cycles without PGD performed.⁵⁰ POST also specify that PGD 'does not adversely affect the health of the newborn child',⁵¹ although it should be noted that the study referred to does not say this. Desmyttere et al. write that it appears that children born after PGD do not 'indicate that cleavage-stage biopsy procedure adds significant risks of major birth defects

⁴⁶ V Goossens and others, 'Diagnostic Efficiency, Embryonic Development and clinical outcome after the biopsy of one or two Blastomeres for Pre-implantation Genetic Diagnosis', (2008) 23 (3) Hum Reprod 481.

⁴⁷ I Liebaers and others, 'Report on a Consecutive Series of 581 children born after Blastomere Biopsy for Pre-implantation Genetic Diagnosis' (2010) 25 (1) Hum Reprod 275; Joe Leigh Simpson, 'Children born after Pre-implantation Genetic Diagnosis show no increase in Congenital Anomalies' (2010) 25 (1) Hum Reprod 6; Peter Braude, 'Pre-implantation Genetic Diagnosis: Safely born but not Designed.' In Sheila McLean and Sarah Elliston (eds) *Regulating Pre-Implantation Genetic Diagnosis, A Comparative and Theoretical Analysis*. (Routledge 2012) 7.

⁴⁸ Interview with embryologist 10 January 2014, Northampton. Therefore an embryo with seven cells could lose three cells during the thaw process and still be used for fertility treatment, albeit the chance of a successful pregnancy is likely to be impeded by such a loss.

⁴⁹ The birth weight appears to be lower in mice as well. Atsushi Sugawara, and others 'Blastomere Removal from Cleavage-Stage Mouse Embryos Alters Steroid Metabolism During Pregnancy' (2012) 87 (1) Biology of Reproduction 4.

⁵⁰ The Parliamentary Office of Science and Technology, 'Pre-implantation Genetic Diagnosis' Post Note Number 445 (September 2013) <http://www.parliament.uk/business/publications/research/briefing-papers/POST-PN-445/preimplantation-genetic-diagnosis> accessed 14 April 2015.

⁵¹ *ibid*.

compared with the ICSI procedure'.⁵² The underlying issue remains; namely, that the risk of major birth defects is 'presumably higher'⁵³ than pregnancies which occur without the use of ICSI. Further, and more poignantly, this study only concentrated on babies up to two months of age; there is no indication of the development of older children. This should be considered alongside long-term studies in mice which have indicated that there is an increased chance of weight gain and memory loss in adult mice.⁵⁴ Clearly there is a need for a long-term study to identify the health of PGD progenies some 20 years after their birth. It appears that parents are not given accurate information about potential risks associated with PGD.⁵⁵ This will leave a void in the informed consent procedure. Whilst noting that it is unlikely that such cases will come to court, technically these procedures may be considered 'unlawful' should such a test case be heard.

The above considerations of PGD are general ones in that they apply equally to those with an intersex/DSD gene or not. However, the testing 'elicits special concerns' for those who have genetic conditions,⁵⁶ and has stimulated arguments from international disability rights movements who perceive PGD to be the equivalent of 'eugenics'. Such opponents see this as an opportunity for a 'search and destroy mission' against those who do not meet the required societal standard.⁵⁷ The converse argument can be found. For example, Cook views parental choosing of PGD as 'ethically pursuing

⁵² S Desmyttere and others, 'Neonatal follow-up of 995 Consecutively born Children after Embryo Biopsy for PGD' (2012) 27 (1) Human Reproduction, 288, 291.

⁵³ *ibid*, 292.

⁵⁴ Yu Y and others, 'Evaluation of Blastomere Biopsy Using a Mouse Model Indicates the Potential High Risk of Neurodegenerative Disorders in the Offspring' (2009) 8 Molecular & Cellular Proteomics 1490; doi: 10.1074/mcp.M800273-MCP200.

⁵⁵ Michelle Lynne LaBonte, 'An analysis of US fertility centre educational materials suggests that informed consent for pre-implantation genetic diagnosis may be inadequate' (2012) 38 (8) J Med Ethics 479.

⁵⁶ SE Gollust and others, as quoted by Sheila AM McLean and Laura Williamson, *Impairment and Disability: Law and Ethics at the Beginning and End of life* (Routledge-Cavendish 2007) 80.

⁵⁷ Disability Awareness in Action, 'Disabled People and New Genetics' [1997] London, as quoted by Shakespeare (n2) 114.

the principle of non-maleficence’ on behalf of the child,⁵⁸ whilst Botkin argues that a huge burden is placed on the families of those with disabilities and therefore ‘would support prenatal testing, as ethically pursuing non-maleficence on behalf of the family’.⁵⁹ PGD is likely to remain a contentious area for the foreseeable future, particularly for those with intersex conditions. It is unsurprising therefore that comprehensive legal parameters are in place.

6.5.1 PGD, Legal Provisions and the Extent of Discrimination

Embryo testing is currently regulated by Schedule 2, Section 1ZA of the HFE Act 1990 (as amended), which states that:

(1) A licence ... cannot authorise the testing of an embryo, except for one or more of the following purposes—

(a) establishing whether the embryo has a gene, chromosome or mitochondrial abnormality that may affect its capacity to result in a live birth,

(b) in a case where there is a particular risk that the embryo may have any gene, chromosome or mitochondrion abnormality, establishing whether it has that abnormality or any other gene, chromosome or mitochondrion abnormality,

(c) in a case where there is a particular risk that any resulting child will have or develop—

(i) a gender-related serious physical or mental disability,

(ii) a gender-related serious illness, or

(iii) any other gender-related serious medical condition, establishing the sex of the embryo,

(...) ⁶⁰

⁵⁸ Rebecca J Cook, Bernard M Dickens and Mahmoud F Fathalla, *Reproductive Health and Human Rights* (OUP 2003) 357.

⁵⁹ Jeffrey Botkin, ‘Fetal Privacy and Confidentiality’, (1995) 25 (5) *Hastings Centre Report* 32, 36, as quoted by Peter Chipman, ‘The Moral Implication of Prenatal Genetic Testing’ [2006] *Penn Bioethics Journal*, Vol II issue ii http://www.bioethicsjournal.com/pdf/pbj2.2_chipman.pdf last accessed 17 January 2014, 13.

⁶⁰ This section also regulates PGD for the creation of ‘saviour siblings’ and testing for parenthood.

Types of PGD include a specific diagnosis for chromosomal abnormalities, including aneuploidy and sexing for conditions carried on the X chromosomes.⁶¹ Due to the sensitive subject of ‘son preference’,⁶² displayed in some communities within the UK, PGD may be considered more controversial when the embryo is sex selected to prevent the birth of a child with a sex-related hereditary condition.⁶³ Currently, in the UK it is unlawful to use PGD for sex selection alone.⁶⁴ Therefore, those in the UK who wish to protect the ‘female’ embryo need have no current concerns in this respect, whilst those who wish to protect the ‘intersexed’ embryo do have cause for concern. Here there *is* a discrepancy in English law. Whilst current law prevents sex selection of embryos per se, in the same breath section 3 (ii) allows for sex selection, or rather, de-selection of the DSD future child. Further, the HFEA have licensed testing for over two hundred separate genetic conditions, which currently include a number of intersex conditions; namely 5-alpha-reductase deficiency ‘insofar as that condition affects males, with simultaneous sex determination’,⁶⁵ Androgen Insensitivity Syndrome (AIS) and CAH (21-OH deficiency).

It is clear from the above discussion that current law, far from preventing discrimination against those with intersex/DSD conditions, positively enforces it. The current legal framework allows the HFEA to authorise the licensing which permits

⁶¹ PGD can identify mono-genetic disorders which are carried specifically on one chromosome. There are a variety of potential disorders that can be tested for – Cystic fibrosis, Huntingdon’s Disease, sicklecell disease, haemophilia AS, and fragile X syndrome. The beginnings of PGD can be traced back to the 1960s, when scientists first sex selected rabbit embryos. Richard Gardner and Robert Edwards ‘Control of the Sex Ratio at full term in the Rabbit by Transferring Sexed Blastocysts’, (1968) 218 (5139) *Nature* 346. However, it was not until fluorescence *in situ* hybridization (FISH) and the development of the procedure of sensitisation of DNA using polymerase chain reaction (PCR), that the ‘breadth and potential scale of the tests that could be offered became apparent as a clinical reality’. Peter Braude, (n 47) 5.

⁶² Cook (n 58) 363.

⁶³ For example, haemophilia, which is carried on the X chromosome. Whilst sex selection of embryos is a worthy ethical consideration, of yet more ethical concern is the legality of the creation of so-called ‘saviour siblings’. This latter concern in particular is a fascinating interface between ethics and law, but beyond the scope of this thesis.

⁶⁴ Schedule 2 s1ZA HFEA 1990 as amended. In other countries, notably the US, PGD for sex selection alone is lawful.

⁶⁵ HFEA website ‘PGD conditions licensed by the HFEA’, <http://www.hfea.gov.uk/cps/hfea/gen/pgd-screening.htm> accessed 19 January 2014.

clinics to test for specific genetic conditions. Further, even if an embryo is not directly destroyed, if it is discovered to contain a chromosome, gene or genetic sequence indicating the intersex/DSD condition, it is highly unlikely that the embryo will be implanted.

In the survey, clinics were asked ‘If, as a result of PGD, your clinic discovered that an embryo had chromosomal abnormalities (such as in Turner Syndrome) would your clinic ever consider implanting the embryo?’ Although one clinic confirmed ‘yes’, the majority of clinics noted that such an embryo would not be replaced.⁶⁶ This response is unsurprising for three reasons.

Firstly, embryos with chromosomal abnormalities carry the statistically higher risk of incidence of miscarriage.⁶⁷ Clinics choose embryos with the best chance of pregnancy, so embryos with chromosomal abnormalities would only be used if there were no other embryos available.⁶⁸ *Prima facie* this approach appears to have a beneficial rationale behind the procedure and therefore any discrimination would be outweighed by the principles of beneficence and non-maleficence. It would be unethical to select embryos likely to result in miscarriage, and bring sorrow to the expectant parents, should other embryos more likely to lead to a successful pregnancy be available.

Secondly, the HFE Act 1990 specifies acting with the ‘welfare of the child’ in mind. It is unlikely, therefore, that clinics would deliberately select an embryo with an intersex/DSD condition above a non-intersex embryo. It should be noted that this is not the same globally. According to Elliston,⁶⁹ a survey of American clinics offering

⁶⁶ A total of 4 clinics who responded to the questionnaire carried out PGD. Of those 4, 3 gave an emphatic no that they would not replace such an embryo.

⁶⁷ 70% of such embryos will lead to a miscarriage should implantation occur. <http://www.advancedfertility.com/pgs-ivf-genetic-testing.htm> accessed 24 September 2015.

⁶⁸ Those of a cynical disposition would intimate that this is because clinics do not want their success rates to be lowered. To some extent this would be true as some clinics have their own lower age limit for treatment, to ensure a higher success rate.

⁶⁹ Sarah Elliston, ‘The Welfare of the child principle and the use of PGD: selecting for disability’ Sheila McLean and Sarah Elliston (eds) *Regulating Pre-Implantation Genetic Diagnosis, A Comparative and Theoretical Analysis*. (Routledge 2012) 95.

PGD found a three per cent incidence in intentional use of PGD to screen *for* a disability, with parents-to-be requesting screening to identify specific disabilities, the aim being to select embryos showing these characteristics. A good illustration of such practice (albeit not an intersex case) can be identified from the somewhat infamously branded episode of the ‘deaf lesbians’,⁷⁰ Sharon Duchesneau and Candy McCullough, who wanted to have a deaf child.⁷¹ This story sparked numerous academic articles on whether parents should be allowed to choose a disability *for* their children,⁷² but the question as to what was in the ‘best interests’ of the child was not straightforward to answer.⁷³ Unlike deafness, which is comparatively understood and accepted, none of my correspondents would actively seek to have an intersex child. Albeit in some societies the intersexed may have their own cultural environment,⁷⁴ this is not the case in the UK. In this society of perfection, there are likely to be a significant number of people who believe that the ‘best interests’ of the child demand the birth of a child that is capable of being allocated to one of the two designated binary sexes, and have difficulties in accepting anything other than ‘the norm’.

⁷⁰ Julian Savulescu, ‘Deaf Lesbians, “Designer Disability,” and the Future of Medicine’ (2002) 325 BMJ 771.

⁷¹ Duchesneau and McCullough, a lesbian couple in the United States, both suffered from congenital deafness and actively chose to find a deaf sperm donor, to increase their chance of having a deaf child. They believed that if their future child were to be born deaf, then he or she would have a better life experience, as they would be able to participate more fully in their culture. The couple were turned down by a number of sperm banks who did not support their rationale. Eventually they approached a family friend who was totally deaf. This arrangement resulted in the birth of Gauvin McCullough, who was born with a slight amount of hearing in one ear.

⁷² In this particular case, the focus was not so much on choosing to have a deaf child, but rather refusing to let that child receive a cochlear implant for fear of ‘cultural genocide’. Neil Levy, ‘Reconsidering Cochlear Implants: The Lessons of Martha’s Vineyard.’ (2002) 16 (2) Bioethics 134; Savulescu, (n 70); R Press ‘People with Partial Hearing need to seek hearing Potential.’ Letters BMJ 2002; 325 1423; Rachel Nowak, ‘Ear implant success sparks culture war.’ New Scientist 23 November 2006

⁷³ Members of the signing-deaf community often view themselves not as being disabled, but rather as belonging to a distinct culture. Stephen Rooney, spokesman for the British Deaf Association, said that ‘(t)he real issue is not whether people are trying to design deaf babies, but how society currently denies deaf children to enjoy the same rights, responsibilities, opportunities and quality of life as everyone’. BBC online news ‘Couple “choose” to have deaf baby’ Monday, 8 April 2002 news.bbc.co.uk/2/hi/health/1916462.stm accessed 17 January 2015.

⁷⁴ As discussed in chapter 3 there are some communities which support boys with 5-alpha-reductase, recognising their condition and their pattern of physical development.

The last and most potent reason why a clinic would be unlikely to transfer an intersex embryo can be found in the amendment of the HFE Act 1990.

Section 14 of the HFEA 2008 amends the previous licensing conditions for treatment so that s 13 (9) of the HFEA 1990 reads:

(9) Persons or embryos that are known to have a gene, chromosome or mitochondrion abnormality involving a significant risk that a person with the abnormality will have or develop—

(a) a serious physical or mental disability,

(b) a serious illness, or

(c) any other serious medical condition, *must not be preferred to those that are not known to have such an abnormality.*⁷⁵

Embryos identified as intersex/DSD may be considered to have a ‘significant risk’ of a ‘serious medical condition’ and therefore they ‘must not be preferred’ to any non-intersex/DSD embryo. This ‘uniquely restrictive step’⁷⁶ seems a rather harsh approach to take. Legislation appears even more tyrannical for the intersex/DSD embryo when considering s13 ss(10) and (11) of the HFEA 1990. These read:

(10) Embryos that are known to be of a particular sex and to carry a particular risk, compared with embryos of that sex in general, that any resulting child will have or develop—

(a) a gender-related serious physical or mental disability,

(b) a gender-related serious illness, or

(c) any other gender-related serious medical condition,

must not be preferred to those that are not known to carry such a risk.

(11) For the purposes of subsection (10), a physical or mental disability, illness or other medical condition is gender-related if—

(a) it affects only one sex, or

(b) it affects one sex significantly more than the other.

An intersexed embryo cannot compete as it will not fit into the ‘one sex’ category. The ‘particular risk’ of being a ‘particular sex’ in (10) is crystal clear, in that these embryos cannot be ‘a particular sex’ but bear a fluid sex quality.

⁷⁵ My italics.

⁷⁶ Elliston, (n 69) 89.

Since amendments to the HFEA 1990 have been in force, should a clinic go against the legal requirements of s13 and implant an intersex/DSD embryo *in favour* of a non-intersexed embryo, that clinic may lose its licence.⁷⁷ Consequently, it can be stated that current English law directly discriminates against the intersexed in this respect.

At this point, it is important to consider English law in the international arena. Reference to the European Court of Human Rights (ECtHR) would suggest that English law is not out of synchronicity in regard to PGD. In the ruling of *Costa and Pavan v Italy*,⁷⁸ a couple who were both carriers of cystic fibrosis challenged Italy's ban on PGD. Here the Court found that fertility treatment fell under the umbrella of Article 8 of the European Convention on Human Rights (ECHR),⁷⁹ and in *not* allowing PGD, the Court found Italy's behaviour to be disproportionate and ordered the Italian Government to pay 17,500 euros in damages and expenses to the couple.⁸⁰

In summary, PGD clearly discriminates against the intersexed as it stigmatises such conditions as undesirable and to be avoided. This does not mean that the provisions are unethical. It would be hard to justify the creation of a child with a lifelong medical condition, such as CAH, when another embryo without that condition is available. In this respect, PGD evokes support of beneficence – identifying an

⁷⁷ s13 offences are not criminal as such, by virtue of s25 (6) HFEA 1990 as amended, but clinics would be loath to do anything to risk losing their licences.

⁷⁸ *Costa and Pavan v Italy* (Application no. 54270/10).

⁷⁹ Article 8 – Right to respect for private and family life.

⁸⁰ The couple gave birth to a daughter in 2006, and it was only when their daughter was diagnosed with cystic fibrosis that they realised they were carriers for the condition. To avoid giving birth to a second child with this condition, the couple requested the use of IVF and PGD. However, under Italian law, law N° 40 of February 19, 2004, only those who were subfertile could use IVF, and PGD was not lawful at all. The range of people allowed to use IVF was extended in 2008 to men who were affected by transmissible viral diseases such as hepatitis or HIV, but was not extended to screening for such conditions as that of the couple. The applicants complained that not being able to access the PGD to select an embryo unaffected by their condition constituted a violation of Articles 8 and 14 of the Convention. In the Court of Human Rights, the main supporting argument for the couple was the inconsistency of the legal approach in Italy. Italian law forbade screening for cystic fibrosis, but should such a child be discovered *in utero*, than Italian law would grant permission for an abortion to take place. Consequently, the Court concluded that there was interference with the applicants' right to respect for their private and family life.

embryo that will lead to a ‘healthy’ baby. However, the main ethical argument in its favour is non-maleficence. Ruling out certain embryos at an early stage spares the expectant parents the difficulty of either suffering a miscarriage or actively ending an established pregnancy should the condition be discovered during routine antenatal testing. A significant ethical dilemma remains as to whether PGD should be allowed for *any* embryos, as the technique has not had time to yield conclusive evidence as to the safety of this procedure.⁸¹ However, this is unlikely to prevent the use of this technique for the foreseeable future.

Whether ethically acceptable or not, it is submitted that it is unlikely that a law would now be passed to prevent PGD in England and Wales. Nor is it likely to be amended. The current English law position appears to resonate with the opinion of the ECtHR, the *Costa and Pavan* ruling indicating that the ECtHR is in favour of preventing the arrival of children with disabilities.

Regardless of this, with an ever-increasing range of conditions that the HFEA are prepared to licence, there needs to be a full audit of the aims and objectives of current PGD testing to ensure that only conditions with *significant* health conditions are discovered, as opposed to identifying and terminating any embryo which might indicate the presence of minor physical difficulties.⁸²

6.6 Antenatal Testing and Abortion

In the first part of this chapter, we considered how the intersexed embryo is discriminated against before implantation. In this second part of this chapter, attention is turned to the vulnerability of the intersexed fetus once pregnancy is established.

⁸¹ It is submitted that the most controversial aspect of PGD is the formation of ‘saviour siblings’, which is outside the parameters of this thesis.

⁸² For example, current legislation would allow the prevention of a boy with red-green colour blindness. Is this really a condition that needs to be eradicated? Likewise AIS does not need the same medical intervention as would a child suffering from a severe form of CAH.

It has often been stated that the Abortion Act 1967 (the Act), the current abortion legislation in England, is discriminatory.⁸³ Whereas the legal limit for abortion is 24 weeks for a 'healthy' fetus, as specified by section 1 (1) (a) of the Act, section 1 (1) (d) allows for any fetus presenting with signs of 'disabilities' to be aborted up to the point of birth, thus raising arguments that antenatal testing is unethical and prejudices the 'disabled child'.⁸⁴ The remainder of this chapter aims to investigate the nature and scope of antenatal testing and the Abortion Act, and to consider whether antenatal testing and current abortion legislation is discriminatory in regard to the intersexed fetus. Treatment of the intersexed *in utero* will also be considered.

6.7 Antenatal Testing

In recent years medical technology has advanced dramatically, giving mothers-to-be an opportunity to discover not only if the pregnancy is viable at an early stage,⁸⁵ but also if there are any severe disabilities indicated. The UK National Screening Committee promotes screening as a pathway, emphasising that it is not a single test,⁸⁶ but rather consists of types of testing,⁸⁷ which are differentiated into two categories, invasive or non-invasive.

As there has yet to be a standardised national system of testing, specific tests offered will depend on the locality of the parents rather than the actual need for such testing. Additionally, not all tests give accurate results, and many congenital disabilities are

⁸³ Sally Sheldon and Stephen Wilkinson, 'Termination of pregnancy for foetal disability: are there grounds for a special exception in law?' (2001) 9, *Med Law Rev* 85.

⁸⁴ A Asch 'Prenatal Diagnosis and Selective Abortion: A challenge to Practice and Policy' (1999) 89 (11) *American Journal of Public Health* 1649, as reported by Belinda Bennett 'Choosing A child's Future? Reproductive Decision-Making And Preimplantation Genetic Diagnosis' in Jennifer Gunning and Helen Szoke (eds) *The Regulation of Assisted Technology* (Ashgate Publishing 2003) 167.

⁸⁵ An ultrasound scan, usually given between 8 and 12 weeks of pregnancy, can detect the number of fetuses present and whether they have heartbeats.

⁸⁶ UK NSC Antenatal & Newborn Screening eLearning Module.

⁸⁷ The aim of each test is that it has 100% sensitivity in identifying all fetuses at risk of the specific condition and 100% specificity, in other words, ensuring that there are no false-positive readings. A false-positive reading occurs when a healthy fetus has been incorrectly identified as at risk. The reverse situation is known as a false-negative reading. As yet this level of specificity has not been met.

not discovered before birth.⁸⁸ Testing requires physicians and parents to balance a number of ethical principles.⁸⁹

6.7.1 Invasive Testing

Currently two tests are relied upon nationally to ascertain fetal disabilities, amniocentesis and chorionic villus sampling (CVS). In the search for genetic abnormalities, amniocentesis is perhaps the most useful test currently available.⁹⁰ Certain intersex conditions will be detected in this fashion, for example TS and KS or some type of mosaicism indicating TS or mixed gonadal dysgenesis. Should any of these conditions be identified, it is likely that a termination will be offered.⁹¹

This test is not administered routinely, but is normally offered to ‘older’ mothers-to-be, based on scientific data which has proved that certain disabilities such as spina bifida or Down’s syndrome are more likely to occur in women over the age of 35.⁹² In terms of intersex/DSD conditions, KS appears to be more likely with an older mother, but TS does not appear to be age specific. Likewise, unless the mother is aware of a specific hereditary intersex condition, such as AIS or CAH, it is unlikely that a young mother will be tested. Therefore many intersex/DSD children remain undetected at this stage.⁹³

⁸⁸ This can be evidenced by case law in the UK and abroad, although even where abnormalities have not been identified, it is quite difficult for a claimant to succeed in negligence. See *B v South Tyneside Health Care NHS Trust* [2004] EWHC 1169 (QB), and *Brindley v Queen’s Medical Centre University Hospital NHS Trust* [2005] EWHC 2647 (QB)

⁸⁹ Namely, parental autonomy, non-maleficence in regard to embryonic structures of any fetus, and non-maleficence regarding medical treatment of developing fetuses.

⁹⁰ During this procedure, a needle is pushed into the mother’s uterus, and amniotic fluid is extracted from the fetal sac. The fluid contains the same chromosomal arrangements as the fetus growing inside it and therefore testing of this fluid will give an accurate prediction of the sex of the child, and an indication of genetic anomalies.

⁹¹ South West Congenital Anomalies Register <http://www.swcar.org.uk/data-open/outcome-region-public.html> accessed 25 May 2015. This will be discussed in more detail later in this chapter.

⁹² Albeit such disabilities can occur to children of women in their twenties.

⁹³ This will not indicate if a child has AIS, so the parent’s would expect a boy, and unless an ultrasound scan is also carried out, the parents will not be prepared for the ‘girl that arrives!’

As amniocentesis has a one to two per cent chance of procuring a miscarriage and some mothers will refuse the test even if they are considered to have a 'high-risk' pregnancy.⁹⁴ An additional disadvantage is the lengthy delay in receiving results. The test is usually carried out at around 16-18 weeks' gestation, but it is not unusual for the results to arrive a month later, leaving the expectant mother to undergo a later abortion,⁹⁵ if this is deemed necessary.⁹⁶ For this reason many mothers elect to undergo CVS testing instead,⁹⁷ as this test can be performed at around 12 weeks' gestation.

One of the disadvantages with CVS is that, as with amniocentesis, it has up to a two per cent chance of miscarriage occurring after the test.⁹⁸ More significantly, the test results are advertised as nearly 100 per cent accurate. Nevertheless sometimes there can be a flawed result.⁹⁹ It is not unknown for a 'mosaicism' of sex chromosomes to

⁹⁴ In *Vo v France* ECtHR (application number 53924/00), owing to a mix-up with a patient sharing the same surname, Vo had to undergo a therapeutic abortion after her amniotic sack was punctured during the procedure. She claimed this action equated to manslaughter, but the Court found no violation of Article 2 ECHR.

⁹⁵ This is due to the change in technique of abortion around 22 weeks, when it is considered to be better for the fetus to be induced after the heart has been stopped. Therefore, the fetus is injected with potassium chloride to stop the heart, and afterwards the labour is induced.

⁹⁶ In future years, this might cause a conflict with English abortion laws, although as will be discussed later, the upper abortion time limit can be circumvented by applying Ground E, but the technique used to perform the procedure will be different at this later stage. Such was the case in *RR v Poland*, ECtHR (application number 27617/04), final judgment 28/11/2011, where a pregnant mother of two carrying a child with suspected disabilities was denied access to tests by her doctor who was an anti-abortionist. By the time the amniocentesis results were established, it was too late for Ms R to ask for an abortion, as by the time the condition was firmly diagnosed, Ms R was already 23 weeks pregnant and the fetus was considered viable. Consequently, Ms R gave birth to a daughter with Turner Syndrome, and she was profoundly disabled. It led to considerable difficulties, including the breakup of her marriage. (At the time of the case, abortions were severely limited in Poland. Under communism, in the region of 150,000 abortions per year were preformed, but after the breakup of the Soviet bloc, the Catholic church in Poland influenced healthcare, leading to a 1993 law which dramatically reduced abortions to approximately 150 per year by 2002. In 2011, there was a vote on a total ban on abortion. This was defeated). In this case, the Court found by a majority that there had been a violation of Article 3 ECHR as she had been 'shabbily treated' and in addition Article 8, as the applicant was not given any mechanisms for testing and treatment.

⁹⁷ During CVS, some chorionic villi, which are the finger-like projections of the placenta, are removed. The chorionic villi have the same chromosomes and genetic make-up as the fetus.

⁹⁸ Another drawback is the potential cost. Some private clinics charge in the region of £650 for the test.

⁹⁹ In 2006, the Ohio Supreme Court ruled that parents could sue on the basis of medical malpractice if genetic counselling or diagnosis is deemed to have been negligent – although this would only allow for damages for the pregnancy and birth itself. The case arose from a CVS test which did not detect

show up in the results, indicating the presence of an intersex condition, which is not identified in the genetic make-up of the baby him/herself.¹⁰⁰ Should mosaicism appear in the results then it is recommended that the mother has an amniocentesis. Normally this will give an accurate diagnosis. If the mosaicism is still present at this stage, an intersex condition should be considered as a possibility.

Boss points out ¹⁰¹ that far from being a benefit to have earlier test results delivered, CVS is ethically less acceptable than later testing, because receiving unfavourable test results at an earlier stage in pregnancy may lead to more abortions in the long run, the argument being that parents have fewer qualms about undergoing a termination at an earlier stage in the pregnancy than later.¹⁰²

6.7.2 Non-Invasive Testing – Ultrasound Scans

Ultrasound scans use sound waves to produce images of the internal physical structures. Images are produced when sound waves are directed at a target, and then reflected back to a scanner which measures them. Targets are elected using different frequencies. Along with checking measurements, gestational age and the general progression of pregnancy, ultrasound scans are used to detect structural defects such as spina bifida¹⁰³ and anencephaly.¹⁰⁴ They can also detect congenital heart defects, gastrointestinal and kidney malformations and cleft palate.¹⁰⁵ These days, NHS trusts

trisomy 22. Dr Philippa Brice, 'Parents sue over incorrect prenatal genetic test results.' 24 April 2006 <http://www.phgfoundation.org/news/2476/> accessed 25 May 2015.

¹⁰⁰ Mosaicism occurs when some cells have chromosomal abnormality whilst others are normal, and certain intersex individuals present a 'mosaicism' in their genetic make-up.

¹⁰¹ JA Boss, 'First trimester prenatal diagnosis: earlier is not necessarily better.' (1994) 20 J Med Ethics 146.

¹⁰² The same argument will occur if the 'new' fetal DNA blood testing becomes a standard test for pregnant mothers, section 6.8.3.

¹⁰³ A congenital disorder affecting in the region of one per thousand births; it occurs when the embryo's neural tube (precursor to the central nervous system) does not develop as expected. A common error leads to incomplete vertebrae which do not fully enclose the spinal cord.

¹⁰⁴ Another neural tube defect, this leads to partial or complete absence of the cerebral hemispheres.

offer an early ultrasound scan, which takes place at about 12 weeks' gestation. This scan is usually limited to counting the number of fetuses present and ensuring that the heartbeat(s) can be detected. Other Trusts will offer a Fetal Nuchal Translucency (NT) scan. The NT scan is particularly useful for detecting whether the fetus has trisomy 21.¹⁰⁶ NT scans have limited use in identifying the majority of intersex conditions, as the test has to be carried out before 14 weeks of pregnancy in order to detect trisomy 21, and only *after* this stage can sex be detected with certainty via an ultrasound scan.¹⁰⁷

Most ultrasound scans provided by the NHS do not occur until 18-20 weeks' gestation. The lateness of the routine scan has been described as 'an active, perverse, unlegislated barrier to late-term abortions',¹⁰⁸ since after this point NHS services become 'foot-draggingly obstructive' in dealing with a request for termination.¹⁰⁹ This is not necessarily the case, as not all anomalies present themselves until considerably later in the pregnancy, and some may remain undiagnosed.¹¹⁰ Whereas it may be possible to detect intersex conditions which manifest in 'genital abnormalities' *in utero*, not all conditions will be identified at this stage. Unless the scan is complemented with chromosomal testing, conditions such as Complete Androgen Insensitivity Syndrome will not be discovered.

¹⁰⁵ It was this defect that spurred Rev. Jepson into action. However, despite what the crusading Jepson might have us believe, very few pregnancies are ended for this reason. According to Dr Lee, of the 600 notifications of incidences of cleft palate in 2001, only 2 were aborted. Ellie Lee 'The abortion debate today' in Horsey and Biggs (eds) *Human Fertilization and Embryology: Reproducing Regulation* (Routledge-Cavendish 2006) 235.

¹⁰⁶ This is a genetic anomaly with three chromosomes (21) usually known as Down (or Down's) syndrome. There is 80% accuracy with this test which increases to 95% if blood tests are performed at the same time. It works by measuring the thickness of the fetus's neck. A measurement of below 2.5mm indicates that the baby does not have any genetic abnormalities, whereas a number over 3mm indicates that a child has chromosomal abnormalities, a heart condition, or both.

¹⁰⁷ A further sexing scan can be undertaken, but this would not be provided free of charge to parents. The current fee is in the region of £200 per scan.

¹⁰⁸ Zoe Williams, 'Time to Speak up' *The Guardian* (London 27 October 2006).

¹⁰⁹ *ibid.*

¹¹⁰ *FP v Taunton and Somerset NHS Trust*, [2009] EWHC 1965 (QB). In this case damages of £1.2 million were awarded for the wrongful birth of 'RP' after scanning failed to diagnose a severely disabled child.

Unsurprisingly ultrasound scans lead to ethical tensions, which involve philosophical debates concerning termination of pregnancies. The more sophisticated three-dimensional (3D) equipment, generating 4D scans,¹¹¹ appears to demonstrate an ‘all-singing, all-dancing, smiling fetus’, and it has been argued that such scans have been used to evoke emotional responses to support anti-abortionists, rather than fulfil their role as methods of detection.¹¹² This is a debate which can be applied to all antenatal testing, and will be discussed later in this chapter. Of more immediate ethical concern is the consideration of the *safety* of ultrasound scans.

Recent research suggests that ‘dancing’ fetuses might behave in such a fashion due to extreme noise, ‘as loud as a subway train coming into a station,’ that they experience during the ultrasound procedure.¹¹³ In fact, although ultrasound is a routine antenatal procedure, it appears that there are increasing concerns regarding its safety.¹¹⁴ It has been linked to the rise in left-handedness in male fetuses,¹¹⁵ and more significantly to a rise in the incidence of autism.¹¹⁶

The American Institute of Ultrasound in Medicine have been reported as saying,

(t)here exists abundant peer-reviewed published scientific research that clearly and convincingly documents that ultrasound at commercial diagnostic levels can produce lung damage and fetal hemorrhage in a variety of mammalian

¹¹¹ Scans taken over time to create a ‘movie’.

¹¹² Jonathon Gornall, ‘Where do we draw the line?’ (2007) 334 BMJ 285, 285; Ellie Lee (n105) 238.

¹¹³ Eugenie Samuel, ‘Fetuses can hear Ultrasound Examinations.’ *New Scientist* (4 December 2001) <www.newscientist.com/article/dn1639-fetuses-can-hear-ultrasound-examinations-.html> accessed 1 May 2015.

¹¹⁴ BBC news online ‘Safety of souvenir ultrasound baby scans in question’ <news.bbc.co.uk/2/hi/health/8493796.stm> accessed 4 January 2015.

¹¹⁵ KA Salvensen and others ‘Routine Ultrasonography in Utero and subsequent handedness and neurological development’ (1993) 307 (6897) BMJ 159.

¹¹⁶ Caroline Rodgers ‘Questions about Prenatal Ultrasound and the Alarming Increase in Autism’ <<http://www.midwiferytoday.com/magazine/issue80.asp> accessed> 23 March 2014. Jennifer Margulis, interview with Dr Manuel Casanova <http://www.jennifermargulis.net/blog/2013/04/ultrasound-exposure-and-autism-dr-manuel-f-casanova-m-d-cautions-against-the-overuse-of-ultrasounds/> accessed 4 January 2015.

species (...). The degree to which this is a clinically significant problem in humans is not known.¹¹⁷

Further, statistics indicate that the greater the exposure to ultrasound, the greater the potential impact on the fetus.¹¹⁸

No one I have spoken to on this issue has ever been warned about potential side effects of fetal diagnostic ultrasonography. As Kresser points out,¹¹⁹ in the UK, along with the US and Australia, there is no compulsory training for obstetricians in ultrasound techniques. This might account for why some healthcare practitioners appear to be oblivious to the dangers. The UK Health Protection Agency (now Public Health England) note that available data is 'sparse',¹²⁰ but that 'no ill effects have been reported' after routine ultrasound scans.¹²¹ However, they also state that 'subtle effects have been reported in studies of brain development in small animals, and some studies in humans indicate changes in neurological functions following *in utero* exposures'.¹²² This leads to the conclusion that the 'possibility of subtle long-term effects cannot be ruled out'.¹²³ Research into scanning is currently being carried out. This is an area where the law may consider it has a role to play in the future.¹²⁴

¹¹⁷ As reported by Chris Kresser, 'Natural childbirth IIb: ultrasound not as safe as commonly thought' <http://chriskresser.com/natural-childbirth-iib-ultrasound-not-as-safe-as-commonly-thought> accessed 31 March 2015.

¹¹⁸ 'In a trial in Helsinki, 9000 pregnant women were divided into two groups. One group was scanned at 16-20 weeks, the other group was not scanned at all. There were 20 reported miscarriages in the scanned group and none in the controls. Saari-Kemppainen and others, 'Ultrasound Screening and Perinatal Mortality: Controlled Trial of Systematic one-stage Screening in Pregnancy' (1990) 336 (8712) *The Lancet* 387, as reported by Beverly Beech 'Who says ultrasound is safe?' (2004/5) 16 (4) *AIMS Journal* <http://www.aims.org.uk/Journal/Vol16No4/ultrasound.htm#4> accessed 21st May 2014.

¹¹⁹ *ibid.*

¹²⁰ HPA (Health Protection Agency, now Public Health England), 'Health Effects of Exposure to Ultrasound and Infrasound', (February 2010) https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/335014/RCE-14_for_web_with_security.pdf accessed 24 June 2015.

¹²¹ HPA, 'Ultrasound: what it is, how it works and Impact of Exposure' (1 February 2012) <https://www.gov.uk/government/publications/ultrasound-what-it-is-how-it-works-and-the-impact-of-exposure/ultrasound-what-it-is-how-it-works-and-impact-of-exposure> accessed 24 June 2015.

¹²² *ibid.*

¹²³ *ibid.*

Regarding the intersexed, it is clear that there is the potential for ultrasound to have a negative impact on the lives of fetuses with genital difference. Once again it is the policy behind the scanning rather than the scanning itself which creates the conflict. It is well known that a number of terminations have occurred because the ‘wrong sex’ was indicated on an ultrasound scan. This was not anti-intersexed, but anti-female;¹²⁵ however, it is understandable that the intersexed may feel discriminated against by scans.

6.7.3 Non-Invasive Prenatal Diagnosis using Cell-free Fetal DNA (cffDNA)

In 1969, fetal cells were discovered to circulate within the maternal blood.¹²⁶ If male fetal cells are present, they can be detected by analysis. This technique in itself is not a reliable form of testing, as fetal cells can remain in maternal tissue for a number of years after pregnancy, but the process helped lead to the discovery of cffDNA in maternal blood.¹²⁷ If located, cffDNA can be tested for a number of conditions, including various DSD conditions such as 45X, 47XXY, 47XXX and 47XYY karyotypes.¹²⁸ Although not 100 per cent foolproof as a means of testing,¹²⁹ cffDNA is ‘unique’ to each pregnancy, and researchers can now reliably sequence the entire

¹²⁴ This is an interesting development but beyond the scope of this thesis, as the use of ultrasound has not been, and is unlikely to be, linked to the incidence of intersex conditions.

¹²⁵ This is noticeable in other countries. Sujatha writes, ‘(U)ltrasound was intended to be a diagnostic tool, but it has facilitated female feticide in urban India.’ V Sujatha, *Sociology of Health and Medicine New Perspectives* (OUP 2014) 33. There is some confusion in English law in this respect. The general belief is that it is illegal to allow a termination on grounds of sex alone, but there is no explicit statement in English law which prevents such abortions occurring. This is discussed later in the chapter.

¹²⁶ J Walknowska, F A Conte and MM Grumbach ‘Practical and theoretical implications of fetal-maternal lymphocyte transfer’ (1969) 1(7606) *The Lancet* 1119, as discussed in Zhiyong Xu and others, ‘Non-Invasive Prenatal Diagnosis: A Comparison of Cell Free Fetal DNA (cffDNA) Based Screening and Fetal Nucleated Red Blood Cell (fnRBC) Initiated Testing’ (2013) 6 (4) *N A J Med Sci* 194.

¹²⁷ YMD Lo and others, ‘Presence of fetal DNA in maternal plasma and serum’ (1997) 350 (9076) 485.

¹²⁸ F Jiang and others, ‘Noninvasive Fetal Trisomy (NIFTY) test: an advanced noninvasive prenatal diagnosis methodology for fetal autosomal and sex chromosomal aneuploidies’ (2012) 5 *BMC Med Genomics* 57; AR Mazloom and others, ‘Noninvasive prenatal detection of sex chromosomal aneuploidies by sequencing circulating cell-free DNA from maternal plasma’ (2013) 33(6) *Prenat* 591.

¹²⁹ Recent screening for sex chromosome aneuploidies showed a sensitivity of 85.5%-96.2% and a specificity of 99.7%-99.9%. *ibid*.

fetal genome using a simple blood test.¹³⁰ Currently, its use is limited; for example in the US, cffDNA test is used for prenatal screening of autosomal aneuploidies,¹³¹ whereas in the UK it tends to be used in the early detection of fetuses who are at risk of sex-linked genetic conditions. As always the early successful detection of a fetus with KS or other conditions may well lead to an increase in terminations of such pregnancies.

In recent months testing for CAH has been developed as part of the RAPID trials, at Great Ormond Street Hospital (GOSH). Although CAH cannot be directly sequenced for cffDNA, a new technique has been developed, with some success.¹³² On paper this appears to be good news for fetuses with CAH; however a number of ethical concerns arise. These will now be addressed.

6.7.4 Ethical Concerns

As prenatal tests can identify specific intersex conditions, it has been argued that prenatal testing is not ethical.¹³³ Others coin it a tool for eugenics,¹³⁴ and indeed significant statistical evidence indicating percentage rates of abortions of fetuses with KS indicate that these are rational concerns.¹³⁵ However, there are arguments to suggest that early neonatal chromosome screening is beneficial. Firstly, there is evidence that prenatal diagnosis reduces maternal stress by assisting parents to come

¹³⁰ Zhiyong (n126).

¹³¹ <http://www.thelondonultrasoundcentre.co.uk/private-pregnancy-harmony-non-invasive-prenatal-downs-syndrome-safe-genetic-DNA-blood-test/> accessed 4 January 2014. Caroline Wright 'Cell-free fetal nucleic acids for non-invasive prenatal diagnosis' January 2009. PHG foundation<www.phgfoundation.org/download/ffdna/ffDNA_report.pdf>accessed 23 January 2011.

¹³² At present, the GOSH team have submitted dossiers to the UK National Screening Committee for consideration. Lyn Chitty, 'RAPID Newsletter' September 2015.

¹³³ TIIF Appendix A.

¹³⁴ Asch (n84).

¹³⁵ As will be discussed later in this chapter, 35.7% of all detected KS fetuses from 2003-2012 in the south-west region were aborted. South West Congenital Anomalies Register <http://www.swcar.org.uk/data-open/outcome-region-public.html> accessed 25 May 2015.

to terms with a disability should the parents decide to carry on with the pregnancy.¹³⁶ Secondly, fetuses with certain conditions, for example TS and KS, will benefit from early treatment, albeit such treatment can be started after birth.¹³⁷ In this respect it is ethically acceptable to carry out testing, provided that the tests themselves do not cause damage.¹³⁸ Further scientific data is required in this respect. Ethical tensions will increase if early diagnosis leads to an intersex condition being *treated in utero*. This predominantly arises in cases of CAH, and thus we must now consider this.

6.8 Testing for and Treating CAH during Pregnancy

CAH can be diagnosed at an early stage using PGD; however, for those embryos conceived naturally, parents have to wait until undergoing cffDNA testing, if available, or more usually CVS testing to discover whether or not their fetus has inherited their condition.

Since the mid-1980s, a low-dosage of dexamethasone has been used as prenatal treatment of CAH, in conjunction with CVS and ultrasound techniques. Dexamethasone, when administered to the expectant mother, is able to cross the placental barrier to the fetus, which then inhibits or reduces the development of ambiguous genitalia in girls. In theory, the aim of drug administration during pregnancy is to stop the fetus undergoing corrective genital surgery once born. *Prima facie* the ability to prevent invasive and unwelcomed treatment would appear to be in the child's best interests; therefore this treatment has been described as a 'unique

¹³⁶ Ralston and others, 'Pregnancy Outcomes after Prenatal Diagnosis of Aneuploidy', (2001) 97 *Obstetrics & Gynecology* 729.

¹³⁷ MB Hodgins, EM Duke and D Ring, 'Carrier detection in the testicular feminization syndrome: deficient 5 alpha-dihydrotestosterone binding in cultured skin fibroblasts from the mothers of patients with complete androgen insensitivity' (1984) 21 (3) *J Med Genet* 178; JA Batch and others 'Phenotypic variation and detection of carrier status in the Partial Androgen Insensitivity Syndrome' (1993) 68 *Arch Dis Childh* 453; Anders Bojesen, Svend Juul and Claus Højbjerg Gravholt, 'Prenatal and Postnatal Prevalence of Klinefelter Syndrome: A National Registry Study' <http://www.rcog.org.uk/files/rcog-corp/TerminationPregnancyReport18May2010.pdf> accessed 13 November 2012.

¹³⁸ As this will be equally applicable to the embryos who have an intersex/DSD condition and those who do not, this is beyond the scope of this particular thesis.

example of the successful prevention of a major congenital malformation',¹³⁹ and 'uniquely important for affected girls'.¹⁴⁰ Not all agree.¹⁴¹

The major ethical consideration with this treatment is that even if both parents are CAH carriers, it will be impossible to tell whether any fetus will have the full condition (there being a one in four chance of such an incidence happening) therefore administration of dexamethasone must be started as soon as pregnancy is confirmed – long before the sex of the fetus is known.

As soon as it is possible, testing will be performed to carry out chromosome arrays. If an XY configuration is detected, doctors stop medication. However, for a fetus with an XX configuration, it will be necessary to carry out DNA tests on the *CYP21A2* gene to see if that gene is affected. Tests can also distinguish between the classical or non-classical forms of CAH. If the gene appears to be normal, or Non-Classical CAH is anticipated, then dexamethasone can be withdrawn. Should the fetus prove to be Classic CAH positive, medication will continue to term.

As dexamethasone is administered with the sole aim of preventing genital difference in girls, it is clear that treatment is unnecessary for a male fetus with CAH. Even if both parents are carriers of the condition only one in eight fetuses will benefit from the drug. This leaves seven out of eight fetuses exposed, unnecessarily, to a potentially dangerous substance for nine weeks, with potential long-term contraindications.¹⁴² Amongst the more concerning side effects are toxicity to the central nervous system.¹⁴³

¹³⁹ I Hughes 'Prenatal Treatment of Congenital Adrenal Hyperplasia : Do we have enough evidence?' (2006) 5 (1) *Treat Endocrinol* 1.

¹⁴⁰ Elizabeth Kitzinger, 'Prenatal Diagnosis and Treatment for Classical CAH' (2003) 2(1) CARES Foundation Newsletter 15 http://www.caresfoundation.org/productcart/pc/news_letter/winter02-03_page_9.htm accessed 24 January 2013.

¹⁴¹ Alice Dreger, Ellen K Feder, Anne Tamar-Mattis, 'Prenatal Dexamethasone for Congenital Adrenal Hyperplasia; An Ethics Canary in the Modern Medical Mine' (2012) 9 *Bioethical Inquiry*:277 DOI 10.1007/s11673-012-9384-9.

¹⁴² Heino FL Meyer-Bahlburg and others, 'Cognitive and Motor Development of Children with and without Congenital Adrenal Hyperplasia after Early-Prenatal Dexamethasone' (2004) 89 (2) *The J Clin Endocrinol & Metab* 610. If cffDNA testing is utilised this will benefit Non-CAH fetuses as drug

On a deeper societal level, there have been questions over what precisely dexamethasone is utilised to ‘cure’ – is it to assist physical female development or to encourage the required female gender behaviour? Research indicates a higher percentage of ‘maleness’ in women with CAH with 30 per cent of such women holding ‘male-dominant’ occupations compared to 13 per cent in control groups.¹⁴⁴ It has also been noted that CAH women exhibit more interest in sports and motor cars than their non-CAH companions,¹⁴⁵ does society require chemicals to be utilised for this? Thea Hillman notes:¹⁴⁶

(...) if our bodies are disordered in some way, they may need medical care, but they don’t need medicalization. I want medical care that seeks to make me happy, not to make me normal.

Without further unbiased scientific data, arguments against administration currently appear to outweigh arguments for. In this respect it is possible that English law needs to review the permitted parameters of experimental drug therapies in relation to fetuses. This has been recommended in Australia by the Senate.¹⁴⁷

administration will cease more quickly, but clearly will not assist XX fetuses with CAH avoid controversial drug treatment.

¹⁴³ H Uno and others, ‘Neurotoxicity of Glucocorticoids in the Primate Brain’ (1994) 28 *Horm Behav* 336; SG Matthews, ‘Antenatal Glucocorticoids and the Developing Brain: Mechanisms of Action’ (2001) 6 *Semin Neonatol* 309; Tatja Hirvikoski and others, ‘Cognitive Functions in Children at Risk for Congenital Adrenal Hyperplasia Treated Prenatally with Dexamethasone’ (2007) 92 (2) *J Clin Endocrinol Metab* 542. HL Claahsen-van Dergrinton and others, ‘Congenital Adrenal Hyperplasia-Pharmacologic interventions for Prenatal phase to Adulthood’ (2011) 132 (1) *Pharmacol Ther* 1, 11.

¹⁴⁴ Louise Frisén and others, ‘Gender Role Behavior, Sexuality, and Psychosocial Adaptation in Women with Congenital Adrenal Hyperplasia due to *CYP21A2* Deficiency’ (2009) 94 (9) *J Clin* 3432.

¹⁴⁵ *ibid.*

¹⁴⁶ Thea Hillman, *Intersex for lack of a better word* (Manic D Press 2008) 148.

¹⁴⁷ Senate; Community Affairs References Committee, (Australia) ‘Involuntary or Coerced Sterilisation of Intersex People in Australia’ (2nd Report, 25 October 2013).
<http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Sec_Report/index>

6.9 The Abortion Act 1967

Certain intersex conditions are vulnerable to being considered a disability. By virtue of section 1 (1) (d) of the Abortion Act, a fetus having been diagnosed with a potential disability may be aborted beyond the usual 24 weeks' limit.¹⁴⁸ This section is effectively discriminatory against the intersexed as if parents are informed that their intersexed child will have a poor quality of life, they may seek an abortion in the belief that it is in the 'best interests' of the child.

In order to assess whether this discrimination is ethically acceptable it is important to identify the arguments for enactment and retention of section (1) (1) (d) to date, and to discover whether, in fact, it is not so much the legal provision itself but the way it is utilised that makes the section potentially or actually discriminatory.

6.9.1 The Abortion Act 1967 – Background

The Abortion Act 1967 started life as a private member's bill introduced by David Steel.¹⁴⁹ This Act sought not so much to legalise abortions as to decriminalise them in certain cases, by providing defences to various offences contained in the Infant Life (Preservation) Act 1929 and the Offences Against the Person Act 1861.¹⁵⁰

Prior to the introduction of the Act abortions regularly took place, but there was disparity of treatment for those with money and those without.¹⁵¹ The Act made

¹⁴⁸ Sheldon and Wilkinson (n83). The argument re-surfaced after the London Paralympics in 2012, when a co-operative of pro-life campaigners used the event to focus on the achievements of disabled athletes. See for example, John Bingham, 'Call for Ban on Disability Abortions after Paralympics', *The Telegraph*, 19 September 2012.

¹⁴⁹ Medical Termination of Pregnancy Bill, HC Deb 22 July 1966 vol 732 cols 1067-165.

¹⁵⁰ If a doctor does not comply with formalities provided in the Act it is *prima facie* child destruction, under the Infant Life (Preservation) Act 1929. If done not in accordance with the Act but for the safety of the mother, it will be considered an offence under s58 OAPA 1861. In such instance, however, the common law defence of necessity 'for the purpose only of preserving the life of the mother', *R v Bourne* [1939] 1 KB 687 will apply.

¹⁵¹ Legislation on abortion was felt to be necessary in the wake of the epidemic of 'back-street abortions' occurring then occurring. Whilst the wealthy could attend a qualified practitioner at a Harley Street surgery, the poor risked their lives at the hands of an (often) unqualified doctor.

abortions available to all and as such it could be regarded as a landmark example of social equilibration.¹⁵² The success of the Act is indicated by the fact that during its forty-eight-year history it has only been modified once,¹⁵³ to ‘clarify’ rather than ‘change’ the statute.¹⁵⁴ Inevitably the Act faced and still faces opposition. Its introduction prompted the formation of various pro-life organisations still active today.¹⁵⁵ Abortion is anathema to these groups as it denies the ‘*sanctity of life*’ and interferes with the rights of the unborn. Their argument focuses on challenging the right to abort a fetus at *any* stage.

When first passed the Abortion Act did not make provision for a legal ‘time limit’ for abortions, although it was generally regarded to be 28 weeks, in alignment with its precursor, the Infant Life (Preservation) Act 1929. Section 1(2) of this earlier act made it illegal to kill a child ‘*capable of being born live*’, and stipulated 28 weeks as the age at which a fetus must be presumed to be viable. Section 37 of the Human Fertilisation and Embryology Act (HFEA) 1990 amended the Abortion Act to incorporate a reduced time limit of 24 weeks. However, in 2008 Parliament voted against a further reduction in the time limit despite campaigning by pro-life activists. Further, a suggestion to alter the British Medical Association’s (BMA) policy to 20 weeks was rejected at the union’s annual conference in Cardiff in 2011 by a margin of 61 per cent to 32 per cent, with 7 per cent abstaining.¹⁵⁶ The main argument against an alteration to the current time limit of 24 weeks is the lack of fetal

¹⁵² Although in reality this is still not the case. Many women will pay for private treatment, due to extensive NHS waiting times. See ‘Abortion wait is cruel’ *Metro* 22 January 2007 www.metro.co.uk However, as there has been a slight drop in the number of abortions during the last two years, there has been a slight reduction in waiting times too.

¹⁵³ The Abortion Act 1967 was modified by the Human Fertilization Embryology Act 1990, to include an upper time limit of 23 weeks and 6 days, unless there are special circumstances.

¹⁵⁴ A comparison here might be made with the Theft Act 1968, which has been modified on numerous occasions. The latest modification came about on 15 January 2007, with the enactment of the Fraud Act 2006 which repeals various sections in the Act. Whilst it is accepted that the Abortion Act is comparatively small in relation to the Theft Act 1968, with the advances in technology in medicine, one may have thought a more radical adjustment would have taken place by now.

¹⁵⁵ Their voices have been joined of late by Disability Rights organisations, who see aspects of the Act as discriminating against disabled babies.

¹⁵⁶ Denis Campbell ‘Doctors vote against cutting the time limit from 24 to 20 weeks’ *The Guardian* Tuesday 28 June 2011

sustainability for babies born prior to a 24 week gestation period.¹⁵⁷ Although medical technology has progressed to the extent where 24 weeks' gestation gives a *possible* chance of survival, for those born prior to 24 weeks survival is a very rare event.¹⁵⁸ Consequently, unless there are special circumstances, the law stipulates that abortion is permissible for a 'healthy' fetus *only* if it is performed up to 24 weeks' gestation.¹⁵⁹ In reality the vast majority of abortions take place before this time.¹⁶⁰

'Surprisingly',¹⁶¹ certain defined special circumstances allow an abortion to legally take place until birth. By virtue of sections 1(1) (b) and 1(1) (c) a termination can be lawful at *any stage* if the mother's health and/or life are in danger.¹⁶² This is in contrast to the special circumstance allowed by section 1(1) (d). This section states that an abortion will be lawful if 'there is a *substantial risk* that if the child were born it would suffer from such physical or mental abnormalities as to be *seriously*

¹⁵⁷ There are three categories of preterm babies: extremely preterm: < 28 weeks; very preterm: from 28 to < 32 weeks; moderate to late preterm: from 32 to < 37 weeks. In England, survival chances increase by 9.5% for each week if the baby is born at 23 weeks, and 16% per week if the baby is born at 25 weeks. Tommy's, 'Premature birth statistics' (February 2015) <http://www.tommys.org/Page.aspx?pid=387> accessed 25 March 2015. Data analysed from 2006 indicated the survival rate of preterm neonates was as follows: 2% (3) of babies born at 22 weeks; 19% (66) of babies born at 23 weeks; 40% (178) of babies born at 24 weeks; 66% (346) of babies born at 25 weeks; 77% (448) of babies born at 26 weeks. NHS, 'Premature Birth Survival Rates On The Rise' (5 December 2012) <http://www.nhs.uk/news/2012/12December/Pages/Premature-birth-survival-rates-on-the-rise.aspx> accessed 25 March 2015. Although survival rates of very premature babies have increased over the past 15 years, children who are extremely preterm are more likely to have a higher incidence of severe disability compared to their full-term counterparts. Neil Marlow and others 'Neurologic And Developmental Disability at Six Years of Age after Extremely Preterm Birth' (2005) 352(1) N Engl J Med 9, as quoted on Tommy's website. Children who are extremely preterm are more likely to have a higher incidence of severe disability as compared to full-term babies.

¹⁵⁸ Lee (n105) 236.

¹⁵⁹ Department of Health, Abortion Statistics in England and Wales: 2013, published July 2013, 13. <<https://www.gov.uk/government/publications/report-on-abortion-statistics-in-england-and-wales-for-2012>> accessed 24 March 2014.

¹⁶⁰ In 2012, 91% of all abortions took place before the 13th week whilst 0.1% abortions took place over 24 weeks. *ibid*.

¹⁶¹ The popular knowledge amongst various correspondents is that abortion has a finite time limit of 24 weeks.

¹⁶² Abortion Act 1967 (as amended)

Section 1 (1) (b) That the termination is necessary to prevent grave permanent injury to the physical or mental health of the pregnant woman; or (c) That the continuance of the pregnancy would involve risk to the life of the pregnant woman, greater than if the pregnancy were terminated.

handicapped'. (This section is referred to as Ground E by doctors).¹⁶³ Shakespeare,¹⁶⁴ amongst others, believes that the law on abortion discriminates against the 'disabled fetus' as it can be aborted legally at any stage, unlike a 'healthy' fetus. It is important to consider the scale of such abortions. During 2012, a total of 2692 abortions were carried out under Ground E, a very small minority of the abortions carried out overall.¹⁶⁵ However, in terms of fetuses with intersex/DSD conditions a significant *percentage* of these were aborted.¹⁶⁶

6.10 'Substantial Risk' and 'Seriously Handicapped'

Ground E requires proof of a 'substantial risk' of a seriously handicap. It is not unreasonable to ask how 'substantial risk' is calculated, and further question the meaning of 'seriously handicapped'. More pertinently to this thesis, can it be said with certainty that those with an intersex condition *will* be 'seriously handicapped'? Currently, there is no legal definition of 'substantial risk', and whether a risk is substantial will very much depend on the potential disability isolated. There is also no definition of 'seriously handicapped', nor it is clear from the Act whether such a disability will have to be present at birth, or whether the disability qualifies if it has the potential to develop later in life.

The Royal College of Obstetricians and Gynaecologists (RCOG) have not offered a definition of it themselves, nor do they recommend changing the current law in this

¹⁶³ It will be referred to as Ground E for the rest of this chapter.

¹⁶⁴ Tom Shakespeare, 'Eugenics, Genetics and Disability Equality' (1998) 13 (5) *Disability & Society* 665, 671.

¹⁶⁵ In 2012, 2,692 abortions (1% of the total) were carried out under Ground E. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/307650/Abortion_statistics_England_and_Wales.pdf accessed 24 March 2014.

¹⁶⁶ When calculating fetal anomalies, from 2003-2012, 9.5% of those with intersex conditions were aborted. Of more significance, 38.7% of TS and 35.7% of KS fetuses were aborted (see section 6.10). South West Congenital Anomaly Register <http://www.swcar.org.uk/data-open/outcome-region-public.html> accessed 23 May 2015. This register is one of seven in England, with another register for Wales. SWCAR is the most comprehensive, but it is likely that similar results would occur in other regions.

respect.¹⁶⁷ Their primary reason is that it is unrealistic to produce a complete list of conditions that may qualify as a serious handicap, and further that:

consequences of an abnormality are difficult to predict, not only for the fetus in terms of viability or residual disability but also in relation to the impact in childhood as well as on the family into which the child would be born.¹⁶⁸

In a previous working party report in 1996, RCOG pointed to sections 3 and 4 of the 1980 World Health Organization classification.¹⁶⁹ The vagueness of these terms has been considered to be ‘an effort to avoid fettering the discretion of the two certifying doctors’.¹⁷⁰ However, it also avoids *fettering the discretion of lawyers*. It would be impossible to legislate for the spectrum of disabilities detected *in utero* but not *quantified* until birth.¹⁷¹

In terms of intersex/DSD conditions, those who strive for perfection would believe such conditions to be a ‘serious handicap’. Some TS girls will have severe medical conditions such as diabetes and kidney failure,¹⁷² but not all these women have such serious medical complications. The primary physical effect of TS is the development of a ‘webbed’ neck,¹⁷³ and generally being shorter than the average non-TS woman. Does this make these girls ‘seriously handicapped’? In today’s society of ‘perfection’

¹⁶⁷ RCOG, ‘Termination of Pregnancies for Fetal Anomalies in England, Scotland and Wales Report of a Working Party’ (RCOG May 2010) www.rcog.org.uk/globalassets/documents/guidelines/terminationpregnancyreport18may2010.pdf accessed 12 May 2015.

¹⁶⁸ *ibid*, 10.

¹⁶⁹ Section 3: Assisted Performance. This includes the need for a helping hand. Section 4: Dependant Performance. This includes complete dependence on another WHO, ‘International Classification of Impairments, Disabilities and Handicaps’ (WHO, Geneva 1980).

¹⁷⁰ Elizabeth Wicks, Michael Wylds and Mark Kilby, ‘Late Termination of Pregnancy for Fetal Abnormality: Medical and Legal Perspectives’ (2004) 12 Med Law Rev 285.

¹⁷¹ As neonaticide is illegal in the UK, doctors cannot judge the severity of a condition after birth and act accordingly.

¹⁷² Discussed in chapter three. Turner Syndrome Support Society ‘Turner Syndrome: A Guide for Patients and Parents’ <http://tss.org.uk/> accessed 7 April 2015.

¹⁷³ This is caused by extra folds of skin extending from the tops of the shoulders to the sides of the neck.

it may well do, but it is submitted that this is not ‘seriously handicapped’ per se. Likewise, KS men will experience a number of physical and mental health problems, including autoimmune disorders, breast cancer and osteoporosis. However, these types of variations will also present in a number of ‘non-intersex’ men. Are *all* KS men ‘seriously handicapped’?

Some KS fetuses will be aborted in the belief that they have severe disabilities. Abramsky and Chapple note that doctors, themselves, see KS men as having severe problems.¹⁷⁴ In reality, they might have a minor physical problem, for example extra height. Likewise, whilst it is accepted that some intersex/DSD individuals will suffer a prolonged unpleasant life, this would not be true for everyone. It should not be assumed that those with disabilities wish to be ‘normal’,¹⁷⁵ nor should it be assumed that those who may be considered ‘intersexed’ wish to be ‘male’ or ‘female’. The risk of eradicating any slight imperfection has given rise to concerns that Ground E allows ‘eugenic’ practices to take place.¹⁷⁶

In 2003 the Reverend Joanna Jepson received considerable media attention when she challenged the lawfulness of *post* 24 week abortions performed on fetuses presenting with a bilateral cleft palate.¹⁷⁷ This characteristic, she claimed, did not qualify as ‘*seriously handicapped*’ as required by section 1(1)(d) of the Abortion Act and abortion was therefore unlawful.¹⁷⁸ This caused the Department of Health (DoH) to stop publishing detailed statistical information detailing the ‘handicap’ for Ground E abortions, for fear this would disclose the names of doctors and patients. In February

¹⁷⁴ L Abramsky, J Chapple, ‘47, XXY (Klinefelter Syndrome) and 47, XYY: Estimated Rates of an Indication for Postnatal Diagnosis with Implications for Prenatal Counselling’ (1997) 14 (4) *Prenat Diagn* 363, 367.

¹⁷⁵ Paul Steven Miller and Rebecca Leah Levine, ‘Eugenics in the Complex Dialogue between the Medical and Disability Communities’ (2013) 15 (2) *Genet Med* 2013 February 95 doi:10.1038/gim.2012.102.

¹⁷⁶ Jonathon Gornall, ‘Where do we draw the line?’ (2007) 334 *BMJ* 285 reports on the findings of a MORI poll on abortion undertaken in November 2006. This indicated that acceptability on the ground of disability had dropped from 70% to 64%.

¹⁷⁷ *Jepson v The Chief Constable of West Mercia* [2003] EWHC 3318.

¹⁷⁸ The doctors concerned were not prosecuted as they were considered to have acted in ‘good faith’. Clare Dyer ‘Doctors who performed late abortion will not be prosecuted.’ (2005) 330 *BMJ* 688.

2005, the Pro Life Alliance requested that the DoH publish the suppressed data on fetal abnormalities for 2003. The DoH declined to do so, citing section 40 of the Freedom of Information Act 2000. Ultimately, in 2009 the Information Commissioner ruled that the DoH was to publish these statistics.¹⁷⁹ An unsuccessful High Court appeal in 2011 by the DoH means these statistics are published once again.¹⁸⁰

‘Intersex’ as a group is mentioned in the statistics,¹⁸¹ and the rate of intersex fetuses which were aborted from 2003-12 is recorded as 9.5 per cent.¹⁸² However, as no definition of specific intersex conditions is given,¹⁸³ it is difficult to assess the true picture,¹⁸⁴ though certain DSD conditions are noted. However, the abortion rate for TS was 38.7 per cent during the same timeframe and for KS 35.7 per cent. Whereas

¹⁷⁹ *Department of Health v Information Commissioner and the Pro Life Alliance* EA/2008/0074 Information Commissioner’s Ref: FS50122432.

¹⁸⁰ *R (On the Application of Department of Health) v Information Commissioner and the Pro Life Alliance* EWHC 1430 (Admin). Cranston J agreed with the decision made by the Information Commissioner that statistics on abortion were not personal data as defined by the Data Protection Act 1998.

¹⁸¹ SWCAR ‘South West Region Cases by Birth Outcome’, www.swcar.org.uk accessed 25 May 2015.

¹⁸² *ibid.* The remaining 90.5% were recorded as live births.

¹⁸³ Some conditions may be counted under headings such as ‘urinary system’, ‘chromosomal abnormality’ or ‘family history of hereditary disorder’.

¹⁸⁴ Current abortion data for anomalies is not specific in its diagnosis, but CAH could be classified as an ‘adrenal’ problem or ‘genital ambiguity’ for female fetuses. It could also be counted as ‘genetic anomaly’. Statistics for all of these groups are available from the South West Congenital Anomaly Register (SWCAR) The website notes that ‘as a baby can occur in more than one row, the numbers of Induced Abortions cannot be taken to infer cases of termination *for that anomaly*, only cases where an anomaly was present in a terminated fetus’. It further adds, ‘Where a pregnancy is terminated following the identification of fetal anomaly, SWCAR aims to obtain post mortem confirmation of the notified anomalies. However, this is not always possible as consent for post mortem may not be given and problems can arise with service provision. Confirming all anomalies risks over-reporting, while simply recording them all as suspected risks under-reporting. The approach taken is to confirm anomalies that have been demonstrated through clinical practice to be diagnosed reliably using appropriate antenatal testing, balanced with a consideration of the specialism of the reporting health professional, along with their own confidence in the diagnosis. In some cases a general anomaly code is allocated where it is clear that an anomaly is present but a specific diagnosis is not possible.’ However, with that in mind, it is interesting to note a rate of 50.9% of abortions of fetuses with adrenal conditions whilst abortion of fetuses with female ‘genitalia issues’ was 16 % for 2003-2012. For boys the figure was substantially lower, namely 1.1%. SWCAR ‘South West Region Cases by Birth Outcome’, www.swcar.org.uk <<http://www.swcar.org.uk/data-open/outcome-region-public.html>> accessed 25 May 2015.

a significant number of TS fetuses will spontaneously abort,¹⁸⁵ a comparatively small number of KS fetuses will miscarry after detection.¹⁸⁶ This raises serious ethical concerns regarding societal knowledge about KS men. It may be that couples are under the illusion that KS is akin to Down's syndrome,¹⁸⁷ which it clearly is not. These statistics suggest that the intersexed fetus is targeted for abortion, regardless of the number of weeks of gestation. It is now important to investigate why this might be the case.

6.11 Parental Choice

Many fetuses with an intersex/DSD condition will spontaneously abort before the second trimester.¹⁸⁸ For example, those with trisomy 22¹⁸⁹ seldom survive to birth.¹⁹⁰

Other such fetuses may be aborted as an unwanted pregnancy at an early stage. So far there is no discrimination. Those fetuses who survive to post-viability stage are usually wanted babies, and the discovery that a fetus may suffer from any type of chromosomal abnormality is 'the worst news possible' for the parents-to-be.¹⁹¹ This will be compounded where the abnormality identified is one that is as unfamiliar to the staff as it is to the parents themselves. For those who are told that their baby is neither male nor female, the news is usually incomprehensible.

¹⁸⁵ *ibid*, 32.4% during the same period.

¹⁸⁶ *ibid*, 4.8% during this period.

¹⁸⁷ *ibid* 49.6% of Down's syndrome fetuses are terminated during this period.

¹⁸⁸ As mentioned in chapter three, a significant number of TS fetuses spontaneously abort during pregnancies (32.4% of all detected TS fetuses from 2003-2012). South West Congenital Anomalies Register <http://www.swcar.org.uk/data-open/outcome-region-public.html> accessed 25 May 2015.

¹⁸⁹ This is the second most common trisomy, the most frequently occurring being trisomy 16. Trisomy 22 is also known as 'Cat Eye Syndrome', as these babies frequently have an eye abnormality, ocular iris coloboma (a gap or split in the iris).

¹⁹⁰ It is unlikely that a child with trisomy 22 in every cell will survive the first trimester, as normally these babies have mosaicism. The extent of this will indicate the prognosis for the child. In addition to eye abnormalities, these children frequently have heart defects and kidney problems and present with genital difference.

¹⁹¹ Healthtalk.org 'Ending a Pregnancy for Fetal Anomaly – Understanding the baby's diagnosis.' <http://www.healthtalk.org/peoples-experiences/pregnancy-children/ending-pregnancy-fetal-abnormality/understanding-babys-diagnosis> accessed 24 May 2015.

In this situation, it is essential that trained specialist counsellors are available, but this is unlikely to occur.¹⁹² As noted by the BMA, there are no legal requirements that provisions for counselling are made, nor any that they be accepted.¹⁹³ However, in these situations parents often feel forced to make a rapid decision as to whether they should continue with the pregnancy or not.¹⁹⁴

According to Daniela Crocetti,¹⁹⁵ evidence from London-based clinical research indicates that terminations occur more frequently if a gynaecologist reports the results to parents, as opposed to a counsellor with expertise in genetics. If a system of *informed* counselling was offered to those identified as carrying an intersex/DSD child, then fewer pregnancies may be terminated. In this regard, a survey from Germany identified an approximate abortion rate of 12.7 per cent for those carrying a child with KS, or other similar genetic abnormality. This was noted by the authors to be a rather low figure.¹⁹⁶ It was suggested that one reason for a comparatively low abortion rate was that parents were provided with literature which educated them as to how the condition would affect their baby's future life.

This can be contrasted with results from another survey, in which data was collected from the notes of the 111 cases of KS diagnosed prenatally between 1986 and 1997 in eight geographical regions in five European countries.¹⁹⁷ The results from this survey

¹⁹² With impending cuts to NHS budgets, as promised by the newly elected government, it seems unlikely that more money will be allocated here.

¹⁹³ BMA, 'The Law and Ethics on Abortion – BMA Views' (November 2014) 9. http://bma.org.uk/-/media/files/pdfs/practical%20advice%20at%20work/ethics/law_and_ethics_of_abortion_nov2014.pdf

¹⁹⁴ 'They just give you maximum half an hour to think whether you want to terminate your pregnancy or not at eight months.' The mother felt pressured into making a decision regarding termination by 'the most unhelpful professional that we met'. Interview 10 Transcript www.dipex.org/EXEC accessed 25 May 2011.

¹⁹⁵ Daniela Crocetti 'Medicalizing Gender: From Intersex to DSD, From Laboratory to Patient Groups.' (PhD thesis, Universita di Bologna 2011). Unfortunately there is no reference to access the research.

¹⁹⁶ D Meschede and others, 'Low Rates of Pregnancy Termination for Prenatally Diagnosed Klinefelter Syndrome and other Sex Chromosome Polysomies' (1998) 80 (4) Am J Med Genet. 330.

¹⁹⁷ The data included factors such as social class, gestational age at diagnosis, and specialties of the health professionals conducting pre- and post-diagnosis consultations. TM Marteau and others, 'Outcomes of pregnancies diagnosed with Klinefelter syndrome: the possible influence of health professionals' (2002) 22 (7) Prenat Diagn 562.

indicated a much higher abortion rate of 44 per cent of fetuses. In yet another survey 50 per cent of KS fetuses were terminated, ‘presumably (...) because of fears about how the condition in question would manifest itself’.¹⁹⁸ (This is slightly higher than the rate in the UK.)¹⁹⁹ Of significance, this latter paper indicated a noticeable overall reduction in the rate of abortions where parents were provided with specialist post-diagnosis counselling to help understand their future child’s condition/anomaly.

In a study conducted in France,²⁰⁰ medical practitioners in the Marseilles Genetic Centre's region were consulted regarding their views on fetal anomalies and abortion. In particular, researchers narrowed down a range of conditions to six targeted areas: Down's syndrome, Turner and Klinefelter Syndromes, cystic fibrosis, spina bifida and haemophilia. Information was gathered in 1985 by a mailed questionnaire answered by 853 practitioners. A total of 78 per cent of those answering, favoured offering an abortion to women carrying a Down’s syndrome fetus, whereas only 21 per cent would recommend an abortion to those with haemophilia. In terms of the ‘intersex’ conditions studied, the overall figure was approximately 50 per cent recommending an abortion. What is striking from these results is that it was the younger members of the profession who were more likely to recommend an abortion, rather than their elders.²⁰¹

The results of these surveys indicate that it is of utmost importance that information on intersex/DSD conditions is shared with medical students. It is clear that healthcare professionals need to address their own views before imparting them to others, for as Adrienne Asch has stated, ‘it will be very difficult for most families to consider bringing children (...) into the world if they know that the society believes their births

¹⁹⁸ L Abramsky and J Chapple, 47, XXY (Klinefelter Syndrome) and 47, XYY: Estimated Rates of an Indication For Postnatal Diagnosis with Implications for Prenatal Counselling’ (1997) 14 (4) Prenat Diagn 363, 363.

¹⁹⁹ TS was 38.7% during the same time-frame and for KS 35.7%, as discussed on page 230.

²⁰⁰ C Julian and others, ‘Physicians’ acceptability of Termination of Pregnancy after Prenatal Diagnosis in Southern France’ (1989) 9 (2) Prenat Diagn 77.

²⁰¹ CM Girardin, GVan Vliet ‘Counselling of a Couple faced with a Prenatal Diagnosis of Klinefelter Syndrome’ (2011) 100 (6) Acta Paediatr 917.

should have been prevented'.²⁰² For those desiring to be parents, the shock of receiving news that their child-to-be will have 'no sex' leaves them vulnerable to their worst imaginings, and they may easily be persuaded, against their better judgment, into an abortion, particularly if they are convinced that there is 'no time to lose'.²⁰³

Much has been made of the argument concerning 'best interests of the child'. Chipman argues²⁰⁴ that testing should only be used to identify a fetus that is at high risk of fatality, severe or chronic pain or severe cognitive impairment. The difficulty would be trying to establish the definition of these terms. For example, how can 'chronic' pain be defined? Surely, when considering an individual child, one should consider the child's place in society when measuring whether it is in the child's best interests or not. Not everyone is destined for a happy life and many, for whatever reasons, choose to end their lives, themselves.²⁰⁵ The feeling of loss and isolation is likely to be even more overwhelming if an 'oddment of society'.²⁰⁶ As noted,²⁰⁷

screening out every compromised pregnancy (...) will not
lessen this concern; equally, compelling the implantation and

²⁰² Adrienne Asch, 'Disability Equality and Prenatal Testing: Contradictory or Compatible?' (2003) 30 Florida State University Law Review 315, as quoted by Shakespeare, (n2) 118.

²⁰³ In this respect, Jane Fisher, Antenatal Results and Choices, is concerned that the Jepson case has increased this difficulty; she notes (on discussing abortion statistics) 'these statistics do not tell us how many women were denied the option of termination, nor do they indicate how many women made a 'pressured' decision before 24 weeks, fearing the option would be taken away'. Jane Fisher, 'Post-24 week termination for fetal anomaly – the chilling effect of the Jepson campaign' in BPAS *Britain's Abortion Law, What it says and Why* (May 2013) 28.http://www.reproductivereview.org/images/uploads/Britains_abortion_law.pdf accessed 24 May 2015.

²⁰⁴ Peter Chipman, 'The Moral Implication of Prenatal Genetic Testing' [2006] Penn Bioethics Journal, Vol II issue ii http://www.bioethicsjournal.com/pdf/pbj2.2_chipman.pdf last accessed 17 January 2014, 13.

²⁰⁵ According to www.statistics.gov.uk, in 2004 there were 5,906 suicides in adults aged 15 and over, which represented 1% of the total of all UK deaths. Almost three-quarters of these suicides were amongst men and this division between the sexes has been broadly similar from 1991 onwards. Published on 30 August 2006

²⁰⁶ Interview with correspondent B, London 1 July 2014.

²⁰⁷ Sheila AM McLean and Laura Williamson, *Impairment and Disability: Law and Ethics at the Beginning and End of Life* (Routledge 2007) 80.

birth of children destined for short or unhappy lives is scarcely a better solution.

Further, what of the best interests of the parent?²⁰⁸ The shock for some mothers of giving birth to a disabled child has led to illness. The Royal Medico-Psychological Association produced a Memorandum on Therapeutic Abortion which its council approved on 5 July 1966.²⁰⁹ The Association held the view that '(e)very child, both for its own sake and that of society, needed conscientious parents to give it care and affection'.²¹⁰ It stressed that children who came from unsupportive families tended to suffer from psychiatric illness and anti-social behaviour. They suggested that it may well be in the 'best interests' of these children not to be born. It is submitted that the intersex child needs even more conscientious parenting and from a parent's point of view it is understandable why a significant number of fetuses are aborted each year on the grounds of intersex conditions.

Some parents are prepared to take on the extraordinary challenges that they will inevitably face with a severely disabled child, sometimes with 'astonishingly good results'.²¹¹ However, not all parents will feel that they have the ability or courage to face a lifetime of care. Further, '(n)ot permitting parents to avoid the birth of a child whose care will require (a) long term demanding commitment...is a tremendous imposition on them'.²¹² Decisions to abort for fetal abnormality consider the social aspects of all concerned rather than 'a eugenic unwillingness'²¹³ to bring an intersexed child into the world.

²⁰⁸ Sheldon and Wilkinson refer to this as the 'Parental Interest Argument.' (n 83).

²⁰⁹ 'The Royal Medico-Psychological Association's memorandum on Therapeutic Abortion' (1966) 112 Brit J Psys. 1071.

²¹⁰ John Keown, *Abortion, Doctors and the Law* (Cambridge University Press 1988) 88.

²¹¹ JK Mason, *Medico-legal aspects of Reproduction and Parenthood* (2nd Edn, Ashgate Publishing Ltd 1998) 281.

²¹² T Baldwin, 'Choosing Who: What is Wrong with Making Better Children?' in J R Spencer and A Du Bois-Pedain (eds), *Freedom and Responsibility in Reproductive Choice* (Hart Publishing, 2006) 26.

²¹³ Tom Shakespeare, 'Eugenics, Genetics and Disability Equality.' (1998) 13 (5) Disability & Society, 665, 677.

6.12 Reflections on Section 1(1)(d)

Although Section 1(1)(d) of the Abortion Act 1967 is *prima facie* discriminatory to those with intersex conditions, it is to be argued that it discriminates in the *right* way. Some mothers feel themselves rushed into making decisions whilst in the midst of a ‘bereavement process’ on hearing news of their child’s condition. It is submitted that matters would be worse if the legal limit was reduced to 24 weeks for *all* pregnancies. If a woman was informed that she was carrying an intersexed child at 23 weeks’ gestation and had less than a week to undergo a lawful termination, it is suggested that it is more likely that she would choose to undergo a termination immediately, rather than losing the chance for a termination altogether. By contrast, given more information and time for reflection, she may carry on with the pregnancy.

When faced with unexpected and unpleasant news about their growing baby, parents often feel a huge sense of guilt and an overwhelming sense of sadness. It is not surprising that they suffer from extreme stress at the time of the decision,²¹⁴ and may not have time to truly reflect on their feelings in the rush to meet the abortion deadline. Instead of reducing the number of pregnancies terminated on the grounds of ‘severe disability’, it is possible that there may become *more* abortions of intersexed fetuses overall if Section 1(1)(d) was repealed.²¹⁵

Consequently, it is submitted that although there is discrimination against the intersexed fetus, the best approach to tackle discrimination would be to liberalise the time limit for *all* abortions, as suggested by other authors.²¹⁶ What is apparent is that healthcare workers need further training in regard to advising abortion of a fetus with an intersex/DSD condition. The ability to *choose* is sometimes all a pregnant woman

²¹⁴ Research has shown that up to 50% of women have mental health difficulties post abortion sometimes due to the stress of the decision making. Julia Alcott, ‘Post abortion stress – the Psychological Stress some Women suffer after Abortion’ Mental Healthy <http://www.mentalhealthy.co.uk/other/features/post-abortion-stress-the-psychological-stress-some-women-suffer-after-abortion.html> accessed 5 May 2015.

²¹⁵ Alternatively, if this section was removed, there may be no change in the number of post-viability abortions occurring, merely an increase in the number taking place on other grounds.

²¹⁶ Sheldon and Wilkinson (n 83).

needs, and to this end it is suggested that those who promote *pro-life* should endeavour not to change the law but to provide a more unbiased counselling accessible to all.

6.13 Conclusions

It is understandable that the intersexed feel discrimination from the medical techniques discussed in this chapter. In regard to abortions, the intersexed fetus appears to be treated in law and medicine as a specific type of disabled fetus, and faces the same potential discrimination as those with disabilities. However, to call for the cessation of abortions under Ground E is too blunt an instrument to wield. Further, although ending diagnostic testing during pregnancy might stop the immediate discrimination at that time, it will not prevent the more dramatic discrimination after birth, and will prevent many fetuses (both intersexed and non-intersexed) receiving the medical attention they need.²¹⁷

There is one final point in this respect. It was previously noted that there is currently no legal wording in the Act to prevent ‘sex selection’ abortions occurring,²¹⁸ albeit government guidance aims to prevent such events.²¹⁹ This is an unsatisfactory situation for many, and in February 2015 Fiona Bruce MP attempted to amend the Act to ‘clarify beyond doubt in statute that sex selective abortion is illegal in UK law’.²²⁰ Her proposal was defeated by a vote of 292 to 201, but her alternative

²¹⁷ For example, fetal heart defect can be diagnosed during pregnancy and so intervention measures can be devised straightaway. Likewise *placenta praevia* pregnancies (where the placenta is low lying near to the cervix) can be detected before labour – hence allowing for a scheduled caesarean section to take place and prevent fetal and maternal deaths occurring.

²¹⁸ Sally Sheldon, ‘Abortion for reason of sex: correcting some basic misunderstandings of the law’ *Abortion Review* (1 March 2012) <http://www.abortionreview.org/index.php/site/article/1143/> accessed 23 May 2015.

²¹⁹ Steven Swinford and Peter Dominiczak, ‘Gender-selective abortion is illegal, Health Secretary Jeremy Hunt to announce’ *The Telegraph* (London, 22 May 2014) <http://www.telegraph.co.uk/news/health/news/10850072/Gender-selective-abortion-is-illegal-Health-Secretary-Jeremy-Hunt-to-announce.html>

proposal, requiring a review of the usage of gender selection abortions in the UK, was backed by 491 to 2.²²¹ It will be interesting to see if this review elucidates if intersexed fetuses are being aborted for their ‘sex’.

For both the intersexed and the disabled, the real threat comes not from the medical or legal provisions but from the social reasoning behind them. Until society is fully attuned to the needs and wants of the intersexed, it will be difficult for parents-to-be to feel brave enough to give life to such a child, particularly in the face of ‘hostility’ from healthcare providers. Consequently, TIIF’s demands are perfectly reasonable and if anything are somewhat too moderate in their language.²²²

As will be discussed in the next chapter, more direct action will be required to assist in the overall wellbeing of the intersexed in society after birth, where significant discrimination can be witnessed.

²²⁰ BBC News, ‘MPs reject backbench bid to amend abortion laws’ 24 February 2015 <http://www.bbc.co.uk/news/uk-politics-31596968> accessed 23 May 2015.

²²¹ *ibid.*

²²² ‘create and facilitate supportive, safe and celebratory environments for intersex people, their families and surroundings (and) to ensure that all professionals and healthcare providers that have a specific role to play in intersex people’s wellbeing are adequately trained to provide quality services’, Demands from the Third International Intersex Forum, Appendix A.

Chapter Seven: Birth, Neonatal Testing and Discrimination

7.1 Introduction

In the previous chapter, I discussed the extent to which the intersexed face medico-legal discrimination before birth. In this chapter I consider the extent to which this discrimination continues as a result of the condition *not* being detected either during pregnancy or at birth, despite the availability of neonatal assessments and screening.

The day-to-day legality of such testing relies on a mesh of legislation,¹ working in tandem with established codes of conduct, ethical considerations and the common law principle of consent.² Additionally, there is a general overriding principle of non-discrimination in English law.³ This is further advanced by Strasbourg jurisprudence.⁴

In practice, the current UK screening programme, described as ‘highly effective’,⁵ is led by the UK National Screening Committee (NSC), chaired by the Deputy Chief Medical Officer for England. The NSC advises Ministers and the NHS throughout the UK.⁶ NSC is now part of Public Health England (PHE), which is an executive agency of the Department of Health.⁷ According to the NSC website, PHE was established to ‘protect and improve the nation’s health and wellbeing and to reduce inequalities’.⁸ A careful examination of available testing indicates that current UK screening programmes may not live up to their aims as they appear to discriminate against intersex children. Albeit these programmes do not directly discriminate against the intersexed, as discussed in chapter one, indirect discrimination will occur

¹ Storage of the test cards must comply with the Data Protection Act 1998, The Health and Social Care Act 2001 and the Human Tissue Act 2004.

² As discussed in chapter five.

³ The Equality Act 2010.

⁴ For example, in *Salgueiro Da Silva Mouta v Portugal* (Application no 33290/96) the European Court of Human Rights held that where a difference of treatment in relation to the enjoyment of Article 8 of the Convention, the right to a private life, on grounds of sexual orientation violated Art 14 in the absence of an objective and reasonable justification.

⁵ Code of Practice for the Retention and storage of Residual spots.
<http://newbornbloodspot.screening.nhs.uk/getdata.php?id=11102> accessed 29 September 2013.

⁶ The role, terms of reference and membership of the UK NSC are reviewed every three years. The current review began in April 2014.

⁷ www.gov.uk/phe. PHE was established in April 2013.

⁸ <http://www.screening.nhs.uk/about> accessed 29 September 2013.

when ‘a provision, criterion or practice’⁹ although applying equally to everyone, puts those with a ‘protected characteristic’¹⁰ at a particular disadvantage,¹¹ unless it can be shown to be a ‘proportionate means of achieving a legitimate aim’.¹² It will be seen that in regard to neonatal testing, the intersexed face discrimination.

This chapter commences by discussing the current neonatal testing available before considering if any further testing should be incorporated into current programmes. It will be noted that those born with genital difference will experience direct, invasive medical attention,¹³ whilst those without genital difference may face equal, albeit more subtle, challenges throughout life. Whilst there appears to be no direct discrimination in regard to such testing, current physical neonatal testing has limited application to many intersexed persons in the UK. It will be argued that the absence of widespread screening for certain intersex/DSD conditions, in particular Congenital Adrenal Hyperplasia (CAH) and sex chromosome anomalies,¹⁴ results in preventable, adverse experiences for sufferers.¹⁵ In this respect those with intersex conditions receive a disproportionately less favourable service than those with non-intersexed medical conditions which are routinely tested for. Consequently, it will be submitted that the intersexed face indirect discrimination as a result of the policies behind current screening programmes. In order to overcome this, it will be recommended that various tests be incorporated into the current screening programmes.

⁹ s19 (1) Equality Act 2010.

¹⁰ s19 (3) Equality Act 2010 specifies these as age, disability, gender reassignment, marriage and civil partnership, race, religion or belief, sex and sexual orientation.

¹¹ s19 (2) (b) Equality Act 2010.

¹² s19 (2) (d) Equality Act 2010.

¹³ This will be explored in more detail in the following chapter.

¹⁴ This chapter will primarily focus on Klinefelter syndrome, as it is the most prevalent sex chromosome anomaly detected, albeit a comparatively small number of KS boys are detected at all under the current system. If, as discussed in chapter six, cffDNA is approved for the testing of CAH, testing at birth may not be required. Nevertheless ethical arguments remain in place. It is essential that CAH boys are not dismissed.

¹⁵ As considered in chapter three of this thesis.

7.2 Routine Neonatal Assessments and the Intersexed

The aims of neonatal assessments are two-fold: firstly to ensure that the baby can survive without immediate intervention, and secondly to identify, pre-symptomatically, any serious congenital condition in order to prevent, or at least ameliorate, the long-term consequences of that condition.¹⁶

The first physical neonatal assessment, known as the Apgar Score Test (named after its creator, Dr Virginia Apgar),¹⁷ is carried out by a midwife one minute after birth and repeated five minutes after birth. This aims to identify neonates at risk of an early death.¹⁸ Five components are considered: breathing, heart rate, reflex responses, muscle tone and skin colour. Each of these components is awarded a mark of zero, one or two, with two being the most desirable score to achieve for each component. The highest possible score overall is therefore ten, the lowest zero. Apgar and her team established that neonates who were given a score of ten had a significantly lower risk of neonatal death (0.13 per cent) compared with those who scored zero to two overall (15 per cent).¹⁹ In modern practice a score of seven to ten after five minutes is considered 'normal' and four to six is classed as 'intermediate'. Those with scores of zero to three will be of high concern. It has been noted that the Apgar score has limitations. In particular it lacks 'both sensitivity and specificity' generally,²⁰ and specifically in relation to preterm neonates.²¹ Regardless of this, the

¹⁶ James J Pitt, 'Newborn Screening' (2010) 31(2) Clin Biochem Rev 57.

¹⁷ In 1952, Apgar devised a rapid scoring system to establish a neonate's ability to breathe, and consequently survive. This early detection ensured that there was 'prompt intervention to establish breathing' should the neonate need such assistance. V Apgar 'A Proposal for a New Method of Evaluation of the Newborn Infant' (1953) 32 Curr Res Anesth Analg 260, as quoted by The American Academy of Pediatrics, Committee on Fetus and Newborn, American College of Obstetricians and Gynecologists, Committee on Obstetric Practice, 'The Apgar Score' (2006) 117 (4) Pediatrics 1444.

¹⁸ A further study involving 15,348 neonates, by Apgar and her colleagues, established a more systematic method of testing. Virginia Apgar and others, 'Evaluation of the Newborn Infant – Second Report.' (1958) 168 (15) JAMA 1985.

¹⁹ The lower scores usually correlated with evidence of asphyxia, identified by extracting samples of blood from an umbilical catheter, and hence acted as a useful indicator to apply resuscitation to the neonate. A low score may also be an indication of potential disabilities that might occur in the future. Ibid.

²⁰ Mainly in establishing the concentration of acidosis in the blood. HA Jepson, ML Talashek, AM Tichy, 'The Apgar score: Evolution, Limitations, and Scoring guidelines' (1991) 18(2) Birth 83; KS Montgomery, 'Apgar Scores: Examining the Long-term Significance.' (2000) 9(3) J Perinat Educ Summer 5.

test is still viewed as an effective tool in international modern obstetrics.²² The test is applied to all neonates and therefore no discrimination occurs against the intersex at this stage.

In addition to the Apgar score test, midwives consider the overall immediate health of the baby, and look for any physical anomalies. For example, in male neonates, midwives will check to see if the testes are present.²³ Consequently, the majority of neonates with severe degrees of genital difference are identified straight away. At this point the baby will be the focus of intensive testing to discover the underlying condition.²⁴ It might appear that routine examinations assist the identification of genital difference, but as neonate genitals tend to be swollen as a result of maternal hormones, 'medium' ambiguities may not be identified immediately after birth. When the effects of the hormones diminish in the following days, irregularities will become more noticeable. Such ambiguities are then likely to be diagnosed by a paediatrician during the more detailed neonatal examination performed in the following 24-48 hours.²⁵

Although neonates with a reasonable degree of genital difference are potentially identifiable by routine neonatal testing, the same cannot be said for those neonates with minor genital difference or no genital ambiguity at all. It is therefore necessary to assess if other screening techniques could assist with identification.

²¹ Apgar (n 18).

²² ME Hübner and ME Juárez, 'The Apgar Score. Is it still valid after a half century?' (2002) 130(8) *Rev Med Chil* 925; M Finster and M Wood, 'The Apgar score has survived the test of time.' (2005) 102(4) *Anesthesiology* 855; M Ahmadpour-Kacho and others, 'Correlation between Umbilical Cord pH and Apgar Score in High-Risk Pregnancy' (2010) 20(4) *Iran J Pediatr* 401.

²³ It is usual for male neonates to be born with the testes already in the scrotum. If the baby is born prematurely, then the testes may not be descended fully. An absence of testes, either fully in position or descending, in a full-term baby boy will indicate the need for further tests, to establish where the testes are lying (or indeed if they are present at all).

²⁴ This is discussed later in the chapter.

²⁵ Midwives also carry out such testing if they have received specialised training. Diane Blake, 'Assessment of the neonate: involving the mother' (2008) 16 (4) *BJM* 224, 224.

7.3 Newborn Blood Spot (NBS) Screening

Newborn blood spot (NBS) screening takes place around five days after birth,²⁶ with the aim of identifying various conditions which, if left untreated, would lead to serious health implications; however, unlike other countries the UK's NBS screening does not currently extend to the identification of intersex conditions.

NBS screening began in the United States in the early 1960s, when microbiologist Robert Guthrie invented a test to detect whether a baby suffered from phenylketonuria (PKU),²⁷ an inherited condition which leads to irreversible mental disability.²⁸ The Guthrie test rapidly became a feature of modern neonatal detection in Western medicine, with several countries adopting the test, including England and Wales in 1969.²⁹ Tests for other conditions were later developed and added to the UK national screening programmes, including congenital hypothyroidism (CHT) in 1981³⁰ and, more recently, sickle cell disease,³¹ cystic fibrosis³² and MCADD.³³

²⁶ The test takes place between 5 and 8 days of age. The 'optimum' day is day 5 counting date of birth as day 0. This test involves the 'pricking' of the neonate's heel to make it bleed. The blood is then put on a screening card, composed of filter paper. The sample is then sent away for analysis. Testing is undertaken by tandem mass spectrometry (MS/MS).

²⁷ In the 1930s it was discovered that a number of mentally retarded patients had phenylketonuria. By the 1950s it was discovered that this condition could be ameliorated with a strict dietary regime. There then followed the search for a test to detect this condition before the person was significantly affected by the build-up of phenylketonuria.

²⁸ This is due to the inability to synthesise phenylalanine ($C_9H_{11}NO$), an essential amino acid and one of the building blocks for protein in the body. The disorder is caused by a deficiency of the enzyme phenylalanine hydroxylase (PAH), which speeds up the conversion of the phenylalanine to tyrosine. If there is insufficient PAH, phenylalanine builds up and is converted into phenylketones, which are toxic in large concentrations. Brain damage can be controlled by diet, e.g. avoiding food high in phenylalanine (milk, nuts and fish). PKU occurs in approximately 11:100,000 babies in the UK. I Smith Cook B and M Besely 'Review of neonatal screening programme for phenylketonia' (1991) 303 BMJ 333, as mentioned by the UK Newborn Screening Programme Centre 2005, in their information sheet 'Why are newborn babies screened for phenylketonuria?' www.newbornscreening-bloodspot.org.uk last accessed 21 March 2015. Brain damage can be controlled by diet, e.g. avoiding food high in phenylalanine.

²⁹ UK Newborn Screening Programme Centre, 'Newborn blood spot screening in the UK: Policies and Standards' (April 2005) 8. Scotland had previously adopted the test in 1965.

³⁰ Congenital hypothyroidism (CHT), is a lack of the hormone thyroxine leading to permanent, physical and mental disability. CHT affects 1:3000 babies. <http://newbornbloodspot.screening.nhs.uk/cht> accessed 12 March 2015.

³¹ 1 in 1900 babies born in the UK has a sickle cell disease (SCD). This affects the red blood cells.

In 2010, a review ³⁴ was undertaken by the PHG Foundation ³⁵ as to whether certain conditions should be added to the current NBS screening.³⁶ The report noted that there is ‘much evidence to support expanding the existing provision of newborn screening to include a wider range of metabolic conditions within the UK, as a means of preventing death and severe disability’.³⁷ Following this report, testing for these conditions underwent trials, and four of the five conditions have since been incorporated into the UK NBS screening programme, namely Homocystinuria (HCU), Maple Syrup Urine Disease (MSUD),³⁸ Glutaric Aciduria type 1 (GA1),³⁹ and Isovaleric Acidaemia (IVA).⁴⁰

³² Cystic fibrosis: 1 in 2500 babies born in the UK has cystic fibrosis (CF). This is inherited and can affect the digestion and lungs. Babies with CF can be treated early with a high energy diet, medicines and physiotherapy. Although a child with CF may still become very ill, early treatment is thought to help them live longer, healthier lives.

³³ MCADD (medium-chain acyl-CoA dehydrogenase deficiency). About 1 in 10,000 babies born in the UK has MCADD. Babies with this inherited condition have problems breaking down fats to make energy for the body. This can lead to serious illness, or even death.

³⁴ Funded by the National Institute of Health Research and Collaboration for Leadership in Applied Health Research and Care, South Yorkshire (CLAHRC-SY).

³⁵ The working name of the Foundation for Genomics and Population Health.

³⁶ Hilary Burton and Sowmiya Moorthie, ‘Expanded Newborn Screening a review of the evidence’ (May 2010) www.phgfoundation.org Following recommendations from a working party, the conditions that underwent trials were Glutaric Aciduria Type1 (GA1), Homocystinuria HCU, Isovaleric Acidaemia (IVA), Long-Chain 3 hydroxyacyl CoA Deficiency (LCHADD), Maple Syrup Urine Disease (MSUD). http://clahrc-sy.nihr.ac.uk/images/genetics%20images%3Alogos/Newborn_Screening_Report.pdf 3 accessed 24 February 2015.

³⁷ *ibid.*

³⁸ With this condition, amino acids leucine, isoleucine and valine are left in the blood stream, causing a variety of health conditions. The disorder affects about 1 in 116,000 babies born in the UK. <http://newbornbloodspot.screening.nhs.uk/msud> accessed 15 March 2015.

³⁹ Glutaric aciduria type 1 (GA1) is a condition where lysine and tryptophan are not efficiently removed, leading to various minor/major illnesses. This condition affects about 1 in 110,000 babies born in Europe. <http://newbornbloodspot.screening.nhs.uk/ga1> accessed 15 March 2015.

⁴⁰ Here, leucine is not broken down. The disorder affects about 1 in 155,000 babies born in Europe. <http://newbornbloodspot.screening.nhs.uk/iva> accessed 15 March 2015. UK National Screening Committee (UK NSC), <http://newbornphysical.screening.nhs.uk/news.php?id=11442> accessed 2 June 2014, and the Press Release <http://www.screening.nhs.uk/meetings> accessed 2 June 2014. However see the minutes of the meeting for 24 November 2013, where at point 13.4 IVA was not recommended to be added. <http://www.screening.nhs.uk/meetings> accessed 2 June 2014.

Only one variety of CAH is considered to be a metabolic disease, namely 3-beta-hydroxysteroid dehydrogenase (3 β -HSD),⁴¹ and therefore CAH in general was not considered in this study. However, *all* of these non-intersex conditions have a significantly lower incidence in the UK than classic salt-wasting CAH. For example, HCU has an incidence of 1 in 144,000 births,⁴² whereas the incidence rate for Classic CAH is 1 in 18,000.⁴³ Not only does this appear to be statistically inequitable, but the lack of screening for CAH does not equate with international practice.⁴⁴ Further, potential screening for CAH has not even been recommended for imminent review, despite the fact that the Endocrine Society have recommended that *universal* newborn screening for 21-OH CAH should be incorporated into all newborn screening programmes.⁴⁵ That said, there are those who oppose the introduction of such testing due to concerns about inaccurate test results and prohibitive costs.⁴⁶ In order to assess whether those with CAH face discrimination as a result of non-testing, it is essential to examine both sides of the argument.

Screening for Long Chain Hydroxyacyl CoA Dehydrogenase Deficiency was also considered but not recommended. In the past CAH has not been recommended. This policy is currently under review but to date appears not to have been finalised.<http://www.screening.nhs.uk/congenitaladrenalhyperplasia> accessed 25 March 2015.

⁴¹ This is said to account for 3% of all cases of CAH, an incidence of 1 in 500,000. Steve Hannigan (ed) *Inherited Metabolic Diseases a guide to 100 Conditions*, Radcliffe Publishing Ltd 2007, 104.

⁴² <http://newbornbloodspot.screening.nhs.uk/hcu> accessed 12 March 2015. The disorder stops the decomposition of the amino acid homocysteine, which then builds up in the blood. This condition leads to long-term learning difficulties.

⁴³ JM Khalid and others, 'Incidence and Clinical Features of Congenital Adrenal Hyperplasia in Great Britain' (2012) 97 (2) Arch Dis Child 101.

⁴⁴ Including the US, New Zealand, Canada and the Philippines. Hilary Burton, Sowmiya Moorthie, 'Expanded Newborn Screening a review of the evidence' [May 2010] www.phgfoundation.org, 59, 61. In the Netherlands just three conditions are screened for – but one of them is CAH. J Gerard Loeber, 'Neonatal Screening Programmes in Europe is consensus Achievable or Unrealistic?' (2007) http://www.aecne.es/boletin/pdf/1_2.pdf accessed 24 March 2015. J Gerard Loeber, 'Newborn Screening in The Netherlands and Europe' (2012) <http://newbornbloodspot.screening.nhs.uk/cms.php?folder=2712#fileid11984> last accessed 4 May 2013.

⁴⁵ PW Speiser and others, Endocrine Society 'Congenital Adrenal Hyperplasia due to steroid 21-hydroxylase deficiency: An Endocrine Society Clinical Practice Guideline.' J Clin Endocrinol Metab, (2010) 95 (9) 4133

⁴⁶ This is discussed later in this chapter.

7.3.1 The Argument in Favour of Introducing NBS Screening for CAH

According to van der Kamp and Wit,⁴⁷ there are three benefits to be achieved by widespread screening for CAH. Firstly, it will potentially save the lives of those with severe salt-wasting CAH. Secondly, it will assist in the reduction of learning disabilities and behavioural problems which appear to occur after episodes of salt-wasting crisis. Thirdly, it will shorten the period of incorrect sex assignment.

Boys with 21-OH deficiency do not usually present with genital difference, therefore their condition is unlikely to be diagnosed immediately, in comparison with other metabolic deficiencies.⁴⁸ In fact, 21-OH CAH boys are not considered intersexed,⁴⁹ albeit their *children*, both male and female, will be carriers if not sufferers of the same condition.⁵⁰ As their condition lies hidden, CAH boys are vulnerable to an unexpected adrenal crisis (and possible death) during their first two weeks after birth.⁵¹ In this respect, non-testing for CAH in boys might be considered to put those with a 'protected characteristic'⁵² (in this case 'sex') at a particular disadvantage.⁵³ However, it is not just CAH boys who are vulnerable to non-detection.

In a survey conducted in Victoria, Australia, results showed that of the 32 males born with classic salt-wasting CAH from 1969 to 1993, 11 were diagnosed in the second week after birth, 8 in the third week, 6 in the fourth week and 5 after this time.⁵⁴ In

⁴⁷ Hetty J van der Kamp and Jan M Wit, 'Neonatal screening for Congenital Adrenal Hyperplasia' (2004) 151 (3) Eur J Endocrinology U71.

⁴⁸ Other CAH conditions such as Aldosterone Synthase deficiency do give rise to genital ambiguity in boys.

⁴⁹ Certainly their bodies are not 'intersexed' the surplus androgens that affect female genitalia *in utero* help to produce a 'normal' boy. The Senate Community Affairs References Committee, (Australia) also point out that very few CAH people are considered intersexed, regardless of whether they are male or female. 'Involuntary or Coerced Sterilisation of Intersex People in Australia' (2nd Report, 25 October 2013).
<http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Sec_Report/index 4.

⁵⁰ In this respect it can be argued that 21-OH CAH is an associated intersex condition.

⁵¹ D Török G Eckhardt, J Sólyom, 'Twenty Years Experience in Rapid Identification of Congenital Adrenal Hyperplasia' Eur J Pediat (2003) 162 (12) 844.

⁵² s19 (3) Equality Act 2010 specifies these as age, disability, gender reassignment, marriage and civil partnership, race, religion or belief, sex and sexual orientation.

⁵³ s 19 (2) (b) Equality Act 2010

comparison 29 out of 34 females were detected and treated early on, but one girl was only identified after an adrenal crisis in her fifth week, when additionally her genital differences were noted. Another 5 girls were diagnosed and treated later.⁵⁵

The importance of early detection of CAH should not be underestimated, as those with Classic CAH may otherwise die in early infancy. For example, in Croatia, where CAH appears to be more prevalent in their population than in the UK, it has been suggested that a ‘substantial number’ of boys with classic salt-wasting CAH die with their condition undetected, as a result of a salt-wasting crisis.⁵⁶ Likewise, a previous survey from Italy indicates that ‘even in a region with adequate neonatal services’, there is a risk of delayed diagnosis or misinterpreted results which could cause the death of a newborn baby.⁵⁷ This is confirmed by retrospective analysis of sudden infant death syndrome in the Czech Republic and Austria, which noted that 3 of the 242 subjects proved positive for Classic CAH.⁵⁸

Previous medical research has suggested that the introduction of neonate screening for CAH would aid the the long-term health of CAH sufferers, by diagnosing and treating the condition at this earlier stage.⁵⁹ Additionally, there are a number of CAH individuals who suffer from the milder virilising condition which does not manifest until later in life. In the interim, the body is subjected to an overdose of adrenaline. This in itself has long-term health implications.⁶⁰ Therefore, *prima facie*, neonatal testing appears to be an ethically acceptable procedure.

⁵⁴ Kate Brameld, ‘Congenital Adrenal Hyperplasia-the Australian Perspective.’ Office of Population and Genomics 31 July 2006.

⁵⁵ *ibid.* There have been several calls to include screening for 21-OH deficiency as routine in Australia, although as of writing, no state has incorporated this test into its screening programme. JY Wu Sudeep and others, ‘Is it time to commence Newborn Screening for Congenital Adrenal Hyperplasia in Australia?’ (2011) 195 (5) *Med J Aust* 260.

⁵⁶ K Dunic, and others ‘Classical Congenital Adrenal Hyperplasia due to 21-hydroxylase deficiency in Croatia between 1995 and 2006’ (2009) 72 (4) *Horm Res* 247.

⁵⁷ A Balsamo and others ‘Congenital Adrenal Hyperplasia; Neonatal Mass Screening compared with Clinical Diagnosis only in the Emilia-Romagna region of Italy, 1980-1995’ (1996) 98 *Paediatrics* 362.

⁵⁸ PW Speiser, (n 45).

⁵⁹ Tony Hunh and others, ‘The Clinical and Biochemical Spectrum of Congenital Adrenal Hyperplasia Secondary to 21-Hydroxylase Deficiency’ (2009) 30 (2) *Clin Biochem Rev* 75.

In order for NBS screening to be considered ethically acceptable, the net effect of the programme must indicate that beneficence outweighs the maleficence of any testing. According to Professor Loeber,⁶¹ there are three overall ‘categories’ that tests can be assigned to to assess whether they are ethically acceptable, the highest, ‘category 1’,⁶² being the prevention of ‘large irreversible damage’, the lowest, ‘category 3’, being damage occurring from the condition regardless of its detection. Loeber indicates that for all ‘category 1’ conditions, of which CAH is one, screening should take place unless there is sufficient evidence to the contrary.⁶³ By not *considering* testing for CAH, there appears to be discrimination, yet few countries have screening for CAH in their NBS programmes.⁶⁴ It is important to discuss why this might be the case.

7.3.2 Arguments Against Introducing NBS Screening for CAH,

7.3.2.1 Inaccurate Test Results

Widespread screening will not be introduced for a specific condition if screening results are prone to be inaccurate. Inaccuracy can occur in two ways. Firstly, the test may yield a false-positive result. This occurs where a test result indicates that the condition is present although the neonate does not in fact have that condition. If the test has a high level of *specificity*, a positive result means the person tested will have the condition.⁶⁵

⁶⁰A Thil'en and others, ‘Benefits of Neonatal Screening for Congenital Adrenal Hyperplasia (21-hydroxylase deficiency) in Sweden (1998) Paediatrics 101 (4).

⁶¹ J Gerard Loeber, ‘Newborn Screening in The Netherlands and Europe’ (2012) <<http://newbornbloodspot.screening.nhs.uk/cms.php?folder=2712#fileid11984>> accessed 4 May 2013

⁶² My nomenclature.

⁶³ Loeber (n 61). The Netherlands does have such screening.

⁶⁴ These include the US and New Zealand.

⁶⁵ Or to put it another way, if the test is 100% specific it means that all the patients without the disease/condition will be detected. Inevitably there will always be the occasion when a mistake occurs, but a test with a specificity of 99.9% is almost certain to indicate that the person tested has the condition *if* a positive result is recorded.

$$\text{Specificity} = \frac{\text{True Negatives}}{\text{True Negatives} + \text{False Positives}}^{66}$$

Secondly the test might yield a false-negative result, (where test results fail to indicate that a child does in fact have that condition). For a perfect test, only those with the condition tested for will yield a positive result. This is known as the sensitivity of the test. A test with 100 *per cent* sensitivity will correctly identify all patients with the condition, this is the ideal test. By comparison, a test with 80 *per cent* sensitivity will only detect 80 *per cent* of patients with the disease (true positives). Therefore, 20 *per cent* of those with the condition will go undetected (false negatives), and may become ill as a result of the lack of medical intervention.

$$\text{Sensitivity} = \frac{\text{True Positives}}{\text{True Positives} + \text{False Negatives}}^{67}$$

It has been alleged that test results for CAH are inaccurate.⁶⁸ In one respect this is true, as CAH is a *collection* of conditions caused by various gene mutations,⁶⁹ and it is not currently possible for one test to identify all the conditions. However, as the predominant cause of CAH is a 21-OH deficiency,⁷⁰ it is logical that routine screening for CAH focuses on this.⁷¹ In this respect, the indicative test results are promising. Screening of 21-OH deficiency has been estimated as having the

⁶⁶ Abdul Ghaaliq Lalkhen Anthony McCluskey, 'Clinical tests: Sensitivity and Specificity' (2008) 8 (6) *Contin Educ Anaesth Crit Care Pain* 221, 221.

⁶⁷ *ibid.*

⁶⁸ Vani Kilakkathi, 'Newborn Screening in America: Problems and Policies' [2012] *Council for Responsible Genetics*, 10.

⁶⁹ Variations include Lipoid adrenal hyperplasia, Aldosterone synthase deficiency, 3β-hydroxysteroid dehydrogenase deficiency, 11β-hydroxylase deficiency, 17α-hydroxylase deficiency.

⁷⁰ In the region of 90% of all cases.

⁷¹ This is the genetic variation that is normally screened for in countries where routine screening for CAH exists.

specificity of 99.5 per cent, resulting in false-positive results in 0.5 per cent of screened infants. Other surveys have indicated an even lower figure of false positives.⁷² Where a neonate has a positive result, the test will be re-done. This second test, which is usually taken in the following few weeks,⁷³ will usually confirm or eradicate the results. However, in the interim, parents are vulnerable to 'great emotional distress' after receiving a positive result,⁷⁴ and the stress on families during this time should not be disregarded.

In 1968, PKU Anxiety Syndrome was first identified amongst parents of neonates after a series of false-positive screening results were recorded.⁷⁵ This failing resulted in acute or chronic parental anxiety, leading to sleep difficulties, sadness in mothers, and breast-feeding difficulties. Until recently, very few studies were carried out as a follow-up to this.⁷⁶ In one study, carried out by Gurian et al.,⁷⁷ researchers discovered that overall stress levels in both mothers and fathers were higher if test results for their child yielded a false-positive, as compared with those whose child's results returned as normal. This, in itself, seems logical. Of more significance, this study indicated that only 35 per cent of mothers and 31 per cent of fathers knew and understood the reason for a *second* test where a false-positive reading had occurred.⁷⁸

⁷² An achievable false-positive rate of less than 0.2% has been indicated. Kate Brameld, 'Congenital Adrenal Hyperplasia-the Australian perspective.' Office of Population and Genomics 31 July 2006.

⁷³ Tests will vary, but if a baby is thought to have PKU parents will 'usually be contacted before the baby is 3 weeks old ... for CF ... 4 weeks,... for sickle cell ... 6 weeks'. NSC, NHS screening programmes, Screening tests for You and your Baby' (2012/2 version) 67.

⁷⁴ Vani Kilakkathi, 'Newborn Screening in America: Problems and Policies' [2012] Council for Responsible Genetics, 9.

⁷⁵ MB Rothenberg and EM Sills, 'Iatrogenesis: the PKU anxiety syndrome' (1968) 7(4) J Am Acad Child Psychiatry 689.

⁷⁶ Elizabeth A Gurian, and others 'Expanded Newborn Screening for Biochemical Disorders: The Effect of a False-Positive Result.' (2006) 117 Pediatrics 1915, 1916. Although an earlier study from the 1980s found that there was no marked increase in parental distress with false-positive results, only confusion because of the lack of literature/information given. JR Sorenson and others, 'Parental response to Repeat Testing of infants with 'false-positive' results in a Newborn Screening Program.' (1984) 73 Pediatrics 183.

⁷⁷ Gurian (n 76), 1918.

⁷⁸ *ibid.*

Mothers who knew the reason for the second test produced a lower reading on the parenting stress index (PSI), as compared with those who did not know the reasons. There appeared to be no significant PSI difference for fathers, regardless of knowledge or not. When asked how the screening process could be made more positive, '61 per cent of parents expressed a need for more information about newborn screening and the test result'.⁷⁹ This research concluded that in the most part 'parents revealed a lack of understanding' of expanded newborn screening.⁸⁰ This is unsurprising, as other research has revealed that 'providers' ability to communicate about newborn screening is poor in both training and in primary care settings'.⁸¹ In this respect, there appears to be a need for further education, and redrafting of screening guidance for parents.

As screening for 21-OH deficiency has the specificity of 99.5 per cent, only a small minority of non-CAH babies will have false-positive results and be sent for further testing (0.5 per cent). The exception to this appears to be preterm babies. Evidence adduced from France indicates that a significant number of false-positive test results occur in premature babies. Consequently, the authors of the report recommended that screening in preterm neonates should be discontinued.⁸² This is not such a severe problem as might be initially thought as other research has indicated that CAH *prolongs* rather than shortens the gestational age;⁸³ consequently, CAH is far less likely to be a factor in preterm births. If this research is accurate it implies that all

⁷⁹ *ibid.*

⁸⁰ *ibid.*, 1919.

⁸¹ Ellen A Lipstein and others, 'Impact of False-positive Newborn Metabolic Screening results on early healthcare utilization' (2009) 11(10) *Genetics in Medicine* 716, 719. Indeed the information supplied by the NBS UK is very general. It reads, 'Occasionally the midwife or health visitor will contact you and ask to take a second blood sample from your baby's heel. This may be because there was not enough blood collected, or the result was borderline or unclear. It may also be because your baby was premature – in babies born at less than 32 weeks of pregnancy; the routine day 5 test may not pick up congenital hypothyroidism. It is advised to have another test either at 28 days of age or immediately before the baby is discharged home, whichever comes first. Usually the repeat results are normal.' <http://newbornbloodspot.screening.nhs.uk/faqs#fileid12598> accessed 12 March 2015.

⁸² Bénédicte Coulm and others 'Efficiency of Neonatal Screening for Congenital Adrenal Hyperplasia Due to 21-Hydroxylase Deficiency in Children Born in Mainland France between 1996 and 2003.' (2012) 166 (2) *Archives of Pediatrics and Adolescent medicine* 113.

⁸³ Jackie O'Sullivan and others 'Congenital Adrenal Hyperplasia due to 21-hydroxylase deficiency is associated with a prolonged gestational age.' (2007) 92 *Arch Dis Child* 690.

children who arrive after the projected 40 weeks should be tested for CAH as of right, even if there is a reluctance to introduce widespread screening.

Although the *specificity* of CAH testing appears satisfactory, the *sensitivity* is arguably not so good, with an estimated range between 92 and 100 per cent.⁸⁴ In other words, potentially up to 8 per cent of Classic CAH babies will not show as positive after testing (although some research results suggest it is nearer to 99.6 per cent).⁸⁵ If the lower figure of 92 per cent is the accurate figure, this means that some children will be initially cleared for CAH, only to be diagnosed after falling ill.⁸⁶ Additionally, up to 33 per cent of those with non-classical CAH will not be identified at this early stage through NBS screening.⁸⁷ This concern has raised questions about the validity of any tests done overall, and has been used as a reason not to introduce widespread screening for CAH. However, new techniques, including the incorporation of molecular testing, have added to the accuracy of testing.⁸⁸

As inaccurate results can occur with any condition, in this respect CAH results appear to be more accurate than for GA1.⁸⁹ Therefore 'inaccurate' results do not seem to be an adequate reason for not introducing the testing for CAH as part of the NBS

⁸⁴ Nejat Mahdih, Bahareh Rabbani and Ali Rabbani,, '21-Hydroxylase Deficiency: Newborn Screening in Iran?' (2012) 22(3) Iran J Pediatr 279.

⁸⁵ Perrin C White, 'Neonatal Screening for Congenital Adrenal Hyperplasia', (2009) 5 Nat Rev Endocrinol, 498. Doi:10.1038/nrendo.2009.148 accessed 23 May 2015. White specifies that aggregated data from the US 2003-2007 indicate CAH results to have a sensitivity of 98.9% and specificity of 99.6%

⁸⁶ BL Therrell and others, 'Results of screening 1.9 million Texas newborns for 21 hydroxylase-deficient Congenital Adrenal Hyperplasia' (1998) 101 Paediatrics 583.

⁸⁷ F Votava and others, 'Estimation of the false-negative rate in Newborn Screening for Congenital Adrenal Hyperplasia. (2005) 152 (6) Eur J Endocrinol 869.

⁸⁸ K Sarafoglou and others, 'Molecular testing in Congenital Adrenal Hyperplasia due to 21 α hydroxylase Deficiency in the era of newborn Screening (2012) 82 (1) Clin Genet 64.

⁸⁹ 'Tandem mass spectrometry was found to be more than 93.33% sensitive and more than 99.42% specific. The screening test proved to be very simple and economical.' Ruby P Babu and others, 'Detection of glutaric acidemia type 1 in infants through tandem mass spectrometry' (2015) 3 MGM Reports 75 <http://www.sciencedirect.com/science/article/pii/S2214426915300069> accessed 23 May 2015. Compare this with Tandem mass spectrometry results from White (n 85), where CAH results are 98.9% sensitive and 99.6% specificity.

programme. It seems beneficent to identify as many CAH babies as possible, especially when the alternative situation may lead to death or brain damage.⁹⁰

7.3.2.2 Prohibitive Cost?

In the annual UK NSC Report for 2011-2012, Anne Mackie stipulates that ‘we must demonstrate that investing in screening is a wise use of money and will provide significant health benefits’.⁹¹ The constant striving to reduce expenditure has led to tensions in many areas of healthcare, but is particularly prominent in proactive, as opposed to reactive, healthcare. Ironically, preventative measures might prove to be more cost-effective in the long run.

The downside of widespread screening is that although the costs are relatively cheap on an individual basis, taken as a whole they have a significant financial implication. Overall costs are worked out on a price per positive rating. It has been indicated that the general assumption is that a particular screening programme will be considered cost-effective if the unit price is less than 50,000 US dollars (USD) per life-year saved.⁹² The estimates relating to CAH vary wildly. One source indicates the figure of 20,000 USD per life-year saved,⁹³ whilst a Swedish study estimated that for each patient diagnosed with CAH, the cost amounted to 53,400 USD.⁹⁴ Further, an American survey suggested that the actual cost was more than double the cost produced by the Swedish survey, and was in fact nearer to 115,169 USD per patient diagnosed.⁹⁵ A later Texan survey indicated an estimate for screening of 200,000 to 300,000 USD per life-year saved.⁹⁶ These wildly fluctuating figures do nothing to help CAH screening to be implemented. However, despite the apparently large costs involved, during the last four years all US states have passed legislation requiring

⁹⁰ Nejat Mahdiah (n 84).

⁹¹ UK NSC Annual Report Screening in England 2011-2012, 8.

⁹² Speiser (n 45)

⁹³ *ibid.*

⁹⁴ Brameld (n54) 4.

⁹⁵ *ibid.*

⁹⁶ White (n 85).

testing for CAH to be a legal obligation on parents.⁹⁷ Screening not only prevents avoidable deaths, but early detection of CAH can also enhance quality of life by identifying the need for medical intervention before long-term damage occurs. In this respect it has been reported that the benefit of NBS screening for CAH can be estimated at ‘\$20,357 per quality adjusted life-year gained’.⁹⁸

The national and international approach to en masse testing for CAH can be compared with the current approach in the UK, and beyond, to testing for PKU. As with CAH, PKU is an autosomal recessive condition. There are approximately 11 babies born with PKU in every 100,000 births,⁹⁹ a figure not dissimilar to the ratio of children born with CAH in the UK.¹⁰⁰ However, unlike testing for CAH, the general screening for PKU has been described as providing ‘a positive net monetary benefit to society (which) justifies the collection of blood samples from neonatal infants’.¹⁰¹ Various authors have identified that the financial benefits of testing for PKU include money saved in treatment, nursing care and special education, and avoiding loss of income. To confirm this viewpoint, the majority of states in the US enacted laws to regulate testing for PKU some 30 years before adding CAH testing to their lists.¹⁰²

⁹⁷ National Newborn Status Screening Report updated 09/06/12
<http://genes-r-us.uthscsa.edu/sites/genes-r-us/files/nbsdisorders.pdf>

Legislation is passed on a state by state basis. Some states will allow parents to refuse testing on religious grounds.

⁹⁸ Rachel L Knowles et al. ‘Late clinical presentation of Congenital Adrenal Hyperplasia in older children: Findings from National Paediatric Surveillance’ *Arch Dis Child* (2014) 99: 30-34, 33 quoting from AE Carroll SM Downs ‘Comprehensive cost-utility analysis of Newborn Screening Strategies’ (2006) 117 *Pediatr* 287.

⁹⁹ I Smith, B Cook and M Besely ‘Review of Neonatal Screening Programme for Phenylketonia’ (1991) 303 *BMJ* 333, as mentioned by the UK Newborn Screening Programme Centre 2005 in their information sheet ‘Why are newborn babies screened for phenylketonuria?’ www.newbornscreening-bloodspot.org.uk last accessed 24 March 2013.

¹⁰⁰ The incidence of PKU is twice as high in Northern Ireland as in England and Wales. CA Seymour and others, ‘Newborn Screening for Inborn Errors of Metabolism: A Systematic Review’ (1997) 11 *Health Technology Review*, 9.

¹⁰¹ *ibid* iv. For the cost analysis benefit of testing for PKU see also X Gu and others, ‘A Cost-benefit Evaluation of Neonatal Screening for Phenylketonuria and Congenital Hypothyroidism (2000) 34(3): *Zhonghua Yu Fang Yi Xue Za Zhi* (Chinese Journal of Preventative medicine) 147 and E Sladkevicius and others, ‘Cost Effectiveness of Establishing a Neonatal Screening Programme for Phenylketonuria in Libya’ (2010) 8(6): *Applied Health Economy Policy* 407.

¹⁰² In all states testing is a mandatory requirement, with only Maryland and Wyoming requiring explicit informed consent from the parents to allow testing to proceed.

Whilst noting that it is admirable that NBS screening identifies serious conditions, it is unclear why the detection of PKU is honoured but the idea of detecting CAH is dismissed.

According to Khalid et al., 27 newborns were diagnosed with CAH in the UK between August 2007 and January 2009.¹⁰³ Of these 27, some 18 children, of which 16 were boys, were not diagnosed until after they were admitted into hospital with a salt-wasting crisis, some two weeks after their birth. The authors conclude that approximately 70 per cent of newborns who first present with a salt-wasting crisis would be detected earlier through newborn screening in the UK,¹⁰⁴ saving death or brain damage to those children.¹⁰⁵ Further, as previously mentioned, early detection benefits *all* CAH sufferers, whether they have the Classic or non-classic presentation, in that early medication assists overall growth and development.¹⁰⁶ Consequently, it seems inequitable that PKU testing is offered routinely in the UK, whereas testing for CAH remains elusive.

Regardless of indications, the cost of adding CAH to the NBS programme would not be significant. According to the UK NSC Report for 2011-12, the total cost of screening in the UK was £400 million a year,¹⁰⁷ yet out of this the cost for NBS screening was only £1,693,457.¹⁰⁸ Further, the report from 2013-14 indicates that in England NBS screening during this financial year came to £1,093,749.¹⁰⁹ If these figures are correct, it seems a paltry sum to spend when compared with the significance of saving lives. Although less than four per cent of classic salt-wasting

¹⁰³ JM Khalid and others, 'Incidence and Clinical Features of Congenital Adrenal Hyperplasia in Great Britain' (2012) 97 (2) Arch Dis Child 101.

¹⁰⁴ *ibid*

¹⁰⁵ Mahdiah (n 83).

¹⁰⁶ A Thil'en and others, 'Benefits of Neonatal Screening for Congenital Adrenal Hyperplasia (21-hydroxylase deficiency) in Sweden (1998) Paediatrics 101 (4) ; Rachel L Knowles and others 'Late clinical presentation of Congenital Adrenal Hyperplasia in older children: Findings from National Paediatric Surveillance' (2014) 99 Arch Dis Child 30, 33.

¹⁰⁷ UK NSC 'Annual Report Screening in England 2011-2012,' 8.
www.screening.nhs.uk/getdata.php?id=14375

¹⁰⁸ *ibid*, 30. (The figures appear to be incorrect on this page. The figure given is the lesser one of £704,698.)

¹⁰⁹ Public Health England 'NHS Screening Programmes in England 2013-2014' <http://www.screening.nhs.uk/publications> accessed 24 May 2015. 23

CAH children will die as a result of non-diagnosis,¹¹⁰ in advanced economic societies it is unacceptable for even that percentage to die if a simple test can prevent it. Further, screening for CAH will also promote the lifelong health of those with milder forms of the condition, as earlier medication assists in decreasing a number of unpleasant effects of the condition such as virilisation in girls, whilst normalising growth¹¹¹ and assisting puberty and fertility.¹¹² It is also suggested that these children will benefit from an improved psychosocial situation.¹¹³ To conclude, looking at the evidence on this issue, it appears that by not offering routine screening, children with CAH are left vulnerable to live-threatening events and/or long-term health implications. Consequently, they face discrimination.

7.4 Consideration of NBS Screening for Sex Chromosome Anomalies

I now consider the current practice of not incorporating routine screening for sex chromosome anomalies as part of neonatal testing regimes. Such conditions occur as a result of an addition or deletion of sex chromosomes. For the purposes of this chapter Klinefelter Syndrome (KS) has been chosen as a study. Not only is KS the most prevalent sex chromosome aneuploidy detected in humans but, additionally, a number of KS boys identify as ‘intersexed’.¹¹⁴ Ironically, although the condition is comparatively common, it is still ‘significantly under-diagnosed’.¹¹⁵

¹¹⁰ SD Grosse, G Van Vliet, ‘How many Deaths can be Prevented by Newborn Screening for Congenital Adrenal Hyperplasia?’ (2007) 67 *Horm Res* 284.

¹¹¹ Ashraf T Soliman and others, ‘Congenital Adrenal Hyperplasia Complicated by Central Precocious Puberty: Linear Growth During Infancy and Treatment with Gonadotropin-Releasing Hormone Analog’ (1997) 46 (5) *Metabolism* 513.

¹¹² A Thil’en (n 106).

¹¹³ *ibid.*

¹¹⁴ In comparison with girls with Turner Syndrome who do not consider themselves intersexed.

¹¹⁵ Nicole Tartaglia and others, ‘48,XXYY, 48,XXXY and 49,XXXXY Syndromes: Not Just Variants of Klinefelter Syndrome’ (2011) 100(6) *Acta Paediatr* 851.

An English survey conducted by Abramsky and Chapple during the 1990s estimated that only 36 per cent of men with KS will be detected during their lifetime.¹¹⁶ Of these 36 per cent, less than ten per cent of XXY cases were diagnosed prenatally.¹¹⁷ Of more concern, studies have revealed that the majority of KS men never know of their condition. Danish studies indicated that only 25 per cent of KS men were likely to be diagnosed in total.¹¹⁸ Other researchers appear to accept this latter, lower figure.¹¹⁹ By comparison girls born with the karyotype 45, X0, Turner Syndrome (TS) appear to be more frequently diagnosed, but not all TS girls are identifiable from physical appearances at birth and these children are likely to benefit from an earlier diagnosis.¹²⁰

7.4.1 The Importance of Testing for KS at Birth.

Physical anomalies which demark an adult with KS¹²¹ are not apparent in male neonates or young boys. Therefore KS children who have not been detected during routine pregnancy tests are unlikely to be diagnosed before they start school. Even at this point, many boys with KS remain unnoticed, often to the detriment of their health and education. Unsurprisingly, those with 48XXYY, 48XXXY or 49XXXXY karyotype are likely to face more physical difficulties than those with standard KS, and may be diagnosed at an earlier stage. Conversely, those with a mosaic form of the condition 46/47XY/XXY are less likely to be detected at all. This is of concern as it leaves KS men vulnerable to physical, social and educational difficulties – some of

¹¹⁶ L Abramsky and J Chapple '47 XXY (Klinefelter Syndrome) and 47 XYY: Estimated Rates of an Indication for Postnatal Diagnosis with Implications for Prenatal Counselling (1997) 17 *Prenat Diagn* 363.

¹¹⁷ *ibid* 365. As discussed in chapter six, a significant number of XXY fetuses are aborted due to their genetic arrangement.

¹¹⁸ Anders Bojesen and others, 'Prenatal and Postnatal Prevalence of Klinefelter Syndrome: A National Registry Study' (2003) 88(2) *J Endocrinol Metab* 622.

¹¹⁹ Seda Purnak and others, 'Diagnosis of Variant Klinefelter Syndrome in a 21-Year-Old Male Who Presented with Sparse Facial Hair' (2012) 24(3) *Ann Dermatol* 368.

¹²⁰ Mayo Clinic Staff, 'Turner Syndrome: Symptoms' <http://www.mayoclinic.org/diseases-conditions/turner-syndrome/basics/symptoms/con-20032572> accessed 23rd March 2015.

¹²¹ This includes tall stature, long legs or arms and the lack of secondary sexual characteristics.

which may be resolved by early diagnosis. For example, the KS child's education can be affected if they are not identified before school age.¹²²

Although there are no accurate statistics to specify how many KS males are detected during their education, statistics that are available indicate that the majority of KS boys will remain undetected throughout their school life.¹²³ This is partly due to the usual presentation of the condition itself. Whereas some KS boys will catch the teachers' attention by displaying symptoms of ADHD,¹²⁴ ('fidgeting' or 'tuning out' if the teacher is giving complex oral instructions),¹²⁵ most KS boys are submissive in demeanour and go unnoticed in the classroom. That is until their unexpectedly poor performance in tests attracts their teachers' attention. Originally, these lower test results led to the belief that KS males had inferior IQs compared to their non-KS peers; this now appears not to be the case.¹²⁶ In fact, most KS boys have average to superior intelligence,¹²⁷ but they do not usually perform as well as non-KS boys under test conditions,¹²⁸ partly due to their difficulties in assimilating language skills. In this regard, an estimated 25 to 85 per cent of KS males have learning or language-related problems.¹²⁹ For example, KS males are slower in developing speech and

¹²² J Visootsak and J M Graham 'Social function in multiple X and Y chromosome disorders: XXY, XYY, XXYY, and XXXY' (2009) 15(4) *Developmental Disabilities Research Reviews*, 328. As quoted by the National Institute for Child Health and Human Development, US Department of Health and Human Development www.nichd.nih.gov/health/topics/klinefelter/.../Pages/symptoms.aspx accessed 25 November 2013.

¹²³ Only 1 in 10 boys are detected before puberty. Eunice Kennedy Shriver, National Institute of Child Health and Human Development, 'How do Health Care Providers Diagnose Klinefelter syndrome (KS)?' <https://www.nichd.nih.gov/health/topics/klinefelter/conditioninfo/Pages/diagnosed.aspx#fl> referring to research conducted by L Aksglaede and others, 'Clinical And Biological Parameters in 166 Boys, Adolescents and Adults with Nonmosaic Klinefelter Syndrome: A Copenhagen Experience.' (2011) 100 (6) *Acta Paediatr* 793.

¹²⁴ Martin Herbert *Developmental Problems of Childhood and Adolescence* (Blackwell 2005) 23.

¹²⁵ National Institute for Child Health and Human Development (n123).

¹²⁶ MG Linden, BG Bender and A Robinson, 'Genetic Counseling for Sex Chromosome Abnormalities' (2002) 110(1), *Am Jour Med Gen*, 3; DH Geschwind and E Dykens, 'Neurobehavioral and Psychosocial issues in Klinefelter Syndrome' (2004). 19(3) *Learning Disabilities Research & Practice*, 166.

¹²⁷ Richard Boada and others, 'The Cognitive Phenotype in Klinefelter Syndrome: A Review of the Literature Including Genetic and Hormonal Factors.' (2009)15(4) *Dev Disabil Res Rev* 284.

¹²⁸ Herbert (n 124) 23; JL Ross and others, 'Cognitive and Motor Development during childhood in boys with Klinefelter Syndrome' (2008)146A(6) *Am J Med Genet* 708.

consequently receive speech therapy.¹³⁰ Likewise, the KS child's ability to read and write is often delayed in comparison with their peers.¹³¹ Additionally, some KS children have poor short-term auditory memory, and poor data retrieval skills.¹³²

The accumulation of these difficulties leads to lower than expected test results. This continues throughout schooling, leading to frustration for KS adolescents. They then develop low self-esteem, which leads to anxiety and insecurity about life in general. It is also frustrating for schools that lack specialised training to identify such a child, and cater for their needs. This is even more unacceptable as modifying teaching to support KS boys need not be costly. Simple teaching techniques such as using pictures and gestures when teaching, and generally speaking more slowly in the classroom, help overall learning for young XXY boys.¹³³

In a structured interview, Connie, the mother of 15-year-old Charlie with XXYY syndrome, explained her exasperation at being ignored by key workers in regard to Charlie's condition.¹³⁴ As an early years' worker herself, Connie was aware that Charlie was not following traditional developmental patterns for his age, but did not know how to identify the specific problem, nor was any advice forthcoming from the school when they were approached. Instead, Charlie was 'ignored throughout his reception year'.¹³⁵ It was only after Charlie's condition had been identified, around the age of six years, that Charlie received the correct educational support.¹³⁶

¹²⁹ Herbert (n 124) 23.

¹³⁰ Jeannie Visootsak and John M Graham Jnr, 'Klinefelter Syndrome and other Sex Chromosomal Aneuploidies' [2006] OJRD 42.

¹³¹ Herbert (n 124) 23.

¹³² *ibid*; JL Ross and others, 'Cognitive and Motor Development during childhood in Boys with Klinefelter Syndrome' (2008) *Am J Med Genet* 708.

¹³³ Deanna Todd-Goodson, 'Klinefelter Syndrome: The Learning Disability Connection, Western Oregon University 47xxy.com/.../THE_LEARNING_DISABILITY_CONNECTION.PD... last accessed 24 March 2012.

¹³⁴ Interview with Connie, mother of Charlie (anonymity preserved) (Dover 17 September 2012).

¹³⁵ *ibid*.

¹³⁶ Charlie now receives education in a special school.

The same was true for Nyall,¹³⁷ a university student, who also had difficulties with his early schooling. His chromosomal arrangement of XYY led to surges of testosterone being released which Nyall admits made him ‘angry’ at times during school, particularly when experiencing pain during growth spurts. Nyall’s diagnosis around the age of 12 ensured that he received the necessary medication to cope physically, and consequently his studies improved.

For both Charlie and Nyall, their early difficulties could have been prevented had their conditions been diagnosed at birth. In both cases, their conditions improved when medication was started. Some never receive this medication. This is unfortunate as KS men face a number of health issues during their lives, including an increased risk of breast cancer,¹³⁸ extragonadal germ cell tumour, lung disease, varicose veins and osteoporosis.¹³⁹ Men who have KS also have an increased risk of autoimmune disorders such as lupus and rheumatoid arthritis.¹⁴⁰ Some of these conditions might be prevented (or at least ameliorated) if testosterone was given during puberty. Although medical trials are still lacking in this area,¹⁴¹ it has been indicated that if started before the age of 20,¹⁴² testosterone injections will increase strength and promote muscular development and improve academic concentration.¹⁴³

Andrew¹⁴⁴ tells his story in regard to having his diagnosis confirmed at a comparatively late stage in his life. He explains that he is ‘very bitter’¹⁴⁵ not to have found out sooner why he had so many physical illnesses, including osteoporosis and

¹³⁷ Interview with Nyall (anonymity preserved) (Buckingham 14 November 2013).

¹³⁸ KS men tend to have enlarged nipples and increased breast tissue.

¹³⁹ For one person’s account see ‘Andrew’s Story: The Buck Stops With Me’ NHS National Genetics and Genomics Education Centre <http://www.tellingstories.nhs.uk/index.php/joy-story?id=212> accessed 15 May 2015.

¹⁴⁰ *ibid.*

¹⁴¹ Anders Bojesen and Claus H Gravholt, ‘Review Nature Clinical Practice Urology’ (2007) 4 (4) *Nature* 192, 201.

¹⁴² Herbert (n 124) 24.

¹⁴³ Anders Bojesen and others, ‘Prenatal and Postnatal Prevalence of Klinefelter Syndrome: A National Registry Study’ (2003) 88(2) *J Endocrinol Metab* 622.

¹⁴⁴ Andrew’s Story (n 135).

¹⁴⁵ *ibid.*

diabetes. Furthermore, not only does he have to cope with such illnesses but he is also exceptionally frustrated that, apart from his consultant, ‘no one has a clue as to what KS is’.¹⁴⁶ Likewise, Stefan says that ‘being diagnosed with KS (at the age of 25) has been, for the most part, a big sigh of relief after a life of frustrations’.¹⁴⁷ It appears that all sufferers, and their parents, would have valued an earlier diagnosis.

As discussed in chapter 3, there are numerous intersex/DSD conditions that are not evident at birth. In addition to neonates with intersex/DSD sex chromosome anomalies, testing for karyotypes at birth will identify those who have a congenital disjunction of internal and external sex anatomy (46, XY DSD) such as Complete and Partial Androgen Insensitivity Syndrome (CAIS and PAIS) and 5 alpha-reductase deficiency (5-ard). Albeit these children are likely to be identified in their lifetime, (at puberty if not before), identification at birth may improve physical health and social wellbeing by treating the condition steadily throughout life, rather than forcing the child to undergo ‘emergency’ treatment upon the discovery of testes in infancy,¹⁴⁸ or a ‘larger than acceptable’ clitoris.¹⁴⁹ It will be noted that the lack of testing for such conditions can be considered a form of indirect discrimination as it has a disproportionately adverse impact upon identifiable groups.

According to Hughes et al.,¹⁵⁰ only 20 per cent of those with a DSD condition will receive a specific genetic diagnosis. Further, only 50 per cent of all people with a 46XY Intersex/DSD condition will be diagnosed. This is significant as the differing conditions lead to differing gender identity outcomes in adulthood. Whereas those

¹⁴⁶ *ibid.*

¹⁴⁷ Stefan Schwarz ‘Living with Klinefelter Syndrome’ <http://klinefeltersyndrome.org/Stefan.htm> accessed 27 May 2015. Email from Stefan Schwarz to author (27 May 2012).

¹⁴⁸ Testes are often discovered in early childhood for girls with CAIS as a result of inguinal hernias.

¹⁴⁹ Which in reality is a micropenis.

¹⁵⁰ IA Hughes and others, ‘Consensus statement on Management of Intersex Disorders (2006) 2 (3) *Journal of Pediatric Urology* 148.

with CAIS are ‘almost universally’ brought up as female,¹⁵¹ remaining in this gender identity throughout their lives, the same does not hold true for those with 5-ard.¹⁵²

Scientific studies indicate that quality of life is enhanced when a diagnosis is made at an early stage, for two reasons. Firstly, medical treatment, if appropriate, can be considered at an early stage; secondly, parents can raise their intersex/DSD child in the full knowledge of their condition and their potential physical development. An early diagnosis of a discordant phenotype/karyotype arrangement will alert healthcare practitioners to seek the actual diagnosis for the condition. If such a condition is discovered at an early stage, the child will benefit from an openness of rearing, and will be given the support, both socially and medically, to transition from the female phenotype to the male phenotype (or vice versa) should such a situation occur.

Failure to ensure an adequate system of testing for various intersex conditions in the UK may be considered a breach of Article 2 of the European Convention on Human Rights (ECHR), the Right to Life,¹⁵³ which has to be secured without discrimination by virtue of Article 14 of the ECHR.¹⁵⁴ Further, this appears to be a failure to comply with the Equality Act 2010. As a government department, the Department of Health

¹⁵¹ Amy Wisniewski, ‘Gender Development in 46,XY DSD: Influences of Chromosomes, Hormones, and Interactions with Parents and Healthcare Professionals’ [2012] *Scientifica* (Cairo).; 2012: 834967. Published online 2012 September 19. doi: [10.6064/2012/834967](https://doi.org/10.6064/2012/834967)

¹⁵² *ibid.*

¹⁵³ Article 2, Right to Life:

1. Everyone’s right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.
2. Deprivation of life shall not be regarded as inflicted in contravention of this article when it results from the use of force which is no more than absolutely necessary: a. in defence of any person from unlawful violence; b. in order to effect a lawful arrest or to prevent the escape of a person lawfully detained; c. in action lawfully taken for the purpose of quelling a riot or insurrection. (None of these would apply here.)

¹⁵⁴ Article 14: Prohibition on Discrimination. The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.

has a duty under section 149 Equality Act 2010,¹⁵⁵ the public sector equality duty, to take into account the need to:

- (a) eliminate discrimination, harassment, victimisation (...);
- (b) advance equality of opportunity (...);
- (c) foster good relations between persons who share a relevant protected characteristic and persons who do not share it.

All these components would be satisfied if an organised and advertised system of testing for sex chromosome anomalies were introduced into the NSC programme.

7.5 Conclusion

In conclusion, the UK's current lack of neonatal screening for intersex/DSD conditions where genital difference does not occur can be considered indirect discrimination. By not promoting tests for these 'hidden' conditions, the NSC is responsible for potentially reducing the quality of physical life for sufferers. Crucially it also inadvertently reduces their social/emotional quality of life by suppressing societal knowledge of such conditions.

Regardless of whether NBS testing is introduced for CAH or blood testing introduced for chromosomal anomalies, it is clear that the dearth of information regarding these and all other intersex conditions continues to stigmatise. In order to mitigate the confusion and distress that occurs during pregnancy and on arrival of a neonate with intersex/DSD conditions, healthcare providers can assist by discussing such conditions during antenatal classes. This will prove no easy task. One flaw of antenatal classes is that, by their nature, they focus on labour and birth rather than on events *after* the birth.¹⁵⁶ Further, face-to-face antenatal classes are being phased out in certain regions,¹⁵⁷ whilst in other areas there appears to be a general lack of

¹⁵⁵ This came into force 5 April 2011. Department of Health Equality and Diversity Webpage, <https://www.gov.uk/government/organisations/department-of-health/about/equality-and-diversity> accessed 6 June 2014.

¹⁵⁶ This I have experienced for myself.

¹⁵⁷ For example, there was controversy regarding York Hospital's decision to offer an online antenatal course as opposed to face-to-face classes. It was alleged that this was because the hospital offered three sessions for mothers, but attendance had dropped to only 25% of those who were eligible. Kate Liptrot, 'York Hospital to replace Antenatal Classes with "Virtual classes"' *The Press* (York, 24 September 2013), also *Metro* (London 25 September 2013) 11.

awareness that such classes take place. It has been stated that ‘nobody knows about them. The midwives in my area don't bother telling new mums they exist.’¹⁵⁸ Further, of those who have been invited to classes, statistics suggest that only one-third attend.¹⁵⁹ Even if parents-to-be do attend classes, they may not receive information on the ‘not-so-good’ experiences surrounding labour, birth and after. They are unlikely to be prepared for the arrival of an intersexed child. Further, even if information were to be available, parents may not want to know. One organisation notes that they have had ‘considerable feedback from women that their antenatal care is often too focused on potential problems, which increases stress and hence may lead to worse outcomes’.¹⁶⁰ Regardless of this, in the event of an intersexed child being born, or identified in childhood, parental fear can be alleviated if the parents are informed that although uncommon, their child’s intersex/DSD condition is not unique.

7.5.1 Recommendations

It is submitted that, in regard to CAH, an appropriate approach to adopt would be the incorporation of CAH testing into the standard UK NBS programme. If this is considered too costly to be introduced for all neonates, then as a minimum requirement, free screening for CAH of all neonates born after 41 weeks should be introduced.¹⁶¹

All evidence obtained, both from structured interviews and a review of the literature, indicates that once born, the benefits of a child being detected with a sex

¹⁵⁸ Post by Gosportgirlie, Hampshire, 25 September 2013 <http://www.dailymail.co.uk/health/article-2430476/York-Hospitals-online-antenatal-lessons-country.html> accessed 14 March 2014.

¹⁵⁹ A particular concern is that vulnerable women (teenage mothers, victims of domestic abuse, drug users and non-English speakers) are least likely to attend antenatal classes. Nick Trigg, ‘Vulnerable pregnant Women ‘miss out on antenatal care’ BBC news 22 September 2010 <http://www.bbc.co.uk/news/health-11381123> accessed 14 March 2014.

¹⁶⁰ Email from AIMS to author (3 September 2012).

¹⁶¹ In addition, those children born early as a result of induction of labour should be tested. As discussed previously, CAH sufferers tend to have a longer gestation period, but obviously if labour is brought forward it will be impossible to tell when the child would have been born without medical intervention. If widespread cffDNA testing for CAH is introduced, then testing at birth should no longer be needed.

chromosomal anomaly far outweigh conflicting interests. No research was identified indicating that it is better for these conditions to remain undetected. Therefore it is submitted that, in regard to sex chromosome anomalies, an appropriate approach to adopt would be the incorporation of such testing into the standard UK NBS programme. This would be seen to be in accordance with the government's framework in the NHS Outcomes Mandate, which amongst other statements wishes to stop premature death and enhance quality of life.¹⁶² Early diagnosis of all conditions would promote better quality of life through social and educational enhancement, as well as healthcare interventions.¹⁶³ Although there would be a substantial cost to the NHS initially, the savings from preventing significant healthcare issues by early detection is likely to offset the cost of the initial testing. Both Nyall and Connie expressed their firm support for early testing. Nyall said, 'the healthcare system should offer a package of testing so that parents will know straightaway (...) even if the parents have to pay for it'.¹⁶⁴ I agree.

Finally, it is imperative that all expectant mothers and their partners have 'easy and timely access' to clear and comprehensive literature on newborn screening.¹⁶⁵ This should include details on conditions that may *not* be routinely screened for, including CAH and sex chromosome anomalies. Whilst acknowledging that the NHS/NSC resources are limited, the very least that should be offered during antenatal visits is the *option* for parents to pay for a 'package' of such testing at birth.

¹⁶² The NHS Constitution, NHS England, 'Planning for Patients 2014/15 to 2018/19' <http://www.england.nhs.uk/wp-content/uploads/2013/12/5yr-strat-plann-guid.pdf>, 7 accessed 15 March 2015.

¹⁶³ Whilst it is likely that this will be achieved via the new technique of analysis of cell-free fetal DNA, this technique is not readily available, nor is it without ethical concerns. Without detailed literature and counselling, it may increase the number of therapeutic abortions that take place should sex chromosome anomalies be identified in routine pregnancy testing, therefore this method of detection could be said to be directly discriminatory in itself.

¹⁶⁴ Interview with Connie, mother of Charlie (anonymity preserved) (Dover, 17 September 2012); Interview with Nyall (anonymity preserved) (Buckingham 14 November 2013).

¹⁶⁵ Gail Pittam Martin Allaby, 'Informed Consent in Antenatal and Newborn Screening: a Report for the UK National screening Committee' (January 2012) www.sph.nhs.uk/publications available through <http://www.screening.nhs.uk/publications> accessed 24 May 2015.

Chapter Eight: Conformity: Early Childhood and Enforced Operations

8.1 Introduction

In the previous chapter it was noted how, as a result of not being tested for specific conditions at birth, those with various intersex conditions face indirect discrimination by being denied the opportunity for early proactive health intervention. The overall aim of this chapter is to assess whether English law discriminates against neonates and young children who, born with genital difference, face immediate intensive testing and potential surgical intervention, often without valid parental consent. In particular, the issue of discrimination will be examined in the light of current legal failings to offer specific protection against unnecessary and intrusive treatment regimes in comparison to other vulnerable groups, such as those with mental incapacity and young women at risk of undergoing Female Genital Mutilation (FGM).

This chapter commences by investigating the routine tests that take place hours after birth, and highlights concerns in regard to the acquisition of valid consent for testing and surgical interventions. The chapter then considers current legal protection afforded to three different clusters of genital procedures, namely male circumcision, sterilisation operations and FGM, to consider whether the supporting established legal safeguards can be used to protect those born with genital difference. The final aim of this chapter is to offer suggestions as to how English law might be best modified to serve the needs of intersexed children who may face surgical intervention.

8.2 Consent and Emergency Neonatal Testing

The arrival of a neonate with genital difference will stun parents; the trauma of such a discovery has been described as second only to perinatal death.¹ Some will ask,

¹ Katrina Karkazis, *Fixing Sex: Intersex, Medical Authority, and Lived Experience* (Duke University Press 2008) 123, quoting Y Low and I M Hudson 'Rules for Clinical Diagnosis in Babies with Ambiguous Genitalia' (2003) 39 (6) *Journal of Paediatrics and Child Health* 406.

‘What the hell did I give birth to?’² Others will be ‘sad and nearly speechless’.³ In addition to this, some of these children will be awarded the ‘emergency status’, signalling immediate operations.⁴ In such situations parents’ capacity to give consent will be diminished.⁵ The shock of giving birth to a child with genital difference is likely to haunt parents for the rest of their lives. As one doctor notes:

The parents are absolutely floored by this. They’ve never heard of it before. They’re just shocked, and they want to know the sex of the baby. It would make our jobs a bit easier if people had already heard about it, because you have to totally educate them (...).⁶

In addition to the discovery that their baby has an intersex condition, limited knowledge of such a condition, along with a mixture of hormone fluctuations, emotions and sheer physical exhaustion, will place new mothers in an ‘especially vulnerable position’.⁷

A rapid number of tests will be performed within the first two days after birth to identify the child’s sex. These tests include fast-track blood testing to identify the child’s karyotype, electrolyte balances and levels of various hormones in the body.⁸

² Ibid 91.

³ William G Reiner and others, ‘Partial Androgen Insensitivity Syndrome’ [2005] 7 (11) *Virtual Mentor*.

⁴ *ibid*. There may be occasions when an intersex child is in need of emergency medical treatment, but that is rarely due to the intersex condition in its own right. For example, it will be needed straightaway if the urethra is blocked – a situation that can occur in a non-intersexed child.

⁵ Louise Moody and others, ‘Parental Views on the Provision of Informed Consent for Expanded Newborn Screening’ Applied Research Centre Health and Lifestyles Interventions, Coventry University, www.coventry.ac.uk/.../ICBMper cent202010per cent20Moodyper cent20v2.pptx accessed 24 March 2012.

⁶ Karkazis (n 1) 125.

⁷ Intersex Society of North America, *Clinical Guidelines for the Management of Disorders of Sex Development, Consortium on the Management of Disorders of Sex Development* (2006) 13. <http://www.dsdguidelines.org/files/clinical.pdf> accessed 24 March 2015.

⁸ Namely gonadotropins (luteinising hormone and follicle stimulating hormone) and testosterone.

Alongside blood testing, doctors may request pelvic scans.⁹ These tests aim to identify physical structures that lie within the abdomen, and to assess the direction of the urine stream.¹⁰ Occasionally a baby will need emergency corrective surgery (regardless of genital difference) and therefore such tests assist surgical planning.¹¹ From the fourth day after birth, doctors will test for 17-hydroxyprogesterone (17-OH), to discover if the baby has Congenital Adrenal Hyperplasia (CAH).¹²

At this point, there is no apparent discrimination against the intersexed, as tests will be carried out for all neonates who present with extreme physical anomalies, regardless of whether they have genital difference or not. However, a deeper investigation notes that these tests are often used to identify the ‘sex’ of the child, rather than the ‘condition’ that the child has. Literature has suggested that, in the past, an almost indecent haste to identify the child’s sex eroded parental involvement.¹³ All testing *should* involve parental counselling and consent, but difficulties arise when clinicians offer varying professional opinions. As one parent notes, ‘(w)e were listening to what these experts were saying to us, but each one was coming in at different times saying different things’.¹⁴ Other parents have been told

⁹ A number of techniques are utilised here: genitography which involves x-raying the pathway of a contrast medium injected into the urogenital sinus, ultrasound and magnetic resonance imaging (MRI) scans.

¹⁰ For a full discussion of the various techniques involved, see Murray Bartlett, ‘Imaging in DSD’ in John M Hutson, Garry L Warne and Sonia R Groves (eds) *Disorders of Sex Development, An Integrated Approach to Management* (Springer 2012).

¹¹ Although genitography for patients about to undergo genitoplasty may have limited value. BA Vanderbrink and others, ‘Does Preoperative Genitography in Congenital Adrenal Hyperplasia Cases affect Surgical Approach to Feminizing Genitoplasty?’ (2010) 184 (4) J Urol, 1793.

¹² Although there are several different enzyme malfunctions that can cause CAH, the most common is the lack of 17-OH. A build-up of 17-OH would indicate an absence of this enzyme.

¹³ Karkazis (n1), Julie Greenberg ‘International Legal Developments Protecting the Autonomy Rights of Sexual Minorities: Who Should Decide the Appropriate Treatment for an Intersex Child?’ in Sharon Sytsma (ed) *Ethics and Intersex* (Springer 2006) 87, 99.

Nancy Ehrenreich and Mark Barr, ‘Intersex Surgery, Female Genital Cutting, and the Selective Condemnation of “Cultural Practices” (2005) 40 Harvard Civil Rights – Civil Liberties Law Review 71, 128 http://www.law.harvard.edu/students/orgs/crcl/vol40_1/ehrenreich.pdf accessed 18 April 2015.

¹⁴ Tamara Dawson as interviewed by Karkazis (n 1) 124.

that their baby's condition is unique,¹⁵ consequently acquiescing with doctors' recommendations.¹⁶ Some were not even consulted.¹⁷

It is submitted that it would be unusual for any parent to think rationally if their baby appears to have any life-threatening condition, but healthcare staff need to ensure that they explain the nature of the difficulties. Greenberg recommends *inter alia*¹⁸ that parents are provided with complete written information about their child's condition, including details concerning genital surgery, along with contact information for intersex support groups. In the event of potential surgery, parents need time to discuss all salient details with an expert. When a child is seriously ill staff may justifiably argue that they do not have time for long discussions, and they are prone to forgetting their legal obligations. An operation will be unlawful without valid consent.¹⁹

8.3 Early Genital Assignment Surgery

Current justifications for early genital assignment can be subdivided into two main categories –those which 'normalise' external genitalia and those which alter internal structures. Until fairly recently, 'normalising' operations were routinely carried out at an early age on intersexed children. This has frequently caused gender dysphoria in later life.²⁰ In a study conducted by Diamond and Watson, 33 per cent of a group of Partial Androgen Insensitivity Syndrome (PAIS) individuals changed their assigned gender in adulthood. Diamond notes that two of the group who were originally

¹⁵ Dawn Vago, who has Androgen Insensitivity Syndrome, explained her parents' dilemma. Sarah Morrison, 'Special report: Intersex women speak out to protect the next generation' *The Independent*, Saturday 30th November 2013 <http://www.independent.co.uk/news/uk/home-news/special-report-intersex-women-speak-out-to-protect-the-next-generation-8974892.html> accessed 24 December 2015.

¹⁶ Karkazis (n 1) 209.

¹⁷ 'They [the hospital staff] just don't bother with you, they were focused on my son, and if I went out for some fresh air, by the time I came back in, they had got my son and were doing something else to him, without explaining why – never mind asking for my permission.' Interview with Parent S (London, 3 August 2011).

¹⁸ Julie Greenberg, 'Legal Aspects of Gender Assignment' (2003) 13 (3) *The Endocrinologist*, 277, 285.

¹⁹ Doctors might believe that they have the blanket protection of *Re F (mental patient: sterilisation)* [1990] 2 AC 1 HL if they act in the 'best interests' of the child. However, it will be hard to justify that acting without parental knowledge and consent is in the overall best interests of any neonate.

²⁰ PW Speiser and others, 'Congenital Adrenal Hyperplasia due to steroid 21-Hydroxylase Deficiency: An Endocrine Society Clinical Practice Guideline.' (2010) 95 (9) *J Clin Endocrinol Metab*, 4133.

assigned female were ‘particularly bothered that, without their knowledge or informed consent, they were castrated and subject to vaginal reconstructive surgery’.²¹ In practice, it may take a number of months to identify the true sex and gender of a child with genital difference, and certain conditions will not fully settle until adolescence when alterations to hormone levels affect the body. Regardless of this, there remain a number of specialists who believe it best to operate at an early age.

In her book *Intersex*, Catherine Harper reports an interview conducted in 2005 with Mr Philip Ransley, a Consultant Paediatric Urologist.²² Often the subject of criticism for the operations he performs, Mr Ransley ‘sees his role as delivering what society has requested’,²³ namely ensuring that a child is ‘male’ or ‘female’. He justifies early intervention by adding that testosterone surges occur in neonates with ovotestis around day 10 and day 60, and will masculinise the children. In his opinion, it is essential to make a rapid decision to act ‘in the first two weeks of life’.²⁴

It is easy to appreciate Mr Ransley’s viewpoint, as societal desire to identify and perfect a child’s sex is embedded in English law. Not only do parents and healthcare workers wish to ascertain the ‘sex’ of the baby, but also current legislation demands it. In the words of Elizabeth Reilly ‘(s)imply, starkly, the law mandates an answer – every child must be male, or female’.²⁵ Therefore, even if parents and medical teams

²¹ Milton Diamond and Linda Ann Watson, ‘Androgen Insensitivity Syndrome and Klinefelter’s Syndrome, Sex and Gender Considerations’ (2004) 13 *Child Adolesc Psychiatr Clin N Am* 623. <http://www.hawaii.edu/PCSS/biblio/articles/2000to2004/2004-ais-and-klinefelters.html> accessed 17 June 2014.

²² Catherine Harper, *Intersex* (Berg, 2007) 32.

²³ *ibid.*

²⁴ *ibid* 33.

²⁵ Elizabeth Reilly, ‘Radical Tweak – Relocating the Power to Assign Sex: From Enforcer of Differentiation to Facilitator of Inclusiveness: Revising the Response to Intersexuality’ [2005] 12 *Cardozo JL& Gender* 297. In this article, Reilly comments on the current US law regarding birth records. These give three categories of ‘sex’ on the initial form, namely Male, Female or Not yet determined. It stipulates on the form that if the record is filed with an ‘N’ code, the record has to be sent to the National Center for Health Statistics (NCHS), but that the hospital must be queried until ‘a determination’ is made. In other words, it is not possible to use the ‘N’ code indefinitely. Dep’t of Health & Human Serv., Ctr. for Disease Control & Prevention, Birth Edit Specifications for the 2003 Revision of the U.S. Standard Certificate of Birth, Item 3, 2 (2005) <http://www.cdc.gov/nchs/data/dvs/FinalBirthSpecs3-24-2005.pdf>. <[http%3a/www.avss.ucsb.edu/layouts/NCHScode.pdf](http://3a/www.avss.ucsb.edu/layouts/NCHScode.pdf)> accessed 10 October 2013.

are prepared to wait, there is considerable legal pressure for a child's sex to be identified straight away.²⁶

Those born with genital difference will face further invasive action. Surgeons frequently remove gonads from intersex children in the hope that this will prevent cancer at a later stage. Research does not necessarily support this assumption;²⁷ in fact, there remains considerable debate as to when operations should occur, if at all.²⁸ This leaves the parents of a child with genital difference extremely vulnerable to coercion for the sake of social conformity. Likewise, healthcare practitioners may feel unsupported and rushed into decision making by parents. Whilst acknowledging the need to act in the 'best interests' of the child, the swift move to surgery at such an early stage may prove counterproductive, if not 'catastrophic'.²⁹ It is important that the best genotype/phenotype alignment is secured to assist the *future* health of the intersex child, not only the present.

It has been noted that such procedures invariably occurred not with valid consent as such, but rather with some degree of acquiescence. This is demonstrated by the lack of court cases in the UK on this issue.³⁰ Suffice it to say that in England, currently, there is no specific legal precedent regarding issues of informed consent and the legality of reassignment surgery and/or gonadectomy of children with genital

²⁶ This will be discussed in detail in the concluding chapter.

²⁷ According to the AISSG website, patients with gonadal dysgenesis (with either a 46XY or 45X/46XY karyotype) seem to be the most at risk of malignancy, in the region of 30%, if gonadectomy has not been performed. By comparison, those with CAIS face a more limited risk of 0.8%, rising to 15% for those with PAIS. Crucially, tumours do not occur before puberty, and therefore there appears to be no medical need for an early gonadectomy, particularly when retaining testes appears to enhance the health of a woman with CAIS or PAIS by reducing the need for HRT. AISSG, 'Overview – Gonadectomies' Overview http://www.aissg.org/32_GDCTOMY.HTM accessed 31 March 2015.

²⁸ *ibid.*

²⁹ Dr Ian Aaronson, 'The Investigation and Management of the Infant with Ambiguous Genitalia: a Surgeon's Perspective' (2001) 31 *Curr Prob Pediat* 168, as quoted by Ryan L White, 'Preferred Private Parts: Incorporating Intersex Autonomy for *MC v Aaronson*' (2014) 37 *Fordham International Law Journal* 777, 807. Dr Aaronson is, ironically, the defendant in this case.

³⁰ And very few globally. The notable exceptions are the three Columbian cases, two cases in Germany and one case in the US. The US case is still unresolved. A discussion of this last case can be found in Ryan L White, *ibid.*

difference. Should parents wish to challenge doctors (or vice versa) on such a specialised area, it would be difficult to anticipate the decision resulting from legal action. The logical approach for the courts would be to refer to legislation and previous case law regarding similar operations, such as gonadal and genital removal, rearrangement or reconstruction, and more significantly to cases on irreversible non-therapeutic measures.

In this respect, three distinct ‘medical’ procedures will now be discussed, namely male circumcision, female circumcision, now referred to as FGM, and sterilisation. All of these procedures have experienced jurisprudential and/or legislative consideration, and all mirror operations that those with genital difference may undergo.

8.3.1 Male Circumcision

Although circumcision is not often thought of as a dangerous medical procedure, it is interesting to note that two fundamental ‘intersex’ studies have arisen as a result of the castration of a ‘normal’ male during routine circumcision. One of these boys was David Reimer, aka Brenda, the famous twin who Money, incorrectly, heralded as a success of his gender allocation programme,³¹ and the other being the subject of the ‘Gonzalez’ case.³² Although neither of these individuals challenged the act of circumcision itself, these stories indicate just how serious circumcision can be. Further, a number in infants have died as a result of circumcision.³³

Regarding ritual male circumcision, a conflict arises between Article 24.3 of the UN Convention on the Rights of the Child³⁴ and Article 9.2 of the European Convention on Human Rights (ECHR), which protects the rights of individuals to practise their

³¹ As discussed in chapter four.

³² Sentencia No T-477/95, as discussed in chapter five.

³³ Karen Dyer ‘Lessons from Germany: Should UK legislation Circumnavigate or Circumvent the issue of Male Circumcision? Judgment of the Landgericht Cologne May 7th 2012 and its Aftermath.’ (2013) 25 Denning Law Journal, 225.

³⁴ Ratified by the UK Government in 1991, it specifies that ratifying states should ‘take all effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children’.

religion. In the UK, for a number of years, the General Medical Council ³⁵ stipulated that doctors are not obliged to carry out requests for non-therapeutic circumcisions, with the caveat that they must explain that they are opposed to it if it is not carried out for medical reasons. Subsequently, faced with ever-increasing anger at the circumcision of young males,³⁶ the British Medical Association (BMA) produced guidance for doctors.³⁷ This states that ‘parental preference alone’ is insufficient reason for this operation. Further, where there are opposing views on non-therapeutic circumcision from those with parental responsibility, a precedent has now been set in *Re J (child’s religious upbringing and circumcision)*.³⁸ As J was able to inform the Court that he did not wish to undergo the procedure, the Court was content to support his refusal. In this respect, it appears that the Court will be happy to listen to the child, provided the procedure is non-therapeutic and that doctors are not demanding treatment. While it can be argued that there is *some* justification for male circumcision if the child is to be initiated into a faith group, such procedures for no sound medical or indeed spiritual reason cannot be said to be in the child’s best interests. Some activists would argue that circumcision is a criminal offence, even if considered *medically* necessary.³⁹ The most notable case on ritual circumcision is a German decision in 2012.⁴⁰ In an ‘astonishingly novel’ judgment,⁴¹ the Cologne Court ruled that non-medical male circumcision met the requisite requirement for the criminal law on battery,⁴² *even if* performed with the consent of both parents.⁴³

³⁵ GMC, ‘Guidance for doctors who are asked to circumcise male children’ September 1997 http://www.gmc-uk.org/guidance_circumcise_1997.pdf_25416429.pdf accessed 12 November 2011.

³⁶ G Boyle and others, ‘Circumcision of Healthy Boys: Criminal Assault?’ (2000) 7 *Journal of Law and Medicine* 301.

³⁷ BMA, ‘The Law and Ethics of Male Circumcision Guidance for Doctors’ June 2006.

³⁸ *Re J (child’s religious upbringing and circumcision)* [2000]1 FCR 307.

³⁹ ‘If “medical necessity” is claimed, we suggest that such a claim is invariably fraudulent. Since in Finland, and in other countries, which have a zero rate of male circumcision at birth, and the risk of needing one later is one in sixteen thousand, six hundred and sixty-seven (1/16,667), every claim for “medical necessity” should fully investigated.’ Canadian Children’s Rights Council *Circumcision of Males / Females* http://www.canadiancrc.com/Circumcision_Genital_Mutilation_Male-Female_Children.aspx accessed 24 March 2015.

⁴⁰ *LG Köln judgment No 151 Ns 169/11*, Monday 7 May 2012. www.justiz.nrw.de/nrwe/lgs/koeln/lg_koeln/j2012/151_Ns_169_11_Urteil_20120507.html

⁴¹ Dyer (n 33) 231.

⁴² As specified by section 223(1) of the German Criminal Code, the *Strafgesetzbuch*.

Although neither of the cases discussed above is a direct parallel to reconstructive surgery applied to an intersex neonate, they serve as a timely reminder. Some male neonates will need penile surgery immediately,⁴⁴ but if the foreskin is completely removed at this stage, long-term complications can occur should the skin be needed for reconstructive surgery at a later date. It is advisable in these circumstances that circumcision is not conducted until it is known for certain that the foreskin will not be needed again.

It can be seen that circumcision, a relatively simple procedure, gives rise to deep anger amongst various parties. It is therefore unsurprising that genital operations enforced on young intersexed children have been at the centre of furious debates, particularly as additional surgery performed frequently renders the patient sterile. Unsurprisingly, in recent years intersex activists have called for an end to such procedures.⁴⁵

8.3.2 Sterilisation

Although there is no English judicial authority on the sterilisation of the intersexed, a parallel can be drawn with the operations carried out on other ‘vulnerable’ people, namely the mentally incompetent. In this respect, it is useful to note the role of the Official Solicitor.⁴⁶

Appointed under section 90 of the Senior Courts Act 1981,⁴⁷ the Official Solicitor’s role is ‘litigation friend’, to speak on behalf of the vulnerable, be it the mentally incapacitated or minors. The Official Solicitor is the litigation friend of ‘last resort’,

⁴³ This case caused uproar in Germany at the time, and the German Government was quick to act to ensure that religious groups were pacified.

⁴⁴ As discussed in chapter three, a related condition is hypospadias. This will often require surgical alteration. The foreskin needs to be maintained for use in the surgery.

⁴⁵ Third International Intersex Forum. Appendix A.

⁴⁶ The Official Solicitor is an independent statutory office holder, supporting those who are legally or mentally incapacitated. The Official Solicitor tends to be a post of last resort, when no other litigation friend can be found. The post only operates in England and Wales.

⁴⁷ s90 (1) There shall continue to be an Official Solicitor to the Senior Courts, who shall be appointed by the Lord Chancellor. As amended by the Constitutional Reform Act 2005.

where no one else is able to speak on behalf of the party,⁴⁸ and will aim to determine the ‘best interests’ of the litigant they protect. As will be seen in the following contrasting cases, the judges seemed to be swayed by the persuasive nature of the arguments given by those holding that role.

When considering the aspect of sterilisation, the starting point in English law is the case of *Re F (mental patient: sterilisation)*⁴⁹ which considered the sterilisation of a mature mentally incapacitated woman. In this case, the Court found in favour of the operation being carried out as it was felt to be in the ‘best interests’ of the woman. Likewise, in *Re W (an adult: sterilisation)*,⁵⁰ Hollis J approved the operation to sterilise a 20-year-old mentally incapacitated woman with severe epilepsy. In this case the judge accepted that pregnancy would have a detrimental effect on all concerned, and again, in *Re X (adult patient: sterilisation)*,⁵¹ the Court granted the declaration in respect of a 31-year-old woman who was severely mentally disabled.

By comparison, in *Re LC (medical treatment: sterilisation)*,⁵² Thorpe J dismissed the application by a local authority to sterilise a 21-year-old woman with an intellectual age of three and a half. One of the arguments against the operation was the high standard of care she was receiving in her local authority care home. Further, the court, in the case of *Re A (male sterilisation)*,⁵³ noted that it would not be in the best interests of A (a 28-year-old man with Down's syndrome) to be sterilised at that specific time. Although this case predated the Human Rights Act, reference was made to A's right to privacy and to found a family. Lady Justice Butler-Sloss noted that as the ECHR was due to have direct application in English domestic law imminently, the courts should be careful to ensure that everyone's rights were protected, not just those who could speak for themselves. It can therefore be seen that courts will protect mentally incompetent adults from sterilisation if a valid argument

⁴⁸ Alistair Pitblando, Official Solicitor, ‘Practice Note’, 1st March 2013 <https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/355822/ospt-practice-note.pdf> accessed 24 March 2015.

⁴⁹ [1990] 2 AC 1 HL at 55 (*F v West Berkshire Health Authority*).

⁵⁰ [1993] 2 FCR 187.

⁵¹ [1999] 3 FCR 426.

⁵² [1997] 2 FLR 258.

⁵³ [2000] 1 FLR 549.

is put forward by the litigation friend. This protection has not been awarded to incompetent intersexed children.⁵⁴

In Australia, the issue of parental consent to sterilisation treatment on behalf of mentally handicapped children was the focus of *Marion's Case*.⁵⁵ Here, it was decided that parental consent would not be valid 'unless for the child's best interests'. On the facts of this case, the court found that such a procedure appeared to be purely of interest to her parents, rather than to the child. It was stated that:

If a parent purports to give consent to treatment which is not for the welfare of the child, the consent is of no effect. A person who acts on such 'consent' is guilty of assaulting the child if the treatment involves any physical interference with the child.⁵⁶

The Australian case of *Re A* ⁵⁷ concerned a 14-year-old who had CAH. Although originally designated as female, this child developed a male identity and wished to undergo surgical procedures to match his phenotype with his gender orientation. Parents and surgeons supported this, but as the operations would sterilise the child, court approval was required.⁵⁸ The court was none too happy to grant approval, preferring to adopt a 'wait and see' approach. However, in the end the court was persuaded that it was in the child's best interests to undergo surgery imminently, for fear of long-term psychiatric harm if a delay occurred.

⁵⁴ A similar position in California has been confirmed by Tamar-Mattis, who identifies that Californian Law, whilst protecting the mentally incompetent adults from sterilisation procedures, is 'deplorably behind' in allowing procedures which involuntarily sterilise intersex children. Anne Tamar-Mattis, 'Sterilization and Minors with Intersex Conditions in California Law' (2012) 3 California Law Review Circuit, 126.

⁵⁵ (*Sterilization of an Intellectually Disabled Child*) (*Department of Health and Community Services v JWB and SMB* (1992) 175 CLR 218).

⁵⁶ *ibid* at 316 (McHugh J).

⁵⁷ 16 FLR 715 (Family Court of Australia) 1993.

⁵⁸ The previous year had seen *Marion's Case* (*Sterilization of intellectually disabled child*) (*Department of Health and Community Services v JWB and SMB* (1992) 175 CLR 218), in which it was said If a parent purports to give consent to treatment which is not for the welfare of the child, the consent is of no effect. A person who acts on such 'consent' is guilty of assaulting the child if the treatment involves any physical interference with the child (McHugh J) 316.

This case is an example of overzealous protection of the child. All the interested parties were in favour of the operations, but the judge had difficulty understanding the concept behind the request. As Greenberg points out, ‘judges are unlikely to have the knowledge to decide these issues, (...) allowing one judge to determine the appropriate treatment for a child with an intersex condition may not always be ideal’.⁵⁹ This should be borne in mind when considering legal decision making in the UK.

This case was recently evaluated in *Re Jamie*,⁶⁰ which considered the plight of a ten-year old boy who wanted to undergo gender assignment. Due to his age the boy was not *Gillick* competent and this proved to be the key issue in this case. It was stated that there were two stages of treatment that the child would have to undergo. ‘Stage one’ involved hormone treatment, which was fully reversible. By comparison, ‘stage two’ required irreversible surgery. Relying on *Marion’s Case*, the judge decided that she could only authorise ‘stage one’ treatment at that time and could not authorise any irreversible treatment until the child was deemed to be *Gillick* competent.

On appeal, the court considered whether, in general, such treatment was a medical procedure requiring court authorisation pursuant to the court’s welfare jurisdiction under s 67ZC of the Family Law Act 1975. It was decided that court authorisation for medical treatment of non-*Gillick* competent children and young people is required when the treatment is invasive, permanent and irreversible and when there is ‘a significant risk of a wrong decision being made as to the child’s capacity to consent to treatment, and where the consequences of such a wrong decision are particularly grave’.⁶¹ The court further noted that such authorisation would not be needed if the child was *Gillick* competent, but it remained for the court to decide whether the child was at that level of maturity. The ‘best interests’ of the child were to remain paramount.

In theory this appears to support those children born with genital difference, but a

⁵⁹ Julie A Greenberg, *Intersexuality and the Law – Why Sex Matters* (NYU Press 2012) 41.

⁶⁰ *Re Jamie* [2013] FamCAFC 110 on appeal from *Re Jamie (special medical procedure)* [2011] Fam CA 248.

⁶¹ *ibid* [196] Strickland J.

new case, suggests that the intersexed remain as vulnerable as before. In *Re Sarah*⁶² a 16-year-old had been diagnosed with 45X/46XY TS within the previous year. Her mother sought a declaration that Sarah was competent to consent to a gonadectomy. As previously mentioned, this procedure is frequently promoted for an intersex child to prevent cancer developing. Such was the case here.⁶³ An independent children's lawyer was appointed, who supported the application. In court, Macmillan J first turned to whether the procedure was one which required court authorisation, and found that this was not necessary as the procedure was a therapeutic one, and therefore *not* in the category established by *Re Jamie*. Only at the request of those concerned did the judge turn her attention to the aspect of competence of the child.

This case shows the potential weakness in such decisions. Should all argue that sterilisation at an early age is in the 'best interests' of a child, then the court will authorise the procedure regardless of the future desire of the child in question. Here, it appears that all parties, including 'Sarah', were in agreement, but this may not be the case for every child.

Although a number of English cases have upheld the bodily integrity of a mentally disabled person, there are no cases currently in UK law that uphold the rights of an intersex child in relation to non-reversible sterilisation procedures. As seen by the Australian cases, the result of such a case would focus on the 'best interests' of the child. In this respect, it is submitted that medical opinion would be relied on. This may not be in the best interests of the child overall. Consequently, it appears that the intersexed remain vulnerable to court decisions to allow unwanted intervention.

It is now essential to assess whether any legislation has been enacted in the UK which can assist in promoting the integrity of the child with genital difference. In this respect, the Female Genital Mutilation Act 2003 (FGM Act 2003) will be investigated.

⁶² *Re Sarah* [2014] Fam CA 208.

⁶³ It should be noted that a higher risk of malignancy occurs in these patients, in the region of 30% or higher, therefore removal of gonads for these patients is not disproportionate. AISSG, 'Overview – Gonadectomies' Overview http://www.aiissg.org/32_GDCTOMY.HTM accessed 31 March 2015.

8.3.3 Female Genital Mutilation (FGM) and the Intersexed

Defined by the World Health Organisation (WHO) as ‘all procedures involving partial or total removal of the external female genitalia or other injury to the female genital organs whether for cultural or other non-therapeutic reasons’,⁶⁴ FGM is perhaps the closest area of comparison as an intrusive medical procedure to enforced operations on the intersexed.

Originally referred to as female circumcision, the term FGM was first coined during the 1970s.⁶⁵ However, it took until 1990 for the term to be more widely adopted. This occurred at the third conference of the Inter African Committee on Traditional Practices Affecting the Health of Women and Children, in Addis Ababa. In the following year, WHO recommended that the United Nations adopt the term FGM, as ‘(t)he use of the word “mutilation” (...) helps to promote national and international advocacy towards its abandonment’.⁶⁶

All of the four ‘types’ of FGM involve the total or partial removal of the clitoris.⁶⁷ Not one of these has any medical benefits attached to it; in fact the reverse. The

⁶⁴ World Health Organization, ‘Female Genital Mutilation: a Joint WHO/UNICEF/UNFPA statement’, WHO, Geneva. 1997
www.childinfo.org/files/fgm WHOUNICEFJointdeclaration1997.pdf accessed 14 June 2015.

⁶⁵ Unicef, *Innocenti Digest Changing a Harmful Social Convention: Female Genital Mutilation/Cutting* (2008) 1 www.unicef-irc.org/publications/pdf/fgm_eng.pdf accessed 25 March 2015.

⁶⁶ World Health Organization, ‘Eliminating Female Genital Mutilation, an Integrated Statement’ (2008)22
<http://www.un.org/womenwatch/daw/csw/csw52/statements_missions/Interagency_Statement_on_Eliminating_FGM.pdf> accessed 25 March 2015.

⁶⁷ Nahid Toubia, ‘Female Circumcision as a Public Health Issue’ (1994) 331 N Engl J Med 712 <http://www.nejm.org/doi/full/10.1056/NEJM199409153311106> accessed 14 June 2014.

Type I is the removal of the prepuce (the clitoral hood which surrounds and protects the head of the clitoris) with or without the total or partial removal of the clitoris itself. It is often known as ‘Sunna mutilation’ or *Sunna Kashfa* (meaning open sunna). This technique is performed most frequently in West African countries. Type II involves the complete removal of the clitoris, and additionally the complete or partial removal of the labia minora. This technique is referred to as ‘Excision’ or *Sunna Magatia* (closed sunna). It is most commonly found in Burkina Faso and Sudan. Type III, known as ‘Infibulation’, involves the removal of the clitoris and prepuce, and removal of the labia minora, and often the labia majora as well. The vulva is then ‘sewn up’, leaving only a small opening to allow urine and menstrual blood to pass. This procedure is commonly practised in Egypt, Ethiopia, Gambia, Mali and Somalia, and is the ‘predominant type of FGM practised in Sudan’. M Ellaithi and others, ‘Female Genital Mutilation of a Karyotypic Male presenting as a Female with Delayed Puberty.’ [2006] BMC Women’s Health, <http://www.biomedcentral.com/1472-6874/6/6> accessed 14 June 2014. Type

majority of the procedures, some several million conducted annually, will be carried out by non-medically trained personnel in unhygienic environments. Some girls die as a result of blood loss during the operation or from resulting infections.⁶⁸ Even if they survive, most women will suffer some type of associated lifelong complication such as recurrent bladder and urinary tract infections, cysts, infertility and an increased risk of complications during childbirth.⁶⁹

Despite these effects, FGM has become ingrained into cultural practice, notably in Africa.⁷⁰ The primary motivating factor to undergo such procedures appears to be the desire to conform to societal rituals. In Sierra Leone, for example, they ‘regard uninitiated indigenous women as an abomination fit only for the worst sort of sexual exploitation’.⁷¹ Likewise, in north-eastern Kenya, Masaai girls state that they want to be circumcised because ‘no-one talks to, let alone marries a girl who is not circumcised’.⁷² The fear of being physically different, and consequently socially ostracised, leads to the continuation of FGM. A similar fear of rejection has led a number of CAH females to undergo cliterodectomies, sometimes at the instigation of doctors and parents, and sometimes at the instigation of the girls themselves.

IV is considered to be a more extreme of Type III, but also can include pricking, piercing, cauterization and ‘introduction of corrosive substances into the vagina’. World Health Organization, ‘Female Genital Mutilation: a Joint WHO/UNICEF/UNFPA statement’, WHO, Geneva. 1997 www.childinfo.org/files/fgmc_WHOUNICEFJointdeclaration1997.pdf accessed 14 June 2015.

⁶⁸ Unicef, *Innocenti Digest Changing a Harmful Social Convention: Female Genital Mutilation/Cutting* (2008) p 16 www.unicef-irc.org/publications/pdf/fgm_eng.pdf accessed 25 March 2015.

⁶⁹ World Health Organization, ‘Female Genital Mutilation: a Joint WHO/UNICEF/UNFPA statement’, WHO, Geneva. 1997 www.childinfo.org/files/fgmc_WHOUNICEFJointdeclaration1997.pdf accessed 14 June 2015.

⁷⁰ I specify ‘cultural’ as opposed to ‘religious’ as there appears to be conflicting opinions regarding the religious inheritance. Some argue that FGM was instructed by the Prophet Mohammed, hence the term ‘sunna’ (which are practices undertaken or approved by the Prophet Mohammed and established as legally binding precedents). However, according to other scholars, ‘female circumcision is neither required nor is it an obligation nor a sunna’. Muhammad Lutfi al-Sabbagh, ‘Islamic Ruling on Male and Female Circumcision in *The Right Path to Health, Health education through religion*’, WHO, Regional Office for the Eastern Mediterranean, 1996 accessed through http://www.iccservices.org.uk/news_and_events/updates/female_genital_mutilation.htm accessed 22 August 2013.

⁷¹ Lord Bingham, *Secretary of State for the Home Department v K; Fornah v Secretary of State for the Home Department* [2006] UKHL 46 para 6.

⁷² Carole Njoki, ‘African Traditions and Practices: Cultural Rights or Human Rights Violation?’ 7 May 2007 <http://www.issafrica.org/iss-today/african-traditions-and-practices-cultural-rights-or-human-rights-violations> accessed 25 March 2015.

Although ‘(n)owadays cliterodectomies should never be done’,⁷³ surgeons still recommend some degree of cliteroplasty in adolescents, particularly if the girls experience ‘embarrassing clitoral erections’.⁷⁴ In other words, both CAH girls and girls from areas that practice FGM are sensitive to the need to ‘belong’ to that society.⁷⁵

Since 1997, considerable work has been carried out to reduce, if not completely stop, FGM, with progress being made at both international and local levels. In 2008, the World Health Assembly passed a resolution (WHA61.16) on the elimination of FGM. This was followed in 2010 by the WHO publication titled ‘Global strategy to stop healthcare providers from performing female genital mutilation’. However, until recently WHO have been less forthright in preventing the genital mutilation of intersex children. The same parallel can be drawn with English law.

Since the FGM Act 2003 came into force on 3 March 2004 in England and Wales, it has been illegal for FGM to be performed on English permanent residents of any age anywhere in the world.⁷⁶ The threat of enforced FGM has been seen as a valid reason for being granted asylum, as evidenced in *Secretary of State for the Home Department v K; Fornah v Secretary of State for the Home Department*.⁷⁷ As quoted

⁷³ Deborah P Merke and Dix P Poppas, ‘Management of Adolescents with Congenital Adrenal Hyperplasia’ (2013) 1 (4) *The Lancet Diabetes Endocrinol* 341 [http://dx.doi.org/10.1016%2FS2213-8587\(13\)70138-4](http://dx.doi.org/10.1016%2FS2213-8587(13)70138-4), 10 accessed 15 March 2015.

⁷⁴ *ibid.*

⁷⁵ Christopher Woodhouse notes that society needs to address this issue, particularly in regard to postponing operations on children. Christopher Woodhouse *Adolescent Urology and Long-Term Outcomes* (Wiley 2015) 207.

⁷⁶ Despite this, it has been estimated that several hundred girls from the UK face such procedures being carried out on them each year. A recent newspaper reported that ‘as many as 100,000 women in Britain have undergone female genital mutilations with medics in Britain offering to carry out the illegal procedure on girls as young as 10’. Andrew Hough, ‘Pair held by police investigating female genital mutilation in the UK’ *The Telegraph*, (London 4 May 2012) <http://www.telegraph.co.uk/news/uknews/crime/9246130/Pair-held-by-police-investigating-female-genital-mutilation-in-UK.html> accessed 24 March 2015.

⁷⁷ *Secretary of State for the Home Department v K; Fornah v Secretary of State for the Home Department* [2006] UKHL 46 in which it was decided that women from Sierra Leone were a particular social group for the purposes of Article 1 A (2) of the ECHR.

by Lord Bingham during this ruling,⁷⁸ Ann Widdecombe MP had previously pronounced in the House of Commons,

I stress that both personally and as a Minister I utterly accept that forcible abortion, sterilisation, genital mutilation and allied practices would almost always constitute torture.⁷⁹

Further, very recently in *Re B and G (children) (No 2)*,⁸⁰ the President of the Family Division confirmed that the act of FGM meets the threshold requirement of ‘significant harm’ in accordance with section 31 (2) of the Children Act 1989,⁸¹ which allows the court to issue a care order for the child concerned.⁸² If FGM meets this criteria then surely to inflict genital modification on a child with genital ambiguities may equally be considered ‘significant harm’ in accordance with section 31 of the Children Act 1989, and ‘torture’ for the purposes of Article 3 of the ECHR. After all, if judicial corporal punishment is deemed torturous,⁸³ changing a person’s sex without their consent surely is also torturous, but whilst FGM is ‘recognized internationally as a violation of the human rights of girls and women’,⁸⁴ it seems not to have been identified with similar procedures undertaken on young intersex children. Indeed, the experience of Cheryl Chase/Bo Laurent in the early 1990s shows that many FGM activists have ignored the parallel procedures that are carried out on young intersex children. In an interview she says, ‘I tried to talk to feminists

⁷⁸ *ibid* [26].

⁷⁹ HC Deb 15 July 1996, vol 281, col 818.

⁸⁰ [2015] EWFC 3.

⁸¹ Para 68, considering the dicta of Baroness Hale of Richmond *Re B (Care Proceedings: Appeal)* [2013] UKSC 33[185].

⁸² s31 (2) A court may only make a care order or supervision order if it is satisfied—

(a) that the child concerned is suffering, or is likely to suffer, significant harm; and

(b) that the harm, or likelihood of harm, is attributable to—

(i) the care given to the child, or likely to be given to him if the order were not made, not being what it would be reasonable to expect a parent to give to him; or

(ii) the child’s being beyond parental control.

In this case the President did not find that the local authority had sufficient evidence that G was at risk of FGM.

⁸³ *Tyrer v The United Kingdom* Application no 5856/72 (ECtHR, 25 April 1978).

⁸⁴ WHO ‘Female Genital Mutilation’ Fact Sheet no 241 February 2014 <http://www.who.int/mediacentre/factsheets/fs241/en/> accessed 24 March 2015.

who worked on (the) issue [of African cliterodectomies] and they wouldn't speak to me or cover what we were doing.'⁸⁵

Under current English law, there is no parallel legal protection for the intersexed. In fact, the FGM Act actively allows doctors to perform genital operations on a girl if they are 'necessary for her physical or mental health'.⁸⁶ (Boys are not mentioned at all.) Intersex activists state that although UK society is against FGM, it has failed to notice that equivalent procedures are (still) frequently carried out on those born with ambiguous genitalia. Some argue that intersex surgery may do more harm than FGM, as although these procedures are carried out in sterile environments, 'it entails many more surgical interventions than does (FGM), with the attendant risk of death (from anaesthesia), infection, pain and discomfort'.⁸⁷ One correspondent (T) states:

our physical differences are medicalised, and approvingly operated on. The operations are approved, as a form of medical ritual; but religious imperatives are illegal. The outcomes are not so very different.⁸⁸

T is keen to see the current law adapted to overcome this idiosyncrasy. It is important to assess whether there is scope under current legislation to afford the necessary protection.

8.4 The Female Genital Mutilation Act 2003

Section 1 (1) of the Act stipulates that a person commits an offence if 'he excises, infibulates or otherwise mutilates the whole or any part of a girl's labia majora, labia minora or clitoris'. The Act then produces a defence under section 1(2) which reads:

⁸⁵ Peter Hegarty in conversation with Cheryl Chase, 'Intersex Activism, Feminism and Psychology: Opening a Dialogue on Theory, Research and Clinical Practice' (2000) 10(1) *Feminism & Psychology* 117, 123.

⁸⁶ s2 (a) FGM Act 2003.

⁸⁷ Nancy Ehrenreich and Mark Barr, 'Intersex Surgery, Female Genital Cutting, and the Selective Condemnation of "Cultural Practices"' (2005) 40 *Harvard Civil Rights – Civil Liberties Law Review* 71, 128 http://www.law.harvard.edu/students/orgs/crcl/vol40_1/ehrenreich.pdf accessed 18 April 2015.

⁸⁸ Email from Correspondent T to author (30 July 2012) (anonymity preserved).

- (2) But no offence is committed by an approved person who performs—
- (a) a surgical operation on a girl which is necessary for her physical or mental health,⁸⁹

Section 1 (2) (a) needs attention. There is no evidence that removing or reducing a clitoris will promote either ‘physical or mental health’: in fact, often the reverse.⁹⁰ Further, what happens if that ‘girl’ gender orientates as a ‘boy’? Performing such a life changing procedure on a small child is likely to create long-term mental health problems, not solve them. In this regard, there is some evidence that even in communities where FGM is the norm, mental health conditions are known to manifest as side effects of the procedure. If girls suffer from depression, when they have knowledge of FGM and the understanding of why it is performed, it is more than likely that children born with ambiguous genitalia, left without knowing why surgery was performed on them, are at serious risk of mental health problems.

At this point it will be pertinent to discuss the Gender Identity, Gender Expression and Sex Characteristics Act passed by the Maltese Government on 1 April 2015. In this Act there is a specific section which aims to prevent unnecessary genital modification operations on minors.

Section 14 (1) reads:

It shall be unlawful for medical practitioners or other professionals to conduct any sex assignment treatment and/or surgical intervention on the sex characteristics of a minor which treatment and/or intervention can be deferred until the person to be treated can provide informed consent

However section 14 (2) further adds:

⁸⁹ The exception in s 2 (1) (b) reads: ‘a surgical operation on a girl who is in any stage of labour, or has just given birth, for the purposes connected with the labour or birth’. It seems reasonable that s 1 (2) (b) should remain in order to promote the health of women in childbirth who may need to have an episiotomy (a surgical cut to assist in delivery) which would fall under s 1 (1).

⁹⁰ There is insufficient medical evidence in this respect. Many intersexed adults resent having their clitoris removed as their sexual sensitivity is compromised. However, sometimes CAH patients request reduction in its size as they are embarrassed by the look. Clearly this should be an issue for the child themselves, at a later stage of life, rather than being their parents’ decision.

In exceptional circumstances treatment may be effected once agreement is reached between the interdisciplinary team and the persons exercising parental authority or tutor of the minor who is still unable to provide consent: Provided that medical intervention which is driven by social factors without the consent of the minor, will be in violation of this Act.

Even within this Act there is a potential for operations to occur, but the Act is very specific, Section 14 (3) sets out guidelines for establishing an interdisciplinary team and further section 14(5) (a) stipulates that teams must:

ensure that the best interests of the child as expressed in the Convention on the Rights of the Child be the paramount consideration; and(b) give weight to the views of the minor having regard to the minor's age and maturity.

This component of the Act is essential to protect the intersexed, and would be a welcome addition to the FGM Act.

Taking all things into consideration, it is submitted that a change in section (1) (2) (a) to:

(2) But no offence is committed by an approved person who performs–

(a) a surgical operation on a person under the age of 18 which is *essential* for her immediate physical health.

Even this may not prove sufficient as many would argue that genital rearrangement would count as essential for immediate physical health – even if not life threatening, so perhaps an even bolder statement should be made, to read:

(2) But no offence is committed by an approved person who performs–

(a) a surgical operation on a person under the age of 18 which is essential for her immediate physical health, which if left unperformed is likely to endanger the life of the child.

As above, this might be wilfully misinterpreted by doctors to read in a way that supports a procedure.

An approach which would provide appropriate protection to this category of children would involve drafting a Children's Mutilation Act, along the lines of the Maltese Act, to prevent genital surgery on *any* intersex child, whether they consider themselves 'female' or 'male'. Therefore, rather than having a Female Genital Mutilation Act, there should be a Children's Genital Mutilation Act, which would protect both males and females. The Act should also outlaw the removal of gonads without extensive testing, and certainly not prior to the age of 16 unless there are compelling reasons to do so. This legislation would give legal support to doctors, who feel that they have been pushed by parents into 'correcting' an intersex child at an early stage, and likewise would help to support the parents of a very young child who are still trying to make sense of their child's condition. It will also allow the child some time to grow and mature and perhaps find their gender identity. The more of a person that is left intact, the easier it will be for an operation to take place when the child is older, *at their specific request*.

8.5 Conclusions

Current English law indirectly discriminates against various intersex children as although legal protection promotes the integrity of the child in specified social groupings; this protection is not offered to those with genital difference. The lack of legal clarity and the general presumption in doctors' favour to date has led to numerous invasive procedures on intersexed children during the last 50 years. Even if parents had been against such operations, it is likely that very few would have been equipped with the knowledge, either medical or legal, to face the necessary court action.

For any parent to be prepared to go to court over their young child's healthcare issues, they must exhibit enormous fortitude and energy; not only that, but traditionally judges have listened to arguments propounded by doctors in preference to those voiced by parents. This puts parents in an impotent position, and consequently makes it hard for them to challenge medical advice, for fear that their children will be removed from their care.⁹¹

⁹¹ Recently we have seen the plight of Ashya King and his parents, who were arrested in Spain on their way to taking Ashya to Prague for treatment. BBC news online, 'Brain tumour boy Ashya King free

For those who know the legal provisions regarding informed consent, they make ‘sense’ or at least can be followed. However, for a non-medic or non-lawyer the current UK legal dimensions to informed consent are not clear, and will be extremely confusing in an emergency situation. This will be the case whether the child has an intersex condition or not. However, whereas *testing* for medical conditions without consent is of relatively small significance, albeit illegal, carrying out operations on neonates and young children without parental consent is entirely another matter. In this regard a more proactive approach is required. Unfortunately, current English legislation does not protect the intersexed from early surgery, despite offering protection from FGM. Consequently, the intersexed face discrimination.

Although the current system is ineffective it is unlikely that the law in regard to children and their parents’ consent to treatment will be changed in the near future. In this respect, it is submitted that in the interim current legal provisions are modified to take account of the intersexed should such a need arise. With this aim in mind, one solution is to adapt the strategy available for those with mental incapacity and appoint an independent lawyer in the form of the Official Solicitor, (or equivalent), for all children identified as having an intersex condition, with or without genital difference. The appointment should take place as soon as possible after the birth of the child. Their role would be to act in the ‘best interests’ of the child, should early surgery be needed, by advising parents and doctors alike in respect of their legal obligations. An emergency helpline number should be issued, and the helpline operated by staff with specialised training in this field.

Additionally, discord and confusion would be, if not eradicated, at least ameliorated if all expectant parents are given information during the pregnancy on intersex conditions. This does not need to be extensive literature at this stage. A one-page leaflet with brief information on genital difference in children at birth and advertising the helpline number might be all that is needed at that stage.

Chapter Nine: the Young Intersex Person's Right to Know

9.1 Introduction

In previous chapters, it was noted that healthcare teams and courts adopted a patriarchal stance in relation to the treatment of young persons, specifically those with intersex/DSD conditions. The historical paternalistic approach required the 'eradication' of the true early life of those born with genital difference,¹ and the 'creation' of a confirmed gender for the child, (which in many cases conflicted with their sense of their true gender). Although this approach has receded in popularity in recent years, there remains dissention as to when a child, or young person, should be informed of his or her 'real' past, if at all.² Further, despite an underlying duty of veracity,³ doctors will withhold certain information from patients if they believe it is in their 'best interests' to do so. Additionally, healthcare records have frequently 'gone missing', and consequently the applicant is denied full disclosure.⁴ It is not only healthcare workers who fail to disclose information. Some parents, perhaps for the best of intentions, are reluctant to talk through their child's medical history with them. Consequently, the young person may not discover the truth until they are adults. At this stage, they often feel violated, and become 'extremely angry' with their parents for keeping their medical condition a secret for so long.⁵

In this chapter, we consider whether current English law discriminates against the young intersex/DSD person by preventing access to medical information, and if so, how this anomaly might be best addressed. The chapter will start by considering the current legislation in place to allow access to medical records generally, and then

¹ As discussed in chapters one and three.

² Ellen K Feder, *Making Sense of Intersex: Changing Ethical Perspectives in Biomedicine* (Indiana University Press 2014) 56.

³ 'The rule of veracity may be defined as the duty that one has to tell the truth.' Ian Kerridge, Michael Lowe, Cameron Stewart, *Ethics and the Law for the Health Professions* (4th edn, The Federation Press 2013) 276.

⁴ This has mainly been in the field of medical negligence, but also applies to adults who seek information about previous treatment of genital difference. Email from correspondent (T) to author (30 July 2012).

⁵ Email from correspondent (C) to author (13 January 2015). See also Katrina Karkazis, *Fixing Sex: Intersex, Medical Authority and Lived Experience* (Duke University Press 2008) 227.

investigate tensions that might arise specifically in relation to the young person with an intersex condition. The chapter then investigates potential means of redress within current legal frameworks. It will be noted that although there are different remedies available for non-disclosure of medical information, these are likely to be time-consuming, costly and emotionally draining. The recommendation will be made for a statutory duty of veracity in regard to those with intersex/DSD conditions during early childhood, in order to assist and empower the young intersexed person's healthcare choices.

9.2 Access to Health Records – Current Legislation

Subject access to healthcare is now 'enshrined as a right' in the NHS Constitution (2009),⁶ but this is a relatively new situation. Patients were first given the statutory right to access their own medical records on 1 November 1991, when the Access to Health Records Act 1990 came into force.⁷ However, patients were not given *unlimited* access to their notes; they were allowed to view their own medical records produced after this date and previous notes *only* if they were needed to explain the later ones (and even then with limitations). The Data Protection (Subject Access Modification) (Health) Order 1987 (SI No 1903) prevented disclosure which might cause 'serious harm to the physical or mental health of the data subject'.⁸ These limitations were confirmed in common law by the Court of Appeal decision of *Regina v Mid Glamorgan Family Health Services Authority and Another ex parte Martin*.⁹ Sir Roger Parker made the following observations:

(1) I regard as untenable the proposition that, at common law, a doctor or health authority has an absolute property in medical records of a patient (...) (2) I regard as equally

⁶ Royal College of General Practitioners, Enabling Patients to Access Electronic Health Records: Guidance For Health Professionals (Version 1.0, 1 September 2010) Introduction<[http://www.rcgp.org.uk/Clinical-and-research/Practice-management-resources/~media/Files/Informatics/Health Informatics Enabling Patient Access.ashx](http://www.rcgp.org.uk/Clinical-and-research/Practice-management-resources/~media/Files/Informatics/Health%20Informatics%20Enabling%20Patient%20Access.ashx)> accessed 14 February 2015.

⁷ This earlier Act still governs access to a deceased person's medical records. The personal representative and anyone else with a claim arising out of death may apply to see the records, by virtue of s3 (1) (f); however, data controllers do not need to disclose information dating from prior to November 1991.

⁸ Article 4 (2) (a) This has since been replaced by the Data Protection (Subject Access Modification) (Health) Order 2000 (SI 2000/413).

⁹ [1995] 1 WLR 110.

untenable the proposition that by reason of a ‘right of self-determination’ a patient has an unfettered right of access to his medical records at all times and in all circumstances; indeed it is accepted for the applicant that this cannot be so. (3) In my view the circumstances in which a patient or former patient is entitled to demand access to his medical history as set out in the records will be infinitely various, and it is neither desirable nor possible for this or any court to attempt to set out the scope of the duty to afford access or, its obverse, the scope of the patient's rights to demand access. Each case must depend on its own facts.¹⁰

Since March 2000, albeit with certain exceptions, patients have had access to all manual and electronic health records available by virtue of the Data Protection Act 1998 (DPA),¹¹ which implemented EU Directive 95/46/EC. Additionally, Article 8 of the European Convention on Human Rights promotes a positive obligation to disclose specific information, including access to medical records.¹² This is in contrast to the court’s position prior to the coming into force of the Human Rights Act 1998, when it was not deemed necessary to consider Article 8.¹³

Section 7 of the DPA specifies that individuals may make a written request to an organisation to see any personal information held about them by that organisation. This is known as a ‘subject access request’ (SAR), and has been described as a

¹⁰ *ibid* at 119 (Sir Roger Parker). This case was considered in the Australian case of *Breen v Williams* [1994] 35 NSWLR 522, which found that a patient did not have the common law right of access to his or her medical records in Australia. This was upheld in the Australian High Court, *Breen v Williams* [1997] 1 LRC 212.

¹¹ This replaced the Data Protection Act 1984.

¹² *McGinley and Egan v. The United Kingdom* (case no.10/1997/794/995-996) 9 June 1998, 27 EHRR 1; *KH and others v Slovakia* (Application no. 32881/04) ECtHR, 28 April 2009, Final judgment 06/11/2009.

¹³ ‘Article 8 of the European Convention of Human Rights (...) was of no assistance. The common law was quite clear and needed no assistance from Europe.’ Ying Hui Tan, ‘Law Report: No right of access to health records: *Regina v Mid Glamorgan Family Health Services Authority and another, Ex parte Martin* – Queen's Bench Division (Poplewell J), 14 May 1993 *The Independent* (London Tuesday 8 June 1993). <<http://www.independent.co.uk/news/uk/law-report-no-right-of-access-to-health-records-regina-v-mid-glamorgan-family-health-services-authority-and-another-ex-parte-martin--queens-bench-division-mr-justice-poplewell-14-may-1993-1490311.html>> accessed 14 February 2015.

‘fundamental right for individuals’.¹⁴ For information to be considered ‘personal data’ it must ‘relate to a living individual and allow that individual to be identified by it’.¹⁵

There are specific guidelines on recording healthcare. Section 68(2) DPA specifies that a health record means ‘any record which—

(a) consists of information relating to the physical or mental health or condition of an individual, and

(b) has been made by or on behalf of a health professional in connection with the care of that individual.’

For a subject access request to be valid, it must be in writing, as stipulated in section 7(2) of the Act. This can take any ‘written’ form, including requests sent by email or via fax machines, and even if requested through social media.¹⁶ The request is usually made to the health practice administration, but office staff are likely to consult with doctors before releasing the information. Furthermore, they are bound to do so if there is potentially distressing or particularly complex medical information present. The organisation has 40 calendar days to respond to such requests.¹⁷

GPs not only hold the medical records from surgery visits, but will also keep summary notes from treatment elsewhere, providing that consent was given by the patient to share such information. Surgeries will not hold records indefinitely; they normally hold such information for ten years after the cessation of treatment, the patient’s death or the patient’s emigration. Hospital records will be kept for a minimum of eight years after treatment, but there are specific exceptions for children and young people, maternity records and mental health records.

9.2.1 Online Access to Health Records

In November 2012, Health Secretary Jeremy Hunt announced that NHS England expected all GP practices to allow patients to see their summary records online by 1

¹⁴ <https://ico.org.uk/media/for-organisations/documents/1065/subject-access-code-of-practice.pdf> 8.

¹⁵ *ibid* 6.

¹⁶ Information Commissioner’s Office, ‘The Guide to Data Protection’ (ico) <<https://ico.org.uk/for-organisations/guide-to-data-protection/principle-6-rights/subject-access-request/>> accessed 5 February 2015.

¹⁷ s 7 (10) DPA 1998.

April 2015. He reiterated this at the Conservative Party Conference in 2014, despite significant indications that the promise was an ambitious one. It was noted recently that although 60 per cent of GP surgeries have data that could be accessed online, only one per cent of surgeries offered this service.¹⁸ Even if all patients are granted access, this does not mean automatic access to their medical history. Practices are to choose the date span of a person's records to be made available, with the latest date permissible being 1 April 2015 itself. It is likely that a number of surgeries will have opted for this date.¹⁹ Regardless of this apparent openness, individual practices are likely to vary in practice in regard to young people. It is to this area that we now turn.

9.3 Young People's Access to Health Records

Unlike Scotland, which specifies the age of 12 for a SAR,²⁰ there is no specific age at which English children are able to ask to view their medical history. In theory the DPA grants children of any age this right, even if the child is 'too young to understand the implications of subject access rights'.²¹ Parents are able to make a SAR on behalf of a young child, but only if it is in the child's best interests.²² Once the child is mature enough to complete a SAR themselves, parents will not be able to do so. Without a definitive age specified by legislation, the difficulty for healthcare workers is in ascertaining when this maturity occurs, in order to fulfil their duties under the DPA. Some medical organisations specify the age of 12 as the starting

¹⁸ NHS London, 'It's Your Record. A Guide to Accessing Health Records Online' <http://londonconnect.org/portfolio-item/its-your-record-a-guide-to-accessing-health-records-online/> accessed 14 February 2015.

¹⁹ Results from research conducted prior to the approval of online access will be discussed at the conclusion of this chapter.

²⁰ The young person's right to make subject access requests in Scotland is covered by section 66 (2) DPA; it considers that 'a person of twelve years of age or more shall be presumed to be of sufficient age and maturity to have such understanding'.

²¹ ICO (n 14).

²² Surrey and Sussex Healthcare NHS Trust's information sheet, 'Accessing Your Personal Information' <http://www.surreyandsussex.nhs.uk/wp-content/uploads/2014/07/Accessing-your-personal-information.pdf> accessed 14 April 2015.

point for a presumption of capacity to make a SAR,²³ but additionally healthcare authorities specify that they have an obligation to assess whether the child is *Gillick* competent.²⁴ Some surgeries may be reluctant to release information below the age of 16, at which point section 8 of the Family Law Reform Act 1969 gives young people the statutory right to consent to medical treatment, and consequently it is assumed that they have the full right to access their records.²⁵

It can be seen that the DPA does not directly discriminate against young people with intersex/DSD conditions; the Act supports them by granting access to their medical information. However, additional subsections of the Act raise difficulties in respect of potential access. Consequently, indirect discrimination may occur.

Section 7 (1) (c) DPA requires that an organisation must provide information in an intelligible form. This could be perceived as indirectly discriminating against the intersexed. According to the Information Commissioner's Office (ICO), 'intelligible form' means 'being understood by the average person'. A bold statement about an intersex condition would count as an 'intelligible form', but as has been noted throughout this dissertation, intersex/DSD conditions are not easily understood by healthcare workers let alone the 'average person'.²⁶ In this respect, release of such sensitive data may cause more distress than it resolves, particularly when dealing with minors. In relation to this, there are additional constraints in terms of disclosure. Article 5 (1) of the Data Protection (Subject Access Modification) (Health) Order 2000 (SI 2000/413)²⁷ specifies that exceptions from disclosure under Section 7 DPA

²³ Medical Protection Society, 'Access to Healthcare Records' (22 January 2015) <<http://www.medicalprotection.org/uk/resources/factsheets/england/england-factsheets/uk-eng-access-to-health-records>> accessed 20 April 2015. Also BMA, Access to Health Records. Guidance for Health Professionals in the United Kingdom (August 2014) 3 <<http://bma.org.uk/practical-support-at-work/ethics/confidentiality-and-health-records>> accessed 14 April 2015.

²⁴ *Gillick v West Norfolk & Wisbech Area Health Authority* [1985] UKHL 7 (17 October 1985) Specified by Surrey and Sussex Healthcare NHS Trust, (n22). For a detailed discussion of this case and *Gillick* Competence see chapter five.

²⁵ The BMA specify that there is 'no automatic presumption of legal capacity below the age of 16', hence the argument that 16 is the age when the child has the presumption in his or her favour. BMA (n23).

²⁶ Information Commissioner's Office, 'The Guide to Data Protection' (ico) <https://ico.org.uk/for-organisations/guide-to-data-protection/principle-6-rights/subject-access-request/> accessed 5 February 2015.

²⁷ This replaced the Data Protection (Subject Access Modification)(Health) Order 1987 (SI No 1903).

apply when such disclosure is likely to ‘cause serious harm to the physical or mental health’ of the person concerned, ‘or any other person’.²⁸ To compound the difficulties there is no legal definition of ‘serious harm’,²⁹ and what might be considered serious harm by one doctor may not be by another. Furthermore, the courts have confirmed that access to information is not an unqualified right, provided the non-disclosure can be justified. An example of this can be seen in the case of *Roberts v Nottinghamshire Healthcare NHS Trust*.³⁰ Here, a patient at a high-security psychiatric hospital was denied full access to a report written about himself by a psychologist, who at the salient time was an employee of the defendant. Due to its sensitive nature, both open and closed judgments were issued after the hearing. In the open judgment, Mr Justice Cranston found there to be ‘clear and compelling reasons based on cogent evidence’ for the non-disclosure of the requested information.³¹ He also noted that it was not in accordance with the DPA, and therefore not in his power to order the release of the report solely to the applicant’s legal team, and not to the applicant.³²

Although the BMA specify that it is ‘extremely rare’ for such information to be withheld,³³ it is possible to see why an intersexed patient may fit into this category. Where an intersex condition is relatively well-known to both the patient and the doctor, and the data subject is receiving lifelong medication, such as for Congenital Adrenal Hyperplasia (CAH), a GP would be able to make an adequate value judgment on disclosure of information. The same will not apply to conditions that

²⁸ 5 (1) Personal data to which this Order applies are exempt from section 7 in any case to the extent to which the application of that section would be likely to cause serious harm to the physical or mental health or condition of the data subject or any other person.

²⁹ A parallel can be drawn with s1 (1) (d) Abortion Act 1967, as discussed in chapter six.

³⁰ *Roberts v Nottinghamshire Healthcare NHS Trust* [2008] EWHC 1934 (QB). At an earlier judgment a special advocate was appointed to read the report, which had been kept from the applicant’s solicitors. The appointment was said to be ‘novel in this context’ [1] (Cranston J).

³¹ *ibid* [31].

³² *ibid*. This case can be contrasted with the case of *RM v St Andrew’s Healthcare* [2010] UKUT 119 (AAC), in which the non-disclosure of a patient’s medication regime would ‘severely hamper his legal team in participating effectively’ in a review case on behalf of that patient. [32] (Edward Jacobs).

³³ BMA (n23) 7.

were treated at an early age by ‘one-off’ surgery.³⁴ In these circumstances, doctors have to fall back on advice from the General Medical Council (GMC) and their own professional expertise. The GMC state that ‘serious harm does not mean the patient would become upset, or decide to refuse treatment’. They do not appear to address the situation when no planned treatment is in mind.

Even where such information is withheld, the organisation has the duty to disclose the remainder of the healthcare records requested. It will be difficult for data handlers to remove sufficient information from the records of intersex/DSD patients without some reference to the underlying condition. The added difficulty of being faced with a young person may prevent doctors disclosing *any* information unless the patient has the support of those with parental responsibility. Indeed, doctors should be mindful that they may be sued under the tort of negligence and/or for breach of statutory duty for allowing the child access to such intricate and potentially distressing material should the child, *or the parents*, suffer ill-health as a result, be it physical or, perhaps more likely, mental ill-health. The disclosure of such information is likely to revive unpleasant memories of extremely stressful times for the parents,³⁵ let alone the child, and it is therefore essential that information is screened with due diligence.

Although *prima facie* a minor has the right of access to medical records, this right is not an unqualified one. It is suggested that doctors will err on the side of caution, for fear of causing any unnecessary distress to the patient,³⁶ and this is not an unreasonable stance. A number of people have suffered mental health problems after discovering their intersex condition,³⁷ particularly when such discoveries were made in late adolescence or even adulthood.³⁸ By contrast, those who were informed of their intersex/DSD condition at an early age appeared to be more accepting of their

³⁴ In reality it is unlikely that only one surgical intervention took place, particularly with CAH girls, but this may occur if a child with Complete Androgen Insensitivity Syndrome has her testes removed as a result of a ‘hernia’ in early childhood.

³⁵ Karkazis (n 5) 227.

³⁶ Royal College of General Practitioners, Enabling Patients to Access Electronic Health Records: Guidance For Health Professionals (Version 1.0, 1 September 2010) [http://www.rcgp.org.uk/Clinical-and-research/Practice-management-resources/~media/Files/Informatics/Health Informatics Enabling Patient Access.ashx](http://www.rcgp.org.uk/Clinical-and-research/Practice-management-resources/~media/Files/Informatics/Health%20Informatics%20Enabling%20Patient%20Access.ashx) accessed 11 February 2015.

³⁷ See Cheryl Chase/Bo Laurent’s story in chapter 1 of this thesis. Karkazis (n 5) 252.

³⁸ Karkazis (n 5) 220.

physicality. As one woman notes, ‘(l)ots of women who found out later in life that they have AIS [Androgen Insensitivity Syndrome] have a crisis about their identity. But I always had complete honesty from my parents and doctors, so I never struggled with who I am.’³⁹ As disclosure at an early stage appears to be more preferable than at a later stage, it is important to investigate whether a young person has any means of redress should medical information not be forthcoming.

9.4 Methods of Redress

Section 7 (9) of the DPA allows an applicant to challenge the non-disclosure of medical records in court;⁴⁰ however, this is time-consuming and costly. It is unlikely that a young person would instigate such proceedings, particularly as such cases are often unsuccessful. Nor is an appeal to the European Court of Human Rights (ECtHR) likely to be met with success. In *MG v United Kingdom*,⁴¹ the ECtHR held that the right of access was not a unqualified one. Here the denial of access was deemed to be proportionate in order to preserve the privacy of third parties. The court did, however, stipulate that the applicant’s human rights had been breached in not having an adequate system of appeals. As a result of this decision, the ICO can now hear appeals against non-disclosure of personal data, provided all internal reviews have been exhausted.⁴² If the ICO find in the appellant’s favour, it has the power to issue legally binding decisions on the matter,⁴³ albeit it has no power to punish bodies or compensate complainants. A direct appeal to the ICO might be an alternative and more satisfactory approach to take at the first instance.

Additionally, complaints can also be made through the NHS complaints procedure, provided the incident in question took place within the previous six months.⁴⁴ If the

³⁹ Wellcome Trust, ‘What it's like for me: Androgen Insensitivity Syndrome’ online interview http://genome.wellcome.ac.uk/doc_WTX059581.html accessed 12 April 2015.

⁴⁰ Sec 7 (9) DPA. If a court is satisfied on the application of any person who has made a request under the foregoing provisions of this section that the data controller in question has failed to comply with the request in contravention of those provisions, the court may order him to comply with the request.

⁴¹ *MG v United Kingdom* [2002] 3 FCR 413. This case concerned social services records.

⁴² <https://ico.org.uk/for-organisations/guide-to-freedom-of-information/complaints/> accessed 15 February 2015.

⁴³ *ibid.* The ICO’s website indicates that they do this for approximately a third of valid complaints.

complaint is not dealt with efficiently, complainants may approach the Parliamentary and Health Service Ombudsman (PHSO).⁴⁵ However, the Ombudsman will only investigate if the applicant has suffered ‘injustice or hardship’.⁴⁶ Most of the cases upheld involve inadequate or delayed treatment,⁴⁷ but it is possible that administrative unfairness will be upheld by the PHSO.⁴⁸

Therefore there are routes for appeal for non-disclosure, but the methods are time-consuming and potentially costly, and risk being emotionally draining. It would appear that young intersex people may need a special advisor to assist them, should their parents be unhelpful.

9.5 Views on ‘Open’ Access and Veracity

The duty of veracity supports patient autonomy, since it is impossible for patients of any age to give valid consent if they are not fully cognisant of their health. The new online access to medical records has been implemented with the aim of giving patients more control over their healthcare,⁴⁹ but as Professor Herring notes, there remains some divergence of opinion as to whether there should be such a right of access in general.⁵⁰ He notes four arguments in support, namely improved accuracy and general quality of records, relief of patient anxiety, improved communication and increased trust between both parties. The arguments against such openness include,

⁴⁴ This would only apply to treatment provided by the NHS.

⁴⁵ The Ombudsman’s powers are established by the Health Service Commissioners Act 1993.

⁴⁶ Section 3 of the Health Service Commissioners Act 1993 specifies the general parameters for investigation.

s3(1) On a complaint duly made to a Commissioner by or on behalf of a person that he has sustained injustice or hardship in consequence of—

(a) a failure in a service provided by a health service body,
(b) a failure of such a body to provide a service which it was a function of the body to provide, or
(c) maladministration connected with any other action taken by or on behalf of such a body.

⁴⁷ According to the PHCO’s report ‘Selected Summaries of Investigations by the Parliamentary and Health Service Ombudsman April to June 2014.’ 28 October 2014, HC744.

⁴⁸ *ibid*, summaries 220 and 224, June 2014.

⁴⁹ NHS London, ‘It’s Your Record. A guide to Accessing Health Records Online.’ <http://londonconnect.org/portfolio-item/its-your-record-a-guide-to-accessing-health-records-online/> 13, accessed 14 February 2015.

⁵⁰ Jonathan Herring, *Medical Law and Ethics* (5th edn, Oxford University Press, 2014) 262.

inter alia, difficulties in discussing complex medical language. This is likely to be more challenging in relation to those with intersex/DSD conditions.

In respect of online access to notes, research from America reveals a similar range of views.⁵¹ Trialled across three states, this research established online links between patients and their own medical records, at their primary care practices. Doctors and patients were asked for their expectations before the trials began, and then again after a year. There were mixed views prior to the trials. Some doctors thought this would bring positive benefits such as increased patient safety, but others were concerned that open access to notes would lead to more time spent in discussion with patients and consequently less on their treatment. Doctors were also concerned that patients would be frightened by what had been written about them, particularly in cases of mental illness and substance abuse.

By contrast the patients surveyed indicated an ‘overwhelmingly positive’ attitude to receiving their full health notes,⁵² with fewer than one in six patients being concerned as to whether their notes would be confusing or distressing to them. Whilst noting the survey’s limitations, the researchers suggested that almost all patients anticipated a positive outcome on receiving their notes.

At the end of the year, in contrast to doctors’ initial fears, it was noted that the majority of doctors recorded that their workload did not alter significantly, nor were many patients confused or offended by their notes. In fact, 99 per cent of patients who completed surveys after the trial recommended that the open approach should continue.⁵³ It is of significance that a ‘remarkable number’ of patients reported being more likely to follow their prescribed medical regimes.⁵⁴ The authors tentatively suggest that sharing medical records online is of overall benefit to patients. Similar

⁵¹ Jan Walker and others, 'Inviting Patients to Read their Doctors' Notes: Patients and Doctors Look Ahead' [2011] *Ann Intern Med* 155 (12) 811-819. <http://annals.org/article.aspx?articleid=1033220> accessed 6 February 2015.

⁵² *ibid.*

⁵³ Tom Delbanco and others 'Inviting Patients to Read their Doctors' Notes: a quasi-experimental study and a look ahead.' (2012) 157 *Ann Intern Med* 461. <http://annals.org/article.aspx?articleid=1363511> accessed 6 February 2015.

⁵⁴ *ibid.*

trials have occurred in the UK, and indicate that there may be improvements to patient safety.⁵⁵ This is clearly one of the overall aims of this NHS policy.⁵⁶

For many years, expectant mothers have been in charge of their own detailed obstetric records. The holding of these records has been said to give ‘high levels of patient satisfaction with few practical problems’.⁵⁷ Likewise, access to child health records has increased rather than decreased parental satisfaction, as it appears that parents having ownership of these documents encourages health professionals to complete them efficiently.⁵⁸ It is submitted that openness in healthcare records is mainly beneficial and should be encouraged, particularly as the ‘vast majority’ of patients of any age want to know the truth about their healthcare,⁵⁹ even if this means that they will receive unpleasant news. Further, Bock notes that ‘when the truth is withheld, children often suspect that their parents are hiding something and may imagine a condition that is worse than their actual diagnosis’.⁶⁰ The same can apply to adults.

The online access to records appears to be a move towards more transparency in treatment, but in reality, for the immediate future, the information currently accessible will be extremely limited, and is not likely to cover more than current medications, allergies and adverse reactions to medications. Furthermore, there will be times when accessing medical records remotely may be *detrimental* to the patient. This would not be a suitable mechanism for allowing a patient to find out about their intersex condition for the first time. If, on the other hand, such a condition had been

⁵⁵ Simon de Luisigan and others, ‘Patients’ online access to their electronic health records and linked online services: a systematic interpretative review’ (2014) BMJ Open <http://bmjopen.bmj.com/content/4/9/e006021.full> accessed 24 April 2015.

⁵⁶ NHS Commissioning Board, ‘Enhanced Service Specification Improving Patient Online Access’ Para 5. <http://www.england.nhs.uk/wp-content/uploads/2013/03/ess-patient-online.pdf> accessed 24 April 2015.

⁵⁷ Kate Saffin and Aidan Macfarlane, ‘How Well Are Parent Held Records Completed?’ (1991) 41 British Journal of General Practice 249, 249.

⁵⁸ *ibid.*

⁵⁹ Kerridge (n3) 277.

⁶⁰ R Bock, ‘A guide for XXY males and their families’ (1993) Office of Research Reporting NIH Pub. No. 93-3202, as discussed in Milton Diamond and Linda Ann Watson, ‘Androgen Insensitivity Syndrome and Klinefelter's Syndrome’ (2004) 13 (3) Child Adolesc Psychiatr Clin N Am 623 online at <<http://www.hawaii.edu/PCSS/biblio/articles/2000to2004/2004-ais-and-klinefelters.html>> accessed 24 March 2015.

disclosed, and knowledge established, some young intersex persons might prefer to read through their medical notes on their own, as opposed to having to listen to a doctor's explanation in a face-to-face meeting, particularly as research suggests that we retain less than 50 per cent of the healthcare information we receive.⁶¹

9.6 Conclusion

In regard to a young intersex person's right to access their own medical records, current English law appears to support this right. However, English law also allows for medical practitioners to depart from this right if they, the doctors, have fears of what blanket disclosure will bring. Therefore young intersexed persons might encounter indirect discrimination. Further, this discrimination may be considered proportionate, particularly as receiving a 'catastrophic diagnosis often limits a patient's ability to immediately process information'.⁶² Giving these young people an unqualified right of access to medical records without an adequate infrastructure of support available has the potential to leave them confused and vulnerable. Conversely, denying them access to their medical records completely leaves them equally vulnerable and confused. As Kerridge and others write:

In the past, concealing the truth from patients was often justified on paternalistic grounds. This is no longer the case. The most important issues now are not whether to tell the truth, but how to tell it, who should tell it and what should be told.⁶³

The obvious course to take would be for doctors to organise a meeting with the young person, to discuss these issues face to face, and with their agreement, encourage parental presence and additional specialist external counselling support if needed. A more preferable option would be to start the process of disclosure at an early age, with set intervals for further disclosure in a less clinical environment.

Arguably, the most significant discrimination facing the young intersexed person is the lack of a legal duty to disclose *unrequested* information. Should a young person be misinformed or not informed of their condition, they will not be in a position to

⁶¹ JL Anderson and others, 'Patient Information Recall in a Rheumatology Clinic' (1979) 18 (1) *Rheumatology* 18.

⁶² Joel Hill, 'Veracity in Medicine' (2003) 362 *The Lancet* 1944.

⁶³ Kerridge (n3) 279.

consider accessing their medical records at all.⁶⁴ Further, without full disclosure, it is possible to argue that all medical treatment received by a *Gillick* competent intersexed person has been unlawful, as the premise for such treatment has been kept away from the subject him/herself. It will be impossible for such a competent child to give valid consent if they are not informed as to the rationale for the treatment. Neither could the young person's parents give valid consent in such a situation.⁶⁵

Puberty can be a difficult time for any young person, but it can be especially difficult for the intersexed.⁶⁶ The majority of young intersex people know they are 'different', but they may not know why and how. Further, they appear to learn very quickly that any questions they would like to ask their parents are 'off limits'.⁶⁷ Sanders and Carter stipulate that professionals and parents need to work together to 'explore creative approaches to information sharing' if the needs of young intersexed persons are to be met.⁶⁸

Goodall notes that children view their medical history in a different way to their parents, and if children do not find out about a condition until later it may 'leave them vulnerable to a shocking revelation at exactly the age when conformity with peers and sexual identity are important'.⁶⁹ He also states that the best approach is to 'unfold the truth stage by stage, matching simple statements to the child's conceptual growth

⁶⁴ This is akin to the current situation of donor-conceived children, who, if they know they are the product of donor gametes, may attempt to find information regarding their genetic parents. However, there is currently no legal duty for their parents to disclose the truth behind their creation. Karen Dyer, 'The need to re-evaluate incest in the age of assisted reproductive techniques: *Stübing v Germany*' (2012) 42 *Fam Law* 1144.

⁶⁵ If the treatment is potentially life-saving, parents may be able to consent to treatment on behalf of their competent minors as a result of the ruling in *W (a minor) (medical treatment: court's jurisdiction)* [1992] 4 All ER 627, although this would not necessarily be the case if the treatment is not urgent. Doctors would be wise to seek court action in such circumstances to ensure that they are not committing a trespass.

⁶⁶ Karkazis (n 5) 220.

⁶⁷ *ibid.*

⁶⁸ Caroline Sanders and Bernie Carter, 'A Qualitative Study of Communication between Young Women with Disorders of Sex Development and Health Professionals' (2015) *Advances in Nursing* Article ID 653624, (page 6) <http://dx.doi.org/10.1155/2015/653624> accessed 24 July 2015.

⁶⁹ J Goodall, 'Helping a child to understand her own Testicular Feminisation' (1991) 337(8732) *The Lancet* 33 as discussed in Milton Diamond and Linda Ann Watson, 'Androgen Insensitivity Syndrome and Klinefelter's Syndrome' (2004) 13 (3) *Child Adolesc Psychiatr Clin N Am* 623 online at <<http://www.hawaii.edu/PCSS/biblio/articles/2000to2004/2004-ais-and-klinefelters.html>> accessed 24 March 2015.

until the personal implications are finally realized as part of a maturing process'.⁷⁰ It is our duty to ensure that they receive the correct information at the correct time. It is recommended that in this respect English law adopts a statutory duty of veracity,⁷¹ with a system of staggered information disclosure be specifically devised for each intersex/DSD child. To this end, it is recommended that the child be allocated a legal advisor to the initial treatment team in order to promote the patient's legal rights. This would include co-ordinating the schedule for information dissemination. Hopefully in this way the young person can assimilate knowledge at a gentle pace during childhood, rather than in one 'shocking' disclosure later in life.⁷²

⁷⁰ *ibid.*

⁷¹ This would adopt the spirit of openness now sanctioned by the new duty of candour imposed on healthcare trusts in relation to serious safety incidents. Care Quality Commission Regulation 20: Duty of Candour Guidance for NHS bodies November 2014.

⁷² The effect on Cheryl Chase of receiving a three-page summary of her intersex diagnosis at the age of 21, as discussed in Karkazis (n 5) 251.

Chapter Ten: Births, Deaths, Marriages and the Intersexed: Concluding Thoughts.

10.1 Introduction

Throughout this thesis it has been noted that those with intersex/DSD conditions face discrimination in the healthcare environment. This is most pertinent in early childhood, partly due to the need for early medical intervention for some children, but more generally due to the lack of information available for parents. Further, until the child reaches the age of 18, the young person does not have the *prima facie* legal right to refuse treatment.¹

Some potential for discrimination will dissolve once a child reaches the age of majority as they will be able to refuse any unwanted medical treatment. They will also have greater capacity, in the eyes of healthcare systems, to demand information regarding their early treatment, should this not have been forthcoming. However, no amount of information received will be able to correct unsuccessful surgery sustained in childhood.² Further, whilst noting that in recent years there has been a significant move away from early surgical intervention as advocated by John Money, on a social dimension little has changed to assist children who are born with an unidentifiable sex. As discussed in chapter eight, doctors still believe that conducting genital modification is carrying out society's wishes.³ Until the demand for a binary system of sex is abated, there is little that can be done to end discrimination in this respect. Even if at the age of majority the intersexed gain independence in the healthcare setting, they may find that in other areas, such as in marriage,⁴ in employment,⁵ in prison and even in death, they face new forms of discrimination.⁶

¹ As discussed in chapter five, albeit that healthcare organisations will generally be sensitive to the wishes of the child in such circumstances.

² By unsuccessful I mean not only operations which did not achieve all of their aims, but also operations which although technically a success, did not meet the needs of the person in later life. This is discussed in chapters four and eight.

³ chapter eight, section 8.3.

In this, the concluding chapter, we consider the overall parameters of English law in respect of treatment of those who do not fall neatly into the ‘male’ or ‘female’ categories and assess how English law could be adjusted to protect the intersexed, not only in the healthcare context, but also in other areas. The chapter commences with an investigation into English law’s approach to registering births, deaths and marriages, and investigates the potential discrimination faced by the intersexed at these three defining moments in their lives. The chapter notes that in terms of the current law, discrimination occurs against children who genuinely are, and are happy to be, ‘intersex’, as there are only two gender options to choose from, namely ‘female’ or ‘male’. In this respect other countries have been more embracing of gender diversity, with numerous countries allowing ‘third’ genders to exist on legal documentation. With this in mind, this chapter then considers to what extent, if at all, English law should adopt aspects of these international innovations. The final part of this chapter summarises the findings of this chapter as well as the main findings of this thesis.

10.2 Registration of Birth – Male or Female?

By virtue of c 20, part I section 2 of the Births and Deaths Registration Act 1953,⁷ (the Act) the child’s birth must be registered ‘before the expiration of a period of forty–two days from the date of the birth’,⁸ by the ‘registrar of births and deaths for the sub-district in which the child was born’.⁹ Although not explicitly noted in the Act,¹⁰ the sex of the child is recorded along with the names and address of the parents

⁴ This is discussed at 10.4.

⁵ As discussed in chapter one section 1.3.1.

⁶ As discussed at 10.4.

⁷ Section 2, in force since 25 July 2013.

⁸ This Act has been amended several times, but the 42 days has yet to be altered. The most recent alterations by virtue of the Welfare Reform Act 2009 c. 24 are yet to be in force. Those who fail to register a birth may be fined. In Scotland, parents only have 21 days to register a birth. <http://www.gro-scotland.gov.uk/regscot/registering-a-birth.html>

⁹ Section 1 as it currently stands has been in force since 6 April 2009.

and the name and date of arrival of the child.¹¹ As current law in England recognises sex as a binary system, there are only two options, ‘male’ or ‘female’,¹² on the register. Guidance issued to registrars by the General Register Office stipulates that ‘in those rare cases where there is doubt about the sex of the child, the registrar should telephone the General Register Office for advice and not proceed with the registration’.¹³ The advice further states: ‘in the best interests of the child, parents are likely to be advised to defer registration until medical investigations have been completed’.¹⁴ That is because it is virtually impossible to change the registered sex at a later stage. Although there are supplementary provisions to cover the situation of delayed registration should the birth not be registered within one year, the written authority of the Registrar General is needed.¹⁵

Until the child is registered and the birth certificate received, it will be impossible for the parents to apply for a passport on the child’s behalf should they wish to travel abroad, or even to receive child benefit. Child benefit can currently be backdated for three months,¹⁶ but if the parents are having financial difficulties they will wish to apply straightaway. Without a birth certificate they cannot.

¹⁰ The only reference to ‘sex’ is in section 33 (2) Short certificate of birth.

(2) Any such certificate shall be in the prescribed form and shall be compiled in the prescribed manner from the records and registers in the custody of the Registrar General, or from the registers in the custody of the superintendent registrar or registrar, as the case may be, and shall contain such particulars as may be prescribed: Provided that any particulars prescribed in addition to name, surname, sex and date of birth shall not include any particulars relating to parentage or adoption contained in any such records or registers.

¹¹ The short time frame specified to register a birth is problematic in other jurisdictions, which has increased the need for reassignment surgery. For example, in Puerto Rico such surgeries must take place no later than 30 days after the child’s birth to allow doctors to define ‘sex’ on the birth certificate. Frances Lorey-González Nieves, ‘The Unarticulated Premise underlying the Medical and Legal Management of intersex People in Puerto Rico: Some Constitutional and Gender Issues’ (2010) 79 Rev Jur UPR 1233.

¹² Email from Her Majesty’s Passport Office to author (14 January 2015).

¹³ *ibid.*

¹⁴ *ibid.*

¹⁵ Part 2 Section 5.

¹⁶ <https://www.gov.uk/child-benefit/how-to-claim> accessed 12 June 2015.

Further, and more significantly, once the birth has been registered, as either ‘boy’ or ‘girl’, it is exceptionally difficult for the birth certificate to be altered to reflect a more accurate birth gender.¹⁷ This is because the Births Register acts as a historical document which records the facts as they were at the time of signing, maintaining this information for posterity. Section 29 (1) of the Act explicitly determines that changes are not to be made, unless provided by ‘this or any other act’.¹⁸ The Act authorises specific changes; for example, if unmarried parents later marry and the child is legitimised, the certificate can be adjusted to record this by virtue of section 10A. Additionally, section 13 (1) of the Act allows for a child’s name to be changed up to one year after the birth.¹⁹ Whereas an administrative error appears to have a straightforward remedy, as specified by s29 (2),²⁰ the same cannot be said for an ‘error of fact’,²¹ which requires a statutory declaration by two persons for an error to be noted. If changes are allowed then the registration is altered, but Chapter III of the Act, s29 (3) demands that the original entry is maintained, and the readjustment noted

¹⁷ As will be discussed later, this is an aspect that is the subject of current Parliamentary campaigns. By virtue of section 1 of the Gender Recognition Act 2004 (which came into effect 4 April 2005), those who are transgendered can be awarded a Gender Recognition Certificate for their ‘new’ sex for the purposes of their *future* life; they are not allowed retroactive change. The Act is unavailable for those who are intersexed, as s2 specifically refers to Gender Dysphoria. Although some intersexed persons do suffer from this (potentially as a result of being wrongly assigned a gender in early life), a number of intersex individuals resent having to ‘lie’ in order to be given a certificate which allows them the legal right to live in the sex of their choice, as a result of wrong diagnoses at infancy. Email from Correspondent (E) to author (14 January 2013).

¹⁸ s29 (1) No alteration shall be made in any register of live-births, still-births or deaths except as authorised by this or any other Act.

¹⁹ Name changes are permissible, but it is a more difficult to change the first name if the child has been baptised, as this requires not just parental involvement, but by virtue of s13 (a) of the Act also the involvement of ‘the person who performed the rite of baptism or by the person who has the custody of the register, if any, in which the baptism is recorded’. (In Scotland only the forename can be changed.) In fact, a child’s name can be changed at any point with parental consent, provided that the child has not undergone baptism, but this would not be altered on the birth certificate itself.

²⁰ s29 (2) Any clerical error which may from time to time be discovered in any such register may, in the prescribed manner and subject to the prescribed conditions, be corrected by any person authorised in that behalf by the Registrar General.

²¹ s29 (3) (as amended). An error of fact or substance in any such register may be corrected by entry in the margin (without any alteration of the original entry) by the officer having the custody of the register, and upon production to him by that person of a statutory declaration setting forth the nature of the error and the true facts of the case made by two qualified informants of the birth or death with reference to which the error has been made, or in default of two qualified informants then either by two credible persons having knowledge of the truth of the case or, where it applies, in accordance with s29A of this Act.

alongside it.²² The Act does not allow alterations to the sex, and should such a request be made, parents are likely to face an ‘epic struggle’ to succeed in their request.²³

One of the rare times that a new certificate was issued was in the case of Joella Farmer, 10, who was born with genital difference as a result of cloacal exstrophy.²⁴ Joella was not expected to live for more than a few hours, and the hospital chaplain encouraged Joella’s mother to baptise her. As the sex of the child was unidentifiable at birth, her mother gave her the name of Joel, and the birth was duly registered as male. Some eight months later the mother was informed that she should raise Joel as female,²⁵ and for a number of years Joella’s mother fought to have the birth registration altered to reflect Joella’s adopted gender.²⁶

Eventually an application was submitted in line with s29 (2) of the Act, stating that there had been an error of fact or substance in the first registration.²⁷ This had the

²² Further, although there are extra provisions that deal with specific circumstances, for example s29(4) specifies errors in relation to the cause of death whilst s29A gives the ability to alter the child’s parentage, there is no extra provision to change the sex of the child.

²³ Diane Miller and Robert Hill, ‘J’s story’ [1999] 149 NLJ764, 765.

²⁴ A non-intersex condition, as discussed in chapter four of this thesis.

²⁵ As mentioned in chapter three, this was standard practice at the time. Today’s recommendation may well be different, particularly as it was discovered on surgery that the child had rudimentary testes as opposed to ovaries. Diane Miller and Robert Hill, ‘J’s story’ [1999] 149 NLJ 764.

²⁶ A series of operations had taken place to alter Joella’s internal and external sexual organs. On paper this appeared to be sex-reassignment surgery. As Joella’s application took place before the Gender Recognition Act 2004 had even been conceived, the General Registrar office considered the case authority of *Corbett v Corbett* [1971] 2 All ER 33, which in effect refused transsexuals the right to have a legal recognition of change of sex, and accordingly rejected Joella’s application. Joella’s family fought publicly for a significant amount of time to change the certificate from male to female. Joella received support from a number of people, including Princess Diana. Gary Finn ‘Girl christened as boy wins right to new birth certificate’ *The Independent* (London, Wednesday 2 December 1998) <http://www.independent.co.uk/news/girl-christened-as-boy-wins-right-to-new-birth-certificate-1188581.html> accessed 11 June 2014; ‘Story of battle to change birth certificate to be told in book’ *Spalding Guardian* <http://www.spaldingtoday.co.uk/news/latest-news/story-of-battle-to-change-birth-certificate-to-be-told-in-book-1-565834> accessed 11 June 2014; <http://www.thefreelibrary.com/GIRL+BORN+MALE+WINS+SEX+BATTLE%3B+Birth+certificate+changed.-a060926192> accessed 11 June 2014; ‘Exclusive: Girl who Made Legal History Celebrates 18th’ *Daily Mirror* (London, 17 May 2006) <http://www.mirror.co.uk/news/uk-news/exclusive-girl-who-made-legal-625454>, accessed 11 June 2014.

²⁷ Miller and Hill (n 23).

benefit of avoiding the ruling in *Corbett*,²⁸ as no ‘initial’ mistake had been made in the *Corbett* case.²⁹ Due to the ‘watertight’ attention to detail in this application, it was approved and Joella’s birth was registered as female.³⁰

Greenberg notes that Joella’s story is unique. It is the only public report of a person’s fight to change her recorded sex on a birth certificate.³¹ She also informs us that although such changes have occurred before in the US, ‘anecdotal evidence’ indicates that there is an increasing resistance to such changes these days.³² By contrast, Miller and Hill believe that should a similar situation occur now, then provided the application is ‘approached with clarity of thought and language’ there is scope under s29(2) of the Act for amendments to sex to be registered.³³ As they particularly note, there is no time limit for making an application. However, this application relied on a statutory declaration by an expert in the field that the sex had been wrongly assigned at birth. Such a declaration may be unforthcoming in a different case, and consequently it is unlikely that the outcome would be successful. In this respect it should be noted that intersex activists in England frequently complain that current English law does not permit them to change their birth certificates, and have campaigned to amend the current law to allow such alterations to take place.³⁴ At the time of writing little headway has been made in this regard.³⁵

²⁸ *Corbett v Corbett* [1971] 2 All ER 33. This somewhat infamous case considered divorce proceedings between a man and a transsexual woman. It was decided that the marriage was void *ab initio* as the woman was never a ‘woman’ for the purposes of marriage.

²⁹ There were plans to take action to the ECtHR if this application was unsuccessful.

³⁰ Miller and Hill (n 23).

³¹ Julie A Greenberg, *Intersexuality and the Law* (New York University Press 2012) 68.

³² *ibid.*

³³ *ibid.*

³⁴ Holly Greenberry and others. Sarah Morrison, ‘Special report: Intersex women speak out to protect the next generation’ *The Independent* (London Saturday 30 November 2013) <http://www.independent.co.uk/news/uk/home-news/special-report-intersex-women-speak-out-to-protect-the-next-generation-8974892.html> accessed 25 November 2014. Holly has been fighting for a number of years to get her birth certificate changed, and actively lobbying Parliament. Email from (G) to author (17 February 2011).

10.3 The Parallel law for Transsexuals

At this point it is pertinent to compare the law concerning transsexuals with the law for those born intersexed. For over 70 years, those with gender dysphoria have been able to undergo operations to match their physical body with their gender orientation.³⁶ However, it was only after the Gender Recognition Act 2004 was passed that transsexuals were able to acquire a birth certificate specifying their new sex, hence allowing them full legal recognition of this for all legal purposes, including marriage.

This Act was passed in response to the Strasbourg judgment in *Christine Goodwin v The United Kingdom*.³⁷ This case considered the ability of a post-operative male to female transsexual to be issued with a birth certificate in her new gender. Maintaining a birth certificate in the male sex meant, amongst other things, that (at the time) Goodwin would not be able to retire until 65 when women could retire at 60, and further that she could not lawfully marry her partner.³⁸ The Court found that there was a violation of Articles 8 and 12 of the European Convention on Human Rights, stating that:

³⁵ A similar situation occurs in other countries. In the Netherlands, Maya Posch fought for 10 years to have her gender changed officially from male to female. Maya Posch, 'Press Release On Official Gender Change' Saturday, 31 March 2012 . <http://mayaposch.blogspot.co.uk/2012/03/press-release-on-official-gender-change.html> accessed 24 May 2015.

³⁶ One of the first Britons to undergo a sex change operation was April Ashley (born George Jamieson in 1935). The operation took place in Casablanca in 1960. Ashley was the subject matter in the divorce case of *Corbett v Corbett* [1971] 2 All ER 33. 'April Ashley: the first Briton to undergo a sex change' *The Independent* Thursday 2 February 2006 <http://www.independent.co.uk/arts-entertainment/films/features/april-ashley-the-first-briton-to-undergo-a-sex-change-525383.html> accessed 13 June 2014.

³⁷ Application No 28957/1995. Also known as *Christine Goodwin and I v United Kingdom* [2002] 2 FCR 577. The Judgment was received on the 11 July 2002.

³⁸ The previous cases of *Bellinger v Bellinger*, EWCA Civ 1140 [2001], 3 FCR 1, and *Corbett v Corbett* [1971] concerned the legitimacy of marriage. In both cases, the marriage was not deemed to be lawful, as the female party had been born male and the birth certificate in hand stated 'male'. (Ironically with the new Marriage (Same Sex Couples) Act 2013, these marriages would be lawful, but would still not address the issue of those who wish to marry in their new gender.)

(...) the situation, as it has evolved, no longer falls within the United Kingdom's margin of appreciation. It will be for the United Kingdom Government in due course to implement such measures as it considers appropriate to fulfil its obligations to secure the applicant's, and other transsexuals', right to respect for private life and right to marry in compliance with this judgment.³⁹

The Gender Recognition Act 2004 was Parliament's answer to the Court's criticism. The Act, which came into force on 4 April 2005, allows applicants the right to apply to the Gender Recognition Panel in order to change the original gender specified on their birth certificates. However, as section 2 (1) (a) of the Act stipulates that the applicant 'has or has had gender dysphoria', this section rules out the possibility of the intersexed using this mechanism to alter their birth certificate, unless they are prepared to 'lie'.⁴⁰ Most intersexed persons who live in conflict with their assigned gender do not believe that they have gender dysphoria; they believe that they were wrongly assigned at birth.⁴¹

10.4 Marriage

Until the passing of the Marriage (Same Sex Couples) Bill 2012-13, to become the Marriage (Same Sex Couples) Act 2013, it was unlawful for people of the same (recorded) sex to get 'married'.⁴² Although same sex couples have been able to enter a civil partnership since 2005,⁴³ this route would prove challenging if they appeared

³⁹ *Christine Goodwin v The United Kingdom*, Application No 28957/1995, [120]. The applicant also claimed that there had been a breach of Article 14 as the lack of legal recognition caused numerous discriminatory experiences and prejudices. The court considered that the lack of legal recognition lay at the heart of the complaint under Article 14 and resulted in violation of that provision. In this respect, as there was not a separate issue there was no separate finding.

⁴⁰ Although some may have 'deliberately lied' by pretending that they have 'gender dysphoria' in order to acquire a 'rectified' birth certificate in the opposite sex. Email from (J) to author (17 February 2011)

⁴¹ It is not possible to acquire adequate statistics as to who is and who is not happy in their allotted gender. In the future, it is hoped that there will be less conflict, as doctors are now more supportive of keeping boys with small penises as boys, and maintaining the integrity of an 'over large' clitoris.

⁴² s1 (1) 'Marriage of same sex couples is lawful'.

⁴³ By virtue of the Civil Partnership Act 2004.

to be (and in reality were) partners of a different sex, for a civil partnership is only valid for 'same sex' couples.⁴⁴ The language of the new Act is identical in this respect. This could leave an intersexed person with no legal right to enter into any official union, as it is extremely unlikely that an intersexed person will meet the right person who is 'the same sex'.⁴⁵

As Greenberg writes,

When I first started writing in this area(...) I firmly believed that courts would treat marriages involving an intersex spouse differently from the way that they would treat marriages in which one spouse is a transsexual. I did not believe that they would subject intersex persons to the same scrutiny as transsexuals.⁴⁶

In reality, the scrutiny appears to be greater. In *Re C and D*,⁴⁷ the Australian Family Court annulled a 12-year-old marriage, because 'the husband was neither a man nor a woman, but was a combination of both'.⁴⁸ This case was widely criticised, and Greenberg suggests it would not be followed today,⁴⁹ but an equally unsatisfactory situation is the more recent English case of *W v W (nullity: gender)*.⁵⁰ Here, the wife, who was diagnosed with Partial Androgen Insensitivity Syndrome and assigned a male gender on her birth certificate, had to undergo judicial scrutiny of intimate

⁴⁴ s1 (1) 'A civil partnership is a relationship between two people of the same sex'

⁴⁵ If 'intersex' is not a recognised 'sex' on a strict application of the law it will be impossible for such a union to take place.

⁴⁶ Julie Greenberg, Marybeth Herald and Mark Strasser, 'Beyond the Binary: What can Feminists Learn from Intersex and Transgender Jurisprudence?' [2010-2011] 17 Mich J Gender & L 13, 25.

⁴⁷ *In the Marriage of C and D (falsely called C)* (1979) 35 FLR 340 (Aust)

⁴⁸ *In the Marriage of C and D (falsely called C)* (1979) 35 FLR 340 345(Aust),

⁴⁹ Greenberg (n 46).

⁵⁰ *W v W* [2001] Fam 111.

physical details before being pronounced ‘female’ for the purposes of having entered into a lawful marriage.⁵¹

In this decision, Charles J considered the somewhat infamous case of *Corbett v Corbett*,⁵² where Ormrod J had propounded a four-point test of sexuality. Rather crucially he said that:⁵³

the biological sexual constitution of an individual is fixed at birth (at the latest), and cannot be changed, either by the natural development of organs of the opposite sex, or by medical or surgical means. The respondent's operation, therefore, cannot affect her true sex. The only cases where the term ‘change of sex’ is appropriate are those in which a mistake as to sex is made at birth and subsequently revealed by further medical investigation.

This somewhat ‘archaic’ test⁵⁴ still stands, and is an anathema to a number of (particularly) transgender persons. However, Charles J had no option but to consider it, and in doing so he expanded it to devise his own six-factor system: namely,⁵⁵

- a. Chromosomal factors.
- b. Gonadal factors (i.e. presence or absence of testes or ovaries).
- c. Genital factors (including internal sex organs).
- d. Psychological factors.
- e. Hormonal factors.
- f. Secondary sexual characteristics (such as distribution of hair, breast development, physique, etc.).

⁵¹ The irony of this was that the marriage had ended and the parties were divorced by this stage.

⁵² [1970] 2 WLR 1306; [1971] P 83.

⁵³ [1971] P 83 [104] (Ormrod J).

⁵⁴ Paul Kavanagh, ‘Slipping Quietly into the Crowd – UKTranssexuals Finally out of Exile’ *Mountbatten Journal of Legal Studies*, 23 http://ssudl.solent.ac.uk/996/1/2005_9_1%262.pdf accessed 24 May 2015.

⁵⁵ Chau and Herring point out that this approved by Lord Nicholls in the House of Lords, in the case of *Bellinger v Bellinger* [2003] UKHL 21; [2003] 2 AC 467; [2003] 2 WLR 1174; [2003] 2 All ER 593; [2003] 1 FLR 1043. See Pak-Lee Chau, Jonathan Herring, ‘Men Women, People: The Definition of Sex’ in Belinda Brooks-Gordon and others (eds) *Sexuality Repositioned: Diversity and the Law* (Hart 2004) 198.

He stated that all of these categories should be considered. In *W v W* he believed that ‘W’ was female, albeit with a male karyotype. On that basis, the application for annulment was refused.

Today, these cases and consequently these issues remain. As things stand, the intersexed are not able to get married in church unless they pass the ‘birth certificate test’.⁵⁶ The new Act may have reduced discrimination for some, but a literal reading of the Act does not suggest that this the case for those who wish to be considered ‘intersexed’.

10.5 Deaths

Births and marriages are not the only events which require formal documentation; even in death registration difficulties prevail for those mourning an intersexed loved one. When registering a death, the next of kin (or representative) has to specify the gender of the deceased. This requires the production of the medical certificate of cause of death (MCDD), which does *not* require the sex of the deceased,⁵⁷ and to be corroborated by the deceased’s birth certificate or some other official documentation which (usually) does. The final death certificate indicates a person’s gender. The situation will be complicated further should a coroner’s inquest be needed.⁵⁸

A potential similarity with transgender people can be drawn here. Not only are transgender people protected by the Equality Act,⁵⁹ but they also have the benefit of

⁵⁶ By this I mean that their lived gender matches their recorded gender.

⁵⁷ However, there are due to be reforms which were postponed in anticipation of the General Election.

⁵⁸ In this case ‘sex’ will be recorded on the form.

⁵⁹ s7 Gender Reassignment (1) A person has the protected characteristic of gender reassignment if the person is proposing to undergo, is undergoing or has undergone a process (or part of a process) for the purpose of reassigning the person’s sex by changing physiological or other attributes of sex.

(2) A reference to a transsexual person is a reference to a person who has the protected characteristic of gender reassignment.

(3) In relation to the protected characteristic of gender reassignment—

(a) a reference to a person who has a particular protected characteristic is a reference to a transsexual person;

(b) a reference to persons who share a protected characteristic is a reference to transsexual persons.

privacy rights by virtue of section 22 (1) of the Gender Recognition Act 2004,⁶⁰ which states that it is an offence ‘for a person who has acquired protected information in an official capacity to disclose the information to any other person’. Therefore any person who discloses that fact that the deceased has had gender reassignment surgery, or is living in a gender contrary to that on their birth certificate, commits this offence and faces a fine of up to £5000.⁶¹ This provision does not extend to those who are intersexed. It appears that the intersexed are discriminated against even at death.

Once again we see that some intersexed persons, designated into the ‘wrong’ sex at an early stage of their lives, face discrimination, not only because they are holding legal documents in the ‘wrong’ gender, but also because they are unable to use relatively simple legal mechanisms which would redress the balance. It is important to consider whether any other jurisdictions approach the issue in a more holistic manner, and hence could act as a role model to current English law.

10.6 International Approaches to ‘Third Gender’ Recognition

10.6.1 Asia

In the face of discrimination suffered by ‘third gender’ communities internationally, there are countries that have been proactive in their recognition of third genders. In this respect, Asia leads the way. In 2007, Nepal started to recognise a ‘third gender’ after a Supreme Court ruling ordered that this new category be added to all citizenship documentation,⁶² and whilst third genders are not recognised in Pakistan

⁶⁰ s 22 Prohibition on disclosure of information (2) “Protected information” means information which relates to a person who has made an application under section 1(1) and which—
(a) concerns that application or any application by the person under section 5(2), 5A(2) or 6(1), or
(b) if the application under section 1(1) is granted, otherwise concerns the person’s gender before it becomes the acquired gender.

⁶¹ s22 (8) A person guilty of an offence under this section is liable on summary conviction to a fine not exceeding level 5 on the standard scale.

⁶² *Sunil Babu Pant and others v Nepal Government, Office of the Prime Minister and Council of Ministers, Legislature-Parliament* 21 December 2007. United Nations Development Programme, ‘Nepal Census Recognizes Third Gender for the First Time’ http://www.undp.org/content/undp/en/home/ourwork/hiv-aids/successstories/Nepal_third_gender_census_recognition/ accessed 14 June 2014.

as such, the removal of a compulsory question on gender on Pakistani national identity cards in 2011 has supported those who do not see themselves as 'male' or 'female'.⁶³ In the last two years dramatic shifts have also occurred in Bangladesh and India, in addressing the discrimination of 'hijras'

There are in the region of 10,000 hijras living in Bangladesh. They are members of multi-faceted communities, covering not only intersex/DSD persons, but also transgender men and women, transvestites and eunuchs. The exact composition of these communities will depend on the region in which they are established. For example, in Boropani the community appears to be very 'male' orientated and a number of Boropani hijras are uncastrated men who are married and have fathered children.⁶⁴

Originally, in ancient Hindu tradition, hijras held important roles. These men, who dressed as females, sacrificed their penis to the goddess Bahuchara Mata, in order to be able to 'bestow blessings on baby boys and fertility on newly-weds'.⁶⁵ Further, as the majority of hijras were castrated, during the time of Muslim rule in South Asia they were used as bodyguards for royalty. However, in more recent times, hijras suffered persecution.⁶⁶

On 11 November 2013,⁶⁷ the Bangladesh cabinet passed a law granting a 'third gender' status to hijras living in the country.⁶⁸ Hijras had already received voting

⁶³ BBC News South Asia, 'Pakistan transgenders pin hopes on new rights' 25 April 2011 <http://www.bbc.co.uk/news/world-south-asia-13186958> accessed 14 June 2014.

⁶⁴ For a detailed discussion on the Boropanihijras see Delwar Hussain, *Boundaries Undermined The Ruins of Progress on the Bangladesh-India Border* (C Hurst & Co Ltd, 2013).

⁶⁵ *ibid* 81.

⁶⁶ Partly as a result of British Colonial rule. Anahita Mukherji, 'Hijra Farsi: Secret Language Knits Community' *The Times of India* (7 October 2013) <http://timesofindia.indiatimes.com/india/Hijra-Farsi-Secret-language-knits-community/articleshow/23618092.cms>

⁶⁷ Lucien Mae, 'Hijras recognized as third gender in Bangladesh' 429 Magazine, 14 November 2013, <http://dot429.com/articles/3467-hijras-recognized-as-third-gender-in-bangladesh> accessed 14 June 2014.

rights in December 2009, but this new law significantly expands their rights, allowing them to acquire passports in the third gender. It is hoped that the new laws will help to end discrimination, and to this effect, under the new laws, hijras will be given the same rights to education, employment, housing and health.

India, which also houses a large hijra community, has allowed its people to vote in a third gender category since 2009. In April 2014, India's Supreme Court was asked to consider whether the non-recognition of the gender identity of transgender persons was a violation of Articles 14 and 21 of the Constitution of India.⁶⁹ In the same case, hijras also sought confirmation of their legal status of third gender. The Court specified that 'by recognising TGs as third gender, this Court is not only upholding the rule of law but also advancing justice to the class, so far deprived of their legitimate natural and constitutional rights (...).'⁷⁰ The Court declared that hijras and eunuchs were to be 'treated as "third gender" for the purpose of safeguarding their rights' under Part III of the Constitution and laws, and that transgender persons' 'right to decide their self-identified gender' was also upheld.⁷¹

In all these instances, we see that countries are prepared to move away from the binary gender system to encompass gender diversity in their states. It might be argued that the cultural backgrounds of these countries have permitted the establishment of a third social grouping, as hijras have been part of the cultural backgrounds in these countries for centuries. Additionally, in Asia traditions of gender diversity are supported by its religious traditions, notably Hinduism. By comparison, England, as a traditionally Christian country, does not have the same cultural heritage to draw upon, and in this respect it may not be so easy to introduce a third gender category at this stage. Regardless of this, a number of predominantly

⁶⁸ Patrick Balbierz, 'Hijras: The Battle for Equality' 29 January 2014, World Policy Blog <http://www.worldpolicy.org/blog/2014/01/29/hijras-battle-equality> accessed 14 June 2014.

⁶⁹ Writ Petition (Civil) No 400 of 2012, *National legal Services Authority v Union of India & others*, with Writ Petition (Civil) No 604 of 2013, KS Radhakrishnan J, presiding, para 2.

⁷⁰ *ibid* [126].

⁷¹ *ibid* [129].

Christian countries have now adopted measures in an attempt to support gender deviations.

10.6.2 Australasia

In recent times Australasia has also seen movement towards promoting gender equality. Since 2011, Australians have been able to select 'X' as their gender on passport applications which represents 'Unspecified/Intersex/Indeterminate' gender, for those who did not wish to adopt one of the two binary labels.⁷² The law was initiated by Organisation Intersex International (OII) Australia,⁷³ and the Australian government considered their applications and those of other advocates. It was decided that only adults were able to adopt a thirdgender designation, as it was felt that babies would suffer from difficulties if such a gender were allotted to them.⁷⁴ The recent High Court, New South Wales (NSW) decision on 'Norrie' has helped to consolidate the law in Australia.

Norrie, who was born male, underwent sex-assignment surgery in 1989 in Scotland. In 2009, Norrie applied to the NSW Registrar of Births, Deaths and Marriages for her sex to be registered in the NSW register as 'non-specific'.⁷⁵ This was the first registration of Norrie's sex in NSW. The application fell under the remit of the 'change of sex' provisions in the Births, Deaths and Marriages Registration Act 1995 (NSW). In 2010, Norrie was issued with a certificate without a sex specification, but the certificate was later revoked. An appeal to the Administrative Decisions Tribunal

⁷² *ibid.*

⁷³ *ibid.*

⁷⁴ *ibid.*

⁷⁵ The legal documentation refers to Norrie as 'she' and 'her' albeit Norrie is seen as adopting a more androgynous role.

was unsuccessful.⁷⁶ It was decreed that a gender must be specified. On appeal, the Court of Appeal of NSW⁷⁷ held that

the word 'sex' in the Act is not confined to 'male' or 'female', it is likely that other appropriate identifications such as 'intersex', 'androgenous', or 'transgender', being words that appear to be recognised designations of sexual identity, may be registered, subject to the applicant satisfying the pre-condition of having undergone sex affirmation surgery.⁷⁸

The Court remitted the matter back to the Tribunal to make findings of fact in relation to Norrie's specific sex classification. The registrar appealed to the High Court. On 2 April 2014, the High Court found that the 1995 Births, Deaths and Marriages Registration Act (NSW) recognised that a person's sex might be ambiguous:

The Act does not require that people who, having undergone a sex affirmation procedure, to remain of indeterminate sex – that is, neither male nor female – must be registered, inaccurately, as one or the other. The Act itself recognises that a person may be other than male or female and therefore may be taken to permit the registration sought, as 'non-specific'.⁷⁹

As of the time of writing, it is too early to assess the impact of this ruling, but it is likely to be used as an authority in other Australian states with similar legislation.⁸⁰

⁷⁶ *Norrie v Registrar of Births, Deaths and Marriages (GD)* [2011] NSWADTAP 53 (26 August 2011).

⁷⁷ *Norrie v NSW Registrar of Births Deaths and Marriages* [2013] NSWCA 145 (31 May 2013)

⁷⁸ [205], (Beazley ACJ). Beazley ACJ also noted 'I should make one final observation. On the argument on the appeal, Norrie's Senior Counsel used the language of "intersex" to describe Norrie's sexual identity. There are two problems with this. First, Norrie did not make an application to the Registrar that her sex be registered as "intersex". Secondly, from the understanding of the term "intersex" I have gleaned from the material, it would seem that Norrie is not an intersex person, although Professor Greenberg's work indicates there is some fluidity around the language relating to these matters. Norrie will need to take care in specifying the "sex" that she contends should be registered.' [206] Although Norrie was not intersex, a person who is can now register as such in NSW.

⁷⁹ *NSW Registrar of Births, Deaths and Marriages v Norrie* [2014] HCA 11 (2 April 2014)[46].

⁸⁰ Helen Davidson, 'Third Gender must be recognised by NSW after Norrie wins legal battle' *The Guardian*, Wednesday 2 April 2014. <http://www.theguardian.com/world/2014/apr/02/third-gender-must-be-recognised-by-nsw-after-norrie-wins-legal-battle> accessed 17 June 2015.

To date, of all the countries who allow for ‘third gender’ documentation, New Zealand appears to have the most consistent approach. By virtue of section 29 of the Births, Deaths, Marriages, and Relationships Registration Act 1995, a birth certificate can be issued stating ‘indeterminate sex’ if it is not possible to assign to one of the two binary sexes.⁸¹ In fact, it has been possible to record sex as ‘indeterminate’ in New Zealand since 1868. Regardless of the fact that fewer than 200 births have been recorded as ‘indeterminate’ from this date until 2013,⁸² the facility to leave the sex unspecified has the flexibility that is needed in English law.

Further, by virtue of section 28 of the Births, Deaths, Marriages, and Relationships Registration Act 1995, an eligible adult can request the Family Court to make a declaration as to the sex specified on the birth certificate. This also includes the provision of ‘indeterminate sex’. However, it is not possible to alter a recorded sex of ‘male’ or ‘female’ to ‘indeterminate’, unless the child was born with indeterminate sex and wrongly recorded as male or female. In this case the Family Court would make an order under section 85 of the Act that the birth certificate should be corrected by the Registrar General. This has occurred on at least one occasion to date.⁸³ A difficulty with this provision may occur where a child’s sex undergoes a natural ‘metamorphosis’ from ‘male’ or ‘female’ to ‘indeterminate’ during their

⁸¹ Section 29 Declarations of Family Court as to appropriate gender identity for children

(3) The court shall issue the declaration if, and only if,—

(a) it is satisfied either that the child's birth is registrable under this Act but is not yet registered, or that there is included in the record of the child's birth—

(i) information that the child is a person of the sex opposite to the nominated sex; or

(ii) information that the child is a person of indeterminate sex; or

(iii) no information at all as to the child's sex;

⁸² OII Aotearoa, ‘Summary of Information about Identity Documents and Requirements & Protections for Intersex people of indeterminate sex in New Zealand.’ <http://oiinz.org/2013/11/summary-of-information-about-identity-documents-requirements-protections-for-intersex-people-of-indeterminate-sex-in-new-zealand/> accessed 15 June 2014.

⁸³ Internal Affairs NZ, ‘General Information Regarding Declarations of Family Court as to sex to be shown on Birth Certificate’ [https://www.dia.govt.nz/diawebsite.nsf/Files/GeninfoDeclarationsofFamilyCourt/\\$file/GeninfoDeclarationsofFamilyCourt.pdf](https://www.dia.govt.nz/diawebsite.nsf/Files/GeninfoDeclarationsofFamilyCourt/$file/GeninfoDeclarationsofFamilyCourt.pdf) accessed 14 June 2014.

lifetime.⁸⁴ The Act informs us that no error would have been made with the initial birth certificate as the birth would have been correctly registered originally.⁸⁵

The ability to register an intersex child correctly on a birth certificate is not the only positive step that New Zealand has undertaken. In response to a Human Rights Commission report published in 2008, since December 2012 a passport can be issued with an 'X' meaning indeterminate or unspecified without any need to amend the birth certificate. This was originally put into place for those who were undergoing transgender reassignment, but passports can be issued to the intersexed in this form. The final advancement has come with an amendment to Section 2 of the Marriage Act 1955, so that intersex persons can marry. (Before they only had the right to enter into a civil partnership.) It is important to bear these legal concessions in mind when addressing English law.

10.6.3 Europe: Germany and Malta

In 2013, Germany became the first European country to allow parents to leave the designation of 'gender' blank on birth certificates, as a result of an amendment to the Law on Civil Status.⁸⁶ The law was said to have been changed 'following a review of cases which revealed great unhappiness'.⁸⁷ This was partly due to the fact that former German law allowed parents only one week to register a birth. The short timeframe

⁸⁴ Such might occur, for example with 5-alpha-reductase.

⁸⁵ Internal Affairs NZ, 'General Information Regarding Declarations of Family Court as to sex to be shown on Birth Certificate' [https://www.dia.govt.nz/diawebsite.nsf/Files/GeninfoDeclarationsofFamilyCourt/\\$file/GeninfoDeclarationsofFamilyCourt.pdf](https://www.dia.govt.nz/diawebsite.nsf/Files/GeninfoDeclarationsofFamilyCourt/$file/GeninfoDeclarationsofFamilyCourt.pdf) accessed 14 June 2014.

⁸⁶ Personenstandsgesetz (PStG) § 22: (3) Kann das Kind weder dem weiblichen noch dem männlichen Geschlecht zugeordnet werden, so ist der Personenstandsfall ohne eine solche Angabe in das Geburtenregister einzutragen.
(If the child can be assigned to neither the female nor the male sex, then the child has to be entered into the register of births without such a specification.)

⁸⁷ Steven Evans, 'Germany allows "indeterminate" gender at birth' BBC news Europe 1 November 2013, <http://www.bbc.co.uk/news/world-europe-24767225> accessed 12 June 2014.

led to a number of ‘emergency operations’ taking place.⁸⁸ The review was based on work by the German Ethics Council, which stipulated that the intersexed must be protected from undesirable medical intervention and from ‘discrimination in the community’.⁸⁹ However, although the law has been seen as a step in the right direction by some,⁹⁰ the current provisions are not without criticism, and others have commented that this will actually lead to more not less discrimination.⁹¹ For example, it has been noted that the new law has been implemented without ensuring that health insurance is available to anyone who is not male or female.⁹² Further, as only ‘males’ or ‘females’ can marry, having the gender ‘X’ on documentation will prevent the intersexed from entering into such a partnership. Of most concern, it appears that doctors have the upper hand. The power to decide the future gender of the child will rest with them, as opposed to parents who are unable to register the child’s gender until it has been settled. Once again, civil law leaves a child with genital difference firmly in the hands of medical practitioners. It is submitted that this would not be a suitable alteration to English law.

By contrast, the most exciting piece of legislation to become law in recent months is the Gender Identity, Gender Expression and Sex Characteristics Act adopted by the Maltese Parliament on 1 April 2015. Hailed as a ‘historic break-through’ by Transgender Europe (TGEU),⁹³ this Act introduces a ‘quick, transparent and

⁸⁸ Jacinta Nandi, ‘Germany got it right by offering a third gender option on birth certificates’ *The Guardian*, 10 November 2013 <http://www.theguardian.com/commentisfree/2013/nov/10/germany-third-gender-birth-certificate> accessed 14 June 2014.

⁸⁹ German Ethics Council, ‘Press Release: Intersex people should be Recognised, Supported and Protected from discrimination’ (Berlin 23 February 2012) <http://www.ethikrat.org/files/press-release-2012-01.pdf> accessed 24 April 2015.

⁹⁰ *ibid.*

⁹¹ Tumblr, ‘Why Intersex Germans Aren’t Crazy about Germany’s New Third Gender Law’ <https://www.tumblr.com/search/germany%20third%20gender> accessed 24 April 2015.

⁹² Hida Vilorio, ‘Op-ed: Germany’s Third-Gender Law Fails on Equality’ [6th November 2013] Advocate.com, <http://www.advocate.com/commentary/2013/11/06/op-ed-germany%E2%80%99s-third-gender-law-fails-equality> accessed 14 June 2014.

⁹³ Transgender Europe (TGEU), ‘Malta Adopts Ground-breaking Trans and Intersex Law’ TGEU Press Release, April 1, 2015 <http://tgeu.org/malta-adopts-ground-breaking-trans-intersex-law/> accessed 24 August 2015.

accessible' route for the recognition of gender change. The whole process appears to have a specified time-limit of one month.⁹⁴ The Act also incorporates the intersexed in several ways (albeit the term is not mentioned as such). Section 3 (1) of the Act gives Maltese citizens the right to:

- (a) the recognition of their gender identity;
- (b) the free development of their person according to their gender identity;
- (c) to be treated according to their gender identity, and, particularly, to be identified in that way in the documents providing their identity therein; and
- (d) bodily integrity and physical autonomy.

Further, not only does the Act forbid any genital assignment surgery on minors,⁹⁵ it also appears to have a mechanism for allowing parents to postpone 'gender' on birth certificates.⁹⁶ TGEU 'encourages' other countries to adopt similar measures.⁹⁷ Whether, in practice, this Act delivers the quick route that it appears to have in place remains to be seen. Should this Act administratively workable, then it is recommended such legislation is adopted by English law. In the meantime, it is essential to see how English law might be modified to assist the intersexed.

10.7 A New Approach to English Documentation?

Throughout this thesis, it has been noted that there remain a number of situations in which current English law discriminates against those with an intersex/DSD condition. Although many intersex/DSD persons are content with the 'sex' that they have been allocated, others are not. Some intersex persons are happy to belong to a

⁹⁴ s 10 (1) of the Act reads A person shall, not later than one month from the publication of the declaratory deed, indicate to the Director the acts of civil status, other than the act of birth, which need to be amended. s 10 (2) specifies 15 days to provide relevant documentation.

⁹⁵ As discussed in chapter eight.

⁹⁶ s7(4).

⁹⁷ TGEU (n 100).

third gender and resent being forced into the binary system. Of perhaps even greater significance, if doctors do not feel pressurised into choosing ‘sex’ at an early stage for neonates born with genital difference, this may end or at least reduce a series of unnecessary and unhelpful genital reassignment procedures. This is one of the key demands of the the Third International Intersex Forum (TIIF).⁹⁸

In addition to ending all ‘mutilating’ and ‘normalising’ procedures,⁹⁹ TIIF also demand a new approach to legal documentation and stipulate that every country must ‘ensure that sex or gender classifications are amendable through a simple administrative procedure at the request of the individuals concerned’.¹⁰⁰ TIIF further demand that ‘all adults and capable minors should be able to choose between female (F), male (M), non-binary or multiple options’ and that eventually, ‘sex or gender should not be a category on birth certificates or identification documents for anybody’.¹⁰¹ It is important to assess these demands to ascertain whether English law could accommodate such changes.

10.7.1 ‘Third Gender’ on Official Documentation

The desire to record ‘sex’ on official documentation can lead to discrimination, particularly for those who do not fit the usual binary system. In this respect, English law should analyse the purpose behind its two-tiered system of ‘sex’ registration and consider whether current law should be adapted in line with other jurisdictions to allow legal documents to be issued with a ‘third gender’ category.

It should be noted, however, that there is some foreseeable difficulty here. Unlike a number of Asian countries that celebrate third genders as part of their cultural

⁹⁸ ‘To put an end to mutilating and “normalising” practices such as genital surgeries, psychological and other medical treatments through legislative and other means.’ TIIF, ‘Public Statement by the Third International Intersex Forum’ (1 December 2013) <http://tgeu.org/third-international-intersex-forum-concludes/> accessed 15 August 2015. Appendix A

⁹⁹ *ibid.*

¹⁰⁰ *ibid.*

¹⁰¹ *ibid.*

heritage, in England there is no historical association with ‘third sexes’. In this respect, it is submitted that documents with a tick box for a ‘third gender’ or ‘gender X’ would not be accepted by current English society as it stands. Albeit a change *should* occur to reform legal identification papers, promoting ‘third genders’ on credentials may cause as much anxiety as not having the facility at all. The specification of ‘sex’ or ‘gender’ on documentation can lead to discrimination in itself, and for a number of years feminists have argued that ‘delineation of sex’ provides for discrimination against women.¹⁰² It might be that the addition of a ‘third gender’ category would lead to more discrimination for those with an indeterminate sex, rather than less, as should an intersexed person, be granted the facility to tick ‘gender X’, that action alone may leave them vulnerable to ridicule. Overall, it is opined that the UK is not yet ready to wholeheartedly embrace a third gender on legal documentation. In this respect, an alternative option will now be considered.

10.7.2 ‘No Gender’ on Official Documentation

It has been noted throughout this thesis that a considerable number of people with a condition that is considered to be a DSD do not identify as intersexed but do identify as ‘male’ or ‘female’, therefore a ‘third gender’ category would not be the most pertinent solution. However, identifying gender on legal documents does cause difficulties for the intersexed. Therefore the most direct method of tackling the issue would be to remove the category of ‘gender/sex’ on official documentation completely. Additionally, eradicating gender from official documentation may prevent, or at least reduce, discrimination happening to every gender, not just those who wish to be ‘intersexed’.

¹⁰² Literature abounds in many forms, and for many years; for example, Jo Freeman ‘How to Discriminate Against Women Without Really Trying’ (1975) <http://www.jofreeman.com/academicwomen/howdiscrim.htm> accessed 14 July 2015. Division for the Advancement of Women, Department of Economic and Social Affairs, United Nations, ‘*Online discussion on Elimination of all forms of discrimination and violence against the girl child, REPORT*’ (14 August to 8 September 2006) http://www.un.org/womenwatch/daw/egm/elim-disc-viol-girlchild/Online%20discussion%20report_Final.pdf accessed 14 July 2015.

If this were felt to be too radical a step to take, then it is submitted that recording ‘sex’ should be obligatory from the age of 18 years only. By this time gender identities will (usually) be formed.¹⁰³ Again, this may appear to be a radical departure from the current registration system, but it is submitted that it is not essential for society to record everyone’s gender at birth.¹⁰⁴

Should there be arguments along the lines that ‘recording “sex” on birth certificates is essential for future planning’, these can be easily rebutted. As mentioned in the introduction, official statistics have indicated that the boy to girl birth ratio in the UK is 105:100. It is well known that globally the male:female ratio in humans is approximately one:one and has been a constant for a number of years.¹⁰⁵ Future societal planning could use this ratio accordingly. It should not matter for the first part of a child’s life who is a ‘boy’ and who a ‘girl’. It is accepted that conflicts in documentation might occur where sex differentiation is part of an organised structure (such as sports, prisons and aspects of healthcare). This type of situation will require an indication of ‘sex’; however, this is not the same as an inerasable official recording of ‘sex’ on birth certificates and passports. Further, as children usually develop their gender identities by school age, any ‘unofficial’ recording of ‘sex’ would not be inappropriate by this stage.

A more liberal approach to registering gender on official certificates allows all parties concerned to take time to ensure that the correct gender is established, regardless of whether it is male, female or indeterminate. If true equality is sought for everyone, then removing the need to be allocated to a binary system at birth would allow all citizens to grow up, discover their gender identities and align themselves accordingly at a later stage in their lives.

¹⁰³ This would also assist the majority of those with gender dysphoria who would have finalised their gender alignment by this stage.

¹⁰⁴ This would also assist transgender children.

¹⁰⁵ This is generally the case for all species that have evolved with a binary system of sex, and is known as the Fisher principle. Ronald Fisher, *The Genetical Theory of Natural Selection* (Clarendon Press 1930).

Regardless of the logic behind such a step, it is submitted that to remove the category of ‘sex’ or ‘gender’ from the register may prove too difficult to legislate for. In this respect another solution must be sought.

10.7.3 ‘Flexible Gender’ on Official Documentation

The current legal requirement to register a baby’s birth within a short timeframe leaves many intersex/DSD children vulnerable. It does not seem equitable that parents can change the child’s name but not the sex on a child’s documentation, even if an error was made in the original diagnosis. The birth registration process needs to be adapted to acquire a more holistic approach, particularly to those with intersex/DSD conditions. As mentioned above, there is no need for a definitive recording of ‘sex’ at such an early stage. The birth of a baby is an event to be recorded, but an initial registration noting time and date of delivery, along with the address of the parents and chosen name, would be sufficient during the first few months of life.¹⁰⁶ Should ‘sex’ be required as a category (and it is unclear why it should be), then at least there should be a ‘stay’ in the final certificate, or at the *very least* the ability to amend such a document.

Ideally then, a simple registration form would be completed with the same timeframe of 42 days.¹⁰⁷ The next stage would be to require *all* parents to ensure that their child has genetic testing to verify their child’s karyotype within the first six months of life,¹⁰⁸ should this not be offered at birth.¹⁰⁹ This later stage testing will allow the parents to understand the nature and importance of the tests at a time when a child’s sleep patterns usually improves to allow parents to be able to concentrate on the full rationale for these tests and give valid informed consent. For the vast majority of

¹⁰⁶ A *provisional* sex allocation might be appropriate also.

¹⁰⁷ c 20, part I section 2 of the Births and Deaths Registration Act 1953.

¹⁰⁸ The tests should just concentrate on the number of chromosomes and in particular the sex chromosomes presented. For reasons of patient confidentiality, the tests should not aim to generate a full DNA analysis of the child. Further, after the test results have been established, the DNA samples should be destroyed.

¹⁰⁹ My recommendation from chapter eight was that sex chromosome testing should be offered to all parents at birth, regardless of whether the child exhibits genital difference or not.

these parents the results will come as no surprise, but for the one percent of parents who receive unexpected results, it will allow for adjustments to be made at an early stage of the child's life. The results of these tests, if appropriate, would be sent to the Registry office, so that a full and final birth certificate can be issued on the child's first birthday. For those still undergoing testing, a clause would allow this final document to be postponed indefinitely until such a time as a firm answer can be established.¹¹⁰

As a final thought, TIIF demand that intersex children be allowed to register 'as females or males, with the awareness that, like all people, they may grow up to identify with a different sex or gender'. There is no difficulty with this in current English law *per se*, provided they are happy to class themselves as 'transgender' and go through the legal route now provided for all who wish to change their gender officially. The weakness in the Act is that it specifically excludes the intersexed, not just that the new 'gender' is only registered from the date of the official change and not from the date of birth.¹¹¹ Therefore the final solution proffered would be to alter the Gender Recognition Act 2004¹¹² to include the group of 'intersexed' so that they are able to utilise this mechanism, and to allow, in their case only, the right to have documentation backdated to birth. This would help to 'ensure the provision of all human rights and citizenship rights to intersex people, including the right to marry and form a family'.¹¹³

¹¹⁰ It is somewhat disappointing that recent regulations designed to incorporate the new socio-biological approach to parenthood, the Welfare Reform Act 2009, have failed to consider the increasing awareness of the socio-biological aspects of the children themselves. (c. 24, Schedule 6 Registration of Births, 2E 'Use of scientific tests with consent of parties' currently relates to the testing for parentage as opposed to medical testing of the child.)

¹¹¹ s9 (2) Gender Recognition Act 2004.

¹¹² s2 (1) (a) refers to a person who 'has or has had gender dysphoria' This could be altered to read 'has or has had gender dysphoria, or has a recognised intersex condition, and was erroneously registered in the gender opposite to that of the established gender identity of the applicant'.

¹¹³ Appendix A.

10.8 Conclusions to this Thesis

Regardless of any legal changes that should or should not be obligatory to prevent discrimination in English law, it is clear that a significant amount of work is required in order to educate *everyone* about intersex/DSD conditions. Indeed, this is one of the demands of TIIF.¹¹⁴ The lack of societal awareness causes difficulties in all aspects of the lives of those with intersex/DSD conditions. Fernández-Balboa¹¹⁵ informs us that discrimination is ‘not natural but learned’ and ignorance of intersex/DSD conditions leads to ignorant medical treatment. The end result is that over the decades doctors have attempted to perfect intersexed bodies, so that those with genital difference were able to adapt to the binary system of sex, rather than trying to alter the binary system to reflect the realities of biology. This pervasive theme affects potentially every stage of the intersexed person’s life in the healthcare environment and, as has been noted in this chapter, will affect their loved ones even when they die.

Discrimination occurs in many forms even before an intersexed child is born. As discussed in chapter six, the very premises of pre-implantation genetic diagnosis (PGD), antenatal screening and current English abortion law spearhead an attack to reduce the number of intersexed children born in England (even if this is not necessarily the rationale behind these techniques). As noted, the cessation of all of these activities is one of the demands of TIIF.¹¹⁶ The non-selection of embryos with an intersex/DSD condition is clearly direct discrimination, and is specifically legislated for in s 13 (9) (c) of the Human Fertilisation and Embryology Act 1990, as amended, which states that those embryos with ‘any other serious medical condition, must not be preferred to those that are not known to have such an abnormality’.

¹¹⁴ ‘To raise awareness around intersex issues and the rights of intersex people in society at large’ Appendix A.

¹¹⁵ Juan-Miguel Fernández-Balboa, ‘Discrimination: What Do We Know and What Can We Do About It?’ in Robyn L Jones and Kathleen M Armour, *Sociology of Sport* (Pearson 2000) 142.

¹¹⁶ ‘To put an end to pre-implantation genetic diagnosis, pre-natal screening and treatment, and selective abortion of intersex fetuses.’ TIIF Appendix A

Whilst embryos exhibiting significant chromosomal abnormalities will be identified easily, other intersex conditions caused by a genetic modification of a single gene will not be detected by PGD unless they are specifically screened for. In this respect, a full audit of conditions currently licensed for screening is required, substantiated with the rationale behind their selection.

In regard to abortion, a close analysis of the law reveals that it would be disproportionate to repeal or alter current legislation. Not only that, but it is possible that the Abortion Act 1967 actually supports the intersexed in that section (1) (1) (d) allows a ‘grace period’ for a mother-to-be to assimilate information regarding her child’s future life. As research indicates, with further education and counselling a number of women decide to continue with the pregnancy of their intersex/DSD child rather than terminate it.¹¹⁷ The issue of abortion does, however, highlight and cement the requirement for more detailed understanding of intersexed conditions. Whilst it is noted that antenatal screening can detect fetuses with intersex/DSD conditions, leaving the fetus vulnerable to a termination, the overriding discrimination results not from the screening per se, but from the lack of easily accessible information on the conditions. It is submitted that it would be disproportionate to ban such antenatal testing, but it is crucial that more training is given to medical practitioners on intersex/DSD conditions. As TIIF highlight, it is essential to ‘ensure that all professionals and healthcare providers that have a specific role to play in intersex people’s wellbeing are adequately trained to provide quality services’.¹¹⁸

The final discrimination pre-birth occurs internationally with the treatment of a Congenital Adrenal Hyperplasia (CAH) girl with dexamethasone to create more feminine genitals. TIIF demand that each country ‘put(s) an end ... (to) medical treatments.’ Treatment with dexamethasone is particularly controversial. As noted,

¹¹⁷ It is noted that this may not be the case in other jurisdictions.

¹¹⁸ TIIF, Appendix A.

the drug has numerous iatrogenic side effects for all fetuses that may have been exposed to it. More research is required before it is adopted as standard treatment.¹¹⁹

In chapter seven it was noted how England currently fails to offer screening in the first few days of life for the life-threatening condition of salt-wasting CAH, whilst it does offer testing for similar non-intersexed conditions (these being no more devastating in consequence, or more prevalent in England).¹²⁰ In the absence of standardised cell-free fetal DNA (cffDNA) testing for CAH,¹²¹ it was posited that this is discriminatory action against the intersexed and needs rectification by adding CAH to the newborn bloodspot screening programme that currently operates in the UK. This is *not* one of TIIF's demands. This might be due to the fact that CAH boys are not (usually) considered to be 'intersexed'.¹²² However, if these boys survive an early salt-wasting crisis that occurs because of their undiagnosed condition and grow up to become fathers, their gene will be transmitted to any of their own children. By not preventing the death of a CAH boy, indirectly CAH as an 'intersex group' faces elimination.¹²³ Not only that, but on a less dramatic note, testing for CAH can identify those girls who have the condition and are then often considered to be 'intersexed'. By not screening for CAH at an early stage in their lives, CAH children face discrimination.

¹¹⁹ This is also the conclusion reached by the Australian Senate. Senate; Community Affairs References Committee, (Australia) 'Involuntary or Coerced Sterilisation of Intersex People in Australia' (2nd Report, 25 October 2013).
<http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Sec_Report/index> accessed 24 August 2015.

¹²⁰ For example, Glutaric Aciduria type 1 (GA1).

¹²¹ This was discussed in chapter six. As of date, CffDNA is not part of standardised testing, nor has it been specifically licenced as such by the UKNSC. CffDNA testing does, of course, have ethical implications in itself as it may cause parents to terminate the pregnancy as the condition would be detected at a relatively early stage.

¹²² It was noted in chapter three that there are many differing types of CAH, and some of these varieties do give rise to genital difference in boys.

¹²³ This may be akin to 'cultural genocide' that was considered as a result of PGD testing to rule out deafness, as discussed in Neil Levy, 'Reconsidering Cochlear Implants: The Lessons of Martha's Vineyard' (2002) 16 (2) Bioethics 134.

In addition to screening for CAH, it was recommended in chapter seven that all neonates have sex chromosome screening to identify at the earliest possible stage whether a child has a DSD condition, such as Klinefelter Syndrome, Turner Syndrome and Complete Androgen Insensitivity Syndrome. If these conditions are detected at an early stage, they can be medically assisted throughout life. It is not recommended that such testing occurs routinely before birth, as may happen with the new blood test using cffDNA,¹²⁴ until such a time as society is more understanding of these conditions, as this may lead to more terminations.¹²⁵

Chapter eight considered the need for legal protection of those children born with genital difference. It was noted that although girls are protected by law against Female Genital Mutilation, by virtue of the Female Genital Mutilation Act 2003, boys are not protected at all. Further, no child with ambiguous genitalia is protected by the Act as it currently stands, as section 1 (2) (a) of the Act stipulates that it is no offence if ‘an approved person (...) performs a surgical operation on a girl which is necessary for her physical or mental health’. ‘Normalising’ operations have frequently been considered to be in the best interests of the intersexed, albeit in reality it was often for the parents’ health rather than their child’s.¹²⁶ This clearly discriminates against children with genital difference. Further, it is one thing to have one’s genitals ‘modified’, but of even greater concern is that sterilisation often occurs at the same time. Unsurprisingly, TIIF demand an end to ‘non-consensual sterilization of intersex people’.¹²⁷

¹²⁴ Often offered privately as ‘Harmony’ testing. The effectiveness of this is considered by Oxford Health Plans, LLC, ‘Fetal Aneuploidy Testing Using Cell-Free Fetal Nucleic Acids in Maternal Blood’ Clinical Policy (Effective 07/01/2015) https://www.oxhpl.com/secure/policy/noninvasive_prenatal_diagnosis_fetal_aneuploidy_715.pdf accessed 21 July 2015.

¹²⁵ Boss JA, ‘First trimester Prenatal Diagnosis: earlier is not necessarily better’ (1994) 20 (3) *J Med Ethics* 146.

¹²⁶ Ellen K Feder, *Making Sense of Intersex: Changing Ethical Perspectives in Biomedicine* (Indiana University Press 2014) 158.

¹²⁷ TIIF Appendix A.

It is important to note that TIIF emphasise ‘non-consensual’ treatment. It may well be that given all relevant information an intersexed child might prefer sterilisation to the risk of developing.¹²⁸ This however, should be for the intersexed person to decide for themselves. Consequently, such medical intervention should not be legislated against, but rather legislated for, with the stipulation that the person concerned has given express informed consent. As TIIF state, ‘Intersex people must be empowered to make their own decisions affecting their own bodily integrity, physical autonomy and self-determination’.¹²⁹

TIIF further demand that countries ‘ensure that intersex people have the right to full information and access to their own medical records and history’.¹³⁰ This demand was borne out by correspondents who identified the difficulty in obtaining notes concerning their medical records, and was investigated in chapter nine. *Prima facie* it appears that English law upholds a right of access under the current Data Protection Act 1998 for everyone; however, it was also noted that in certain discrete situations this information need not be disclosed.¹³¹ The Data controller will contemplate requests on a case by case basis, but ultimately will give due diligence to whether disclosure of a person’s medical records is likely to cause ‘significant harm’ to the recipient or any other person.¹³² To overcome this difficulty and potential discrimination it was recommended that a duty of ‘veracity’ be endorsed by English law to ensure that intersex/DSD children were given access to their medical notes in appropriate stages as they grew up.

Finally, in the first part of this chapter it was noted that the tour de force behind early genital assignment surgery is the societal need to answer that all important question at birth, ‘Is it a boy or a girl?’ The short period of time for birth registration has ensured the utilisation of medical assistance for children with genital difference, regardless of

¹²⁸ This would be akin to a number of women undergoing mastectomies to prevent breast cancer.

¹²⁹ *ibid.*

¹³⁰ *ibid.*

¹³¹ *ibid.*

¹³² *ibid.*

whether it helped or, conversely, created lifelong difficulties for the patient. It has been recommended that the law be altered to allow for some type of flexible birth registration, specifically in relation to the category of ‘sex’.

10.8.1 Final Thoughts

This thesis has concentrated on discrimination of the intersexed in the current healthcare environment. As noted throughout this thesis, the starting point for this discrimination is the universal lack of awareness of intersexuality, not just in the UK, but globally. Lack of quality information on intersexuality, even amongst healthcare practitioners themselves, indicates that there is a desperate need for educational programmes to be devised to reach every member of society. This is only likely to be effective if such learning becomes part of an established education strategy, i.e. the National Curriculum.¹³³

At the same time, there needs to be further academic debate on how to reduce gender imprinting at an early age, for all children. A reduction in gender imprinting would allow ‘non-conformists’ to be themselves. In an ideal world, society would be more accepting of intersexuality (or indeed non-sexuality), but this is not a situation that will be achieved in the foreseeable future. As Vince Cable has recently stated, ‘we live in a society of fear’.¹³⁴ The intersexed are not ‘monsters’;¹³⁵ they are human and

¹³³ The most logical place for this would be the National Curriculum for Science at Key Stage 2 level (7-11 year olds). Students need to be informed at a stage where they will be advanced enough to understand such information, but young enough to be open to such ideas.

¹³⁴ Vince Cable, ‘Vince Cable on the Lib Dem collapse: the Tories won because fear triumphed over hope’ *NewStatesman* (20 May 2015) <http://www.newstatesman.com/politics/2015/05/vince-cable-lib-dems-were-victims-tory-fear> accessed 20 May 2015.

The collapse of the Lib Dems has meant a significant weakening in political support for the intersex, as the 40 signatures to the Early day motion 907 included 14 Lib Dem MPs, who have subsequently lost their seat.

UK Parliament, ‘Legal Recognition for those who do not associate with a Particular Gender (No. 2)’ Early day motion 907 session 2013-4 <http://www.parliament.uk/edm/2013-14/907> accessed 25 August 2015.

¹³⁵ This was the view of the original Romans according to Luc Brisson, *Sexual Ambivalence; Androgyny and Hermaphroditism in Greco-Roman Antiquity* (Janet Lloyd (tr), University of California Press 2002) 2.

deserve to be treated humanely. In this respect, there are a number of actions that can assist those with intersex/DSD conditions, not just in the healthcare environment but in a wider society.

Finally, it was noted in chapter 4 that the intersexed lack protection under the current anti-discrimination law, namely the Equality Act 2010. It was posited that s11(a) Equality Act be altered to read:

a reference to a person who has a particular protected characteristic is a reference to a man, a woman or a person who is intersexed.¹³⁶

This would hopefully support the intersexed in various aspects of their lives, not just in the healthcare environment.

These relatively small but achievable aims would help to ensure more equal treatment not just of the intersexed, but of members of English society in general. With this in mind it is essential, that the new Parliament appoints and commands a Select Committee to investigate and analyse all aspects of discrimination that an intersexed person may face,¹³⁷ not just in the healthcare environment but in all aspects of their lives, with the aim of promoting legislation to eradicate all forms of discrimination currently found against the intersexed in English law.

¹³⁶ Or similar wording that meets the approval of the intersex community.

¹³⁷ There is a Health Committee, but it is submitted that this needs to be addressed by a committee with a broader remit overall.

Additional Material:
Appendices and Bibliography

Appendices

Appendix A: Public Statement by the Third International Intersex Forum¹

Preamble

We affirm that intersex people are real, and we exist in all regions and all countries around the world. Thus, intersex people must be supported to be the drivers of social, political and legislative changes that concern them.

We reaffirm the principles of the First and Second International Intersex Fora and extend the demands aiming to end discrimination against intersex people and to ensure the right of bodily integrity, physical autonomy and self-determination.

Demands

To put an end to mutilating and ‘normalising’ practices such as genital surgeries, psychological and other medical treatments through legislative and other means. Intersex people must be empowered to make their own decisions affecting own bodily integrity, physical autonomy and self-determination.

To put an end to preimplantation genetic diagnosis, pre-natal screening and treatment, and selective abortion of intersex fetuses.

To put an end to infanticide and killings of intersex people.

To put an end to non-consensual sterilisation of intersex people.

To depathologise variations in sex characteristics in medical guidelines, protocols and classifications, such as the World Health Organization’s International Classification of Diseases.

To register intersex children as females or males, with the awareness that, like all people, they may grow up to identify with a different sex or gender.

To ensure that sex or gender classifications are amendable through a simple administrative procedure at the request of the individuals concerned. All adults and capable minors should be able to choose between female (F), male (M), non-binary or multiple options. In the future, as with race or religion, sex or gender should not be a category on birth certificates or identification documents for anybody.

To raise awareness around intersex issues and the rights of intersex people in society at large.

To create and facilitate supportive, safe and celebratory environments for intersex people, their families and surroundings.

¹ December 2013. Accessed 4 May 2015, through Advocates for Informed Choice website, <http://aiclegal.org/public-statement-by-the-third-international-intersex-forum/>

Appendices

To ensure that intersex people have the right to full information and access to their own medical records and history.

To ensure that all professionals and healthcare providers that have a specific role to play in intersex people's wellbeing are adequately trained to provide quality services.

To provide adequate acknowledgement of the suffering and injustice caused to intersex people in the past, and provide adequate redress, reparation, access to justice and the right to truth.

To build intersex anti-discrimination legislation in addition to other grounds, and to ensure protection against intersectional discrimination.

To ensure the provision of all human rights and citizenship rights to intersex people, including the right to marry and form a family.

To ensure that intersex people are able to participate in competitive sport, at all levels, in accordance with their legal sex. Intersex athletes who have been humiliated or stripped of their titles should receive reparation and reinstatement.

Recognition that medicalization and stigmatisation of intersex people result in significant trauma and mental health concerns.

In view of ensuring the bodily integrity and well-being of intersex people, autonomous non-pathologising psycho-social and peer support be available to intersex people throughout their life (as self-required), as well as to parents and/or care providers.

In view of the above the Forum calls on:

1. International, regional and national human rights institutions to take on board, and provide visibility to intersex issues in their work.
2. National governments to address the concerns raised by the Intersex Forum and draw adequate solutions in direct collaboration with intersex representatives and organisations.
3. Media agencies and sources to ensure intersex people's right to privacy, dignity, accurate and ethical representation.
4. Funders to engage with intersex organisations and support them in the struggle for visibility, increase their capacity, the building of knowledge and the affirmation of their human rights.
5. Human rights organisations to contribute to build bridges with intersex organisations and build a basis for mutual support. This should be done in a spirit of collaboration and no-one should instrumentalise intersex issues as a means for other ends.

Appendices

Appendix B: Hippocratic Oath; Classical Version²

I swear by Apollo Physician and Asclepius and Hygieia and Panacea and all the gods and goddesses, making them my witnesses, that I will fulfil according to my ability and judgment this oath and this covenant:

To hold him who has taught me this art as equal to my parents and to live my life in partnership with him, and if he is in need of money to give him a share of mine, and to regard his offspring as equal to my brothers in male lineage and to teach them this art—if they desire to learn it—without fee and covenant; to give a share of precepts and oral instruction and all the other learning to my sons and to the sons of him who has instructed me and to pupils who have signed the covenant and have taken an oath according to the medical law, but no one else.

I will apply dietetic measures for the benefit of the sick according to my ability and judgment; I will keep them from harm and injustice.

I will neither give a deadly drug to anybody who asked for it, nor will I make a suggestion to this effect. Similarly I will not give to a woman an abortive remedy. In purity and holiness I will guard my life and my art.

I will not use the knife, not even on sufferers from stone, but will withdraw in favor of such men as are engaged in this work.

Whatever houses I may visit, I will come for the benefit of the sick, remaining free of all intentional injustice, of all mischief and in particular of sexual relations with both female and male persons, be they free or slaves.

What I may see or hear in the course of the treatment or even outside of the treatment in regard to the life of men, which on no account one must spread abroad, I will keep to myself, holding such things shameful to be spoken about.

If I fulfil this oath and do not violate it, may it be granted to me to enjoy life and art, being honoured with fame among all men for all time to come; if I transgress it and swear falsely, may the opposite of all this be my lot.

² Ludwig Edelstein, *The Hippocratic Oath: Text, Translation, and Interpretation*, (John Hopkins Press, 1943), as posted on NOVA by Peter Tyson 27 March 2001 <http://www.pbs.org/wgbh/nova/body/hippocratic-oath-today.html> accessed 23 May 2015.

Appendices

Appendix C: WMA Declaration of Geneva³

Adopted by the 2nd General Assembly of the World Medical Association, Geneva, Switzerland, September 1948, and amended by the 22nd World Medical Assembly, Sydney, Australia, August 1968 and the 35th World Medical Assembly, Venice, Italy, October 1983, and the 46th WMA General Assembly, Stockholm, Sweden, September 1994 and editorially revised by the 170th WMA Council Session, Divonne-les-Bains, France, May 2005 and the 173rd WMA Council Session, Divonne-les-Bains, France, May 2006

AT THE TIME OF BEING ADMITTED AS A MEMBER OF THE MEDICAL PROFESSION:

I SOLEMNLY PLEDGE to consecrate my life to the service of humanity;

I WILL GIVE to my teachers the respect and gratitude that is their due;

I WILL PRACTISE my profession with conscience and dignity;

THE HEALTH OF MY PATIENT will be my first consideration;

I WILL RESPECT the secrets that are confided in me, even after the patient has died;

I WILL MAINTAIN by all the means in my power, the honour and the noble traditions of the medical profession;

MY COLLEAGUES will be my sisters and brothers;

I WILL NOT PERMIT considerations of age, disease or disability, creed, ethnic origin, gender, nationality, political affiliation, race, sexual orientation, social standing or any other factor to intervene between my duty and my patient;

I WILL MAINTAIN the utmost respect for human life;

I WILL NOT USE my medical knowledge to violate human rights and civil liberties, even under threat;

I MAKE THESE PROMISES solemnly, freely and upon my honour.

³ <http://www.wma.net/en/30publications/10policies/g1/> accessed 23 May 2015.

Appendix D: The Nuremberg Code⁴

1. The voluntary consent of the human subject is absolutely essential.

This means that the person involved should have legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, over-reaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved, as to enable him to make an understanding and enlightened decision. This latter element requires that, before the acceptance of an affirmative decision by the experimental subject, there should be made known to him the nature, duration, and purpose of the experiment; the method and means by which it is to be conducted; all inconveniences and hazards reasonably to be expected; and the effects upon his health or person, which may possibly come from his participation in the experiment.

The duty and responsibility for ascertaining the quality of the consent rests upon each individual who initiates, directs or engages in the experiment. It is a personal duty and responsibility which may not be delegated to another with impunity.

2. The experiment should be such as to yield fruitful results for the good of society, unprocurable by other methods or means of study, and not random and unnecessary in nature.
3. The experiment should be so designed and based on the results of animal experimentation and a knowledge of the natural history of the disease or other

⁴ *Trials of War Criminals before the Nuremberg Military Tribunals under Control Council Law No. 10'* (Vol 2, US Government Printing Office, 1949) 181, as reproduced by the US Department of Health & Human Service, <http://www.hhs.gov/ohrp/archive/nurcode.html> accessed 23 May 2015.

Appendices

problem under study, that the anticipated results will justify the performance of the experiment.

4. The experiment should be so conducted as to avoid all unnecessary physical and mental suffering and injury.
5. No experiment should be conducted, where there is an *apriori* reason to believe that death or disabling injury will occur; except, perhaps, in those experiments where the experimental physicians also serve as subjects.
6. The degree of risk to be taken should never exceed that determined by the humanitarian importance of the problem to be solved by the experiment.
7. Proper preparations should be made and adequate facilities provided to protect the experimental subject against even remote possibilities of injury, disability, or death.
8. The experiment should be conducted only by scientifically qualified persons. The highest degree of skill and care should be required through all stages of the experiment of those who conduct or engage in the experiment.
9. During the course of the experiment, the human subject should be at liberty to bring the experiment to an end, if he has reached the physical or mental state, where continuation of the experiment seemed to him to be impossible.
10. During the course of the experiment, the scientist in charge must be prepared to terminate the experiment at any stage, if he has probable cause to believe, in the exercise of the good faith, superior skill and careful judgement required of him, that a continuation of the experiment is likely to result in injury, disability, or death to the experimental subject.

Appendices

Appendix E: Questionnaire sent to ART Clinics:

Question 1

In your clinic have you treated individuals with any of the following conditions? Please indicate whether this was NHS funded, and comment on success of treatment if known.

- a) Congenital Adrenal Hyperplasia Yes/No

If yes, what treatment(s) did you use? If no, could you recommend any course of action for the individual?

- b) Complete or Partial Androgen Insensitivity syndrome Yes/No

If yes, what treatment(s) did you use? If no, could you recommend any course of action for the individual?

- c) Klinefelter Syndrome Yes/No

If yes, what treatment(s) did you use? If no, could you recommend any course of action for the individual?

-

- d) Turner Syndrome Yes/No

If yes, what treatment(s) did you use? If no, could you recommend any course of action for the individual?

- e) Swyer's Syndrome or another type of Gonadal dysgenesis Yes/No

If yes what treatment(s) did you use? If no, could you recommend any course of action for the individual?

Appendices

f) Hypospadias Yes/No

If yes what treatment(s) did you use?

g) Any other condition (please specify)

Question 2

a) Does your clinic offer Pre-implantation genetic testing/diagnosis ?

Often/Fairly Often/Occasionally/ Never (please circle)

b) If PGD/T takes place, how frequently, if at all, do you come across embryos that appear to have the genetic arrangement associated with an intersex condition /disorder of sex development/missing or extra sex chromosome?

Often/Fairly Often/Occasionally/ Never (please circle)

c) If, as a result of PGT, your clinic discovered that an embryo had chromosomal abnormalities (such as in Turner's Syndrome) would your clinic ever consider implanting the embryo?

Question 3

To your knowledge, have any of your treatment cycles given rise to a baby born with an intersex condition or disorder of sex development? Yes/No

If yes, what condition (s) did the baby have?

If you have any further comments then please use the back of this sheet to write them down. Thank you for your time.

Appendices

Appendix E: Questionnaire sent to ART Clinics: Responses

19 returns from 65 forms sent. Response rate 29.2%

Question 1

In your clinic have you treated individuals with any of the following conditions? Please indicate whether this was NHS funded, and comment on success of treatment if known.

Congenital Adrenal Hyperplasia Yes 6 No 13

Hormone Replacement therapy

Self funded IVF

NHS

Refer to IVF unit endocrinologist

Donor insemination for same sex couple

If diagnosed early are seen in a paediatric clinic and followed up in the endocrinology clinic

Steroid Treatment

Complete or Partial Androgen Insensitivity syndrome Yes 4 /No 15

Hormonal replacement after gonadectomy

Referred to specialist clinic

Referred to tertiary centre for Donor treatment

Refer to IVF unit endocrinologist

Would recommend egg donation

Refer to specialised intersex clinic

Counselling, explanation, discussion bilateral removal of gonads, information about adoption

Klinefelter's Syndrome Yes 13 No 6

If sperm is obtained from testes biopsy they will be referred for ICSI

ICSI

IVF & ICSI

Diagnosis made referred to genetic counsellor.

Endocrine Replacement

Donor Sperm x 7 (IUI or IVF)

(both private & NHS)

Testosterone supplementation

Surgical sperm retrieval the IVF/ICSI own sperm- successful treatment 2xpreg

Attempted surgical sperm retrieval NHS funded

DI (azoospermia) or Sperm Retrieval

If Oligozoospermia – IVF & ICSI NHS funded

Referred to tertiary centre for Donor treatment

Appendices

Turner's Syndrome Yes 15 No 4

If yes, what treatment(s) did you use? If no, could you recommend any course of action for the individual?

Oestrogen replacement

Donor Eggs x 12 (both private & NHS)

One clinic noted 40% success rate

HRT egg recipient & treatment

Referred to tertiary centre for Donor treatment

HRTx2, fertility treatment donor eggs both NHS & Private One patient with mosaic TS requested a letter to confirm that she is fit & healthy as a travel insurance company was not keen on offering her Travel Insurance!

Swyer's Syndrome or another type of Gonadal dysgenesis Yes 7 /No 12

If yes what treatment(s) did you use? If no, could you recommend any course of action for the individual?

HRT

Egg donationX4 for females

Not yet

Referred to tertiary centre for Donor treatment x2

Bilateral removal of gonads

Hypospadias Yes 7 /No 11

If yes what treatment(s) did you use?

ICSI own sperm

ICSI

IUI

If normal sperm count IUI

If retrograde ejaculation, IUI using urine sample NHS

Not yet

Standard IVF & ICSI if sperm is normal

Treatment cancelled by patient

Treated by urologists

Any other condition Genetic causes of azoospermia- donor insemination

Appendices

Question 2

Does your clinic offer Pre-implantation genetic testing/diagnosis ?

Often/ Fairly Often/ Occasionally 3 / Never 16

But would be referred to another centre if requested/Indicated x3

Yes but only for single gene defects

If PGD/T takes place, how frequently, if at all, do you come across embryos that appear to have the genetic arrangement associated with an intersex condition /disorder of sex development/missing or extra sex chromosome?

Often/Fairly Often/Occasionally 3

I turner syndrome

If, as a result of PGT, your clinic discovered that an embryo had chromosomal abnormalities (such as in Turner Syndrome) would your clinic ever consider implanting the embryo?

One clinic noted that they were not informed of the nature of the abnormality. The report would just state abnormality of XY chromosomes- would not be implanted.

yes

no

N/A

N

Question 3

To your knowledge, have any of your treatment cycles given rise to a baby born with an intersex condition or disorder of sex development? Yes 4 / No 15

Turner's Syndrome 1: 2000

Turner's Syndrome

1 x Turner Syndrome

Referred to another centre (not followed up)

Appendices

Appendix E: Questionnaire sent to Individuals:

This questionnaire is for research in connection with PhD on Intersex and the Law. All data obtained will be securely stored for 10 years. No identifiable material will be kept with the answers of the enclosed questionnaire.

By returning this questionnaire, you are consenting to allow your answers to be incorporated in published work. If you wish to see the results prior to publication, then please enclose a contact email/address, otherwise there is no need to identify yourself, unless you wish to. (However, if names are supplied, these will be kept confidential and not incorporated into research).

The questionnaire is written as if an adult were answering it, but obviously it may be that you are a parent writing on behalf of your child.

If you are *not* living in England and Wales, please write down your current country of domicile _____

1) a) What type of intersex condition or affiliated condition do you have?

b) Which one of these should be used to describe your condition?

- Intersex
 - Disorder of Sex Development
 - Variation of Sex Development
 - Other
- (please specify _____)

Reasons, if any:

2) When and how did you find out that you had this condition?

3) Did doctors inform you or your parents that you needed to undergo medical treatment and/or surgery related with this condition?

YES/ NO (please circle correct answer) **If NO please go to Question 9**

If YES please explain briefly:

Appendices

- 4) Have you undergone surgery at any time as a result of your condition?
YES/ NO (please circle correct answer) **If NO please go to Question 9**

If YES, please indicate what surgical procedures you underwent:

- 5) How old were you when you first had surgery?
- 6) Who consented to the surgery? (This could be yourself, or if you were a minor then it is likely to have been your parents or another adult with responsibility for you.)
- 7) Were you (or your adult) fully informed of the nature and risks of the surgery?
- 8) How effective do you believe this surgery to be?

QUESTION 9: Legal Challenges

What, if any, legal difficulties are you currently experiencing or have you faced, as a result of your condition? (These might be employment issues, sports participation, or more family orientated issues such as marriage and adoption.) **If none**, please state none, and go to **Question 11**.

Please explain how these legal difficulties have affected/are affecting your life.

QUESTION 10: LEGAL ADVICE

Have you ever sought legal advice as a result of these difficulties? **YES/NO**

If **YES**, what, if any, solutions were offered to you as a way forward?
How successful were these in overcoming your difficulties?

If **NO**, why have you not sought legal advice?

Appendices

QUESTION 11: LAW REFORM

In your opinion, should Parliament legislate to improve the law to support those with your condition? **YES/NO**

If yes, in what way would you like to see the law changed?

QUESTION 12: Is there anything else you would like to mention?

Thank you for your cooperation.

(Most answers were highly personal, and not strictly relevant to the questions asked, therefore not included here).

Appendices

CONSENT FORM (Name of Interviewer: Karen Brown)

This questionnaire is for research in connection with PhD on Intersex and the Law. All data obtained will be securely stored for 10 years. No identifiable material will be kept with the answers of the enclosed questionnaire. I confirm that confidentiality will be maintained where requested. The interviewer will never disclose the identity of the interviewee to a third party.

I require your consent for the following:-

- a) Face-to-face interview
 - b) Recoding the interview in written form.
 - c) Making an audio recording of the interview.
-

Name of Interviewee, or name that you wish to be referred to as:

I (name of Interviewee.....), *agree to being interviewed.*

Yes/No (Please *delete as applicable*)

I hereby give consent for my answers to be recorded in *written* form

Yes/No

I consent for my answers to be recorded by *audio/video tape.*

Yes/No

I consent to *my name being used* as part of this process.

Yes/No

I understand that I am being asked these questions in relation to assessed coursework *for the Degree of PhD* at the London Metropolitan University.

Yes/No

I consent for my answers to be *incorporated* in any written thesis in relation to the above degree and also in *any other publication* that may arise from this postgraduate research degree programme.

Yes/No

Any other comments from Interviewee

Signed:

Dated:

Appendices

Appendix F: The HDC Code of Health and Disability Services Consumers' Rights Regulation 1996 New Zealand

RIGHT 5

Right to Effective Communication

- 1) Every consumer has the right to effective communication in a form, language, and manner that enables the consumer to understand the information provided. Where necessary and reasonably practicable, this includes the right to a competent interpreter.
- 2) Every consumer has the right to an environment that enables both consumer and provider to communicate openly, honestly, and effectively.

RIGHT 6

Right to be Fully Informed

- 1) Every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, would expect to receive, including -
 - a) An explanation of his or her condition; and
 - b) An explanation of the options available, including an assessment of the expected risks, side effects, benefits, and costs of each option; and
 - c) Advice of the estimated time within which the services will be provided; and
 - d) Notification of any proposed participation in teaching or research, including whether the research requires and has received ethical approval; and
 - e) Any other information required by legal, professional, ethical, and other relevant standards; and
 - f) The results of tests; and
 - g) The results of procedures.
- 2) Before making a choice or giving consent, every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, needs to make an informed choice or give informed consent.
- 3) Every consumer has the right to honest and accurate answers to questions relating to services, including questions about -
 - a) The identity and qualifications of the provider; and
 - b) The recommendation of the provider; and

Appendices

- c) How to obtain an opinion from another provider; and
 - d) The results of research.
- 4) Every consumer has the right to receive, on request, a written summary of information provided.

RIGHT 7

Right to Make an Informed Choice and Give Informed Consent

- 1) Services may be provided to a consumer only if that consumer makes an informed choice and gives informed consent, except where any enactment, or the common law, or any other provision of this Code provides otherwise.
- 2) Every consumer must be presumed competent to make an informed choice and give informed consent, unless there are reasonable grounds for believing that the consumer is not competent.
- 3) Where a consumer has diminished competence, that consumer retains the right to make informed choices and give informed consent, to the extent appropriate to his or her level of competence.
- 4) Where a consumer is not competent to make an informed choice and give informed consent, and no person entitled to consent on behalf of the consumer is available, the provider may provide services where -
 - a) It is in the best interests of the consumer; and
 - b) Reasonable steps have been taken to ascertain the views of the consumer; and
 - c) Either,
 - i. If the consumer's views have been ascertained, and having regard to those views, the provider believes, on reasonable grounds, that the provision of the services is consistent with the informed choice the consumer would make if he or she were competent; or
 - ii. If the consumer's views have not been ascertained, the provider takes into account the views of other suitable persons who are interested in the welfare of the consumer and available to advise the provider.
- 5) Every consumer may use an advance directive in accordance with the common law.

Appendices

6) Where informed consent to a health care procedure is required, it must be in writing if -

- a) The consumer is to participate in any research; or
- b) The procedure is experimental; or
- c) The consumer will be under general anaesthetic; or
- d) There is a significant risk of adverse effects on the consumer.

7) Every consumer has the right to refuse services and to withdraw consent to services.

8) Every consumer has the right to express a preference as to who will provide services and have that preference met where practicable.

9) Every consumer has the right to make a decision about the return or disposal of any body parts or bodily substances removed or obtained in the course of a health care procedure.

10) No body part or bodily substance removed or obtained in the course of a health care procedure may be stored, preserved, or used otherwise than

- (a) with the informed consent of the consumer; or
- (b) For the purposes of research that has received the approval of an ethics committee; or
- (c) For the purposes of 1 or more of the following activities, being activities that are each undertaken to assure or improve the quality of services:
 - (i) a professionally recognised quality assurance programme;
 - (ii) an external audit of services;
 - (iii) an external evaluation of services.

Appendices

RIGHT 10

Right to Complain

- 1) Every consumer has the right to complain about a provider in any form appropriate to the consumer.
- 2) Every consumer may make a complaint to -
 - a) The individual or individuals who provided the services complained of; and
 - b) Any person authorised to receive complaints about that provider; and
 - c) Any other appropriate person, including –
 - i. An independent advocate provided under the Health and Disability Commissioner Act 1994; and
 - ii. The Health and Disability Commissioner.
- 3) Every provider must facilitate the fair, simple, speedy, and efficient resolution of complaints.
- 4) Every provider must inform a consumer about progress on the consumer's complaint at intervals of not more than 1 month.
- 5) Every provider must comply with all the other relevant rights in this Code when dealing with complaints.
- 6) Every provider, unless an employee of a provider, must have a complaints procedure that ensures that -
 - a) The complaint is acknowledged in writing within 5 working days of receipt, unless it has been resolved to the satisfaction of the consumer within that period; and
 - b) The consumer is informed of any relevant internal and external complaints procedures, including the availability of –
 - i. Independent advocates provided under the Health and Disability Commissioner Act 1994; and
 - ii. The Health and Disability Commissioner; and
 - c) The consumer's complaint and the actions of the provider regarding that complaint are documented; and
 - d) The consumer receives all information held by the provider that is or may be relevant to the complaint.
- 7) Within 10 working days of giving written acknowledgement of a complaint, the provider must, -

Appendices

- a) Decide whether the provider -
 - i. Accepts that the complaint is justified; or
 - ii. Does not accept that the complaint is justified; or
 - b) If it decides that more time is needed to investigate the complaint, -
 - i. Determine how much additional time is needed; and
 - ii. If that additional time is more than 20 working days, inform the consumer of that determination and of the reasons for it.
- 8) As soon as practicable after a provider decides whether or not it accepts that a complaint is justified, the provider must inform the consumer of -
- a) The reasons for the decision; and
 - b) Any actions the provider proposes to take; and
 - c) Any appeal procedure the provider has in place.

3. Provider Compliance

A provider is not in breach of this Code if the provider has taken reasonable actions in the circumstances to give effect to the rights, and comply with the duties, in this Code.

The onus is on the provider to prove it took reasonable actions.

For the purposes of this clause, "the circumstances" means all the relevant circumstances, including the consumer's clinical circumstances and the provider's resource constraints.

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