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Living Intersex
Reconceptualising dualistic notions of sex and the body

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**Living *Intersex*: Reconceptualising dualistic notions
of sex and the body**

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Thesis submitted for the degree of PhD

24 November 2017

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Abstract

This thesis explores living *Intersex* in Western society. *Intersex* is an umbrella term which refers to biologically atypical bodies, where physical and/or chromosomal features more commonly considered to be either *male* or *female* are combined in one body. It is currently case managed as a medical emergency in Western societies which involves routine genital surgeries on *Intersex* babies and young children. These surgeries are primarily performed to erase *Intersex* difference and include supplementing or removing healthy internal or external genitalia so that the *Intersex* child can be more clearly identified and categorised as *male* or *female*. *Intersex* is referred to in the medical literature as a 'sexual disorder' which advances a narrative of *Intersex* as pathology and erases it from common knowledge. It is not a new, rare or inherently life-threatening phenomenon, yet *Intersex* people remain a hidden, socially stigmatised and marginalised group.

It is within this context that my study seeks to document and theorise the experiences of *Intersex* adults. The study draws on empirical social science and, more specifically, qualitative research methods to analyse the viewpoints of *Intersex* people on the medicalisation of *Intersexuality* in Western culture, including how they have conceptualised and navigated their *Intersex* difference throughout their lives and in a variety of situations. The study analyses the accounts of seventeen *Intersex* adults and consists of biographies and case studies. Since *Intersex* people comprise a hard to reach and hard to access group, participants have primarily been sourced from online communities. *Intersex* online forums are typically composed of an international

membership, on account of this in-depth semi-structured interviews were conducted using Skype, the telecommunications software which permits video and/or telephone calls between computers and other electronic devices.

The theoretical framework for this study is predominantly informed by literature from the fields of Gender Studies, Feminist Theory, Feminist Post-structuralism and Queer Theory. The study examines sex categorisation in the West to reveal its purpose as a mechanism of social regulation and control. It does this by exposing how the dominant categories of sex, *male* and *female*, are unstable, volatile, temporal and multiply contingent. The study also engages with philosophical literature to present the central argument of the thesis, namely, that the imposition of a dualistic Cartesian world view which constructs the body as a defective and disordered mechanical object, permits unfettered biomedical access to human bodies in Western societies, and for *Intersex* bodies this means the sanctioning of infant genital surgeries to fix, repair and correct their *Intersex* difference.

My project has demystification, consciousness-raising and emancipatory aims. It is hoped that it will provide valuable insight for educational, medical, therapeutic and health networks - including any professionals who encounter, treat and advise *Intersex* people and their families - and in so doing inform how *Intersex* people are supported in the wider community. It also seeks to assist in crucial policy-making decisions regarding highly contested 'genital-normalising' surgeries.

Dedication

To AJ and GM, thank you.

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Nothing could have prepared me for the Mount Kilimanjaro climb that has been my PhD. Mountain climbing requires preparation, support, people, expertise and resources. Climbing Mount PhD has involved the same and it gives me great pleasure to acknowledge that here.

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Thank you for the honour of telling your stories.

Glossary of Medical Terms

Androgens	<p>A group of steroid hormones.</p> <p>Testosterone is an androgen which is produced in the reproductive organs and adrenal glands of both <i>males</i> and <i>females</i>. Although overwhelmingly associated with <i>males</i>, due to their role in stimulating and controlling <i>male</i> sexual development, androgens perform many key functions in the physiology of <i>females</i>, especially those related to the synthesis of estrogen which affects libido and bone density.</p>
Chordee	Curvature of the penis.
Chromosomes	Contain strings of genes with DNA.
Congenital	A medical condition, disease or trait that is present from birth (but not necessarily inherited).
Clitorectomy/ clitoridectomy	Surgical removal of the clitoris.
Clitoromegaly	An enlarged clitoris (also known as hypertrophy of the clitoris).
DNA	Deoxyribonucleic acid which contains instructions for the genes.
Endocrinology	The study of hormones.
Genes	The basic physical and functional units of heredity arranged on the chromosomes. They are comprised of DNA containing instructions required for making proteins which human bodies require to work.
Gene mutation	A permanent alteration in genetic information which can facilitate a genetic condition, creating a variation, incorrect instruction or fault. A gene mutation may or may not result in a health condition, but can occasionally increase the

	likelihood of one. In some instances, it creates no problems at all – such as in the case of eye colour - and in others can even be beneficial.
Gonads	An organ that produces gametes or reproductive cells, such as a testis or an ovary.
Gynecomastia	The benign enlargement of breast glandular tissue in <i>males</i> .
Hormones	A chemical made by specialist cells of the body which when released into the bloodstream sends a message to another part of the body. They are also referred to as 'chemical messengers'. Hormones affect a wide range of physiological activities including growth, metabolism, appetite, puberty, libido, fertility and more.
Hypospadias	A condition where the urinary opening of the penis is not at the tip but is located along the shaft (or length) of the penis, the scrotum or perineum, often requiring seated urination.
Karyotype	The appearance and arrangement of the chromosomes when viewed in a genetic testing laboratory.
Mastectomy	Surgical removal of one or both breasts.
Orchidectomy	Surgical removal of one or both testicles.
Phenotype/ phenotypical	The observable physical properties and characteristics of an organism.
Vaginal stenosis	A narrowing or loss of flexibility of the vaginal wall.
Vaginoplasty	Surgical vaginal construction or reconstruction.

List of Acronyms and Interview Transcription Codes

Acronyms	
AISSG	Androgen Insensitivity Syndrome Support Group
CARES Foundation	A support group for people with Congenital Adrenal Hyperplasia
DSD	Disorders of Sex Development
DSM	The Diagnostic and Statistical Manual of Mental Disorders
EDH	Ego-Dystonic Homosexuality
GID	Gender Identity Disorder
GIDoC	Gender Identity Disorder of Childhood
ISNA	The Intersex Society of North America
LGBTQ	Lesbian, Gay, Bisexual, Transgender, Queer
LGBTQIA+	Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual, plus other marginalised groups
OGR	The Optimal Gender Rearing policy
OII	Organisation Intersex International
SOD	Sexual Orientation Disturbance
Interview Transcription Codes	

Int	Interviewer
...	Slight pause
[...]	Some words have been omitted
[ss]	Inaudible
<i>italics</i>	Words that are emphasised by the speaker

Introduction

There is a profound academic and policy silence in the social sciences about *Intersex*.

Intersex is a blanket term that is used to categorise over forty different conditions in which human sex development is deemed to be atypical and physical and/or chromosomal features (and more) commonly considered to be either *male* or *female* are combined in one body (Feder and Karkazis, 2008; Feder, 2009; Reis, 2009).

Despite a prevailing belief that *Intersex* is a rare occurrence, some studies report the frequency of *Intersex* births to be as high as 1.7 – 2% (Fausto-Sterling, 2000; Preves, 2008). Yet, research from the social sciences concerning *Intersex* people is distinctly less substantial than research from medicine and biology (Holmes, 2008), which may have contributed to a dominant discourse of *Intersex* as pathology and its erasure from common knowledge (Holmes, 2008). Indeed, ‘first-world feminist discourse’ has been criticised for not considering people with *Intersex* conditions as ‘proper subjects of feminist concern’ (Chase, 1998: 208).

The deeply problematic terrain of *Intersexuality* is illustrated by the current medical model for *Intersex* births (Creighton, 2004 et al.; Roen, 2008). Medical treatment for *Intersex* people was established by theories of gender proposed by psychologist Dr. John Money and colleagues in 1955 at John Hopkins University, USA (Kessler, 1998; Dreger, 1998a). Money posited that gender identity must be fixed early in children to offset gender confusion later in life (Dreger, 1998a). Subsequently, in accord with Money’s hypothesis, when an *Intersex* child is born in Western culture, typically it is placed into a programme of medical management within forty-eight hours, consisting

of genital reconstructive surgery and hormone treatment (Morland, 2001). To become 'more clearly male or female' its anatomy is brought in line with the normative signifiers of 'boy' and 'girl' (Morland, 2001: 529), so that, as stated by Money, 'the individual does not feel like a freak' (Money, 1975: 66). Healthy body parts, including the clitoris, the penis, the testes and ovaries, are surgically altered or removed to correct somatic 'undermasculinisation in males' and 'overmasculinisation in females' (Meyer-Bahlburg, 1998: 12). This case management has become known as the *Optimal Gender Rearing* policy (OGR); it stipulates that genital surgery is best initiated before the child is two years of age, when their development is thought to be malleable and they can be steered towards their new sex assignment without any negative repercussions. Money's treatment paradigm remained virtually unchallenged for four decades (Karkazis, 2008).

Research on *Intersexuality* from fields other than medicine constitutes a small, relatively recent body of work. As a consequence, *Intersexuality* remains enclosed within a discourse of medicalisation and pathologisation, with comparatively no language apart from the medical, with which to frame alternative descriptions or conceptualisations of *Intersex* people (Karkazis, 2008). Gender theorists insist *Intersexuality* should be treated as part of a continuum of human morphology (Butler, 2004) with *male* and *female* at its extremities (Fausto-Sterling, 2000). They welcome the challenge *Intersexuality* poses to traditional notions of sex and gender which hold male/female and masculinity/femininity to be exclusive, acceptable and 'normal' categories (Kessler, 1998; Holmes, 2008). As such, *Intersex* research in the social

sciences has predominantly centred on the male/female binary underpinning the medical management of *Intersexuality* in Western societies and the power this exerts over the lives and well-being of *Intersex* people. Gender theorists assert that *Intersex* bodies demonstrate there are more than two sexes (Fausto-Sterling, 2000; Butler, 2004), and problematise a binary culture consisting of only two genders (Kessler, 1998; Holmes, 2008). They have importantly documented the ways that *Intersex* explodes, and troubles these dichotomous classifications, how the male/female dualism has shamed, stigmatised and oppressed *Intersex* people for not fitting these culturally intelligible, dualistic, normative categories, and provided a large body of evidence to suggest that the medical management and treatment of *Intersexuality* is culturally, socially and politically motivated and sanctioned.

Social science research on the subject of *Intersexuality* is critical. A dearth of theoretical material on *Intersexuality* impacts how those born and living with *Intersex* conditions are conceptualised and treated in contemporary Western culture (Holmes, 2008). *Intersex* adults contend the main problem is 'stigma and trauma, not gender' (as cited in Dreger and Herndon, 2009: 216). They have denounced 'first-world feminist' discourse for condemning female genital mutilation in African countries whilst meeting the topic of 'genital mutilation' of *Intersex* people in Western culture 'with a blank stare' (Chase, 1998: 207). The harrowing testimonies from *Intersex* people who have been subjected to the OGR policy in infancy – including the accounts presented in the empirical chapters of this thesis - suggest that it needs to be urgently re-evaluated and even overhauled. These include claims that routine infant surgeries

frequently necessitate multiple follow-up surgical procedures and invasive medical examinations throughout childhood and adolescence that cause irreparable damage and blights the adult lives of *Intersex* people. There are also reports of deprived sexual function, permanent and unsightly physical scarring, painful scar tissue and reduced or complete loss of sensation in the genital area, which all carry lifelong consequences to physical, psychological and emotional health (Fausto-Sterling, 2000; Butler, 2004; Holmes, 2008; Karkazis, 2008). *Intersex* people also state that infant surgeries are unethical since neither they, nor their parents (in many cases), granted permission for these medical procedures based on fully informed consent (Beh and Diamond, 2000; Hester, 2004).

Research Aim and Questions

My study is exploratory and interpretative; it seeks to document and theorise the experiences of and challenges for *Intersex* adults through in-depth semi-structured interviews with an internationally diverse sample of seventeen *Intersex* adults.

Through exploring their individual life-histories, my aim is to examine how people diagnosed as *Intersex* experience living in a society constructed upon an exclusively two-sex, two-gender, heterosexual model. My research questions ask:

- How does an *Intersex* adult comprehend and negotiate their sex, gender, body, sexual identity and sexuality in contemporary society?
- How far and in what ways do these understandings and negotiations interface with, ratify and/or challenge key theoretical texts, as well as dominant discourse on sex, gender and identity?

- In what ways does the current medical management of *Intersexuality* affect an *Intersex* person and how does this medical model interact with societal discourse on *Intersexuality*?
- Can people diagnosed as *Intersex* be better supported? If so, in what ways?

Intersex is a very under-researched area within the social sciences. A search of the British Library's database shows that in the last ten years there have been fifteen books published on *Intersex* worldwide. Seven of those books were published over a two-year period (2007-2009), with eight published in the following seven years (2010-2017). A closer investigation reveals that a mere six out of these fifteen books were based on empirical research. One of the authors, Catherine Harper, noted that her book *Intersex* (2007) was the first originating from the U.K.¹ Empirical social science research on *Intersex* is overwhelmingly North American and white. This is consistent with the emergence of *Intersex* activism and the mobilisation of an *Intersex* community which originated in North America.

My study is one of only three empirical social science studies issuing from the UK in a decade.² Comprised of participants from continents which include Asia, Europe, North America and South America and countries as diverse as Colombia, Germany,

¹ 'Intersex', Dr Catherine Harper, <https://drcatherineharper.wordpress.com/research-portfolio/intersex/> [online] accessed October 2017.

² The other empirical study *Intersex, Variations of Sex Characteristics, and DSD: The Need for Change. Research Report* (Huddersfield: University of Huddersfield, 2017) by Surya Munro et al., was published on completion of my study.

Iceland, Taiwan, New Zealand, the United Kingdom and the United States, it hopes to be distinctive by making an international contribution to the existing literature on *Intersex*. What this offers for my study is an up-to-date, international and unique account of what *Intersex* people worldwide are insisting is important in infancy, family-life, educational facilities, medical management, social work and therapeutic care, as well as in community movements and activism on their behalf. A minority indicated to me that they were speaking for the very first time. The majority were clear that they would like to contribute to the direction of the future treatment of *Intersexuality*; to help steer the course of *Intersex* medical management.

Structure of the Thesis

My thesis is divided into three sections:

Section One, comprising Chapters One to Five is contextual. Chapter One provides an introduction to the phenomenon known as *Intersex* with subsequent chapters in the section presenting the historical background to the study and the theoretical resources that have informed my research design and data analysis. Previous studies are employed to interrogate the primary function of sex categorisation in Western societies (Chapter Two), some of the key factors that have determined the trajectory and fate of those classified as *hermaphrodite* and as *Intersex* (Chapters Three and Four) and the development of the resistance to the case management of *Intersexuality* by the first generation of adults who were subjected to it as children (Chapter Five). Included in these chapters are the valuable contributions of scholars and activists who have written on *Intersex* (Grosz, 1996; Chase, 1998; Dreger,

1998a; Kessler, 1990, 1998; Fausto-Sterling, 2000; Morland, 2001, 2004, 2009, 2012, 2015; Butler, 2004; Creighton and Minto, 2001; Creighton and Liao, 2004; Holmes, 2008; Karkazis, 2008; Lev, 2006b; Liao and Boyle, 2004a, 2004b; Preves, 2008; Roen, 2008, 2009; Dreger and Herndon, 2009; Spurgas, 2009); *hermaphrodites* (Foucault, 1980; Dreger, 1998b; Mak, 2012; Malatino, 2009; Reis, 2009); gender (Schiebinger, 1989; Butler, 1990; Kessler and McKenna, 1978; Gatens, 1996); sex (Laqueur, 1990; Wittig, 1992); sexuality and sexual identity (Foucault, 1998; Katz, 1995; Oosterhuis, 2000; Cameron and Kulick, 2003); and the body (Butler, 1993; Gatens, 1996; Grosz, 1994; Oudshoorn, 1994). They helped me to assemble what is akin to a genealogy of *Intersex*; a progression which:

1. Shows some of the socio-political mechanisms at work in crystallising the categories *male* and *female* and how these have facilitated the conceptualisation, representation and treatment of those categorised as *hermaphrodites* and *Intersex* in the legal, social, medical and academic spheres.
2. Assesses the significance of the development of a male/female dualism and other dualistic categories associated with 'natural' sex and 'normal' sex behaviour, and maps how dominant discourses on sex and sexuality caused the category *hermaphrodite* (and others who did not fit dualistic sex categories in normative ways) to be viewed with suspicion, surveilled, controlled and even erased, laying the groundwork for the contemporary treatment of *Intersex* people.

3. Examines the philosophical epistemologies and psychological theories which precipitated 'surgical correction' of *Intersex* babies and children as standard practice from the 1950s to the present day.
4. Charts how this ultimately led to the radical mobilisation and resistance of *Intersex* adults in the 1990s who insisted on new medical protocols and new constructions of *Intersex* people by contesting the pathologisation and medicalisation of *Intersexuality* and by advocating for a queer-oriented, pansexual *Intersex* identity aligned to LGBTQ politics.
5. Discusses the schisms and controversies in the *Intersex* movement related to the re-adoption of the medical word 'disorder' by key activists in the *Intersex* movement, and analyses medico-psychiatric, psychoanalytic and sexological literature – past and present - to critique the significance of this controversial word.

Taking a multi-disciplinary approach, I elaborate on the above themes which are drawn from the fields of anthropology, bioethics, biology, biomedicine, gender studies, history, law, linguistics, philosophy, psychoanalysis, psychology, religion, science, sexology, social work, sociology, technology dynamics and healthcare, to apprehend and articulate the salient elements in current debates on *Intersexuality*.

Section Two contains my **Methodology and Data Analysis** chapters. In **Chapter Six**, my **Methodology**, I detail my selection of feminist research methodologies and methods for my *Intersex* research project. **Chapter Seven, Introducing the**

Participants, contains biographical portraits of the seventeen participants of my study. **Chapters Eight** through to **Eleven** each open with a detailed and indicative case study that foregrounds some of the key themes raised in my data. Each case study is then followed by a variety of accounts from my in-depth, semi-structured interviews that explore, affirm, problematise and/or challenge certain dimensions and properties of the key data themes that form the focus of each chapter with the assistance of the theoretical resources presented in Section One. The key themes discussed in this section are:

- What is it like to have a body marked as unintelligible in a society that uses sex and gender norms as the benchmark of intelligible humanness and personhood (Chapter Eight)?
- How does parental secrecy and shame affect the self-image, well-being and life of an *Intersex* person (Chapter Nine)?
- What does the full range and scope of the medicalisation of *Intersexuality* involve as experienced first-hand by *Intersex* people (Chapter Ten)?
- In what ways is 'coming out' as *Intersex* both a painful and liberating journey? (Chapter Eleven)

Finally, **Section Three** consists of **Chapter Twelve and Thirteen, Conclusions and Recommendations** in which I respectively draw together the threads of the analysis in the preceding chapters and offer some practical recommendations to help those living *Intersex*. These practical recommendations are undergirded by a new

philosophical paradigm of embodiment which, I suggest, holds positive implications for *Intersex* case management. Chapter Thirteen evaluates what it would mean for an *Intersex* baby and infant to be conceptualised and treated as a whole and integrated person for whom the surgical encounter constitutes as much a part of their development as any other experience.

Writing About *Intersex*

Terminology for Sex and Gender

Using words and applying concepts to write about *Intersex* is not easy. When you are repeatedly using words such as sex, gender, sexual identity, sexual desire, sexual activity, *male*, *female*, *Intersex*, masculine, feminine and more, it quickly becomes apparent how language is a delimiting, misleading, 'irremediably slippery' and predisposing mechanism (Fausto-Sterling, 2000; Butler, 2004; Kosofsky Sedgwick, 2008: 27; see also sub-heading 'The Already Speaking Language' in Chapter Eight). Even relatively new theoretical terminology, such as gender, cannot circumvent this issue or prevent displacement (Gatens, 1996). One reason for this is, as biologist, feminist and historian of science Anne Fausto-Sterling (2000) writes in *Sexing the Body: Gender Politics and the Construction of Sexuality*, that language in European and American culture is resistant to any possibilities outside the idea 'that there are only two sexes' (Fausto-Sterling, 2000: 31). A second reason is, as linguists Deborah Cameron and Don Kulick (2003) point out in *Language and Sexuality*, that old assumptions never die out with the adoption of new words or more precise definitions (or, in the case of reappropriation, new ways of using old words), rather, they linger

as 'ghostly' presences haunting contemporary debates and usage (Cameron and Kulick, 2003: 2). Another reason that cannot be overlooked is mutual dependence, as expressed here:

[S]ome speakers still cling to traditional beliefs (e.g. that the way women or men behave socially and sexually is a direct expression of innate biological characteristics). But it may also be partly because the phenomena denoted by the three terms – having a certain kind of body (sex), living as a certain kind of social being (gender), and having certain kinds of erotic desires (sexuality) - are not understood or experienced by most people in present-day social reality as distinct and separate. Rather, they are *interconnected*.

Cameron and Kulick,
2003: 4, 5
(italics in original)

When writing about *Intersex* I discovered that some of these 'ghostly presences' would appear, not only because of the way that words used in sex and gender theorising are interlinked, but also because there is a (worrying) tendency to use them synonymously. In *Gender: an ethnomethodological approach* (1978), psychologists Suzanne Kessler and Wendy McKenna intentionally used the term 'gender' throughout their analysis, even when referring to biological processes, to underscore that 'social construction is primary in all aspects of being female or male' (Kessler and McKenna 1978: 7). They justify their decision with the observation that 'gender' and 'sex', although purported to be culturally and biologically distinct, are frequently used interchangeably in literature from the social and biological sciences. Overall, Kessler

and McKenna's usage was intended to demonstrate that if the terms 'gender' and 'sex' can be confused, then the cultural/biological distinction 'may be open to question' (Kessler and McKenna 1978: 7).

My Use of Sex and Gender Terminology

With respect to my use of terminology, I have attempted to counter the habitual confusion and pitfalls in the following ways:

1. When speaking in the context of their origin and purpose, I decided to always italicise four key words that are an integral part of my research, to help emphasise that they are discursively constructed categories, labels or classifications. They are:

male

female

Intersex

hermaphrodite

This may be a good place to also note that none of the above terms are to be understood as fixed or homogeneous. They are all unstable categories inflected by time, race, location, class, physical abilities and other frames of reference.

There are other terms that I use less frequently that I believe (and would like to take this opportunity to make clear) are also discursively constructed categories, although I decided not to italicise them. They are:

sex
 gender
 heterosexuality
 sexual orientation
 sexual desire
 sexual activity
 masculine
 feminine
 (and more...)

2. To emphasise a dualism, the two words will be divided by a forward slash and they will be deliberately put in order of the hierarchical function they form in society (unless referencing others):

male/female
 mind/body

Closely related to this point is my decision when writing about *male* and *female* as categories to always place *male* first. I did this in accordance with their contextual relationship. I am writing about the position of *male* within a patriarchal society that always constructs it as a privileged and superior category.

My Use of the Word *Intersex*

The next point concerns my use of the word '*Intersex*'. When I first began writing this project I would use the terms *Intersex*, *Intersex* people, the *Intersex*, and so on. Mid-way, I discovered *People First Language*, as devised by Kathie Snow (2017), which puts the person before the medical condition, for instance, 'a person with an *Intersex* condition' or 'a person who has an *Intersex* condition'. This is employed as a way of respectfully foregrounding the person, who can habitually be made invisible by society

due to their condition. I quickly amended all of my writing. However, I then discovered the *Identity First* movement; they are happy to place their identity or condition first when writing or speaking about themselves (Ladau, 2015), and so (in the case of my study) would prefer to be identified as 'an *Intersex* person'. After reflecting on this, I eventually settled on using '*Intersex*' in the multiple ways I have witnessed it being used in the online *Intersex* forums which encompasses both the *People First* and *Identity First* models.

I have capitalised '*Intersex*' and '*Intersexuality*' throughout this study (apart from when referencing others) in the spirit of the critical race theorist Cheryl I. Harris (1993) who capitalises the racial identity 'Black' in her work. This is part of a 'counterhegemonic practice' that rejects the oppositional strategy of juxtaposing 'Black' and 'white' as though they were racial equivalents, which masks the fact that inhered in the racial identity 'white' is white domination and Black subordination (Harris 1993: 1710). The domination and subordination inhered in the dualistic arch-categories *male* and *female*, which *Intersex* is subject to, shall be analysed in my study and I would like to emphasise this by capitalising *Intersex* throughout.

One last word about terminology is related to my choice of *Intersex* in general, rather than the new nomenclature 'Disorders of Sex Development' (DSD). By way of a brief explanation, I insert a copy of a footnote I put in my Interview Information Sheet that I gave to potential participants to inform them about the research:

As explained in 'Brief Guidelines for *Intersex* Allies,' I recognise that not everyone born with a mix of anatomical sex traits identifies or feels comfortable with the term '*Intersex*,' and it is not my intention to exclude those who describe themselves differently or identify as 'DSD' (Please see: <http://oii-usa.org/1000/information-Intersex-allies/> , accessed October 2014). On the contrary, I have chosen to use '*Intersex*' in line with its political usage as a term which raises awareness of the naturally occurring diversity and variety of sex characteristics in human beings.

Writing About Medicine

This thesis is aimed at exposing and dismantling the systematic arrangements and philosophical models that have made possible the controversial, debated and contested routine genital surgeries of *Intersex* babies and infants in Western societies. What this involves is scrutiny of the systems, philosophies, ideologies, discourses, assumptions and institutional structures that underpin and/or maintain the medical management of *Intersexuality*. In short, it is essential to get to the root. It is therefore important for me to make plain that it is not my wish to alienate or appear overly critical of individual medical staff and their teams who are directly involved in *Intersex* care. I do not want to overlook the valuable work performed by many people within the medical profession (and as corroborated by some of the participants in my study). This issue is bigger than them, for my focus is structural. However, in getting at this root, I will be unapologetically critiquing the epistemic paradigm in which they work and in which the whole of Western culture operates.

Section One: Dualistic Notions of Sex and the Body

The overarching aim of Section One is to understand what is it that allows highly controversial surgical access to bodies sex typed as *Intersex* which subsequently has a marked effect on how people categorised as *Intersex* experience living *Intersex* in Western societies. To examine this it is important to understand the circumstances that have converged to make genital normalising treatment move from theory to practise in Western societies. It is an examination which involves looking at history and some of the powerful societal influences at work. It requires charting how sex categorisation, sex roles, sexual difference, bodies, sexual behaviour and difference has been dealt with over time by the political, medical, scientific, religious, philosophical and legal realms. Specifically, Section One will answer the following questions:

- What is sex?
- What does the category *Intersex* delineate?
- Who are the beneficiaries of sex categorisation and other dualistic categories associated with sex, bodies and behaviour?
- Who are targeted by these dualistic categories?
- What are some of the philosophies, theories, ideologies and discourses that underpin the contemporary medical management of *Intersexuality*?
- Why has there been a mobilisation of resistance to the contemporary medical management of *Intersex* since the 1990s?
- Why has that resistance involved contestation of the term 'disorder'?

All of these questions are at the heart of *Intersex* theorising and current debates on *Intersexuality*. Chapter One begins by introducing the phenomenon categorised as *Intersex*. It explains what criteria delineates a person as either *male*, *female* or *Intersex*, and why it is that if a person is categorised as *Intersex* they are perceived as 'disordered' and there is a compulsion to surgically alter them.

Having considered some of the ways that those classified as '*Intersex*' do not fit the categories of *male* and *female* and how an *Intersex* birth is perceived, Chapter Two interrogates the purpose of dualistic sex categorisation. What is it doing? What is it for? Who does it benefit? It critiques the status of *male* and *female* categories as 'natural', inevitable, fixed, ahistorical and biological 'facts' and uncovers their socio-political functions. The key argument of the chapter is that the dichotomous categories *male* and *female*, along with other dualistic sub-categories associated with sexual difference, namely, masculine/feminine; procreative sex/sodomy; heterosexual/perversion (to name but a few), have historically functioned to organise, regulate, control and steer society in normative ways. They are not based on scientific 'facts', but are volatile, historical, cultural and discursive notions which are manufactured by discourses of sex and sexuality. The chapter reveals how medicine's role in disseminating discourses of sex and sexuality, via the criminalisation and pathologisation of human sexual behaviour, consolidated its power in the public realm and solidified its function as an agent of social control. Using Michel Foucault's analysis of bio-power, it will show how examinations, therapeutic confessions,

observation and report-writing were used by many institutions since the nineteenth century in the service of the state. Fundamentally, these are disciplinary procedures that provide unprecedented access to human anatomies, behaviours and activities.

Chapter Three shows how regulatory discourses of sex and sexuality have historically been applied to the bodies of those who do not fit dualistic categories. The *hermaphrodite* classification was given to persons who could not (or would not) be sex typed as *male* or *female* due to their faces, bodies, genitalia and/or incongruencies with their outward appearance and occupation, or comportment and mode of urination. The chapter will analyse how with the rise of medicine and advancements in medical techniques, the *hermaphrodite* became medicalised, pathologised and erased. It examines medical case histories, medical narratives, societal discourses on degeneracy and perversion, sexological texts and the philosophical and medico-cultural context of the late eighteenth to the early twentieth century to ascertain what claims, assumptions and anxieties were at the heart of social encounters and medical interactions with *hermaphrodites*.

Building on the theoretical and historical context provided in the previous chapters, Chapter Four analyses the contemporary case management of *Intersexuality*. What philosophies and theories have allowed for the emergence of genital normalising surgery on *Intersex* babies and young children to become legitimised as routine, standard practice in *Intersex* management and in what ways are these tied to historical socio-political discourses and ideologies on sex and sexuality? The chapter

critically examines three key phenomena. First, the seventeenth century philosophy of the mind/body dualism and how this epistemology, adopted by biomedicine in Western societies, permits access to bodies perceived as defective, mechanical objects in need of repair and reconstruction. Second, how the application of the sex/gender dualism instates the 'one true sex' doctrine and champions heteronormative ideologies relating to the sexed body, sexual difference and sexual activity. It illustrates how the sex/gender dualism is apparent in the theories of gender proposed by Dr. John Money and is evident in his now infamous case of David Reimer which sanctioned genital surgery in *Intersex* case management. Third, it will examine the construction of medical practitioners as hierarchically superior to their patients and how this negatively constructs the patients in their care as inferior and passive. The chapter will argue that these three factors are pivotal when attempting to decipher 'surgical correction' in the current treatment of *Intersexuality* in Western societies.

Finally in this section, Chapter Five depicts how *Intersex* people responded to their medical management by mobilising an *Intersex* movement. The chapter shows how the word 'disorder' has been the site of contestation and rupture within the *Intersex* community. How should *Intersex* people view the medical term 'disorder'? Should concessions be made with nomenclature to secure better medical care? Or, based on its history within the psycho-medical sphere should it be rejected entirely? Due to its significant function in the construction and treatment of *Intersexuality* - both historically and present-day - the chapter addresses these important questions.

Chapter One: Categorising *Intersex*

The purpose of this opening chapter is to introduce the reader to the category called *Intersex*. It does so by first explaining how *Intersex* is used to categorise human organisms that do not fit within the dominant categories *male* and *female*. By looking in detail at five *Intersex* conditions relevant to my study, the chapter illustrates the difficulties of organising people into just two discrete categories when there are many exceptions, anomalies and instances of doubt. Next, it addresses the often asked question of whether *Intersex* is a rare phenomenon since it remains relatively unknown in comparison to *male* and *female*, and it links this invisibility to surgical coercion. Finally, the chapter briefly outlines the current treatment of *Intersexuality* in Western societies which involves genital reconstruction on healthy *Intersex* bodies to assimilate them into the male/female category and what this treatment shows in a preliminary way about acceptance of difference, a theme which will be examined in subsequent chapters of the thesis.

What is *Intersex*?

Each human cell usually contains a total of 46 chromosomes or 23 pairs. If the twenty-third pair possesses one X and one Y chromosome it is identified as a 46, XY karyotype and classified *male*, whereas if the twenty-third pair contains two copies of the X chromosome it is identified as a 46, XX karyotype and classified *female*. For this reason the twenty-third pair of chromosomes is known as the X and Y chromosomes; in medical literature they are frequently referred to as the 'sex chromosomes' and are

overwhelmingly associated with the development of human sexual characteristics.³ However, there exist a number of humans with cells that flout this apparently simple genetic taxonomy. There are people who possess a 46, XY karyotype (therefore classifiable as *male*), who can develop in ways that would usually be associated with a 46, XX karyotype and therefore be phenotypically identified as *female*, such as in the case of those with *Androgen Insensitivity Syndrome* and *Swyer Syndrome*. There are other people who do not fit the *male* or *female* karyotype at all. They possess either 47, XXY (*Klinefelter's Syndrome*), 45, XO, where an entire chromosome is missing (*Turner Syndrome*), or they have XX cells in one part of the body and XY cells in another (*Mosaicism*, as found in some cases of *Turner Syndrome*). Additionally, there are still other people who are identified as 46, XX karyotype (therefore classifiable as *female*), but phenotypically their bodies may be anomalous and do not conform to what is conventionally expected for either *female* or *male* designations, such as in some instances of *Congenital Adrenal Hyperplasia*.

People who have *Androgen Insensitivity Syndrome*, *Swyer Syndrome*, *Klinefelter's Syndrome*, *Turner Syndrome* or *Congenital Adrenal Hyperplasia* are all classifiable as *Intersex*. *Intersex* is a relatively new term coined by German biologist and geneticist Richard Goldschmidt (1878 - 1958), who used it to identify 'a definite step between

³ Historian of medicine and bioethicist Alice Dreger (1998b) writes that labelling X and Y chromosomes the 'sex chromosomes' is a misnomer and creates confusion. Dreger explains that not only are genes that contribute to sexual development *found on other chromosomes*, but equally, genes related to *non-sexual development* are to be found on X and Y chromosomes (1998b, italics added).

the two sexes' in his hybridisation experiments on gypsy moths (1916: 708).

However, crossing over to the medical literature *Intersex* has not been unanimously adopted as a diagnostic term in the medical world, since no uniform agreement has been reached on what exactly constitutes *Intersex*. For the most part, doctors avoid using the term *Intersex* in clinical settings with their patients (Feder and Karkazis, 2008; Reis, 2009).

Within the medical literature *Intersexuality* is referred to as a 'sexual disorder' and is characterised as possessing the following 'errors':

1. Chromosomal anomalies: 'errors present in the parents prior to conception'.
2. Hormonal or gonadal anomalies: 'errors that occur subsequent to conception, from the first division of cells to postnatal life'.
3. '[E]rrors in which sex development is normal and sexual differentiation is abnormal'

(for example, *Androgen Insensitivity Syndrome (AIS)*, where the chromosomal sex can be clearly identified as *female*, but the person has 'male' gonads)

(Grosz, 1996: 59).

Intersex is used as shorthand to categorise over forty different conditions in which sex development is deemed to be atypical in humans (Feder and Karkazis, 2008; Feder, 2009; Reis, 2009). Each *Intersex* condition represents a spectrum which varies in degrees and comprises a wide range of presentations.

Five *Intersex* Conditions

Below is a bio-medical summary of the five *Intersex* conditions mentioned in the two preceding paragraphs, which I have selected due to their frequency of occurrence, relevance to my study and illustrative capacities.⁴ They contain all or some of the following etiological descriptors:

- Name and karyotype
- Description of condition
- Phenotypical presentations
- Internal reproductive structures
- Any other distinguishing features
- Puberty
- Fertility
- Any accompanying health concerns

In presenting these *Intersex* conditions it is my hope that the ‘multiply contingent character’ of the categories *male* and *female* also becomes apparent (Holmes, 2009: 9).

1. Androgen Insensitivity Syndrome: 46, XY

Androgen Insensitivity Syndrome (AIS), formerly known as ‘testicular feminization syndrome’ (Dreger 1998b: 38), is an inherited genetic condition – except for

⁴ The source material from which all of this information was gathered is in the Appendices (see ‘References for Five Intersex Conditions’).

spontaneous mutations – that occurs when an individual has an XY chromosomal pattern (recognised as the typical *male* karyotype). Although their testes produce the required amounts of androgens required for *male* development, their body lacks the receptors with which to respond to the androgen's 'masculine developmental pathway' messages (Dreger 1998b: 38; Liao and Boyle, 2004a). In *Complete Androgen Insensitivity Syndrome* (CAIS) the XY infant typically has *female* external genitalia resulting in a labia, clitoris and frequently a short vagina. The infant is without ovaries, womb and cervix and has undescended abdominal testes (Liao and Boyle, 2004a). At puberty, a person with AIS will continue to develop along 'the more "typical" feminine pathway' as their body does not respond to the androgen secretion of the testes, resulting in the growth of breasts, rounded hips, but usually no, or very sparse, pubic hair (Dreger 1998b: 38). The condition may not be diagnosed until adolescence, usually prompted by the absence of menstruation. Individuals diagnosed with CAIS are predominantly assigned *female*. (Conway, 2014). Testicular cancer risk is reportedly low in CAIS so many opt to retain their testes and benefit from a process called 'aromatization' where excess testosterone is converted into estrogen with the help of the enzyme 'aromatase'.

In *Partial Androgen Insensitivity Syndrome* (PAIS), depending on the degree of androgen receptivity/sensitivity, the XY infant may present partially masculinised external genitalia, also known as 'mildly virilised', such as clitorimegaly or hypertrophy of the clitoris or partially feminised external genitalia, also known as 'mildly under-virilised', such as hypospadias, and/or a micro-penis (Reis, 2009). As with CAIS, the testes function and secrete androgens which inhibit the growth of a uterus, fallopian

tubes and an upper vagina. Individuals with PAIS have an increased risk of cancer so testes removal is often advised (Liao and Boyle, 2004a: 446). A distinguishing feature of CAIS and PAIS is infertility.

2. Congenital Adrenal Hyperplasia (CAH): 46, XX; 46, XY.

Congenital Adrenal Hyperplasia (CAH) encompasses a range of conditions affecting the adrenal glands of both XX *females* and XY *males*. The adrenal glands, located at the top of the kidneys, are responsible for producing and regulating the following three hormones: (1) androgens (for *male* sexual development), (2) cortisol (for maintaining stress, energy and blood sugar levels), and (3) aldosterone (for maintaining fluid volume, sodium and potassium levels).

The most common form of CAH is related to the production of cortisol. When the pituitary gland senses a lack of cortisol in the bloodstream it tries to stimulate the adrenal glands to produce more by releasing the hormone ACTH (or adrenocorticotrophic hormone). To produce cortisol the adrenal glands require an enzyme called 21-hydroxylase (21-OHD). However, because individuals with CAH have insufficient amounts of 21-OHD, they respond to the release of ACTH by producing an excess of the androgenic hormones instead. In both XX and XY infants, androgen excess can lead to virilisation, early puberty, increase of body hair, premature growth and bone aging that results in short adult stature. Moreover, insufficient amounts of cortisol in the body can impact sugar metabolism, stress response and ultimately lead to an adrenal crisis.

Phenotypically, excess androgen exposure from the adrenals of the XX *female* fetus (during gestation) can result in 'virilisation' of the external genitalia, including an enlarged clitoris (clitoromegaly) and fusion of the labial folds which can resemble a scrotum (Preves, 2008). Internally the XX *female's* reproductive system is unaffected and contains a uterus, ovaries and upper vagina (Conway, 2014; Liao and Boyle, 2004a). Moreover, research reveals increasingly improved fertility outcomes (Conway, 2014; Liao and Boyle, 2004a). The XY *male* shows no atypical outward physical manifestations of CAH. Both XX and XY individuals require endocrine adjustment with an adrenal steroid hormone to replace the hormone deficiency at birth and throughout lifespan (Conway, 2014; Liao and Boyle, 2004a).

The form of CAH which affects the aldosterone production of the adrenal glands is called *Salt Wasting* (SWCAH) or *Classical* CAH. Aldosterone is responsible for the body's fluid volume as well as sodium and potassium levels which among other vital functions stabilises the heart. Since SWCAH is an aldosterone deficiency it is CAH in its severest form. If undetected and untreated SWCAH can result in dehydration and low blood pressure, which due to their impact on the heart, can lead to death.

3. Klinefelter's Syndrome: 47, XXY

Klinefelter's Syndrome describes a condition where an infant classifiable as *male* (XY) possesses extra X chromosomes in each cell. As the number of X chromosomes increases (48, XXXY or 49,XXXXY), so does the likelihood of greater health concerns.

Even though some affected individuals can have undescended testicles, hypospadias and micro-penis, there are frequently no discernible signs or symptoms of *Klinefelter's Syndrome* (47, XXY) at birth. Due to this, many individuals remain undiagnosed, since phenotypically they develop a recognisably *male* body, with above average height and long limbs. Owing to this, some individuals are diagnosed at puberty when their testes fail to grow, or others when investigating fertility issues. Infertility is a distinguishing feature of *Klinefelter's Syndrome* and small testes leads to reduced testosterone production, which can result in delayed or incomplete puberty and minimal facial and body hair (Chase, 1998). In some cases, breast development (gynecomastia) and broadening of the pelvis occurs and is managed with testosterone treatment along with surgery for breast removal (mastectomy). There is a higher risk of breast cancer among *males* with *Klinefelter's Syndrome*.

4. Swyer Syndrome: 46, XY

In *Swyer Syndrome*, the infant possesses a 46, XY karyotype (usually associated with a genetic *male*), however, particular mutations in the genes that regulate *male* sex determination signalling inhibit the development of testes, thereby facilitating the development of an internal and external *female* reproductive structure, including uterus and fallopian tubes. The infant does not have ovaries; instead it has clumps of tissue called 'streak gonads', or minimally developed gonadal tissue, which due to the high risk of malignancy, removal is advised (Conway, 2014). Children with *Swyer Syndrome* are raised as girls and require estrogen replacement therapy throughout their lives to induce puberty and maintain health (Conway, 2014). Due to the

development of the uterus, fertility via egg donation is possible (Creighton and Liao, 2004; Conway, 2014).

5. Turner Syndrome: 46, XY and 45, X0 or 46, XX and 45 X0

Turner Syndrome is defined by an XO genetic karyotype: an X chromosome is present and an entire chromosome is missing or structurally altered. There are cases of *Turner syndrome* where the missing chromosome is found in some cells in the body, but not in others, this is called *Mosaicism* (Kipnis and Diamond, 1998: 44). *Turner Syndrome* is habitually associated in the medical literature with *female* births, a claim contested by *Intersex* people who maintain genetic males can also have this *Intersex* condition (Simon, 2014). The infant's internal genitalia may proceed along typical *female* developmental lines with a uterus and vagina, but the ovaries can be subject to a premature loss of function. If ovarian failure occurs, estrogen replacement therapy is required to trigger puberty and offset osteoporosis.

Other distinguishing physiological characteristics of *Turner Syndrome* are short stature, extra folds of skin on the neck, swollen hands and feet (lymphoedema) with occasional skeletal, kidney and heart complications.

Fertility can be assisted with a donor egg and in vitro fertilisation (IVF) treatment.

Is *Intersex* a Rare Occurrence?

In order to appreciate how extensive the category of *Intersex* is, it is important to first understand that sex development can be determined by the following criteria

(Grosz, 1996):

- 1) Genes
- 2) Gonadal structure
- 3) External genitalia
- 4) Internal genitalia
- 5) Hormonal constitution
- 6) Rearing

Given that *Intersex* is a catch-all term for many different variations of sex development (Rosario, 2009), it thus follows that whenever there is discordance between *any* of the above criteria and binarily opposed conceptions of *male* and *female*, then we are talking about an *Intersexed* subject (Grosz, 1996). It does not neatly end there. As demonstrated in the preceding section, there exist 'various gradations of *Intersexuality*', dependent on the strength and degree of the hormonal, gonadal and chromosomal anomalies which depart from what is recognised as a 'normal' sex category (Grosz, 1996: 60). Sociologist Sharon Preves (2008) corroborates this point by asserting that if chromosomal, gonadal, genital or hormonal features were stringently assessed, then 2% of babies could be considered *Intersex*, noting how additional estimates gauge the frequency to be 1 to 4% of all births. These estimates differ merely because definitions of 'normal', 'abnormal' and

'ambiguity' are unstable and variable. On account of what it can be used to classify and characterise *Intersexuality* cannot be called a rare phenomenon. When comparing the frequency of Albinism with *Intersex*, Fausto-Sterling (2000) notes that Albinism occurs far less frequently (1 in 20,000), concluding that 'Intersex births are not rare but rarely visible', since children born *Intersex* are 'a fairly common phenomenon', but 'disappear' due to surgical intervention (2000:31). Essentially, and as shall be shown in this thesis, the category *Intersex* has been used as the exception to prove the rule and the norm of the dominant categories *male* and *female*.

The Current Treatment of *Intersexuality* in Western Society

Believing they can discern the 'one true sex' of their *Intersex* patients (see Foucault, 1980), surgeons have removed or supplemented the healthy body parts of people with *Intersex* conditions to create genitalia more easily identifiable as *male* or *female* (Fausto-Sterling, 2000; Holmes, 2008; Karkazis 2008). The decisive factor determining *Intersex* surgery is the appearance of the clitoris and penis based upon a scale of genital masculinisation, which is deemed influential to the formation and internal experience of gender identity in the child (Morland, 2004; Lev, 2006b; Reis, 2009). The *Intersex* child's genitals are surgically shaped or constructed to correct somatic 'undermasculinisation in males' and 'overmasculinisation in females' (Meyer-Bahlburg, 1998: 12), so that, 'the individual does not feel like a freak' (Money, 1975: 66). Yet, what comes to be dichotomised as the primary signifiers of *male* or *female* genitalia are in fact analogous in their developmental form (Morland, 2004). In embryology the penis and clitoris are both referred to as the 'phallus' (Dreger, 1998a;

Morland, 2004). The phallus is the 'protogenital' to both the penis and clitoris, which means that genital surgery guided by phallic principles is not uncovering a 'truth of sex', for - in medicine's own terms - the prehistories of all human genitalia is 'decidedly intersexual' (Morland, 2004: 449).

Surgical intervention for *Intersexuality* is not to be confused with medical assistance for *Intersex* related health concerns. As already depicted in my etiological descriptions of five *Intersex* conditions, and as to be expected in over forty known different presentations of *Intersexuality*, there are some that present mild to extreme health concerns. They genuinely require medical assistance in order for the individual to flourish or even in some cases to survive. For example, people diagnosed with *Swyer syndrome* are at high risk of gonadal malignancy so removal of the gonads is advised along with lifelong estrogen replacement therapy, *Congenital Adrenal Hyperplasia* (CAH) requires urgent adrenal steroid treatment and the *Intersex* condition *Cloacal exstrophy* affects multiple organ systems of the body and for this reason can be life-threatening (Conway, 2014).

Conclusion

So, what is *Intersex*? This chapter has endeavoured to answer this question by first delineating the categories *male* and *female* and how they are ostensibly employed to sex type all human organisms. In so doing, this chapter has shown how the category *Intersex* marks instances of overlap, anomaly, atypicality and discordance based on the sex typing criteria for *male* and *female*. Those marked as *Intersex* are referred to

in the medical literature as possessing a 'sexual disorder' or 'errors' in their sex development. Yet the chapter has shown how these 'errors' occur with remarkable regularity and that their presentations are the site of a spectrum containing a wide variety of complex manifestations. Nevertheless, *Intersexuality* is constructed as disrupting a 'one true sex' requirement in Western societies comprised of only *males* and *females* and is therefore subject to surgical intervention for the 'correction' of its 'errors' of sex, even in cases which do not present any health concerns. This may explain why despite its statistically stable frequency *Intersex* remains relatively unknown and invisible. Genital reconstruction on healthy *Intersex* bodies to assimilate them into the dominant *male* or *female* classifications is controversial. It shows the lengths to which a dualistic society is prepared to go to maintain the coherence of its dominant categories.

Chapter Two: Categorising Sex

The very act of placing human organisms with over forty conditions within a separate - but not equal - category called *Intersex* provides evidence that there exist over forty anomalies, exceptions, instances of doubt and overlap in the categories *male* and *female*. This raises pointed questions regarding the adequacy and purpose of this two-fold categorisation. For we might ask, if two categories meant to sex type all individuals are, by their own criteria, failing to classify everyone, why are they viewed as adequate? Does this not undermine their purpose? We might also ask, if these two categories overlook and exclude certain individuals, why do we still have them? If *Intersex* people are routinely undergoing surgical procedures to be categorised as *male* or *female*, what is the true purpose of these dominant categories of sex? Are they describing or in fact prescribing human organisms?

Kessler and McKenna (1978) report that biologists often prefer to say that *Intersex* is 'a combination' of *male* and *female* and seek criteria to place an *Intersex* person in one of the two mutually exclusive categories, rather than conclude that they are 'neither female nor male' or perhaps 'a third gender category' (1978: 1). Along different lines, in *Confounding Gender*, political scientist and gender theorist Mary Hawkesworth (1997) writes that chromosomes, hormones, sperm production or egg production fail to incontrovertibly differentiate all men from all women, or even provide an indisputable common core which is peculiar to all *males* or all *females*. In spite of this, *male* and *female* are very well-known, visible, normalised, self-explanatory, unquestioned categories of sex, whilst *Intersex* remains lesser-known,

invisible, exoticised, unfathomable and questionable by comparison. How has this happened? How have these two categories of sex dominated and retained their dominance in Western societies? Do they have a history? If they do have a history then what really is sex? And what is to be said about the 'natural', 'scientific facts' of sex?

In this chapter I will interrogate what it is that primarily constitutes and upholds the dominant categories of *male* and *female*, since, as already demonstrated, they signify an important aspect in the social acceptance and medical management of *Intersexuality*. I will argue that these arch-categories do have a history and serve political and social interests, that they are sustained and enabled by the ideology of sexual difference, the elevation of heterosexuality to the obligatory social relationship and discourses of sex and sexuality. All of which serve to obscure and justify the operation of a biopolitical power involved in social regulation, hierarchy and control.

Male, Female and the 'One-Sex Model'

Historically, the arch-categories of sex recognised as *male* and *female* have changed over the centuries and were not conceptualised in the ways that they are today (Oudshoorn, 1994). Prior to the nineteenth century, *males* and *females* were not viewed as opposite sexes, but merely variations of the same form (Oosterhuis, 2000; Holmes 2008). American medical historian and sexologist Thomas Laqueur (1990), who traces conceptualisations of sex and bodies in Europe and North America in *Making Sex: Body and Gender From the Greeks To Freud*, calls this the 'one-sex

model', explaining how women were believed to have the same sex organs as men, the only difference being: *male* sex organs were located on the outside, and *female* located on the inside (Laqueur, 1990: viii, 4; Preves, 2008). Verifying this challenge to contemporary perceptions of *male* and *female*, Dutch Professor of Science, Technology Dynamics and Healthcare Nelly Oudshoorn (1994), writes how the 'one-sex model' - which dominated biomedical discourse for 2000 years - is discernible in anatomical nomenclature: the ovary was described as a *female* testicle and there was no terminology to designate either the vagina or the clitoris. This is not to suggest that men and women were regarded equally. On the contrary, the 'one-sex model' was hierarchical and inextricably tied to patriarchal thinking. It was a *male* public world and women simply did not exist as an ontologically distinct category (see Laqueur in Oudshoorn, 1994). *Females* bodies were viewed as less developed and therefore inferior versions of *male* bodies (Laqueur 1990; Oudshoorn, 1994; Oosterhuis, 2000). In support of this, historian of science and gender Londa Schiebinger (1989) writes that heat was 'the immortal substance of life' in the ancient world. Hot and dry were superior to cold and moist, with the former perceived as active, whilst the latter as sluggish. This may explain why the Greek physician Galen (129 CE–circa 216 CE)⁵ wrote that it was a defect of heat in the womb which caused the *female* foetus to have imperfect 'generative parts' which could not propel outwards, whereas man 'is more perfect than woman' due to his 'excess heat' (Schiebinger, 1989: 163).

⁵ 'Galen of Pergamum', *Encyclopaedia Britannica*,

<https://www.britannica.com/biography/Galen-of-Pergamum> [online] accessed August 2017.

According to Laqueur, evidence of two distinct and incommensurable sexes was not sought 'until such differences became politically important' (Laqueur, 1990: viii). The fundamental shift to a 'two-sex model' was a consequence of major changes brought about by the Enlightenment, the French Revolution and the Industrial Revolution (Oosterhuis, 2000; Mak, 2012). The birth of sexual science from the eighteenth century onwards defined women as biologically opposite to men in regard to their anatomy, physiology, temperament and intellect (Oosterhuis, 2000). Therefore when the industrial revolution seemed set to permanently disrupt traditional hierarchical divisions by promoting a more egalitarian social realm, biomedical arguments were used to make prescriptive claims about the social order and as a ruse for the social organisation of human bodies (Laqueur, 1990; Oosterhuis, 2000). Hence, current dichotomous conceptions of sexed bodies cannot be called ahistorical, 'natural' or stable (Wittig, 1992). Before the Enlightenment period differences were socially and culturally contingent and not biologically determined (Oosterhuis, 2000; Mak, 2012).

The Purpose of Diametrically Opposed Sexed Bodies

Diametrically opposed sexed bodies supplied justification for differences in the 'political, economic, and cultural lives of men and women' (Laqueur, 1990: 6; Wittig, 1992). A man or woman's place in society became based on the 'facts' of their biology and 'natural' differences purported to be rooted in nature (Laqueur, 1990:6; Wittig, 1992; Oosterhuis, 2000). Women's bodies were constructed and represented as frail, imperfect, anarchic, liable to intrusions and unpredictabilities (Grosz, 1994; Gatens, 1996). A woman's defining cultural characteristic became the obligation of

reproduction, thereby rendering her in need of protection or special treatment (Wittig, 1992; Grosz, 1994), which, as defined by patriarchy, meant circumscription to the private sphere, for as social beings they were to be invisible (Wittig, 1992; Oosterhuis, 2000). Early in the twentieth century, the new field of endocrinology introduced the concept of *male* and *female* sex hormones. These were depicted as chemical messengers of masculinity and femininity, directing various behaviours, functions and characteristics as typically *male* or typically *female*. As stated by Oudshoorn, this hormonal construct of the body 'developed into one of the dominant modes of thinking about the biological roots of sex differences' (Oudshoorn, 1994: 8). This development portrayed the *female* body (and not the *male*) as one which was completely controlled by hormones. Furthermore, the overlaying of the mind/body duality onto the male/female opposition - where mind is equivalent to the masculine and body to the feminine - implied a 'natural inequality', where women were deemed incapable of men's cognitive abilities (see Chapter Four). Historically, the effect of this cross-pairing ruled women out as possible subjects of knowledge; barring them from the realms of philosophy, politics, science and more (Schiebinger, 1989; Wittig, 1992; Grosz, 1994; Oosterhuis, 2000).

Can Sex Categorisation Be Beneficial?

Notwithstanding this, Dreger (1998b) suggests that sex categorisation can be used to benefit society. Dreger explains how sex categories can help people to learn important information about their bodies, in order to be aware of the signs for and to assist in treating certain conditions or diseases which may only be specific to certain

sex category types. For instance, those classified as *Intersex* who have the condition *Partial Androgen Insensitivity Syndrome* understand that there is an increased possibility of developing testicular cancer (see Chapter One). The problem lies in the naturalisation of sex categories, established to legitimise social hierarchies by classifying some human bodies as inferior, defective and abnormal (Karkazis 2008). When employed in this way, bodies are not sexed to grant an autonomous and active corporeal specificity, they are sexed to explain and justify unequal social positions (Grosz, 1994). For in a society which has organised its sexual boundaries according to the dichotomy of *males* and *females*, the appearance of a person revealed to be neither *male*, nor *female*, but perhaps both at the same time, literally embodies a political challenge.

A popular argument in favour of sex dimorphism, as noted by Kessler and McKenna (1978), is that it is a necessary identifying tool with which sperm and egg cell carriers can recognise each other for reproductive purposes, without which the human species could become extinct. For this reason, those who produce sperm cells are classified as *male* and those who produce egg cells are classified as *female*. However, the force of this argument depends on a misleading conflation of *male* and *female* with 'sperm carrier' and 'egg carrier' (respectively), when, as already demonstrated in Chapter One, this is not always the case. Simply put, it does not always follow that every assigned *male* or every assigned *female* has the capacity to reproduce and those who do may not wish to. Furthermore, the ability to reproduce 'is not a continuous fact of life', an egg cell carrier has only a few days each month for approximately thirty to forty years when they could be defined as 'capable of reproduction', and 'sperm cell

carrier [s]' carry an increasing number of defective cells as they mature (Kessler and McKenna, 1978: 165). Nevertheless, this reproductive dichotomy is constituted as a lifetime dichotomy. At birth, an individual is placed into the category *male* or *female* and they are compelled to perform and behave in accord with one or other of these socially defined roles for the duration of their life. It should be noted too, that even after death a person has to retain their assigned sex categorisation. Taken all together, what this expressly suggests is that *male* and *female* encompass far more than reproduction. They are social constructions integral to the maintenance of a sex dimorphous society.

The Ideology of Sexual Difference

One of the questions posed at the opening of this chapter was: how have two categories of sex dominated and retained their dominance in Western societies? In *The Category of Sex*, French feminist theorist Monique Wittig (1992) says that there is no sex and it is *oppression* which creates the category of sex. Sexual difference is an ideology underpinning the social opposition of the sexes - with negative effects for those classified as women - concealing itself by insisting upon an immunity to historical, cultural and social factors and by claiming its grounds entirely in nature or biology (Wittig, 1992; Grosz, 1994). It is this concealment which facilitates the domination of the sex categories *male* and *female*. Wittig refers to this as 'the perennality of the sexes', a dominant discourse regurgitated at every level of society (1992: 2). It is the idea of the sexes as prediscursive or 'already there', which by appealing to naturalism and biologism, masks a wholly political and social agenda

(Butler, 1990), namely: the restriction of women's social and economic capacities and space in society. Anthropologist and bioethicist Katrina Karkazis (2008) likens human sexual difference to a 'carefully crafted story': although seemingly 'obvious' and 'real', it is more accurately a product of a volatile history of human social relations consistent with a particular time and place, mapped onto all human bodies (Karkazis 2008: 6). Thus, sexual difference is a mobile and volatile concept that possesses the ability to insinuate itself into places it should not be by making its influences and effects unrecognisable and invisible (Grosz, 1994). This ideology has a 'body of discourses' at its disposal (Wittig, 1992: 5). Most notably, in theories from biology and medicine, which claim that certain biological, physiological and hormonal differences have unequivocal sociological consequences. These theories have inextricably tied women to the body and reproduction by conferring upon them a '*more biological, more corporeal, and more natural*' state of being than men (Grosz, 1994: 14, italics in original).

Heterosexuality: The Obligatory and Compulsory Social Relationship

As mentioned above, categories of sex in dualistic societies are primarily concerned with social relationships and heterosexuality is designated as the obligatory and compulsory social relationship for the sexes (Wittig, 1992; Katz, 1995). As Wittig states, 'heterosexuality is always already there within all mental categories' (1992: 43). This is evident in:

- 1) The normalisation of heterosexuality via its conflation with human reproduction.

- 2) The naturalisation of heterosexuality via its conflation with nature.
- 3) The universalisation of heterosexuality to the extent where no human relationship, culture, society and concept can be imagined without the existence and domination of heterosexuality.

Moreover, heterosexuality continues to resist examination and sustained critical analysis (even Michel Foucault in *The History of Sexuality* neglected to critique heterosexuality) by laying a primordial and intimidating claim to *everything* that is differently sexed, gendered and eroticised (Katz, 1995). However, in *The Invention of Heterosexuality*, American historian of human sexuality Jonathan Ned Katz (1995) maintains that sexual reproduction, sex difference and eroticism between men and women has been defined and combined in radically different ways across many different social systems. For example, heterosexuality has both been denounced as a non-procreative perversion and elevated to the ideal social contract. It is a modern invention, a dominant, erotic ideal which signifies one historically specific system of organising the sexes and their pleasures. It is a master category in a sexual regime that normatively regulates an individual's intimate desires and activities. Similar to the concept of sexual difference, which – as already demonstrated - casts women as different and other, heterosexuality's coherence is also reliant upon a variety of 'differents' and 'others'. These are comprised of different sexual desires, sexual behaviours, communities, anatomies and identities (Wittig, 1992; Katz, 1995; see Seidman in Katz, 1995) which will be examined in relation to *Intersexuality* in my study. As Wittig (1992) states, heterosexuality cannot work economically,

symbolically, linguistically, or politically without exerting its social dominance and power by controlling and oppressing those it constitutes as 'different' and 'other'.

Heterosexuality as 'Reproductive Deviance'

Katz (1995) reveals that the first recorded use of the term 'heterosexual' was in 1868 by Viennese writer, journalist and early sex-law reformer Karl Maria Kertbeny in private letters written in German to German lawyer and sex-law campaigner Karl Heinrich Ulrichs. In his letters, Kertbeny defined 'heterosexual' as erotic acts of men and women characterised by their 'unfettered capacity for degeneracy'. Kertbeny listed other degenerate acts alongside heterosexuality such as, incest, child abuse, bestiality, necrophilia, wounding and torture. What they all had in common was their capacity for 'unfetteredness'. These activities included an excess of same-sex acts indulged in by these 'heterosexual' men and women. 'Heterosexual' first entered the English language – together with 'homosexuality' – publicly in 1892, in the English translation of *Psychopathia sexualis*, an annual collection of sexual perversions which also featured new vocabulary such as 'sadism', 'masochism' and 'pedophilia' (Oosterhuis, 2000). What is important to note here is that 'heterosexuality' had its debut - privately and publicly - as a word signifying erotic acts of women and men lacking a procreative imperative. Fundamentally, 'heterosexuals' were people guilty of 'reproductive deviance' by engaging in sexual degeneracy, excess and perversion (Katz, 1995: 20; Cameron and Kulick, 2003).

Thomistic Doctrine and 'Procreative Sex'

To understand why heterosexuality was portrayed in this way gender and sexuality historian Harry Oosterhuis (2000) traced its roots to the thirteenth century and the doctrine of Thomas Aquinas. Italian theologian and philosopher Aquinas (1224/1225 – 1274)⁶ decreed that sexual intercourse was designed by God for procreation and any sexual activity without this as its aim was 'sodomy'. Notably, this doctrine did not differentiate between 'same-sex' and 'opposite-sex' activity; rather, emphasis was centred on what was adjudged to be 'natural', 'unnatural', 'rational', and 'irrational' sexual behaviour. According to this religious tenet, any extra-marital sexual activity – including coercive activity – was deemed 'natural' if it resulted in offspring, although it was not viewed as 'rational'. Coitus interruptus, anal sex, bestiality, masturbation, same-sex activity and even sexual intercourse between Christians and non-Christians were grouped together as 'unwarranted lust' and variously referred to as: 'unnatural', 'sinful' and 'sodomy'. This edict sanctioned the death penalty for sodomy in many European countries from the late medieval period to the end of the eighteenth century. Heterosexuality stemmed from Thomistic doctrine and was part of a lexicon of non-procreative sexual activity.

The far-reaching effects of this highly influential doctrine which determined Roman Catholic sexual ideology, can be seen in the New England colonies of America (1607–1740). The sexual organs were generative organs to be solely used as a procreative

⁶ 'St. Thomas Aquinas', *Encyclopaedia Britannica*, <https://www.britannica.com/biography/Saint-Thomas-Aquinas> [online] accessed August 2017.

resource for the community, to increase the numbers and labour force of their new, economically fragile and undeveloped agricultural economies (Katz, 1995). This resource was not to be squandered in acts of pleasure. As a result of this 'procreative economy', incited by religious exhortations and enforced by severe punishments (twenty to thirty-nine lashes or even hanging for adultery), the New England settlers created a birth rate higher than that of their European contemporaries (Katz, 1995). Hence, in its original form 'heterosexuality', with its focus on unfettered erotic deviance, was coined to signify a perversion. It did not denote 'normal', 'natural' or 'moral' sexual conduct (Oosterhuis, 2000; Cameron and Kulick, 2003), which was the sole preserve of procreative sexual activity. It was the theories of Freud in the late nineteenth and early twentieth centuries which helped to ideologically transform, publicise and normalise heterosexuality's status to a new social ideal (Katz, 1995; Oosterhuis, 2000; Cameron and Kulick, 2003).

The Pathologisation of Sexual Behaviours and the Rise of Medicine

Modern-day discourses on sex and sexuality in Western societies originated from institutional intervention into human sexual conduct, specifically, the nineteenth century medical classification and pathologisation of sexual behaviour (Foucault, 1998). Prior to this, eighteenth century explanations for sexual aberration tended to foreground an individual's moral condition or sinful inclinations, believed to be variously incited by seduction, power and hedonism, or by the impact of particular social environments and situations (Cameron and Kulick, 2003). As explained by Oosterhuis (2000), primarily concerned with the control of procreation, finance, social

hierarchy, organisation and obligations, pre-modern views on sexual mores were fundamentally part of a configuration of legally negotiated inherited property, wealth, marriage contracts and heirs. Anything not falling within this remit – for example, children born out of wedlock – could neither be legitimised, nor tolerated. Any act of sodomy – as previously defined in Thomistic doctrine - could at best be disruptive to, and at worse destroy, a family's economic entitlements and social status. The nineteenth century migration of people from close-knit – and therefore surveilled - rural communities to the anonymity of crowded industrial cities allowed for an increase in clandestine sexual encounters, in areas such as public parks, saunas and toilets owing to innovations in urban infrastructure. Whilst sodomy was no longer punishable by death, new public indecency and ages of consent laws sparked frequent confrontations between members of the public on the one hand and the police and the courts on the other. As prosecutions grew, physicians were increasingly called to the courts to give forensic evidence delineating sexual activities considered indecent and deviant. Human sexual behaviour was brought more into the domain of medical science as debates began to circulate regarding possible links between a predilection to sexual deviance and congenital disorders or mental illness (Reis, 2009).

It is within this cultural context that both medicine's involvement with, and relationship to the state solidified, via the emerging disciplines of public hygiene and psychiatry. Medicine became indispensable to the maintenance of the social order. This consolidation of medicine's power in the public realm challenged the authority of the church, particularly in matters of sexual conduct (Cameron and Kulick, 2003;

Preves, 2008). Several psychiatrists in Europe rejected the notion that sexual deviance resided in a person's sinful inclinations and was a temporary departure from what is 'normal' and 'natural', and instead advanced the ground-breaking view that it was an innately pathological state of being, and, as with any other type of illness or 'disorder', required observation and treatment from the medical sphere (Oosterhuis, 2000).

Foucault's Analysis of Discourses of Sex and Sexuality

Bio-power: The Modern-Day Regulation of Bodies

For French post-structuralist, philosopher and historian Michel Foucault (1926-1984), discourses on sex and sexuality were firmly established by the nineteenth century development of sophisticated techniques of 'bio-power': the modern-day regulation of bodies and modern form of power (Foucault, 1998; Fairclough, 1992; Grosz, 1994). In the nineteenth century the confessional, medical examinations and legal practices all converged to focus on the sexual conduct of criminals, same-sex desire and perverts - set against opposite-sex marriage and a burgeoning heterosexual norm (Foucault, 1998; Fairclough, 1992; Grosz, 1994). For Foucault (1998), this is illustrative of how knowledge and power work together to seize hold of the body by intertwining itself into human desires and practices (Grosz, 1994). Knowledge aligns with regimes of power and devises micro-techniques to extract information from individuals - by examining, observing, interviewing, counselling and measuring the body's behaviour and interactions with others - which are in turn, codified and reformulated according to criteria deemed relevant by knowledge, to produce

'knowledges'. These are then fed back into the regimes of power, enabling power to operate in more effective, systematic and subtle ways (Foucault, 1998; Fairclough, 1992; Grosz, 1994). Power is constantly transformed by knowledge generation and knowledge is legitimised and sanctioned into discourses by power.

Discourses on sex and sexuality are not only an effect of power, but are integral to bio-power. They individualise disciplinary processes which regulate minute details of the lives - dispositions, habits, behaviours and movements - of individuals and they efficiently manage populations via statistics which are produced from them (Foucault, 1998; Fairclough, 1992; Grosz, 1994). Power deploys discourses of sex and sexuality over human bodies by instating certain knowledges - such as anatomy, biology, sexology and psychology - as the 'truth' of bodies and their pleasures, as well as discursively constituting certain bodies as bodies of determinate types (Foucault, 1980; Foucault, 1998; Grosz, 1994).

The Examination and The Confession

Bio-power, with its two major technologies - the examination and the confession - created sexual profiles and histories encompassing psychological types, personalities, features and characteristics (Foucault, 1998; Fairclough, 1992; Grosz, 1994). At its starting point was the mandate that investigation into sexual identities could locate and forestall sexual anomalies in the individual and therefore the nation (Foucault, 1980). Foucault identifies the nineteenth century as a time of intense classification, noting how the years covering 1860 to 1870 were characterised by a zeal for

identifying and categorising 'different types of perversions', bodies and behaviours for the socio-political organisation of society (Foucault 1980:xi/xii; Foucault, 1998).

Institutions such as hospitals, prisons and schools were mobilised in this widespread knowledge generation of social subjects (Foucault, 1998). A key mechanism enabling access to people is the examination, which sanctions the exposure of each body in turn to normalising disciplinary procedures, for the creation of a whole host of documentation: medical files, welfare agency records, therapists' notes and the internal correspondence of professionals (Waitzkin, 1989; Foucault, 1998).

Essentially, each person is produced as a 'case' that contributes towards – and is brought into being by – a branch of knowledge producing a specific set of discourses (Foucault, 1998). In this way, not only is the individual discursively constructed and constituted, but fundamentally, information can be deployed to advance disciplinary norms, controls and agendas.

Foucault's analysis also asserts that the confession works in tandem with the examination as a means for drawing more of the social subject into the domain of power (Foucault, 1998; Fairclough, 1992). The confession is a 'ritual of discourse' peculiar to modern society which gained scientific status in the nineteenth century (Foucault, 1998: 61; Fairclough, 1992). It describes the structured interaction of one person divulging to another their interior world through talk. This confessional act is evidenced in medical examinations, therapy, counselling, case histories and autobiographical writing (Fairclough, 1992; Cameron and Kulik, 2003; Miles 2003). Expressly concerned with issues of power, Foucault traces its origin to the Christian

religious ritual of a guilty 'sinner' compelled to seek atonement and forgiveness from an authority figure; when confessing sexual activities to a priest, the latter would counsel what liaisons were appropriate and what conduct required penance (Foucault, 1998; Waitzkin, 1989). For Foucault, the institutional confession is a mechanism embedded within the medical disciplines of psychiatry, psychoanalysis and sexology; they encourage subjects to willingly participate in uncovering the 'truth' which purportedly lies at the heart of everyone and that is hidden in sex, sexuality, and sexual identity (Foucault, 1980; Foucault, 1998; Grosz, 1994; Cameron and Kulick, 2003). According to Foucault, this is just another way in which power makes itself tolerable to citizens by masking a substantial part of itself and hiding its own mechanisms (Foucault, 1998; Fairclough, 1992).

Conclusion

The objective of this chapter was to seek answers to the questions, what is the purpose and function of sex categorisation? And, what produces and sustains the arch-categories of sex *male* and *female*? Sex categorisation overwhelmingly connotes 'natural', 'normal' and inevitable biological 'facts' about health, bodies and reproduction in dualistic societies. The analysis in this chapter has sought to expose its volatile history and regulatory function. Sex typing primarily serves political and social interests and is enabled by ideologies of sexual difference and discourses of sex and sexuality, of which heterosexuality plays an integral part. Beginning with the one-sex to the two-sex model, biological and 'natural' facts about sex have historically been used to obscure the cultural and social roots of the subjugation and oppression

of those classified as women and *female*, whilst perpetuating the superiority and domination of those classified as men and *male*. This status quo of sex inequality has been supported and overlaid by discourses from biology and medicine.

The chapter explored the supporting role that heterosexuality plays in the dualistic sexual regime. It is designated as the obligatory, compulsory, 'natural' and 'normal' social relationship. The chapter has argued that heterosexuality has been manufactured and perfected across time to attain the pre-eminent position it holds today.

Moreover, the chapter has revealed how modern-day discourses of sex and sexuality stem from institutional intervention into human sexual behaviour and historically were used to classify and pathologise. It has exposed medicine's role in delineating sexual deviance for the state by tying it to particular, determinate types of 'deviant' and 'disordered' people. Ultimately, bodies, behaviours and desires have to be controlled in order for a sex dichotomous society to be maintained.

A pattern is emerging. It appears that dualistic sex categorisation and their associated dualistic categories of sexual behaviour are not 'normal', 'natural' and inevitable facts of being human. Rather, this chapter has hoped to show that they are highly sophisticated socio-political tools of regulation and control. This begins to offer an explanation as to why *Intersex* poses such a threat to dualistic societies. These claims

will now be assessed in relation to the treatment of the *hermaphrodite* (in Chapter Three) and the modern-day treatment of *Intersex* people (in Chapter Four). The treatment of the *hermaphrodite* is highly significant for my study, since *hermaphrodite* is a term historically applied to a person who did not conform to dualistic categories of sex and is therefore recognised today as the precursor to an *Intersex* person.

Chapter Three: Categorising *Hermaphrodite*

Chapter Two demonstrated how powerful ideological forces began working to cohere, restrict and influence the activities of human beings in the social realm via the *male* and *female* categories, ideologies of sexual difference, heterosexuality (as the obligatory social relationship) and discourses of sex and sexuality. As is to be expected, many human beings challenged these modes of social control by their activities, desires, behaviour, appearance and anatomies. One such group were those historically classified as 'hermaphrodites'. They are understood to have had much in common with the contemporary category *Intersex* and for this reason are an important historical component of my thesis. This chapter will show how the societal and medical treatment of *hermaphrodites* exposes many anxieties and fears surrounding sex categorisation, sexual difference, sexual behaviour and bodies. My thesis will argue that these fears have not diminished, rather they are a hallmark of the contemporary medical management of *Intersex* people.

A look at the change in status and treatment of the *hermaphrodite* in this chapter reveals a great deal about the rise of medicine in the social sphere. Medicine has staked out a powerful position for itself in the social realm by its investment in sex dichotomous categorisation. Incorporated in this was the emergence of a 'one true sex' doctrine; a declaration that everyone has 'one true sex' that they are allotted and should stick to. Those who do not (or could not) pose a threat to the social order. This guided the conceptualisation and treatment of bodies and behaviours that could not be easily dichotomised. It precipitated a prurient interest in, surveillance of and

eventually erasure of many *hermaphrodites* in the nineteenth century who were condemned in medical texts from that period as sexually perverse, degenerate and deviant. It circumscribed *hermaphrodites* as *males* or *females* in disguise who could be tamed by opposite-sex/heterosexual desire, activity and marriage. A corrective expressly designed to uphold the male/female dichotomy.

Hermaphrodite, an Overview

In her review of the variety of discourses historically applied to *hermaphrodites*, Australian philosopher and feminist Elizabeth Grosz (1996) concludes they have undergone 'a remarkable medicalisation' (1996: 61). Formerly, the *hermaphrodite* was an enigma who permeated mythical, dramatic, religious and exhibitionist discursive realms, in addition to holding an exoticised space of fascination and/or horror - eliciting special privilege and awe or danger - depending on the cultural context and location (Grosz, 1996). Originally issuing from Greek mythology, Hermaphroditus was the child of the Greek gods Hermes and Aphrodite, who was born both *male* and *female* within one body. In biology, *hermaphrodite* describes organisms that have fully functioning sets of both *male* and *female* reproductive organs, for example, some orchids, fish, barnacles and snails.⁷ Historically, *hermaphrodite* denoted a person who existed 'outside of or beyond the human', and therefore was cast as freakish or monstrous (Grosz, 1996: 57). Nineteenth century medical texts featured *hermaphrodite* as both a disorder and a problematic type of person in often 'vague, demeaning, and sensationalistic' ways (Feder and Karkazis, 2008; Reis, 2009: 154).

Through processes of medicalisation the *hermaphrodite* has become the sole preserve of the clinical and scientific disciplines. All vestiges of alternative descriptions, interpretations, framings and understandings have been – comparatively - neutralised or eradicated.

⁷ 'Hermaphroditism', *Encyclopaedia Britannica*, <https://www.britannica.com/science/hermaphroditism> [online] accessed August 2017.

Sociologist Irving Zola (1976) argues that medicine's institutional authority is characterised by:

- 1) Absolute access into certain taboo areas.
- 2) The use of medical rhetoric and evidence to argue or advance any cause.
- 3) The ability to constrain or direct human behaviour.
- 4) Absolute control over technical procedures.

This chapter will show how all of these elements have factored in the management of *hermaphroditism*. Essentially, the treatment of *hermaphroditism* exemplifies the powerful influence which medicine exerts on society.

Hermaphrodite and Sex Categorisation

Gender historian Geertje Mak (2012) examined over three hundred medical case histories of adult *hermaphrodites* (predominantly from France and Germany) during the late eighteenth and the beginning of the twentieth century. Mak chose to study these texts since they were reports on people whose sex had been called into question and by exploring these accounts of sex in doubt, Mak was then able to decipher and historicise what has constituted dualistic sex categorisations. Mak found that *hermaphrodite* and *hermaphroditism* were unfiltered, catch-all terms for a plethora of situations and manifestations occurring whenever the categories of *male* and *female* were threatened. *Hermaphroditism* is multiply enacted across the nineteenth century, says Mak, an effect of discourses of sex shaped by the available knowledge, medical

expertise and institutions, such as marriage, hospitals, churches or courts. Sustained and upheld by social mores, political agendas and finance, these discourses have guided how bodies are read, framed, experienced and perceived discursively. In *hermaphrodite* medical case histories, Mak discovered short biographies which always contained the following three descriptors: 'X, baptised or registered as a girl, having worn female clothing and done female work since [...]' (Mak, 2012: 25). Essentially, a routine genital inspection at birth, clothing, comportment and occupation were key signifiers of a person's sex in the public sphere. If there were any incongruencies between a person's outward appearance and occupation or outward appearance and comportment – particularly their mode of urination - then their sex assignation was called into question, for these were the primary markers of sexed bodies, heavily imbued with dichotomous social and cultural implications (Mak, 2012).

In fact, occupation and mode of urination were often more decisive factors in a person's sex classification than the look and procreative capacity of their genitals - which were rarely inspected outside of childbirth - as demonstrated in the case histories of Anna Barbara Meier and Johanna K (Mak, 2012). Baptised as a girl and from the parish of Wössingen in Germany, at age forty-nine Anna Barbara Meier had impregnated Christina Knoll, 'through masculine intercourse' (Mak, 2012: 19). Meier requested permission to adopt masculine attire and marry Knoll and significantly, Meier's medical records recount Meier declaring to the physician their strength in performing physically demanding, hard labour (code for men's work) and not in their ability to impregnate a woman. Similarly, Johanna K's medical records detail that

Johanna - who lived as a woman for thirty-seven years - had engaged in sexual activity with Maria Oh for three years when the latter became pregnant. In spite of this, the medical expert writes with concern that 'She discharges urine like a woman [...] thus cannot wear the usual men's leg attire' (Mak, 2012: 29). Both examples demonstrate nineteenth century discourse surrounding corporeal sex and clothing, occupation, along with mode of urination and how these could on occasion usurp the look and procreative function of the genitals in the assignation of sex. A person's sex classification primarily indicated their place in the 'social, economic, moral and legal' orders of society (Mak, 2012: 40).

In charting change in Western societies towards *hermaphrodites*, Michel Foucault notes how in the Middle Ages under canon and civil law, the categorisation *hermaphrodite* was recognised and given to those 'in whom the two sexes were juxtaposed' (Foucault, 1980: viii). What this entailed in practice was those charged with naming the *hermaphrodite* child took a decision at the time of its baptism which sex the child would retain. Notwithstanding this, *hermaphrodites* had a stake in their own sex determination. At the threshold of adulthood, *hermaphrodites* were free to choose if they wanted to continue their lives as their assigned sex or not, says Foucault, and, if they preferred life as the other sex, they were allowed to change; the only caveat being that once a decision was made it had to be kept to, in order to prevent the libellous charge of sodomy (Foucault, 1980; Preves, 2008). Crucially, Foucault emphasises that it was 'not the anatomical mixture of the sexes', but changes of option that drew heavy condemnation of *hermaphrodites* in texts from

France in the Middle Ages and the Renaissance (Foucault, 1980: viii). What this suggests is that juridically and socially *hermaphrodites* were intelligible, readable and recognisable - as merely possessing bodies in which two sexes were mixed or resided in variable proportions (Foucault, 1980; Creighton and Liao, 2004; Preves, 2008; Feder, 2009). Fausto-Sterling (2000) similarly recounts the acknowledgement legal experts in France and England afforded to *hermaphrodites*. With reference to their sex assignment, in the early seventeenth century *hermaphrodites* shared the decision-making process with medical and legal experts; moreover, they could marry and serve as witnesses in the courts. In agreement with Foucault, Fausto-Sterling (2000) observes that choice was curtailed once a decision regarding sex determination had been made. Any *hermaphrodites* found to have reneged on their decision were severely punished since maintenance of the social order was paramount.

Fausto-Sterling (2000), notes that it was during the late eighteenth and early nineteenth centuries as biology emerged as a discipline that it acquired greater jurisdiction over human bodies. Biologists and physicians of medieval times by contrast, had far less power, competing as they were with the authority of the church, law and politics. This is believed to be the reason why outright condemnation of *hermaphrodites* is rare in medieval medical texts, as biologists and physicians were not the only ones in a position to define and to regulate them. This was to change with the advent of social engineering in Victorian Britain, when law and medical

science worked together with the new science of social investigation and statistics.⁸

Statistics began to be collected on births, deaths and marriages, leading to a rise in regulatory legislation deployed to regulate and reform culpable behaviours and bodies (Smart, 1992). This statistical analysis supplied nineteenth century scientists with the social leverage required to pronounce certain bodies as ‘abnormal and in need of correction’ (Fausto-Sterling, 2000: 36).

The ‘One True Sex’ Doctrine

According to *Intersex* academic and activist Morgan Holmes (2008), in the ‘socially charged philosophical context’ of the nineteenth century vis-à-vis the appropriate place of *male* and *female* bodies, it was an opportune time for medicine to profess that an individual had only ‘one true sex’ which could subsequently be placed into its allotted social realm (Holmes, 2008: 29). This greatly influenced how medicine interpreted *hermaphrodites* (Foucault, 1980). When presented with a *hermaphrodite*, a doctor was no longer concerned with recognising the presence of two sexes in a single body, but instead became preoccupied with deciphering what was ‘the true sex [...] hidden beneath ambiguous appearances’ (Foucault, 1980: viii; Creighton and Liao, 2004). *Hermaphrodites* became a disguise of nature. The doctor’s role was to strip the *hermaphrodite* of its ‘anatomical deceptions’ in order to reveal the ‘one true sex’ hidden behind dissembling sexual organs (Foucault, 1980: viii). This resulted in the disappearance of choice. Juridically and socially *hermaphrodites* could no longer

⁸ For a more detailed discussion, please see chapter ‘Disruptive bodies and unruly sex. The regulation of reproduction and sexuality in the nineteenth century’ in *Regulating Womanhood: Historical Essays on Marriage, Motherhood and Sexuality*, by feminist sociologist Carol Smart (1992).

decide which sex categorisation they wished to belong to, the decision now fell under the jurisdiction of 'the expert' (Foucault, 1980: ix). The expert not only decided which sex nature had selected for *hermaphrodites*, but also which sex society required *hermaphrodites* to adhere to (Foucault, 1980). The underlying premise being, that if nature might try to deceive an observer by hiding the 'true sex' of a person, correspondingly, a person might conceal knowledge of their 'true sex' and use their 'anatomical oddities' for licentious behaviour (Foucault, 1980: ix; Feder, 2009). Notably, Holmes credits the 'one true sex' doctrine within the study of *hermaphrodites* as instrumental in medicine's hegemonic rise from 'a healing art to a science' (Holmes, 2008: 29).

The Yoking of *Hermaphroditism* with Homosexuality

On account of the 'one true sex' doctrine, the late nineteenth and early twentieth centuries saw homosexuality and *hermaphroditism* become intertwined (Holmes, 2008). According to Holmes, this was a 'medico-cultural mechanism', having as its overwhelming focus the combining of medical research and cultural mandates to organise bodies into 'ontological identities and matching political/social roles' (Holmes, 2008: 35; Reis, 2009). Within this medico-cultural context, the establishment of *males* and *females* as opposites rendered homosexuality a social indicator of biological degeneracy, for it blurred the distinction between *male* and *female* roles. Many influential European sexologists conceptualised homosexuality as a disorder of the *male* and *female* categories. Magnus Hirschfield (1868–1935), a German pioneer for the rights of homosexuals theorised homosexuality as an 'intersexual stage' between

the polarities of *males* and *females* (as cited in Oudshoorn, 1994: 57). Although assigned to *male* or *female*, Hirschfield was of the opinion that homosexuals were sexually and emotionally *hermaphrodites*, due to their purported possession of characteristics of the opposite sex. Another pervasive view linked homosexuality to a mental form of *hermaphroditism* and held *hermaphrodites* to be 'deeply disturbing physical entities' whose bodies held the threat of and potential for sodomy (Holmes, 2008: 35; Preves, 2008; Feder, 2009). Connections were drawn this way: a *hermaphrodite's* 'strange' sexual organs masked their 'true sex', so it followed their sexual activities must constitute erroneous, sexual deviancy, similarly, a person practising same-sex activity suffered from a 'strange' mental or psychological *hermaphroditic* deformity in their brain (or mental organ) compelling them to act transgressively (Foucault, 1998; Feder, 2009; Reis, 2009). Clinical psychologists Lih-Mei Liao and Mary Boyle (2004a) write how the inordinate focus on these two 'perverse' bodies was in direct proportion to their perceived threat to a social order built upon 'gender separation and hierarchy', and that this is a corollary of the ubiquitous social, medical and psychological project to manage people and their bodies (Liao and Boyle, 2004a: 446).

Hermaphrodite Hysteria

Nineteenth century medical literature abounded with stories of *hermaphrodites* as dissemblers, arch-deceivers and 'passing' to indulge in sexual deviancy (Reis, 2009). Such stories were rarely taken from genuine medical case studies. Nonetheless, these anecdotes of speculation, hearsay and innuendo centred upon *hermaphrodite* lives

were published. *Hermaphrodites* were habitually depicted as ‘social harbingers of family destruction’: women with large clitorises passing as men to gain ‘greater social independence’ (Reis, 2009: 60). In 1886, Dr. George DuBois Parmly wrote in a major obstetrics journal of *hermaphrodites* who ‘masquerade as men’, are ‘strong-minded’ and ‘lovers of women’ who desert their husbands and destroy families (Reis, 2009: 60, 61). The conflation with same-sex desire meant *hermaphroditism* was unequivocally and unescapably yoked to negative associations of degeneracy and perversion (Feder, 2009; Reis, 2009). By the late nineteenth to early twentieth century, *hermaphroditism* was a term applied to: *males, females, hermaphrodites, homosexuals, transvestites and feminists, ergo anyone who challenged sexually dichotomous social borders* (Dreger 1998b; Reis, 2009).

The spectre of homosexuality, deviant sexuality and the promotion of heterosexual marriage, were narratives frequently galvanised within the context of surgery for atypical bodies in the nineteenth century, even before such category lines were drawn (Dreger 1998b; Fausto-Sterling 2000; Karkazis 2008; Dreger and Herndon, 2009; Feder, 2009; Reis, 2009). Gender theorist and bio-ethicist Elizabeth Reis (2009) examined a very early recorded case of the surgical removal of testes in a person assigned *female* in 1849 by leading American surgeon Dr. Samuel D. Gross. A three-year old assigned and raised as a girl was brought to Dr. Gross at Louisville University, USA, for having a sudden propensity for ‘boyish sports’ (2009: 46). During a genital inspection, Gross discovered a small clitoris along with testes growing inside - and either side - of the girl’s labia, although there was no vaginal opening or penis. When

citing his reasons for removing the girl's testes, Gross asserted that if allowed to mature, they could arouse 'masculine sexual desire' followed by 'matrimonial connection' and result in 'the ruin of her character' (Reis, 2009: 46). For Dr. Gross, the girl was destined to be a societal outcast, forever denied 'the joys and pleasures of married life' (Reis, 2009: 47). In Reis' summation of this medical case, she draws attention to Gross' peculiar and untimely preoccupation with the marital prospects of a child just three years old as expressed in his assessment of her testicles leading to marital connection with an unmarriageable partner - alluding to a *female* partner. Essentially, the justification for genital surgery was based upon hypothetical 'deviant' social scenarios and fears for the child's sexual future. Correspondingly, published medical discussions on *hermaphroditism* advanced the notion of 'the freakish or perverse hermaphrodite' who could be treated and normalised by surgery, with the primary indicator of surgical success being heterosexual intercourse and marriage (Feder, 2009; Reis, 2009: 71).

In this way, medicine reinforced particular cultural norms surrounding sexual difference including: traditional and prescribed roles for *males* and *females* and heterosexual sex (Dreger and Herndon, 2009; Reis, 2009). Reis refers to this as doctors in the business of creating men and women according to a normative template of sexual difference, and a heteronormative marriage paradigm. Dreger (1998b) adds an interesting dimension to this by reporting on how all of the primary source texts up to the late nineteenth century on *hermaphrodites* were written by

medical and scientific men.⁹ *Female* physicians and surgeons were scarce as women were excluded from obtaining medical degrees and licenses - opposition being particularly fierce from the fields of obstetrics and gynaecology (Schiebinger, 1989). Hence, those who would have had the possibility of encountering a *hermaphrodite* would have been very rare. Dreger claims that this accounts for the 'peculiarly masculine' (Dreger, 1998: 24) biomedical portrayal of masculinity, femininity and *hermaphroditism* within nineteenth century medical texts, as is apparent in the cases of Dr. George DuBois Parmly and Dr. Samuel D. Gross. It also underscores the connection 'between social *beliefs* and the production of medical *knowledge*' (Holmes 2008: 29, italics in original). 'Surgical sexing' (Creighton and Liao, 2004: 661) to meet a heteronormative ideal is a leitmotif in the treatment of non-normative bodies and will be examined in its contemporary format in the next chapter (see subheading, "Surgical Sexing' and the Heteronormative Ideal' in Chapter Four).

Disappearing *Hermaphrodites*

In 1876, German pathologist Theodore Albrecht Klebs (1834-1913) theorised regarding the existence of *hermaphroditism* based on what kind of tissue was found in the gonads (Malatino, 2009).¹⁰ If ovarian tissue was found, the person would be classified as a *female pseudo-hermaphrodite*, if it was testicular tissue then the person

⁹ Dreger focused on the time period 1860–1915 in France and Britain and mentions only one exception in approximately three hundred published medical accounts of human *hermaphroditism*, namely, *Herculine Barbin: Being the Recently Discovered Memoirs of a Nineteenth-Century French Hermaphrodite* (see Foucault, 1980), a primary source text written by a *hermaphrodite*.

¹⁰ Due to the lack of anesthesia and antiseptic, gonadal tissue was predominantly examined for classification during autopsies or extracted after castration (Dreger, 1998b; Fausto-Sterling, 2000).

would be classified as a *male pseudo-hermaphrodite*, irrespective of the appearance of their external genitalia (Malatino, 2009). *Pseudo-hermaphrodites* were understood as individuals who were *male* or *female* with mixed external anatomies obscuring their 'one true sex' (Karkazis, 2008). In practice this meant that a person with a penis, descended testes and no breasts (phenotypically *male*) was classified as a *female pseudo-hermaphrodite* if they had ovaries and a uterus, and a person with breasts and vagina (phenotypically *female*) was classified as a *male pseudo-hermaphrodite* if they had undescended testes (Fausto-Sterling, 2000). Furthermore, according to Klebs a *true hermaphrodite* was someone with both ovarian and testicular tissue in their body, either in the same gonad (also referred to as an ovo-testis), or in the opposite gonads (one ovary and one testis). This 'true' classification and somatic configuration, with its exclusion of numerous atypical anatomical presentations (now categorised as *pseudo*) accounts for fewer than five percent of *hermaphrodite* cases; in fact, occurring so rarely that few ever fit within it (Kessler, 1998; Morland, 2001; Malatino, 2009). In 1896, two British physicians George F. Blacker and Thomas William Lawrence, used this stringent criteria - reliant upon microscopic examination - to re-categorise twenty-seven historic cases of *true hermaphroditism*, and, finding that only three qualified, retrospectively disqualified the rest (Dreger, 1998b; Malatino, 2009). In this way, *true hermaphroditism* was framed as the exception which proved the rule of an unequivocal 'true sex' trope and incontrovertibly left intact a system of two dichotomous sexes, illustrating how far medicine has gone to uphold the male/female dichotomy (Reis, 2009; Malatino, 2009).

Crucially, since 'tools of science' - namely a microscope along with the medical expertise to prepare gonadal tissue for microscopic examination - were a necessary requirement for the application of this sex determination mandate, the authority for naming *hermaphrodites* into existence (or conversely disappearing *hermaphrodites* from existence) was completely absorbed and confined to the medical sphere (Fausto-Sterling, 2000). Gone was the rendering of *hermaphroditism* as a condition encompassing a range of features including anomalous bodies, faces, genitalia and incongruencies with outward appearance/occupation and comportment/mode of urination. In the 1890s, this gonadal frame of reference for sex intelligibility portrayed *true hermaphroditism* to be a condition which existed as a tissue sample on the slide of a microscope, and from which only biomedical expertise could secure a 'true sex' assignation (Dreger, 1998b). Historically, institutional classification has unduly impacted *hermaphrodites*, not only in authorising what they are and circumscribing how they live, but even determining whether they exist at all.

Conclusion

This chapter has shown how *hermaphroditism* has undergone a remarkable medicalisation. *Hermaphrodites* were once recognised and acknowledged in canon and civil law, and had free choice in their own sex determination, but with the rise of medicine in the social realm they began to pose a socio-political threat to the organisation of bodies in society. As outlined in the beginning of this chapter, Zola (1976) has claimed that the powerful influence medicine exerts in society is characterised by: 1) absolute access into certain taboo areas, 2) the use of medical

rhetoric and evidence to argue or advance any cause, 3) the ability to constrain or direct human behaviour, and 4) absolute control over technical procedures. When evaluating these four aspects in the context of a discussion of *hermaphroditism* it becomes evident how medicine:

- 1) Employed medico-cultural, paternalistic taboos regarding sex, bodies, sexual difference, 'perversion', sexual identity and same-sex desire to foment hysteria over the lives of *hermaphrodites*.
- 2) Utilised a 'one true sex' doctrine to construct *hermaphrodites* as duplicitous, disguises of nature to be properly unmasked by the medical expert and placed into their 'true sex' realm.
- 3) Participated in institutional regulation and correction of *hermaphroditism* as demonstrated in the early recorded cases of the surgical removal of testes in assigned girls, procedures that were based on suppressing same-sex desire and activity, whilst elevating opposite-sex desire, activity and partnership.
- 4) Assisted with the erasure of the *hermaphrodite* by restricting its classification to microscopic examination of gonadal tissue. This restriction, which is controlled by medical procedures and confined to the medical sphere, has invalidated and erased many bodies formerly categorised as *hermaphrodites*.

The history of *hermaphroditism* as catalogued in this chapter has revealed how medicine is a powerful institution of social control that exists in a reciprocal

relationship to political and cultural ideas of sex categorisation and discourses of sex and sexuality. It is an institution that has created 'truths' which are influenced by the social milieu and re-shape the cultural environment by its construction of social subjects. It has used its authority to intervene into *hermaphrodite* lives, to determine how they live and even whether they exist at all. Chapters Four and Ten will show how each of these aspects have had serious implications for people with *Intersex* conditions and continue to factor in contemporary *Intersex* case management.

Chapter Four: The Mind/Body Dualism and the Contemporary Medical Management of *Intersexuality*

This chapter presents my point of divergence from the existing body of research on *Intersex*. The preceding three chapters laid the historical, contextual and theoretical groundwork for my study by examining the social functions of the male/female dualism (and its associated binary categories) and how these have influenced how the categories *hermaphrodite* and *Intersex* have been conceptualised, represented and treated. The majority of *Intersex* research in the social sciences tends to foreground and centre the male/female dualism as that which exerts the most harm to *Intersex* people by legitimising corrective surgeries. In this chapter I will analyse the impact of the mind/body dualism on biomedical theory and practice and argue that it is this which allows surgical access to *Intersex* bodies as routine practice.

I begin by tracing the development of the mind/body dualism which originated with Plato and re-emerged in Western philosophy with René Descartes and his proclamation *I think, therefore I am* which regarded the body as inferior to the mind. I next explore how the adoption of this philosophical epistemology crystallised with the mechanisation of biology which regarded bodies as mechanical objects that were regularly out of order or disordered and required frequent interventions for repair. I assess the numerous ways that the mind/body dualism has consistently produced and reinscribed the male/female dualism and its associated ideologies of sexual difference. The chapter then gives an account of how theories of gender put forward by Dr. John Money and colleagues based at the John Hopkins Hospital, USA, rationalised the use of

surgery in the case management of *Intersexuality*. Intrinsic to the widespread acceptance and endorsement of Money's controversial theories concerning *Intersex* babies and infants was the now infamous case of David Reimer which is chronicled in the chapter. This is followed by my argument that Cartesian dualism is integral to the case management of *Intersexuality* as proposed by Money. Here I isolate and examine in turn what I believe are the three key areas where the mind/body dualism is apparent:

1. The construction of *Intersex* patients.
2. The authority of medical practitioners.
3. The application of the sex/gender dualism in *Intersex* treatment.

Essentially, this chapter takes a careful look at how the mind/body dualism dovetails with male/female and sex/gender dualisms in *Intersex* medical management. This convergence enables invasive access to *Intersex* bodies compelling them to fit and to function in a dualistic society comprised of disembodied heterosexual *males* and disembodied heterosexual *females*.

The Mind/Body Dualism

I think, therefore I am. This quote by French philosopher René Descartes (1596-1677) is one of the most famous in the history of modern Western philosophy. In fact, in Europe and North American societies you do not need to have studied philosophy to have heard of it, for it is frequently quoted across many genres of literature, drama, music, art and film. It can be found in the columns of newspapers and popular magazines, and is used by businesses as a slogan in their advertising campaigns. It first appeared in French (*Je pense, donc je suis*) in *Discourse on the Method* (1637) and next in Latin (*Cogito, ergo sum*) in *Principles of Philosophy* (1644) (Damasio, 1994). Lauded as the father of modern Western philosophy, Descartes proclaimed that fundamental humanness is located in the mind or the *thinking substance* (*res cogitans*) and not the body which is an *extended substance* (*res extensa*) (Damasio, 1994; Grosz, 1994; Paechter, 2004). The thinking mind incorporates the soul and consciousness, whereas the non-thinking body or extension is comprised of mechanical parts, it represents a separate sphere that is governed by physical laws and functions in accordance with the laws of nature (Grosz, 1994). Originating from Greek philosophy, Plato (circa 428–348 BC)¹¹ claimed that the word 'body' (*soma*) came from the word 'dungeon' (*sema*) where humans as spiritual, non-corporeal beings were imprisoned (Grosz, 1994). *I think, therefore I am* is somatophobic, it suggests that thinking and the awareness of thinking alone constitutes being. Of the very many people who have encountered this famous

¹¹ 'Plato', *Encyclopaedia Britannica*, <https://www.britannica.com/biography/Plato> [online] accessed July 2017

proclamation, hailing from the Enlightenment period, few could ever begin to fathom its enduring impact and legacy in Europe and North American society.

Cartesian Dualism and the Mechanistic, Disordered Body

The eighteenth and nineteenth centuries ushered in the mechanisation of biology with accompanying mechanical metaphors, building upon Descartes' separation of a material body regarded as a machine, instrument and tool at the disposal of an immaterial soul (Sarbin, 1997; Cromby, 2015). Assisted by the increased secularisation of Europe and North America and the rise of science, these Cartesian concepts were advanced by the production and domination of a mechanistic world view. In fact, 'disorder', a term which is routinely applied to many somatic symptoms in bio-medicine, has its linguistic roots in the vocabulary of mechanism - with machinery being in, or out of order - and perpetuates a portrayal of the body as a mechanistic, physiological object (Sarbin, 1997). This may explain the collective preoccupation with understanding the 'disordered body', with an emphasis on malfunctioning organs, systems and symptoms (Grosz, 1994). A result of this is a phenomenon that Irving Zola (1976) has termed the 'omnipresence of disorder', where the majority of people believe they have a medical problem and that a plethora of conditions, substances and activities, arguably implicated in the business of living, are injurious to their health and warrant control, regulation, diagnosis and treatment by experts in the medical sphere (Zola, 1976: 212).

How the Mind/Body Dualism Reinforces the Male/Female Dualism

The mind/body dualism which began with the philosopher Plato (and continued with Descartes, Husserl and Sartre) has consistently produced, maintained and rationalised the male/female hierarchy where, - either explicitly or implicitly - the mind has always denoted *male* and the body invariably has denoted *female* (Butler, 1990; Grosz, 1994). To understand why it is important to return to Greek philosophy, Londa Schiebinger (1989) explains how Greek philosopher and mathematician Pythagoras (circa. 570 BC–500/490 BC)¹² articulated the following dichotomies:

female/male
 left/right
 curved/straight
 dark/light
 bad/good

Later, the Greek philosopher and scientist Aristotle (384 BC–322 BC)¹³ elucidated the following dualisms:

female/male
 passive/active
 matter/form
 imperfection/perfection
 potential/actual

¹² 'Pythagoras', *Encyclopaedia Britannica*, <https://www.britannica.com/biography/Pythagoras> [online] accessed August 2017

¹³ 'Aristotle', *Encyclopaedia Britannica*, <https://www.britannica.com/biography/Aristotle> [online] accessed August 2017

French feminist philosopher Hélène Cixous (2004) calls these *dual hierarchical oppositions* where all concepts, codes and values are subject to a binary system based upon man/woman. By reading these oppositional cross-pairings vertically *male* is always privileged and sustained and *female* is always passive or does not exist at all. Thus, 'superior' masculine qualities remain in opposition to 'inferior' feminine ones. This is exemplified with the matter/form dualism outlined above by Aristotle (a student of Plato), who believed that reproduction and maternity symbolised the mother - or *mater* - a passive (*female*) receptacle of shapeless matter which was given form, shape and attributes by the active (*male*) father (Butler, 1993; Grosz, 1994; Fausto-Sterling, 2000).

It was within this existing context of sex and gender relations that the Cartesian epistemology and ontology of a pure, truth-seeking, highly abstract reason separated from the demands of the body and the practical affairs of daily life reinscribed the male/female dichotomy (Schiebinger, 1989; Grosz, 1994). The public realm was envisioned as a place of abstraction and concepts (mind) in contrast to the physical demands of the private realm (body). Nature as the object of scientific study has always been conceived of as 'unquestionably female' and women as representatives of private life 'became repositories for all that was not scientific' (Schiebinger, 1989: 122, 236). Thus, norms of femininity were portrayed as a virtue in the private, domestic sphere of the family and home, but antithetical to the world and methods of science. These dualistic representations of human existence are a common feature of dominant socio-political theories and transpose onto distinctions between

reproduction/production, family/state, private sphere/public sphere and individual/social (Gatens, 1996). The side featuring body, nature, passion, reproduction, family, private and individual is customarily applied to women and femininity, whereas the side featuring mind, culture, reason, production, state, public and social is applied to men and masculinity (Gatens, 1996; Jaggar, 1989). Women and femininity are conceived as timeless, static and repetitive aspects of nature, whereas men and masculinity are conceptualised as possessing a dynamic and developmental character aligned to history and change (Gatens, 1996). It is because the replication of these cultural associations produces, perpetuates and rationalises hegemonic sex and gender hierarchies that any reproduction of the mind/body dualism by theorists and institutions should unequivocally be avoided (Butler, 1990). Taking this injunction into account the theories of Dr. John Money at the John Hopkins University, USA, which provided the foundation for the contemporary medical management of *Intersexuality*, shall now be examined.

Dr. John Money and the Medical Management of *Intersexuality*

The work of Dr. John Money and the Hampsons is widely credited with shaping current protocols for *Intersex* treatment in Western societies (Downing et al., 2015).

Dr. John Money (1921-2006) was a New Zealand born psychology graduate from Harvard who as a result of his doctoral thesis in 1952 entitled *Hermaphroditism: An Inquiry into the Nature of Human Paradox*, was invited by the founder of pediatric endocrinology, Lawson Wilkins, to join the world's first clinic dedicated to the study and treatment of *Intersex* people based at the John Hopkins University, USA (Chase,

1998; Preves, 2008; Downing et al., 2015). Over the next five years Money, with his mentor Joan Hampson and her husband John Hampson (who were both psychologists and physicians), formed the 'Psychohormonal Research Unit' and studied '105 hermaphroditic patients' (Money and the Hampsons, 1957: 333; Downing et al., 2015). Together they theorised that the sex of assignment and sex of rearing superseded the five 'physical sexual variables', namely: (1) chromosomal sex, (2) gonadal sex, (3) hormonal sex, (4) the internal reproductive structures, and (5) external genital morphology (Money and the Hampsons, 1957: 333). Money, who is credited with coining the influential expressions 'gender role' – to describe cultural expectations of behaviour deemed appropriate for a *male* or *female* – (Money and the Hampsons, 1957; Money, 1985; Kessler, 1990) and 'gender identity' – to describe an inner sexed psyche categorised as either *male* or *female* that a person feels connected to or has a sense of belonging to – (Money and Ehrhardt, 1972; Money, 1985; Kessler, 1990; Meyer-Bahlburg, 1998), believed that gender is neither a purely hereditary, nor a purely environmental doctrine, but is something which becomes established in children as they become acquainted with a continuous multiplicity of gender differentiating signs directing them towards being a 'boy' or being a 'girl' (Money and Hampsons, 1957; Reis, 2009).

The Optimal Gender Rearing Policy (OGR)

Money's ground-breaking role in the 1950s was to rationalise the use of surgery in the management of *Intersexuality*, he did not – as is often believed – perform or invent any medical procedures (Downing et al., 2015). Money and the Hampsons

developed what came to be known as the *Optimal Gender Rearing* policy (OGR). This policy proposed that gender and children are malleable, and psychology and medicine can mould them without negative consequences (Kessler, 1990; Meyer-Bahlburg, 1998; Creighton and Liao, 2004; Lev, 2006; Dreger and Herndon, 2009; Reis, 2009). Based on this theory, Money advocated for taking ‘as little diagnostic delay as possible, on the sex of assignment and rearing when a hermaphroditic baby is born’, and advised uncompromising adherence to the medical decision of sex assignment which included early (below two years of age) surgical reconstruction of the child’s genitals (Money and Hampsons, 1957: 334; Meyer-Bahlburg, 1998; Liao and Boyle, 2004a; Reis, 2009). Medical professionals were to assign a sex immediately, decisively and irreversibly, thereby ensuring that the parents would proceed with the job of gender rearing in no doubt as to the ‘true sex’ of their child (Kessler, 1990; Creighton and Liao, 2004; Morland, 2005; Reis, 2009). To that end, Money recommended that the child’s parents receive special education and counselling to enforce their resolve and avoid ‘ambiguity and uncertainty of gender’ in rearing the child, which would subsequently establish a stable gender identity (Money, 1975: 66; Meyer-Bahlburg, 1998; Preves, 2008; Reis, 2009).

The OGR Policy in Practice

The majority of *Intersex* children at the John Hopkins Clinic were assigned *female*, a practice which continues to drive contemporary *Intersex* management (Money, 1975; Creighton and Liao, 2004). According to Money, it is easier to habilitate a

boy with a 'grossly defective penis' as a girl with the help of surgery and hormonal therapy (Money, 1975: 66; Creighton and Liao, 2004). Subsequently, early genital surgery is frequently proposed for the following 'deviations of the genitals from the norm': hypospadias, chordee and penis size in children born with Y chromosomes (Meyer-Bahlburg, 1998: 10-11). These children, usually classifiable as *male/boy*, are assigned *female/girl* if they are adjudged to have inadequate penis length at birth, which is stated to be less than 2.5 centimeters when stretched (Dreger, 1998a; Creighton and Liao, 2004). The penis and testes are removed and the child will receive hormone therapy at puberty to induce *female* secondary sex development. Additionally, the child undergoes vaginal reconstructive surgeries (vaginoplasty) as an infant or later in life to permit 'a normal sex life' (Money, 1975: 66; Creighton and Liao, 2004). Deviations of the genitals from the norm with respect to children born without Y chromosomes (and usually classifiable as *female/girl*), are based on clitoral size and appearance of the labia (Meyer-Bahlburg, 1998: 10-11). Children with clitorises exceeding 1 centimeter in length are also assigned *female/girl*, but undergo an operation to either recede the clitoris (clitoral recession or clitoral reduction) or to amputate it completely (clitoridectomy or clitorectomy) (Ismail and Creighton, 2005). Although Money was not a trained medical doctor or surgeon, he promoted clitoral amputation which he hypothesised did not affect erotic sensitivity and responsiveness (Money and Hampsons, 1957; Reis, 2009; Downing et al., 2015).

Cartesian Dualism and the Management of *Intersexuality*

Cartesian dualism is integral to the case management of *Intersex* infants in Western societies. It undergirds and is apparent in: 1) the construction of *Intersex* patients, 2) the authority of medical practitioners, and 3) the application of the sex/gender dualism in *Intersex* treatment. These three points will now be examined.

1. The Construction of *Intersex* Patients

As shown in the preceding paragraphs, the Cartesian model treats bodies primarily as mechanical objects distinct from minds, therefore based on this philosophical tenet babies, due to their incapacity to reason (*I think, therefore I am*), are constructed as undeveloped and malleable subjects, or, objects *par excellence*. The result is a medical protocol which routinely sanctions surgical procedures on *Intersex* babies and infants with the well-intentioned belief that the surgical encounter will have minimal impact on their adult lives. However, the many first-hand accounts of *Intersex* people dispute this claim. They say that surgical intervention in childhood causes irreversible damage that permanently impacts their adult lives and relationships (Kessler, 1998; Holmes, 2008; Karkazis, 2008; Preves, 2008; see also participants' accounts in Chapter Seven and Chapter Ten). For example, and as described above, surgeries are performed to reduce or amputate completely the clitorises of *Intersex* babies. With respect to clitoral surgery, gynaecologist Sarah Creighton and clinical psychologist Lih-Mei Liao (2004) who have researched the surgical, gynaecological, psychological and sexual aspects of surgery for *Intersex* women in the U.K write, 'the only known function of the clitoris is erotic pleasure' and the neuroanatomy of the

human fetal clitoris reveals a vast network of nerves which *any incision* risks damaging (Creighton and Liao, 2004: 660).

Infants diagnosed as *Intersex* are effectively perceived as bodies with disordered components requiring surgical management so that they can be placed into a singular 'true sex' category of *male* or *female*. Phrases such as 'under-developed', 'over-developed', 'unfinished', 'isn't complete' and 'excess of skin' are all used to describe *Intersex* genitalia, which allows for an accompanying surgical management expressed as, 'surgically corrected', 'repaired', 'put back in its proper position', 'reduced', 'enlarged' and 'reconstructed' (Kessler, 1998). Undergirding this medical 'corrective' approach and rhetoric lies the perspective that everyone has 'one true sex', but in the case of an *Intersex* infant, their genitals are obscuring their 'true sex' determination, therefore surgery is necessary to resolve this physical, treatable and temporary condition of the genitals (Hester, 2004). Morgan Holmes (2009) calls this language evasive, for rather than illuminating the existence of *Intersex*, it circumvents it whilst simultaneously reifying the coherence of the 'true sex' categories of *male* and *female*. Correspondingly, some *Intersex* people select to refer to their infant genital surgery as their 'sex change' to call attention to their profound loss of being forcibly transferred from out of the category of *Intersex*, and their validation and promotion of *Intersex* as a discrete category (Kessler, 1998).

2. The Authority of Medical Practitioners

The mind/body dualism secures the position of doctors as the 'arbiters of knowledge' in the management of *Intersex* bodies (Holmes, 2009: 4). Since this dualism places the mind in a hierarchically superior position to the body, medical practitioners as holders and purveyors of professional scientific knowledge (mind), control the subordinated patient (body). Scientific knowledge and formulations are ostensibly gained by inference, deduction and projection - in the name of objectivity - and for this reason are separated from subjectivity and the considerations of the subject (Jaggar, 1989; Grosz, 1994). This separation disregards the relationship of the patient to the full potential and active capacities of their body and privileges it instead as a diagnostic tool and treatment oriented enterprise to be repaired, disciplined and remade (Grosz, 1994). The bio-medical body is what patients *have* and not what they *are*. Family therapist and social worker Arlene Istar Lev (2006b), whose research focuses on the needs of LGBTQ people notes:

Children and adolescents are often examined by medical specialists who are checking on previous surgeries, or making plans for further surgeries, with little regard to how those who inhabit intersex bodies may feel. Body parts of intersex people are publicly examined in medical hospitals and photographed with eyes properly blocked out, furthering the sense of objectification and alienation; the process of being photographed is often experienced as invasive and abusive. Cheryl Chase says, "Surgeons are not trained to deal with patients who are upset. They are trained to 'fix' things. When people like me grow up and say, 'this hurt

me', they don't want to hear it, because they would have to see how they had hurt their patients, and they would have to admit their impotence in addressing this by surgery".

Lev 2006b: 40

A growing number of *Intersex* people are contesting the medical management of *Intersexuality*, legitimised by Money, on the grounds that it causes irreparable harm which blights their adult lives. They cite unsightly physical scarring and scar tissue, loss of sensation in the genital area affecting sexual relationships in adulthood, unsuccessful infant surgeries, necessitating multiple repeat procedures throughout childhood and adolescence, and psychological trauma. They also argue that surgery in infancy is non-consensual and unethical, and that medical examinations are very invasive, intrusive and even abusive (see Chapter Ten). In spite of these objections, the contemporary status of medical staff as experts allows them to 'provide a sealed and self-confident narrative of the important issues in the treatment of *Intersexuality*', and to eschew all other viewpoints and interpretations on *Intersex* as fringe perspectives (Karkazis, 2008: 6). Recommendations for genital surgery and hormone medication are presented to parents by medical staff as imperative and non-negotiable, often without informing them of their child's *Intersex* condition or involving them in the full decision-making process (Kessler, 1998; Lev, 2006; Preves, 2008). Many parents of children with *Intersex* conditions - taking their cues from medical staff - have never met anyone else in their situation due to receiving an implied message that their child's condition is to be confined to discussion in the medical domain (Kessler, 1998). This has engendered parental feelings of shame and secrecy

and increased their feelings of isolation and powerlessness (see Chapter Nine). All of these scenarios occur with frequency due to an environment that bestows absolute authority upon medical practitioners. It justifies a lack of full transparency and disclosure, disregard for patient/parent/primary caregiver input and involvement and resists public scrutiny of the controversial procedures involved (Zola, 1976, Beh and Diamond, 2000; Hester, 2004).

3. The Application of the Sex/Gender Dualism

John Money's medical mandate for *Intersexuality* also prescribes that in order to guarantee a stable gender identity for the *Intersex* infant, genital reconstructive surgery is best initiated before the infant is two years of age, when their development is thought to be malleable and they can be steered towards a particular gender category without permanent negative repercussions. Within the sex/gender distinction as theorised by Money, the sexed body is construed as true, whereas gender is seen as a volatile social category (Paechter, 2004). This distinction was originally intended to disprove biological determinism or the 'biology-is-destiny' formulation (Butler, 1990), and hence why a number of feminists originally endorsed and enthusiastically supported Money's work (Kessler, 1998). Yet if gender is radically independent of sex, as this theory suggests, what prevents man and masculine from also signifying *female* and woman? And woman and feminine from signifying *male* and man? And why would there be only two versions of this 'free-floating artifice'? (Butler, 1990: 9). Placing sex and gender in a dualistic relationship suggests that gender is cultural and discursive, whilst sex is natural and prediscursive. Yet, as

already shown in Chapter Two, scientific discourses have produced numerous biological, physiological, psychological and hormonal 'natural' scientific 'facts' in order to explain and justify repressive social hierarchies that are purportedly based upon sex and gender. It is this erroneous designation of sex as ahistorical, unconstructed, prior to culture and politically neutral which has been central to the continued dominance of binary sex categories (Wittig, 1992; Butler, 1990). This problematic split reinforces the view of sex/body as a fixed and stable biological object of science, and gender/mind as culturally constructed (Gatens, 1996). It echoes Descartes by locating identity in the mind, which is construed as distinct from – rather than implicated in – the sexed body (Paechter, 2004; Holmes, 2008). More accurately, sex is as culturally constructed as gender. Gender produces sex as prediscursive. It obscures the hegemonic power relations which culturally construct dualistic sex categories (Butler, 1990; Gatens, 1996).

'I would have been way better off if they had just left me alone'.

John Money and The Sex Reassignment of David Reimer

On 27 April 1966, David Reimer,¹⁴ an identical twin, was eight months old when he had surgery at St Boniface Hospital, Winnipeg, Canada, to rectify phimosis, a condition where the foreskin of the penis prevents urination (Diamond and

¹⁴ A clarifying note about the many and potentially confusing first names in the David Reimer sex reassignment case. At birth, David Reimer was originally called 'Bruce' by his parents and later after undergoing sex reassignment surgery was renamed 'Brenda'. When Brenda was told about her sex reassignment as a teenager, she elected to live as a man called 'David'. In medical journals this is referred to as the 'John/Joan' case. In accordance with Butler, 'I will use the name he uses' (Butler 2004: 59), which was 'David' when he began speaking publicly. I shall only use one other name, 'Brenda', when historically appropriate.

Sigmundson, 1997; Colapinto, 2000; Hausman, 2000; Butler, 2004). Against the advice of colleagues, the operating surgeon – Dr. Jean-Marie Huot - used a new machine he had had no previous experience with, and when encountering difficulties increased its electrical current, resulting in the accidental burning and severing of David's entire penis (Money, 1975; Diamond and Sigmundson, 1997; Colapinto, 2000; Hausman, 2000; Butler, 2004). A team of top specialists examined David, and Dr. G. L. Adamson, then Head of the Department of Neurology and Psychiatry at the Winnipeg Clinic, is recorded as predicting:

[H]e will be unable to consummate marriage or have normal heterosexual relations...he will have to recognise that he is incomplete, physically defective, and that he must live apart.

Colapinto, 2000: 16

What this quote suggests is that, although David was born with XY chromosomes and assigned *male/boy* at birth, without his penis David's gender identity was suddenly called into question (Butler, 2004), summarily rendering him 'incomplete' and 'defective' (Colapinto, 2000: 16). Furthermore, since the criterion for judging a person as a gendered being informs our intelligibility as humans to others, if David became unintelligible, he would be condemned to living 'apart' from others - those who have been granted gender coherence (Colapinto, 2000: 16). According to David's own account his parents did indeed begin to live apart. They withdrew in

'misery' with their 'secret' from their friends and neighbours, and 'felt like prisoners in their house' (Colapinto, 2000: 17; Hausman, 2000).

One year later, the Reimers watched Dr. John Money on television talking about transsexual and *Intersexual* surgery, explaining his hypothesis that if a child 'underwent surgery and started socialisation' as a different sex and gender from that assigned at its birth, it could adapt well and live happily (Money, 1975; Butler, 2004: 59; Morland, 2015). In Money's discourse, both transsexuals and *Intersexuals* were 'unfinished' prior to body modifications (Morland, 2015). A key distinction being that, with transsexuality, the patient's feelings of belonging to a gender category preceded surgery, whereas, with *Intersexuality*, surgery was deemed to create the belonging (Morland, 2015). The Reimers made an appointment with Money at the *Psychohormonal Research Unit* at John Hopkins University, where Money gave them advice and counselling on raising David as a girl, based on his work with 'similar reassignments in hermaphroditic babies' (Money, 1975: 67; Hausman, 2000; Butler, 2004; Reis, 2009). The parents agreed and their baby underwent an orchidectomy (surgical removal of the testes) and preliminary feminisation surgery (where the empty scrotum is shaped to resemble a labia), with a full vaginoplasty delayed until the baby's body was fully grown (Diamond and Sigmundson, 1997; Hausman, 2000; Butler, 2004). The baby was registered at John Money's *Gender Identity Institute* for adjustment and reinforcement to life as a girl called Brenda (Hausman, 2000; Butler, 2004). Money was particularly keen to take on this case since Brenda had 'an

identical brother as a control', and in reporting on the child always did so in comparison to the twin brother (Money, 1975: 65).

Brenda's behaviour, words and genitals were all intensely monitored throughout childhood and adolescence (Money, 1972; Money, 1975; Butler 2004) by medical and psychological professionals. In academic literature Money details information regarding Brenda's clothes, hair-style, neatness, mode of urination, future goals, reactions to her mother's breasts and sanitary products and her brother's genitals based upon the 'Mother's observations and reports' (Money, 1975: 67). The basis for this scrutiny, which both twins revealed in adulthood to be unethical and abusive especially during their annual appointments with Money (Diamond and Sigmundson, 1997; Colapinto 2000), was to interrogate whether the gender norm applied to David's body had been sufficiently accomplished (Butler, 2004). This is an idealising gender norm, a component of a heteronormative ideal, where success is determined by marriage and motherhood as is discernible in Money's words here:

They were broadly informed about the future medical program for their child and how to integrate it with her sex education as she grows older. They were guided in how to give the child information about herself to the extent that the need arises in the future; and they were helped with what to explain to friends and relatives, including their other child. Eventually, they would inform their daughter that she would become a mother by adoption, one day, when she married and wanted to have a family.

Money and Ehrhardt,
1972: 119

Essentially, Brenda's parents were offered a new coherent gender for their child which was tantamount to a restoration of its intelligibility and subsequent humanness to others, in a world where gender norms presuppose humanness (Butler, 2004). Nevertheless, things did not proceed as Money predicted or reported (Money, 1975; Diamond and Sigmundson, 1997; Hausman, 2000). Brenda vehemently resisted her sex reassignment throughout childhood and adolescence, with local psychiatrists reporting on her preference for – what they referred to as – *male* behaviour and activities (Diamond and Sigmundson, 1997; Beh and Diamond, 2000; Hausman, 2000). At twelve years old, Brenda's body began to change with the regular administrations of the hormone estrogen, and Brenda became despondent and eventually suicidal (Beh and Diamond, 2000). At age fourteen, Brenda refused to attend any further appointments with Money at John Hopkins and said of the local psychiatric team, who were charged with fostering *female* identification and role modelling whilst redirecting *male* ideation, 'they kept making me feel as if I was a freak' (Diamond and Sigmundson, 1997: 301). After a number of suicide attempts, Brenda's parents decided to renounce the instructions of John Money and instead revealed to Brenda all that had occurred at the hospital in Winnipeg in 1966 and the events this had precipitated (Diamond and Sigmundson, 1997; Beh and Diamond, 2000; Reis, 2009). However, in spite of these turn of events, the 'John and Joan' case was reported in the medical literature by Money as a success and he was widely referenced in numerous academic texts on sex and gender (Morland, 2015).

Meanwhile, in response to her sex assignment revelation, Brenda requested a mastectomy at age fourteen and phallus constructions at ages fifteen and sixteen, and began living life as a man called 'David' (Beh and Diamond 2000; Butler, 2004; Reis, 2009). In his autobiography David summed up as follows:

If I had grown up as a boy without a penis? Oh, I would still have had my problems, but they wouldn't have been compounded the way they are now. [...] I would have been way better off if they had just left me alone, because when I switched back over, then I had two problems on my hands, not just one, because of them trying to brainwash me into accepting myself as a girl.

Colapinto, 2000: 262

In 2004, David Reimer died by suicide at thirty-eight years of age; his identical twin brother Brian had taken his own life two years earlier.¹⁵ In spite of these tragic events, the 'John/Joan' case 'firmly established the contemporary medical model for dealing with cases of ambiguous or traumatised genitalia' which included the treatment of *Intersexuality* (Beh and Diamond, 2000: 5; Butler, 2004; Creighton and Liao, 2004).

¹⁵ 'Dr. Money and the Boy with no Penis', *BBC Horizon* documentary (2004).

'[H]e is apparently happy although living as a male without a penis'.

The Sex Reassignments of John

Although it seemed inconceivable to John Money and colleagues at John Hopkins Hospital for a 'genetic male' to live happily with a micro-penis or no penis at all without feeling 'like a freak' (Money, 1975: 66), a look at historic records from their own hospital archives could have informed them otherwise. In October 1925, a seven year old boy named Frank was admitted to John Hopkins Hospital with undescended testicles, hypospadias and a short vagina (Reis, 2009). During an internal examination Frank was also revealed to possess a uterus, a right ovary and fallopian tubes; subsequently, what was formerly read as a boy's penis was instead recorded as an enlarged clitoris, Frank was pronounced *female* and his name was changed to Frances (Reis, 2009). Notably, although Frank's sex was reassigned, no surgical procedures were deemed necessary (Reis, 2009). Two years later, Frances returned to John Hopkins, complaining of the 'clitoral appendage' and how she felt under pressure to hide it (Reis, 2009: 94). The doctors recorded that it was comparable in size to the penis of a ten year old boy and Frances had surgery to remove it. Aged sixteen, Frances returned to John Hopkins complaining of a 'mass in her lower abdomen' and announcing her intention to live as a man (Reis, 2009: 94). A medical examination revealed testicular tissue and a rudimentary vas deferens (a duct which conveys sperm from the testicle to the urethra) which was removed by the medical team. Frances changed her name to John and commenced work as a truck driver. It is revealing that John's medical report reads, 'he is apparently happy although living as a male without a penis or testicles and with the vagina still present' (Reis, 2009: 94). What I would like to highlight as very significant about this case is the

autonomy, self-determination and consent that John was able to exercise during each phase of his various sex re/assignments. Over a period of nine years John felt confident in returning to his physicians for repeat medical consultations. The environment appears to be one of full medical disclosure, transparency and open communication. And, despite what can be read as certain misgivings on the part of his physicians, they were able to cooperate with John – without reproach, abuse or coercion - in the achievement of his chosen ('happy') outcome, irrespective of the fact that it defied prescribed sex and gender norms.

'Surgical Sexing' and the Heteronormative Ideal

Theorists have noted that underlying the contemporary 'surgical sexing' (Creighton and Liao, 2004: 661) of *Intersex* patients are primarily Western notions of what constitutes 'successful maleness' (Morland, 2004: 448), with the accompanying equation that a large penis equals *male*, whereas the absence of a large penis equals *female* (Kessler, 1990). Surgical sexing renders the *female* body as an absence that can be constructed with ease, since it is merely 'an elimination, a cutting away' (Butler, 2004: 64). This is consistent with what Hélène Cixous (2004) referred to as dual hierarchical oppositions, where the *female* is represented as passive or does not exist at all. It is also observable in the etymologies of the words 'penis' and 'vagina' which originate from late seventeenth century Latin; 'vagina' is derived from the words 'sheath' or 'scabbard', and 'penis' is from 'sword' (Kessler, 1998). This dichotomous view of male/female biology is implicated in the ideology of heterosexuality, which has historically been featured as the optimum (read orderly)

outcome for *hermaphroditic* or *Intersex* (read disorderly) people (see Chapter Three). It formed the basis for how David Reimer and John were conceptualised by the professionals who medically managed them. It stipulates that the active *male* penis penetrates the passive *female* vagina which is a shapeless receptacle, a hole or a lack (Gatens, 1996). These dualistic heteronormative representations have been confronted by critics who contend that the vagina could just as easily be viewed as actively enveloping or embracing the penis, and who cite biological research which suggests that during reproduction the ovum can in fact select or reject sperm (Gatens, 1996). Similarly, British sociologist of sex and sexualities Tamsin Wilton (2000), provides this powerful description of the vagina:

The 'objective' vagina is a complex organ, muscular, self-maintaining and dynamic. If it happens to belong to a cow, it can easily break your arm. The labouring uterus is the largest muscle in the human body and works away for twenty hours or so with a degree of effort which would flatten your average gym addict...

Wilton, 2000: 245

The conflation of normalised genitals with normalised psycho-sexual development, as depicted in the cases of David Reimer and John, which is a cornerstone of the OGR policy exposes what some psychologists have called 'a leap of faith' in a conjectured predictability and projected trajectory in the relationship between anatomy, identity development and psychological well-being (Creighton and Liao, 2004: 661). It also disregards evidence which indicates that throughout a human life the many facets of

sexual development and sexuality, which may include a person's sex and gender positioning, sex and gender identification, sexual partner orientation and sexual activities, can be subject to many incongruencies and numerous shifts as they navigate many different situations in the social world (Creighton and Liao, 2004).

Arguments for infant genital surgery are primarily based on assumptions which posit the existence of not only a normative ideal, but equally a normative reality (Roen, 2009). All of the adults involved in the decision-making process for genital surgery are imagining a particular type of subject that they do or do not wish the child to become, and they are moulding the child into this image in the hope that it will embody the normativity that they imagine (Roen, 2009). This could explain why the gynaecological procedure vaginoplasty is routinely performed on *Intersex* infants under two years of age - when they are too young to either menstruate (if they have a uterus) or be sexually active - rather than later in life (Roen, 2008).¹⁶ Whilst there is no data to support improved anatomical, cosmetic or functional outcomes when vaginoplasties are performed in infancy, the data that is available does identify a trend of repeat procedures in adolescence required due to the development of vaginal stenosis (Roen, 2008; Creighton and Liao, 2004; Liao and Boyle, 2004b). Essentially, surgical decisions such as vaginoplasties 'create a reassuring appearance for significant adults' (Creighton and Liao, 2004: 660). They are primarily influenced by sexually dimorphic ideologies which mark individuals as intelligibly human only if they conform to the culturally recognised standards of gender intelligibility (Butler, 1990;

¹⁶ For more information, please see subheading, 'Girls Don't Need Vaginas' (Roen, 2008: 56).

see Chapter Eight). A function of these intelligible genders is to enforce and maintain coherence, continuity and stability between sex, gender, sexual desire and sexual practice. It is part of the project of the 'heterosexualisation of desire' (Butler, 1990: 24) that requires the production of masculine and feminine as asymmetrical oppositions and 'natural' expressions of *male* and *female*. This is a regulatory cultural matrix which assures that certain kinds of bodies, behaviours and identities cannot exist, and that their existence is the site of a developmental failure or a logical impossibility (Butler, 1990) because their sex, gender, sexual desire and sexual practices will not line up in heteronormative ways, such as is perceptible in the case of David Reimer, John and the management of people with *Intersex* conditions.

In many ways, the case management of *Intersexuality* represents Cartesian philosophy taken to its extreme. It treats people as inferior, passive body-objects whilst granting absolute superiority and agency to its medical practitioners within a culture that defines all human beings in terms of two arch-categories. Indeed, Cartesian dualism as expressed in the contemporary management of *Intersexuality* prizes the arch-categories of *male* and *female* and their associated dualistic categories. Whilst Money endeavoured to radically show that gender is socially constructed and malleable, he retained the dualisms of *male* and *female* by an insistence on fitting *Intersex* babies and infants into one of these two classifications. By assigning the majority of *Intersex* children to the category *female* and sanctioning irreversible genital surgeries and hormones for these children, the construction of the sexed body remained unquestioned. Successful maleness was equated to a large penis, whereas successful femaleness was equated to a hole and an absence, thereby sustaining the

dual hierarchical oppositions of the superior active *male* and the inferior passive *female*.

As described in Chapter Two, scientific 'facts' and knowledge claims exist because of their social and cultural embeddedness. They acquire the status of universal, 'natural' facts by discourse building processes, which in their contemporary format are determined by: 1) the extent to which they become interwoven with the institutional settings and practices of scientists and their audiences, and, 2) how well these scientists create alliances with other important groups and networks (Oudshoorn, 1994). This could explain why Money's theories reached a wide and receptive audience with 'extraordinary speed' garnering him worldwide renown (Morland, 2015: 77). Essentially, Money's work championed socio-political heteronormative ideas of sexual difference, sexual desire and sexual activity, coincided with advancements in the surgical techniques for *female* genital construction and endocrinology, and resonated with contemporary ideas about children, psychology and medicine (Kessler, 1990). Acceptance and acclaim quickly followed; his theories were endorsed by the *American Academy of Pediatrics* (Lev, 2006) and adopted as standard practice in the management of *Intersexuality* in the USA, Europe and South-East Asia (Meyer-Bahlburg, 1998; Hausman, 2000; Ismail and Creighton, 2005; Spurgas, 2009).

Conclusion

Our understanding of human bodies, development and behaviour is to a large extent formed and guided by the dynamic enterprise of biomedicine. Informed by Cartesian

philosophy which advocates for a mechanistic, passive body-object world view, biomedicine intervenes in the lives of individuals under the guise of health/illness, transforms the world we live in and cements its authority as progressive and beneficial. As catalogued in the case of David Reimer and depicted with the new protocols for *Intersex* babies and children, biomedical discourses are not harmless ideas, ideologies and theories. They possess a material authority that people interact with in very personal ways (Oudshoorn, 1994). Encompassing a multitude of diagnostic tools and preparatory procedures which are to be found in screening tests, X-rays and medical examinations; they involve body parts, bodily tissue extraction, blood and urine samples, specialised laboratory equipment and techniques, and the prescribing of drugs and hormone medication (Oudshoorn, 1994). This materiality of discourse building should not be overlooked or reduced to primary texts and theories (Oudshoorn, 1994). It has enormous implications. It deftly intertwines cultural assumptions, diagnostic testing and laboratory equipment and forms powerful alliances (Oudshoorn, 1994). The chapter has shown how this amalgamation has surgically wrested bodily autonomy and control from *Intersex* people since the 1950s.

The objective of this chapter was also to bring to light how Cartesian dualism forms the bedrock of biomedical discourse and is a defining part of the medical case management of *Intersexuality*. It is this which permits biomedicine to take liberties with *Intersex* bodies in intrusive, invasive and unethical ways. This dualism is tied closely to genital interventions because it explicitly allows access to bodies. It does so by constructing bodies as mechanical objects in need of reconstruction, repair and

correction. This informs the language used to describe and to speak about *Intersex* conditions in ways that are analogous to disorder. It also socialises the patient into a state of passivity and non-involvement with their bodies, their condition, their medical management and their treatment. They become bystanders. Their bodies are handed over to medical practitioners who have the jurisdiction to perform surgical procedures and interventions to restore them to order, with - little to no regard for the (current or future) mental, emotional and psychological implications to the *Intersex* person. Medical practitioners are constructed as the absolute authority in *Intersex* case management. No other viewpoints or perspectives gain entry or are even seriously evaluated. Cartesian dualism in the case management of *Intersexuality* disempowers, disembodies and even disfigures *Intersex* people.

Chapter Five: Reclaiming *Intersex* and Categorising Disorder

In many ways this final chapter of Section One brings together some of the key issues raised in the theoretical review of my study. The chapter charts the mobilisation and resistance of the first generation of *Intersex* adults who were subjected to the medical protocols for *Intersexuality* as defined by Dr. John Money and colleagues. Although their medical management was confined within a sphere that ostensibly deals with health/illness, this community of *Intersex* people fully recognised that their treatment was not fundamentally driven by health concerns. As such, they rejected the medicalisation of *Intersexuality* entirely, critiqued surgical 'correction' and were explicit in their aim to destabilise heteronormative assumptions underlying, what they termed as, the 'violence' directed at their bodies.

Understanding that the genital normalising surgeries performed on them as children were based upon a heteronormative model, they aligned themselves with LGBTQ groups who were actively involved in resisting the same oppressive norms. The *Intersex* movement also grasped that '*Intersex*' as a category was not privileged in the way that their *male* and *female* counterparts were because of socio-political factors. Therefore they rejected their societal position as hidden, invisible and stigmatised and came together as a worldwide community of *Intersex* survivors seeking to politicise a new pan-*Intersexual* identity, making themselves very visible and very vocal to the world with their public protests.

Chapter Five is also about the difficulties of securing better medical management from institutions heavily invested in the dualistic enterprise of sex categorisation, sex difference and heteronormativity when you are an *Intersex* person. It uses textual analysis of medico-psychiatric literature - past and present - to decipher why medicine insists on categorising non-normative identities, bodies and behaviours as 'disordered', and why, as a result, the newly formed *Intersex* movement felt cornered. Ultimately, this chapter is about politics and the complex negotiations and navigations involved in living when you are a person whose existence defies the criteria set out for intelligible personhood. It analyses the politics of resistance and considers contestations surrounding the adoption of the nomenclature 'disorder' to self-identify.

The Beginning of an *Intersex* Movement

In 1993, Cheryl Chase (now Bo Laurent) founded the first movement and community for people with *Intersex* conditions (Chase, 1998; Feder, 2009; Spurgas, 2009). This was formed to 'critique the normativist biases couched within most scientific practices' and to destabilise 'the heteronormative assumptions underlying the violence directed at [Intersex] bodies' (Chase, 1998: 199, 202). Prior to 1993, there were in existence four other groups for people with *Intersex* conditions, but these were diagnosis specific support groups (Rosario, 2004; Preves, 2008) listed as follows:

- Androgen Insensitivity Support Group, USA, formed in 1985.
- Turner Syndrome Society, USA, formed in 1987.
- Androgen Insensitivity Support Group, UK, formed in 1988.
- Klinefelter's Syndrome & Associates, USA, formed in 1989.

In 1993, Anne Fausto-Sterling published two articles concerning *Intersex* simultaneously: "The Five Sexes" in *The Sciences* and "How Many Sexes Are There?" in *The New York Times* (Karkazis, 2008; Dreger and Herndon, 2009). It was the former that provoked Chase to respond with a letter to the editor of *The Sciences* publicly announcing the creation of the *Intersex Society of North America* (ISNA) (Preves, 2008; Dreger and Herndon, 2009). Up until its dissolution, ISNA (1993-2008) was the longest-running, best funded and most influential advocacy and community support group that connected *Intersex* people from across North America,

Europe, Australia and New Zealand (Dreger and Herndon, 2009; Rosario, 2009; Spurgas, 2009).

The Influence of LGBTQ Activism upon the *Intersex* Movement

Since *Intersex* bodies were systematically and negatively targeted by dualistic regimes requiring sex, gender, the body, sexuality and desire to line up in heteronormative ways, it was unsurprising that alliances with LGBTQ organisations were forged and radical practices shared. The basis for this was a common pursuit of carving out, what Chase referred to as, 'liveable spaces for people with reconfigured forms of embodiment, identity, and desire' (Chase, 1998: 208). Influenced by LGBTQ theorising and activist movements which had successfully reclaimed the pathologising and pejorative words 'gay' and 'queer', the *Intersex* movement also became keenly engaged in a 'wresting away of meaning and control' of the terms *hermaphrodite* and *Intersex*, from their medical articulation of a pathologised and disordered state of being, to a positive signifier of a non-normative and queer identity (Holmes, 2009: 4; Spurgas, 2009). Many LGBTQ groups empathised with the struggle of *Intersex* people to assert their agency and autonomy over their own bodies within medical discourse, and as a result were ready allies who incorporated *Intersex* as part of their own political agendas (Chase, 1998; Feder, 2009). Queer, and most notably, trans activists provided practical advice on activism and logistical support. The first direct action by members of the *Intersex* movement in 1996 - picketing the annual meeting of the *American Academy of Pediatrics* in Boston, USA - was planned and assisted by the trans activist group *Transsexual Menace* (Chase, 1998; Kessler, 1998).

ISNA sought to challenge the medicalisation of *Intersex* people by 'politicising a pan-Intersexual identity' (Chase, 1998: 199) which would allow for the constitution of a radical, queer oriented *Intersex* identity (Spurgas, 2009). The popular adoption and deployment of queer had developed out of lesbian and gay studies in the early 1990s in response to structured debates about lesbian and gay identity. In *Queer Theory: An Introduction*, New Zealand queer theorist Annamarie Jagose (1996) explains how queer has been used as an umbrella term for culturally marginalised sexual self-identifications. A focus of queer is to dramatise inconsistencies in the heteronormative model which naturalises links between chromosomal sex, gender and desire. It emerged out of the post-structuralist theorising of Althusser, Lacan, Saussure and Foucault, which radically denaturalised identity, and Jagose credits Michel Foucault with explicitly denaturalising the dominant understandings of sexual identity.¹⁷ Part of queer's analytical framework, rubric and quest is to debunk 'natural' sexuality. A constituent characteristic of queer is its definitional indeterminacy and elasticity. It represents a zone of possibilities and is resistant to being fixed or annexed to any specific identity category. Fundamentally, queer theory is (1) a debunking of the idea of a coherent sex, gender or sexuality; (2) not new, but marks a development in the spectrum of lesbian and gay theorising; and (3) represents a reworking of post-structuralist understandings of identity (Jagose, 1996).

However, the last decade has seen a shift in ISNA's trajectory of political identity, alliances and activism. ISNA transformed from a radical and queer activist movement

¹⁷ Jagose only references *male* theorists.

bent on 'challenging its medicalisation entirely' and 'politicising a pansexual identity' (Chase, 1998: 199) to Accord Alliance (2008-current), a lobbying group that distanced itself away from radical queer and transgressive sex and gender identity politics and activism in favour of working alongside clinicians and surgeons within a medicalised framework for 'children's rights'. This has controversially included relinquishing the nomenclature *Intersex* in favour of the exclusive adoption of *Disorders of Sex Development* (DSD) (Spurgas, 2009).

Disorders of Sex Development (DSD)

Whereas *Intersex* was used to mobilise a community of people for peer-support, autonomous self-identification, validation of *Intersex* as embodied difference and 'the advent of an activist *Intersex* opposition' (Chase, 1998: 208; Holmes, 2009), DSD emerged out of the need for 'a clearly articulated patient-centred model of care' (Dreger and Herndon, 2009: 211; Morland, 2012), built on alliance with physicians, *Intersex* adults, parents/primary caregivers of *Intersex* children and other diagnosis specific advocacy and support groups (Feder and Karkazis, 2008; Dreger and Herndon, 2009; Morland, 2012). Whilst the term *Intersex* is preferred and used extensively by scholars and activists, many parents, doctors and advocacy groups take issue with it (Dreger and Herndon, 2009). This has created barriers to dialogue, collaboration and critically, to any possibility of improved medical care (Feder and Karkazis, 2008; Dreger and Herndon, 2009; Reis, 2009). Some parents contend that *Intersex* conjures negative associations similar to its predecessor 'hermaphrodite', someone who is freakish and monstrous, others reject the allusion their child inhabits

a third gender or in-between category, when in their case gender assignment was not an issue and their child was easily classifiable as a 'girl' or a 'boy' (Feder and Karkazis, 2008; Reis, 2009). Still other parents believe the word *Intersex* prematurely draws attention to their child's sexuality - their orientation and eroticism - when what they would prefer instead, is for the focus to be solely on their child's anatomy and physiology (Feder and Karkazis, 2008; Dreger and Herndon, 2009; Reis, 2009). These perspectives are shared by some diagnosis specific support groups such as AISSG (*Androgen Insensitivity Syndrome Support Group*) and the CARES Foundation (for the *Congenital Adrenal Hyperplasia* community), whose members claim that *Intersex* sexualises them (or their children), imposes a queer identity upon them which they cannot relate to, or implies that they have no clear sex or gender identity (Dreger and Herndon, 2009).

It is from out of this contentious backdrop that a collective comprised of 'Intersex' people, parents and clinicians came together in 2005 to create new clinical guidelines for a patient-centred model of care (Dreger and Herndon, 2009). It soon became apparent that agreement on practice could not be achieved without agreement on terminology, or who would the guidelines be for (Dreger and Herndon, 2009)?

Accordingly, a consensus was reached endorsing the new term 'Disorders of Sex Development' (DSD) which was felt to downplay any perceived sexual and identity politics, whilst foregrounding the medical and scientific aspects. Below are some of the directives featured in the guidelines which were distributed as handbooks (see Lev, 2006: 37, 38; Dreger and Herndon, 2009: 206 italics in original):

Provide medical and surgical care when dealing with a complication that represents a real and present threat...

Delay elective surgical and hormonal treatments until the patient can actively participate in decision-making...

Respect parents by addressing their concerns and distress emphatically, honestly, and directly...

The family should be an integral part of the entire treatment team process, receiving adequate attention, education, and time to understand complex medical issues.

The child's birth should be celebrated as one would celebrate any other birth. The medical staff should emphasize positives and refer to the baby as a "whole" child, not just a set of genitals. Parents should be reminded that sexual ambiguity is a minor anomaly compared with many other congenital conditions. The child should not be needlessly isolated in the neonatal intensive care unit for the convenience of medical access to the child, or to spare the family from having visitors see their newborn child.

Therapeutic support should continue to be available to the family, including offering medical information, education about sex and gender development, and assistance in making informed medical decisions. Linkages with other families and adults with intersex conditions should be encouraged.

Directly address the child's psychosocial distress (if any) with the efforts of psychosocial professionals and peer support.

Always tell the truth to the family and the child.

Hence, incorporated in the new nomenclature was the belief that it would promote better medical and therapeutic care whilst discouraging sensationalism of atypical anatomies (Dreger and Herndon, 2009; Reis, 2009).

The Diagnostic and Statistical Manual of Mental Disorders (DSM)

The adoption of the word 'disorder' has caused deep fissures in the *Intersex* community. Objectors believe that it unnecessarily medicalises and pathologises people with *Intersex* conditions thereby legitimising genital surgeries. Supporters state that 'there is no terminology that can eradicate the stigma of atypical anatomies' (Feder and Karkazis, 2008: 35). In order to understand the significance of any word it is important to attend closely to the discourse in which it is embedded along with the purpose it serves and the associated assumptions and values it may hold. To do this I shall scrutinise how medical discourse uses the word 'disorder' by evaluating its use in *The Diagnostic and Statistical Manual of Mental Disorders (DSM)*, an internationally prestigious and highly influential publication in biomedicine, of which Dr. John Money was a contributor in its 1987 revised edition (Downing et al., 2015).

The Diagnostic and Statistical Manual of Mental Disorders (DSM) is the official nomenclature of the *American Psychiatric Association*, and as such, it has been called 'the bible' of contemporary psychiatry, psychology and social work fields (Sarbin, 1997: 233; Lev, 2006a: 36). Its effects are far-reaching. Increasingly published globally it is used as a handbook by mental health professionals, clinical psychologists and teaching staff in medical schools.¹⁸ The DSM is credited with:

- Systematising scientific observation and knowledge.
- Providing a common language for clinicians and researchers to communicate about patients.
- Guiding treatment.
- Developing medication and interventions.
- Influencing new research initiatives.

All of the above points show that the DSM is a handbook whose contents have very material consequences for millions of people. This is underscored by its role as the official authority for medical claim administration and reimbursement by U.S insurance companies (Sarbin, 1997; Thakker and Ward, 1998).

¹⁸ 'DSM history', *American Psychiatric Association*,

<https://www.psychiatry.org/psychiatrists/practice/dsm/history-of-the-dsm> [online] accessed September 2016.

Criticisms of the DSM

In spite of the above impact and institutional authority, critics of the DSM abound.

These include theoreticians, academics, clinicians, activists and social commentators (Karasic and Drescher, 2006; Lev, 2006a). They charge that its categories and definitions are merely the legacy of the historic medico-psychiatric foray into 'human sexual deviations' and that the 'classification zeal' of the DSM works to pathologise human diversity, behaviour and experiences (Lev, 2006: 43). Considering the DSM is hailed as 'the primary source of scientific information for sorting people into psychiatric categories' (Sarbin, 1997: 234), it is highly significant it is accused of being *unscientific*. It is criticised for, (1) not stating its central hypothesis, (2) its omission of any theoretical references and failure to explicitly state its theoretical approach, which subsequently, (3) impedes debate and inhibits any challenge to, or test of, its theoretical assumptions (Follette and Houts, 1996; Thakker and Ward, 1998). These are serious accusations. How is it possible that a book which wields authority and influence over psycho-medico theory and practice, and controls access to and dispensation of medical treatment for millions of people can evade these three vital areas of scientific rigour? If the DSM's psychiatric categories are not based on scientific knowledge, upon what exactly are they based? An evaluation of its handling of homosexuality and gender identity can provide some answers.

The DSM and Homosexuality

The first two editions of the DSM published in 1952 (DSM I) and 1968 (DSM II) contained 'homosexuality' (Drescher, 2015). This entry was listed under a category called 'Sexual deviations' and described as follows:

302.

Sexual deviations

This category is for individuals whose sexual interests are directed primarily toward objects other than people of the opposite sex, toward sexual acts not usually associated with coitus, or toward coitus performed under bizarre circumstances as in necrophilia, pedophilia, sexual sadism, and fetishism. Even though many find their practices distasteful, they remain unable to substitute normal sexual behaviour for them. This diagnosis is not appropriate for individuals who perform deviant sexual acts because normal sexual objects are not available to them

302.0 Homosexuality

DSM II Behaviorism
and Mental Health
2015: 44

The above excerpt shows that not only did the DSM classify homosexuality as a mental disorder (Preves, 2008; Drescher, 2015), but the 'scientific' justification it supplies is that homosexuality is sexually deviant behaviour; it is 'bizarre' and not 'normal sexual behaviour'. It makes clear that 'normal sexual behaviour' is sexual interest directed towards 'people of the opposite sex'. In 1973, after 'intense pressure

from gay activists' (Kosofsky Sedgwick, 1991: 20) who challenged the *American Psychiatric Association* 'publicly and forcefully' (Drescher, 2015: 387), 'homosexuality' was removed from the sixth printing of the DSM II and replaced by 'Sexual Orientation Disturbance' (SOD) (Spitzer, 1981; Silverstein, 2008; Drescher, 2015). SOD was modified in 1980 to 'Ego-Dystonic Homosexuality' (EDH) in the DSM III (Spitzer, 1981; Silverstein, 2008; Drescher, 2015). Notably, EDH was designed to focus on the experience of unhappiness or distress with same-sex desire, in contrast to someone who is comfortable with their same-sex desire, leading some to argue that evidence of distress as a result of societal oppression is frequently labelled as a mental disorder (Lev, 2006a).

The DSM and 'Gender Identity Disorder' (GID)

In 1980, while the DSM modifications for homosexuality were still underway, many gender theorists were alarmed to see a new category published in the DSM III called *Gender Identity Disorder* (GID) (Kosofsky Sedgwick, 1991). Defined as 'a strong and persistent cross-gender identification', GID included a sub-category for children, Gender Identity Disorder in Children (GIDiC) (Zucker, 2010) which many observed was considerably more detailed in outlining what this classification meant for boys rather than girls, by focusing attention on their clothes, games and pastimes and whether these were based on 'female attire' or 'preoccupation with female stereotypical activities' (Kosofsky Sedgwick, 1991). This focus led theorists such as Eve Kosofsky Sedgwick (1991), who has been called the founder of Queer Theory, to voice concerns for 'effeminate boys' who do not conform to socially ascribed notions of

masculinity; based on the GIDiC's rationale they can be diagnosed as mentally ill. Others felt GID could be applied to LGBTQ youth and adolescents considered 'pre-homosexual' or mis/used by clinicians who believe that homosexuality is a treatable and curable mental illness (Lev, 2006a: 50). All of these concerns have raised pointed questions as to the motivations for the new category GID and whether it was simply a ploy to circumvent the removal of 'homosexuality' as an explicit category in the DSM.

Why 'Disorders'?

It is not difficult to see why many claim that social biases continue to drive the creation of medical diagnostic categories and that history supports the view these categories are 'subjective, culture bound and reflect societal efforts to control the behaviour of its citizens' (Lev, 2006a; Drescher, 2015: 393). This would also explain why the DSM falls short as a manual that is based upon rigorous scientific knowledge. As already detailed in Chapters Two and Three, in Europe and North American societies, sexed bodies, sexual desires, behaviours and sexual identities are severely prescribed and any deviations are believed to require classification and management within the medical and/or psychiatric spheres (Lev, 2006a). Discourses from medicine, most notably from the fields of psychiatry, psychology and sexology have been very influential in shaping modern classifications based upon theoretical assumptions of 'disordered' physiologies and personalities (Cameron and Kulick, 2003). These are in evidence when psychiatrist Robert L. Spitzer (2006) from the *American Psychiatric Association* (the publishers of the DSM) responded to criticisms

and questions regarding the appropriateness of using the term 'medical disorder' to describe non-conforming people as follows:

However you understand the concept of "design", it is clear that the eye has a certain function. When somebody has an eye that cannot see, there is some mechanism – which we may or [may] not understand – that is not working. You can think of all kinds of other examples. Whenever you think of a medical disorder you are thinking of some biological function that is expected – that is part of being human – that is not working. Does this concept of what is a medical disorder apply to human behaviour? The answer is "yes". There are certain human qualities or behaviours that are part of being human, that are part of normal development.

Spitzer 2006: 113

Based on the above comment by Spitzer, to be labelled with a 'medical disorder' is in keeping with the term's mechanical origins (see Chapter Four). It is to be deemed not working, not functioning and not developing 'normally', therefore necessitating medical intervention. As noted by gender theorist and philosopher Judith Butler (2004), to be diagnosed with GID is to suffer a certain amount of stigmatisation for being found ill, sick, wrong, out of order and abnormal. Using this rationale, the classification of homosexuality and GID in the DSM as 'mental disorders' assumes that when people want to exercise their autonomy and self-determination in their sexual object choice, in relation to decisions regarding their sex and gender assignment

and/or to explore or inhabit non-conforming possibilities for their sex and gender identifications, (rather than submit to sex and gender norms), an error and a failure has taken place (Butler, 2004). This observation lends itself to Foucault's analysis of the 'one true sex' rhetoric in its contemporary format and how the existence of increased tolerance for certain non-normative identities remains infused by an enduring and underlying belief that there is 'an "error involved in what they do' that is insulting to "the truth"' (Foucault 1980: x).

Butler writes that to diagnose GID is to both uphold a 'dominant fantasy' of the contemporary constitution of gender norms and to pathologise any efforts to produce gender in ways that are deemed non-conformative (Butler, 2004: 77). In other words, to diagnose is to assume the language of correction and normalisation. Using Gramsci's theory of 'ideologic hegemony' to analyse medical discourse, sociologist Howard Waitzkin (1989) writes that 'ideologic hegemony' is a mechanism of control used by institutions – such as churches, schools, the media and the family - to 'inculcate a system of values, attitudes, beliefs, and morality', that support the established order (Waitzkin, 1989: 223). Thus, when medical professionals convey 'ideologic notions' of desirable behaviour they are expressly endorsing and contributing to hegemonic ideology (Waitzkin, 1989: 223).

What About the Strategic Adoption of Medically Pathologising Terms?

Notwithstanding these pathologising and normalising assumptions, in accord with supporters of the new nomenclature DSD, supporters of GID argue that within medical

domains, the label 'disorder' is a routine, clinically descriptive term providing vital medical certification and assistance. They point to the valuable medical benefits to be had, including medical insurance for gender and/or sex reassignments, and for these reasons they encourage looking at the situation strategically (Butler, 2004; Reis, 2009). This is in line with the views of supporters of DSD who hope that incorporating the medical term 'disorder' will be a successful strategy to count them among the many other medical 'disorders' that mark differences in the functioning of human bodies and are routinely dealt with in a clinical and more ethical fashion (Feder and Karkazis, 2008; Feder, 2009). In responding to arguments in favour of taking a strategic approach to a pathologising term as a vehicle in the attainment of one's long-term goals, Butler questions whether there is still a certain amount of subjection inherent to this 'purely instrumental attitude' (Butler, 2004: 82). For example, this approach may involve internalising some of the term's pathologising aspects, including conceiving of oneself as failing at normality. How successful may children and young adults be at adopting the emotional distance necessary for this stance and could it incur emotional injury or self-esteem issues? (Butler, 2004). And, why is it that only one narrative is available and acceptable in order to facilitate medical treatment and medical insurance coverage (for those strategically adopting GID) and clinical and ethical medical care (for those strategically adopting DSD)? Moreover, similar to the terms *pseudo-male* and *pseudo-female hermaphrodites* (as discussed in Chapter Three), people categorised as DSD are understood as men and women who have a congenital birth condition; they are no longer *Intersex*. Their *Intersexuality* has been erased. They are patients with a treatable disorder (Spurgas, 2009).

Nevertheless, theorists such as Harry Oosterhuis (2000) cautions against looking at medicine as a monolithic agent of stigmatisation and control and the majority of people as helplessly subjected to it. Oosterhuis would rather it be interpreted as symbiotic: beneficial as well as harmful, an insight he gained from his research on Richard von Krafft-Ebing and nineteenth century sexology. Richard von Krafft-Ebing (1840-1902) was a psychiatrist from Vienna who regularly acted as an expert witness in court cases for sexual offenses by submitting forensic reports on the mental health of accused sexual offenders (Oosterhuis, 2000). Krafft-Ebing's interest in this area led him to authoring *Psychopathia sexualis* – an encyclopedia of sexual pathologies originally intended to assist lawyers, officials and doctors in the courtroom (as mentioned briefly in Chapter Two; Katz, 1995; Oosterhuis, 2000). *Psychopathia sexualis* was a compilation of 'psychiatric diagnostics of perversions' comprised of patient letters and autobiographical accounts which were displayed as its empirical material (Katz, 1995; Oosterhuis, 2000: 235).¹⁹ Oosterhuis was given unprecedented access to Krafft-Ebing's estate and was able to examine 440 published and unpublished letters, case histories and autobiographies of patients and contributors to *Psychopathia sexualis*, and reported on finding the following:

- 1) Some of the people who wrote to Krafft-Ebing about their sexual experiences did so providing their own suggestions for new labels, categories and explanations of their sexual behaviour and desires.

¹⁹ This is not to be confused with its predecessor *Psychopathia Sexualis* written by Heinrich Kaan (1844), which although considerably smaller and not as widely read (it listed only six sexual aberrations and was written in Latin), is credited with creating and having a significant impact on the field of sexology, Krafft-Ebing and Havelock Ellis (see Kahan, 2016).

- 2) Krafft-Ebing was attacked by his professional peers for challenging the moral and legal climate of his day; for instance, he openly supported the decriminalisation of homosexuality.
- 3) Although published within a medicalised context, Krafft-Ebing did not manipulate or censor the narratives of his patients and contributors but printed them verbatim.
- 4) Amongst the contributors to *Psychopathia sexualis* were many doctors and students of medicine – such as a physician whose autobiography of over thirteen pages was published in spite of its criticism of the medical profession.
- 5) Krafft-Ebing acknowledged that he had been influenced by his patients and contributors.

The above points demonstrate the ambivalence and some of the complexities of what Foucault referred to as the confessional space (as discussed in Chapter Two) which allowed people to assert their value and individuality in a society which refused to recognise or acknowledge them. It indicates that within the confessional sphere medical pathologisation, bias and judgement sometimes exist alongside medical acceptance, patient self-expression, self-acceptance, self-comprehension and even catharsis. By centring their voices in his work, medical professionals like Krafft-Ebing gave the many people in dialogue with him access to a public platform previously denied to them. This played a significant part in enabling sexual behaviour to be debated in society, changing 'the space of possibilities for personhood' and influencing

the forging of new subcultural communities of belonging (Oosterhuis, 2000; see Hacking in Feder, 2009: 235; Mak, 2012), which brought with it the prospect of meaningful change through struggle, with oppressed groups collectively resisting dominant discursive norms, conventions and systems (Fairclough, 1992). It is possible to see similarities with these arguments and some of the arguments presented by supporters of the nomenclature DSD.

Medical encounters are at their base micro-level processes (involving the interaction of individuals) which are generated by macro-level structures in society (Waitzkin, 1989). The macro-level structures set the specific social context and tone for the micro-level encounters and are primarily designed to reinforce the social order. Professor of French discourses of sexuality Lisa Downing (2015) writes how Krafft-Ebing utilised religious discourse to reify the social institution of marriage, suggested that marriage was necessary for sexual health and promoted censorship of pornographic material. During medical encounters technical statements devised to direct the individual's responses towards symptoms, signs and treatment are rallied as 'scientific fact' for the individual's 'disordered' physiology and/or personality, whereas social structures, relations and issues impinging upon the individual are routinely immune to criticism.²⁰ In fact, Oosterhuis (2000) concedes that the confession fostered compunctious and obsessive self-scrutiny, often exacerbating painful feelings of social rejection and individual failure, without offering any social solutions to an

²⁰ For an in-depth insight into the structural elements in a typical medical encounter please see Waitzkin 1989 where he explicates how the questioning, interrupting and steering are mechanisms used to exclude and/or include certain discussion topics conveying ideologic messages and invoking social control.

individual's outcast status. Essentially, by overlooking social change as a viable therapeutic option, medicine's role in dealing with subjects can be interpreted as the defusing of socially caused distress, which if left unchecked, could potentially fuel political outrage and even resistance (Waitzkin, 1989). Zola (1976) says that the labels 'health' and 'illness' are remarkable depoliticisers of an issue by locating the source and treatment of a problem in an individual. In this way, as bio-power's regulation of bodies, behaviours and interactions via the institutional sphere of medicine extends, the societal causes of suffering become further 'mystified and depoliticized' (Waitzkin, 1989: 225; Preves, 2008).

Correspondingly, whilst Foucault (1981) acknowledges reverse and resistant discourse in his work - the power of a pathologised group to speak its own name and use the terms by which it was medically disqualified - for Foucault this is always circumscribed by power's oppressive terms and limited by the parameters of the oppressor's discourse formation (Fairclough, 1992; Katz, 1995; Foucault, 1998; Feder, 2009). Commensurate to the erstwhile discourses on sodomy and procreative sex (as discussed in Chapter Two), contemporary discourses of sex and sexuality are power-serving and value-laden signifying processes of socio-sexual normalisation developed out of the convergence of criminalisation, pathologisation and the creation of taxonomies for sexual perversions (Katz, 1995). They are not biologically given, scientific 'facts', nor are they ahistorical, but represent institutionalised practise and ideology (Katz, 1995; Cameron and Kulick, 2003).

Pathologisation, medicalisation and normalisation permeate contemporary diagnostic classifications of particular sexed bodies, sexual identities and sexualities (Lev, 2006a). As the DSM's categorisation of heterosexuality and gender identity show medico-psychiatric nomenclature is not random and does not occur because of new scientific knowledge, ground-breaking discoveries or breakthroughs. These 'expert' discourses mirror ideological shifts in the wider society, as is apparent when certain classifications such as the frigid woman, the nymphomaniac, onanists and frottists, are quietly removed (Cameron and Kulick, 2003). Cameron and Kulick (2003) write that our ideas on what is good, bad, normal, permissible, acceptable and real are all bound up in the language we use to define and to speak. Sexologist Milton Diamond (2009), whose research covers anatomy and reproductive biology, rejects the taxonomy DSD preferring instead the terms 'differences' or 'variations' of sex development. Diamond argues that 'pregnancy' is a condition which is not labelled a 'disorder' and still benefits from US medical insurance coverage without the accompanying demeaning and stigmatic associations (Diamond, 2009). I believe this is a good and telling example. Pregnancy, like *Intersexuality*, can carry a spectrum of health concerns ranging from mild to life-threatening (as discussed in relation to *Intersexuality* in Chapter One). However, due to its proximity (and conformity) to ideologies of sexual difference and heterosexuality, which uphold and sustain the male/female dualism, pregnancy does not have to be surveilled and regulated in the ways that *Intersexuality* has to be. Essentially, DSD is a part of a regulatory discourse. Ultimately, this discourse deploys labels, names, incursions and invasions as part of an arsenal designed to gauge individuals against its standards of normalcy (Butler, 2004).

Conclusion

The aim of Section One was to decipher what it is that allows surgical access to bodies categorised as *Intersex* in ways that have a profound effect on how *Intersex* people live *Intersex* in Western societies. It brought together some of the major themes from the existing literature to intellectually examine this issue. Chapter One considered the criteria for classification of people as *male*, *female* and *Intersex* and showed how this classificatory project is multiply contingent and variable. It questioned whether *Intersex* is in fact a rare phenomenon or if this speculation has something to do with its medical definition and treatment as a 'sexual disorder'. Chapter Two exposed how sex categorisation, and other dichotomous categories related to sex support the political, economic and cultural differences of those classified as *male* and *female*. Sex categories are a vehicle for the social organisation of bodies.

Chapter Two also revealed how medicine gained its professional status by becoming indispensable to the public order in organising and typing human sex behaviour in the nineteenth century. Medicine pronounced certain sexual behaviour as 'disordered' or as a sickness in need of medical attention and attached these behaviours to profiles of particular types of people. This proved invaluable to the state at a time of intense interest in the regulation of bodies - what Foucault refers to as 'bio-power'. Bodies and behaviours were adjudged to be degenerate or perverse set against opposite-sex desire, activity, marriage and a burgeoning heterosexual norm. This assessment sanctioned intimate examinations, confessional counselling, case histories, report-

writing and more. These institutional mechanisms are in evidence in many medical disciplines. They allow bio-power to operate in more effective, systematic and subtle ways with the full compliance of the subject who believes they are uncovering a 'truth' about themselves. Essentially, sex, sex behaviour and the body are manipulated for social control.

Chapter Three portrayed how medicine gained jurisdiction over the *hermaphrodite* body and consolidated its institutional authority. The postulation that everyone has only 'one true sex' which can be placed into its proper social realm allowed for an inordinate focus on bodies that did not fit and were perceived as a threat by blurring societal boundaries. *Hermaphrodites* were soon proved guilty of possessing such bodies. Medical texts depicted *hermaphrodites* as women in disguise, masquerading and 'passing' to wreck families, gain independence and indulge in licentious behaviour. They were anatomical oddities whose bodies needed correction. Significantly, medical narratives advanced heterosexual marriage as the desirable and orderly outcome for *hermaphrodites* revealing how medicine enforces cultural norms.

Chapter Four looked at the philosophy undergirding Western societies since the seventeenth century to ascertain its influence on the medical case management of *Intersexuality*. It analysed the mechanistic world view promoted by Cartesian dualism that pits a superior, truth-seeking mind against an inferior body-object. It showed how this mind/body dualism has always been infused by socio-political hierarchies and cultural representations related to sex and gender. It also supplied evidence to

suggest that the mind/body dualism permeates the biomedical realm in Western societies and is apparent in the contemporary medical management of *Intersexuality* in three key areas. First, the construction of patients as passive, disordered, mechanical objects with mechanical parts in need of repair and correction. This legitimises genital normalising treatment performed on *Intersex* babies and infants, as they are constructed as objects par excellence and surgical procedures are believed to have little to no impact on their adult lives. Second, by equating medical practitioners to the mind and patients to the body. This dichotomy places medical practitioners in a hierarchically superior position to their patients within an environment which accords them absolute power. With respect to *Intersex* patients this translates to: not being involved in the full decision-making processes for their own bodies, being subject to treatment that is objectifying and alienating, not having their concerns addressed when they complain of harm or injury, being discouraged from meeting other *Intersex* people and an insistence on confining all aspects related to their condition to the medical sphere. All of these scenarios are disempowering. They reduce *Intersex* people to diagnostic tools to simply be acted upon. Third, the application of the sex/gender dualism in the management of *Intersexuality* that treats sex as natural and prediscursive and gender as cultural and discursive allows for the surgical sexing of *Intersex* babies and infants to fit them into a heteronormative ideal. Successful outcomes are based on heterosexist ideologies that connote *male* with a large penis for penetration and *female* with an empty receptacle to receive the *male* penis. These factors underpinned the case that established the treatment for *Intersex* people in Western societies, namely the tragic case of David Reimer. His case brought into sharp relief the way that surgical sexing is primarily influenced by sex dimorphic

ideologies which mark individuals as intelligibly human only if they conform to culturally recognised standards of sex and gender intelligibility, which demand coherence and stability between sex, gender, the body, sexual desire and sexual practice.

Based on the previous four chapters it is not difficult to apprehend why the first *Intersex* movement forged alliances with LGBTQ activists and groups. They joined together with people who had also been fighting against their classification as disordered and sick stemming from nineteenth century typologies of sex and sexual behaviour. Chapter Five has mapped this important moment in the genealogy of the *Intersex* movement which occurred in the early 1990s and described how since living *Intersex* was impossible in a dualistic society they fought to carve out their own liveable spaces by challenging their medicalisation and the management protocols established by Dr. John Money and colleagues. Rejecting their pathologisation entirely included positive reclaiming of the words *hermaphrodite* and *Intersex*. For the new *Intersex* movement, this was part of a process of validating *Intersexuality*. They refused to be engulfed by secrecy and shame by being 'out' and living proud as *Intersex* people which for them involved embracing and publicly articulating *Intersex* difference as a queer, non-normative identity. Chapter Five also outlined the struggle to eradicate pathologisation and secure healthcare that is on a par with normative categories of sex.

Finally, the nomenclature 'disorder', and the motivations for and against its adoption by the *Intersex* community, was analysed to illustrate the complexities of navigating institutions when your body, behaviour and identity has been problematised. The endorsement of dualistic philosophies, ideologies and discourses based on sex and gender by these institutions are discernible in the use of the word 'disorder' in the DSM. It would appear that social bias, regulation and control still provide the raw materials for contemporary biomedical diagnostic classification and treatment. These and the points covered in the previous four chapters are key themes in *Intersex* management and form the backdrop to Section Two where they are utilised to inform and animate the analysis of my interviews with my seventeen study participants about their experiences of living their lives as *Intersex* people.

Section Two: Living *Intersex*

Section Two is comprised of Chapters Six to Eleven. Chapter Six explains how I designed and implemented my *Intersex* research. It examines the methodological justifications for the many decisions I made and grappled with during the research process. As described in Section One, *Intersex* people are part of an invisible, hidden and marginalised demographic due to societal conceptualisation and medical case management that currently results in traumatic genital normalising surgeries. What this means is that *Intersexuality* represents a highly sensitive research area. The chapter therefore also outlines some of the key ethical dilemmas that need to be addressed when pursuing this type of subject matter, as well as how to be alert to power hierarchies and avoid the pitfalls of representation (however well-intentioned). Some of these had very practical solutions, whilst a few will remain unresolved. Finally Chapter Six details the strategies I used to analyse the data from my seventeen in-depth interviews.

Chapter Seven, 'Introducing the Participants' presents the biographical portraits of the seventeen *Intersex* people at the heart of my study. This is followed by Chapter Eight, 'Intelligibility and *Intersex*' which expands on the theme of sex and gender intelligibility as discussed in Chapter Four to explore the challenges that living *Intersex* in a binarised society presents when you are marked as unintelligible and how these challenges are navigated.

Chapter Nine, 'Parental Secrecy and Shame' takes a closer look at the family to foreground the parents of *Intersex* children. Parents convey what is 'normal' and 'abnormal' to their children, but what if your child is *Intersex* within a sex dichotomous society? What if you are without therapeutic resources or educational tools with which to adapt yourself and your child to their *Intersexuality*? The magnitude of being a parent of an *Intersex* child is confronted in this chapter. It shows how sex and gender norms invade family life and the many ripples these create. Specifically, it deals with how *Intersex* adults experienced their childhood within such circumstances, their subsequent adjustment to living *Intersexuality* and how they believe things could be improved.

Chapter Ten draws on some of the key theoretical resources presented in Section One to explore 'The Medicalisation of *Intersexuality* in Practice' with a specific focus on *Intersex* babies and infants as malleable, body-objects and the never-ending treadmill of *Intersex* medical management once it has been set in motion. It covers the 'one true sex' rhetoric and whether this is compromising medical expertise in *Intersexuality* and how the operation of sex and gender norms is discernible in the removal of testes and restriction of access to testosterone to *Intersex* people who are assigned *females*. It also considers what the construction of *Intersex* as rare and a medical emergency legitimises.

Chapter Eleven elaborates on the themes discussed in Chapter Five on the emergence of the *Intersex* movement. It is a chapter about metamorphosis and forging a new

identity which examines the challenges associated with 'coming out' and being 'out' when you are from a demographic in society that is silenced, hidden and erased. It addresses the proximity of *Intersex* people to LGBTQ and other oppressed groups, and some complexities of appropriating and contesting self-identifying nomenclature originally intended to pathologise. In addition to these aspects, the chapter considers whether *Intersex* should engulf a person's life. What about other intersecting identities, such as race, disability and transgenderism? The ambivalent space of community is also explored. As shown in Chapter One, *Intersex* is an umbrella term for over forty different conditions, yet can this diversity ever be properly represented and accommodated by an all-inclusive *Intersex* community? Will some conditions always be elevated at the expense of others? The role of education and love as a positive vehicle for transformation and healing is emphatically proffered and concludes the chapter.

Chapter Six: Methodology

This chapter describes how feminist research methodologies and methods helped me to think about what it means to be a researcher representing a marginalised group, by encouraging me to recognise ethical dilemmas relating to power and equipping me with the tools and techniques to disrupt power hierarchies throughout the various phases of my research project. The chapter also reviews some of the complex concerns I had to reflect on and address when planning and undertaking my *Intersex* research. *Intersexuality* is a highly sensitive research topic; therefore abiding by ethical guidelines of confidentiality and fully informed consent, drafting sensitive and respectful interview questions and keeping a research diary to document my engagement with this very sensitive issue are discussed in the chapter. The chapter also examines my use of qualitative methods in the research and the recruitment challenges I encountered in seeking research participants for a hard to reach and hard to access group. Finally, the chapter chronicles the different stages and strategies of my data analysis. It describes how I employed spidergrams, tables, lists, and wrote case studies and biographies as part of this cyclical process. It links all of these techniques to my engagement with the research population, the theoretical resources presented in Section One and my research aim and questions, all of which assisted me with the task of unearthing and generating the theoretical concepts that were subsequently elaborated upon in my data analysis writing.

Feminist Research Methods

In researching people with *Intersex* conditions, I selected to use feminist research methodologies and methods. Feminism identifies and challenges ideologies that justify, ignore and conceal societal discrimination, exploitation and inequality based upon sex and/or gender categories (Roberts, 1981). Guided by feminist theory, feminist research and knowledge production examines and exposes how information has been gathered, distorted and overlooked by androcentrism (Reinharz and Davidman, 1992). It continues to demand a reassessment of empirical inquiry, holding the view that all social, psychological and economic phenomena are gendered and embedded in power relations (Reinharz and Davidman, 1992). Feminism is concerned with emancipation (Francis, 2003). The feminist research project re-evaluates and reforms knowledge by overturning systemic gender disparities, rejecting hierarchies between the researcher and research participant and questioning social policy to promote social change (Gunaratnam and Hamilton, 2017).

Feminist methodological imperatives are well-suited to my *Intersex* research study since they are informed by a demystification paradigm. This incorporates the claim that knowledge production which demystifies a group's situation can exert a powerful and life-changing influence on their circumstances. Conversely, silence and invisibility stemming from a lack of research can perpetuate powerlessness. Since the 1980s, the concepts, devices and practices of feminist research have named new topics, made the invisible visible, brought the margins to the center, rendered the trivial important and questioned why certain topics are ignored; it has done this whilst

inciting debate about the politics of knowledge-production (Reinharz and Davidman, 1992; Gunaratnam and Hamilton, 2017). Feminist research demystifies theories and practices in society. In so doing, it can raise the political consciousness of the research population who have been rendered powerless by their situation, and enlighten those in society who are ignorant of them, causing both parties to reappraise and even resist distorted ideological definitions of reality (see Ferguson in Reinharz and Davidman, 1992). With respect to my study, *Intersex* people remain a marginalised, silenced, invisible group who are routinely subjected to surgical interventions and lifelong medical management motivated by dualistic cultural assumptions and patriarchal definitions of sex and gender (Fausto-Sterling, 2000; Holmes, 2008; Karkazis, 2008). My project is one of demystification since its objective is to provide education about *Intersexuality* and show how it is treated in Western societies. It aims to do this by revealing what it is that underpins current invasive treatment protocols and the effects of these on the lives of *Intersex* people. It is my hope that this analysis will help to empower *Intersex* people (and their loved ones) by initiating positive change in the medical management of *Intersexuality*.

A key feminist position is to recognise issues of power in the research process, in particular, the power a researcher has in representing the lives of others in written research, along with the moral, ethical and political dilemmas this can entail (Stanley, 1996). To represent another is to be in a position of power and therefore responsibility (Wilkinson and Kitzinger, 1996). The very act of representing is an expression of one person's powerfulness relative to another's powerlessness

(Wilkinson and Kitzinger, 1996). As explained by feminist, post-colonial theorist and independent filmmaker Trinh T. Minh-ha (1989), a conversation about 'them' among 'us' is a conversation where 'them' is silenced; 'them' is only admitted among 'us' when accompanied or introduced by 'us'. In other words, the danger is that those involved in representing others could be viewed as 'authenticating presences' who legitimate and confer credibility onto the subjects that are represented (Martín Alcoff, 1995: 99). The speaker is positioned as the authoritative, empowered and knowledgeable subject (Martín Alcoff, 1995). This can serve to reinforce the dependency and silence of 'them' – the powerless object and victim who must be championed - and emphasise the power and privilege of 'us' (Minh-ha, 1989; Martín Alcoff, 1995). Hence, a crucial preoccupation to emerge which problematises a critical feminist analysis has been the question of whether feminist researchers should be representing Others and what is it that qualifies a feminist researcher to speak from and about a position (Roof and Wiegman, 1995).

Representing Others?

There has been much debate surrounding whether feminist researchers should in fact be speaking for Others (hooks, 1986; Martín Alcoff, 1995; Roof and Wiegman, 1995; Stanley, 1996; Wilkinson and Kitzinger, 1996). As my research explores the experiences of *Intersex* people and I do not have an *Intersex* condition, this question was very pertinent to my study and required scrutiny. On the one hand, feminists who advocate speaking only for ourselves and leaving Others to represent themselves, promote maintaining a respectful silence whilst 'pointing to the silence' of Others

(Wilkinson and Kitzinger, 1996: 10). What this means is working to create the social and political conditions necessary for Others to both speak from and be heard on their own terms (Wilkinson and Kitzinger, 1996). On the other hand, a question posed to feminists who take this stance is: who exactly would they define 'us' or 'ourselves' to be? Group identifications rarely contain fixed and clear-cut boundaries and the concept of 'membership' can be arbitrary, making the task of delimiting and demarcating a group identity - an 'us' - open to many differing and conflicting interpretations (Martín Alcoff, 1995). One fear is that speaking only for 'ourselves' as feminists could give rise to an 'over-representation of the views of white, middle-class, western women' whose privilege affords them comparatively more opportunities to both speak and be heard (hooks, 1981; Wilkinson and Kitzinger, 1996:12).²¹ This essentialises the category 'woman' by submerging or completely disregarding the multiple ways that women are oppressed due to their race, gender, class, sexual orientation and more (hooks, 1981; Wilkinson and Kitzinger, 1996). It is reminiscent of the charge levelled at second wave feminism by Black feminists who accused 'bourgeois white women' of having a 'romantic reverie' of Sisterhood (hooks, 1986: 127) which created a false universalising of 'us' by overlooking ethnic, race, class, as well as other differences and distinctions, thereby contributing to what Black feminists saw as violent, oppressive and imperialising tendencies (hooks, 1981; Carby, 1982; Phoenix, 1987; Hill Collins, 1991; Wilkinson and Kitzinger, 1996).

²¹ In *'Ain't I a Woman: black women and feminism'*, bell hooks writes, 'it is significant that in our society white women are given grant money to do research on black women but I can find no instance where black women have received funds to research white women's history' (hook, 1981: 10).

Researcher/Research Participant 'Fit'

It was an ongoing ethical concern to consider that my *Intersex* research could unwittingly be reinforcing and reinscribing the Otherness of people diagnosed as *Intersex* because I am not a person with an *Intersex* condition (Wilkinson and Kitzinger, 1996). Nonetheless, it has also been called 'methodologically misleading' (Ang-Lygate, 1996: 54) to assume affiliation to research participants based on one identity category, for example, *Intersex*, whilst neglecting to account for other concurrently occurring axes of identities such as: ethnicity, sexuality, class, whether the person has a disability and so on (Ang-Lygate, 1996). Moreover, feminist literature has shown that even when there is an identity 'fit' between the researcher and the research participant, 'problematic differences can still arise' (Francis, 2003: 64; Bhopal, 2010). Moments of empathy, due to a shared experience, can be positive and enlightening but equally, 'psychically painful' (Francis, 2003: 64) and 'fraught with tensions' (Bhopal, 2010:191). As already highlighted, group membership is re-negotiable (Stanley, 1996) and rarely, if ever, homogenous (Wilkinson and Kitzinger, 1996). No group speaks in a single voice with only one point of view that can be faithfully represented (Wilkinson and Kitzinger, 1996). This applies to my *Intersex* research. As detailed in Chapter One, *Intersex* is an umbrella term which is used to describe over forty different conditions that confound conventional notions of *male* and *female* (Holmes, 2008). What this means is that one person could identify as *Intersex* in a way that is completely unknown and unrecognisable to an entire demographic of *Intersex* people possessing other conditions. Accordingly, even if I identified as *Intersex* I could not presuppose affiliation with an *Intersex* research participant. No

identity category is 'fixed, distinct and uniform'; they are multiple and shifting, as well as affected by context, space and time (Carabine, 1996: 168).

Celebrating Otherness

In attempting to circumvent issues raised with speaking for Others, some feminists have instead opted to celebrate Otherness (Wilkinson and Kitzinger, 1996). The rationale behind this being that the dominant culture typically portrays marginalised Others as inferior and pathological, so a rejection of this representational tactic would be celebration. Documenting the survival skills, strengths, cultures and traditions of Others is therefore a strategy used to counter their pathologisation (Wilkinson and Kitzinger 1996). This approach appealed to me due to the erasure and stigmatisation of *Intersex* (Fausto-Sterling, 2000; Butler, 2004; Holmes, 2008; Karkazis, 2008), the very recent entrance of *Intersexuality* into the social sciences and my activist sensibilities. Nevertheless, this strategy is not risk free. In championing the cause of the Other, and wishing to avoid any criticism of them, feminist researchers need to beware of romanticising them, exaggerating the heroic and inadvertently projecting onto the oppressed Other their own political and social ideals (Wilkinson and Kitzinger, 1996). Positive claiming of the Other could be accused of universalism. Its point of departure is contingent on positioning the Other in a dichotomy of oppressed/oppressor. This binary not only fixes and reinforces existing hierarchical power relations, rather than working to erode them (Carabine, 1996), but also neglects to consider that some Others may prefer to 'fit' dominant social norms rather than represent a minority role.

Representing *Intersex* People in My Research Project

There are no easy solutions to the many ethical decisions on how to work 'with/for/despite those cast as Others' (Fine as cited in Wilkinson and Kitzinger, 1996:16). For a feminist researcher it carries accountability, responsibility and a willingness to remain open to criticism (Martín Alcoff, 1995). All representation is problematic because it is implicated in power, discourse and location in very complex ways (Martín Alcoff, 1995; Stanley, 1996; Wilkinson and Kitzinger, 1996; Francis, 2003). Feminist researchers need to be alert to those material differences between researcher and participant, such as class, age and ethnicity, which hold power implications and try hard to ensure that these do not disempower their research participants (Francis, 2003). In writing up the research, feminist researchers need to be sensitive to disrupting discursive hierarchies and the dynamics and relationships of power which have historically and politically determined how the Other is being represented (Martín Alcoff, 1995; Ang-Lygate, 1996). Using this rationale, I was determined that, although my participants supplied the data for my study, they were not wholly constructed as data, but recognised as people with valuable life stories and experiences to share in an important and under-researched field of study. I endeavoured to acknowledge and communicate this (implicitly and explicitly) in my research project in the following ways:

- I took note of an observation that the word 'respondent' can be understood as part of a masculine paradigm which defines research participants as passive and part of a context where the interviewer is actively engaged in constructing their role as passive (Oakley, 1981). This paradigm overlooks the ways that interviewing is an interactive process, where accounts produced are acknowledged as a result of

the interviewee's interaction *with* the interviewer and can be affirmed in the power to name/rename interviewees as 'participants' rather than 'respondents' (Oakley, 1981; Edwards, 1993; see also subheading 'The Semi-Structured Life World Interview'). Involved in this construction is a refusal by the researcher to reveal any information regarding their own beliefs and values (Oakley, 1981). To disrupt this power hierarchy I refused to use 'respondent' in my study selecting 'participant' instead, a word which centres the active contributions of research participants and the interactive process of the research project. Additionally, I was transparent with regard to my aims, values, beliefs and motivation for the project (see subheading 'Activist work and Online Engagement with Intersexuality').

- I refused to put any personal descriptions or information relating to my participants in the Appendices section, as though they were an unimportant attachment or appendage to my study.
- I was careful not to 'talk over' my participants in my data chapters. Rather than repeatedly using my words to paraphrase theirs, I have inserted large quotes of their speech in my analysis chapters.
- When providing details of my sample in this chapter, in the table I compiled (see 'My Sample') of brief profiles of my participants including their name (or pseudo-name as appropriate), age, *Intersex* condition, place of residence, marital status (and more), I chose to add a column beside these 'facts and figures' with a self-descriptive sentence or two in the words of my research participants.
- In addition to composing brief biographies of each of my seventeen participants (the longest comprising 426 words and the shortest 196 word), I compiled detailed case studies of four participants for my research project. These four life-histories are deliberately placed at the beginning of each of my data analysis chapters.

Finally, attention also needs to be paid to where the research is going. The feminist researcher has a responsibility to evaluate the historical discursive context when disseminating their research; where words interact with their hearers in very precise historical contexts (Martín Alcoff, 1995). This needs to incorporate consideration of

where those they are representing, they (as the speaker) and their listeners are located (Martín Alcoff, 1995).²² With regard to dissemination of my research, before I joined King's College London, I asked an *Intersex* person how I could help *Intersex* people be better supported. Their answer was assisting with *Intersex* visibility and education. In light of their answer, from the outset of my research it was my wish to make it accessible and available to all. Although writing within the constraints set by academic conventions, I have paid close attention to my expression in writing and tried to distil and clarify key theoretical concepts and terminology by writing in a way that is comprehensible (an example of this is in the introductory paragraph of Chapter Two, where I have posed five questions before embarking on the topic matter). Ultimately, I would like my work to be used as an educational resource in both academic and non-academic realms encompassing biomedical theory and practice, the social sciences, activist settings, social policy and practice, diversity training, places of employment and a plethora of cultural and artistic spaces where sex, gender, identity, sexuality, the body (and related) concerns are explored; whether in person, on stage, online and in exhibitions. It is also my wish that, if invited to speak about my *Intersex* research, to endeavour, where possible, to have an *Intersex* person present, since, as already discussed above in 'Representing Others?', they can importantly speak from and be heard on their own terms.

²² In 'The Ethics and Politics of Sensitive Research', *Researching Sensitive Topics* (1993), Joan E. Sieber provides some helpful practical considerations when interacting with the press, politicians, talk show hosts and special interest groups which may avert social backlash, bad public policy and more.

Rather than pursuing a 'voyeuristic', 'one-way mirror' approach, feminist researchers are encouraged to recognise themselves in Others by explicating the dynamics of privilege and mutual investment (Burman, 1994). This is done with a view to disseminating new perspectives on the disciplinary matrix which constructs us as well as Others (Burman, 1994). 'Intellectual autobiography' is an epistemological project which explicates the personal in feminist research (Stanley, 1996: 45). It is reflexive, therefore open in declaring the standpoint of the researcher and how their discursive position impacts on research findings and dissemination (Francis, 2003). In poststructuralist terms, this acknowledges that representing Others is an act of constructing the subject position of the Other based on the researcher's 'own situated interpretation' (Martín Alcoff, 1995:101). The emphasis is analytic, rather than descriptive, for it conspicuously acknowledges that there is an 'experiencing and comprehending researcher' (Stanley, 1996:45) who is intellectually engaging with knowledge production techniques, and is subsequently able to display their argumentative processes and grounds for knowledge claims (Stanley, 1996). This is in direct contrast to the absent and 'detached scientific observer/researcher' (Stanley, 1996:45), for it incorporates and elevates feminist consciousness by analytically exploring it as a form of praxis (Stanley, 1996). In this way, the researcher's ontological reasonings are foregrounded and any issues of representation can be critically engaged with by readers (Stanley, 1996). In the spirit of intellectual autobiography and reflexivity, 'My introduction to *Intersexuality*' (see Appendices) gives an account of how I became interested and involved in *Intersex* research and activism.

Access to and Recruitment of a Hard to Reach Group

People with *Intersex* conditions comprise a hard to reach and hard to recognise group making research recruitment challenging. One large *Intersex* organisation I approached explained that they would only agree to support and participate in research which their members had helped to design from its inception. An administrator of another large online *Intersex* group told me I would be unable to recruit participants via their forum and shortly afterwards posted a piece on their page condemning academic research. I was not wholly surprised at these reactions; it was after all the academic research of Dr. John Money advocating a post-natal surgical intervention model on babies diagnosed as *Intersex* in the 1950s, which many adults with *Intersex* conditions have been subjected to and are now daily grappling with the physical, mental and psychological side-effects of. My attendance at the *Intersex and Trans Alliance Conference*, held in Edinburgh on 31 October 2014, also underscored the challenge of sourcing participants for my research study. I registered in anticipation of meeting many *Intersex* people in person, but was surprised to find that out of approximately 150 attendees (on Day One) only three were *Intersex*, two of whom were registered as speakers. 'We're expecting two more tomorrow', one of the speakers replied in response to my inquiry, adding, 'They never come...' It was still a fruitful trip, and one of the speakers interested in my project later became a participant.

Snowball Sampling

Direct recruitment requests posted onto the online groups *Intersex UK* and *Intersex and Trans Alliance* proved very effective, and then once interviewed, 'snowballing' by participants recommending me to people they knew - by group email and Facebook - occurred. 'Snowball sampling' (Kaplan et al., 1987; Atkinson and Flint, 2001) is frequently used in qualitative research as a method for social researchers to gain access to socially stigmatised, hidden and otherwise impenetrable populations (Atkinson and Flint, 2001). Its main value lies in uncovering aspects of social experience obscured from the mainstream by obtaining evidence of the lives of concealed and marginalised populations, where conventional methods of identification and contact would prove ineffective (Atkinson and Flint, 2001). This referral-based technique, often found to be economical and efficient, is not without its limitations. The primary deficiency of snowballing is selection bias or a skewed sample (Van Meter, 1990; Kaplan et al., 1987), since participants are selected based on the subjective choices of an initial participant - or the referee - who usually belongs to the same social network, which could lead to an over-representation of a particular group, whilst ignoring individuals who may not be part of any cohesive social network (Van Meter, 1990; Atkinson and Flint, 2001).

Snowball sampling worked well for me although my sample does have noticeable characteristics which may have been inevitable given the subject matter and my timescale. It is a conspicuously older sample and the majority are *Intersex* activists. As Section One has shown, and my data chapters corroborate, there is typically an

immense amount of secrecy and shame entailed in living *Intersex* which starts before the *Intersex* child is physically aware of their *Intersex* condition (see Chapter Nine). *Intersex* people who have grown up within such an environment sometimes only start the process of seeking accurate and comprehensive information about their condition during estrangement from, or after the death of, one or both of their parents which eventually can lead to 'coming out' as *Intersex* in private and public ways (see Chapter Eleven). This could account for the age range of my sample which is predominantly comprised of *Intersex* people who are in their fifties and older. They also represent the pre-internet generation where information on *Intersex* was neither easily accessible, nor obtainable (the ramifications of this are also discussed in Chapter Nine). With respect to the activist slant of my sample, social visibility has been cited as a 'strategy for destigmatisation and empowerment'; it externalises feelings of secrecy and shame (Preves, 2008: 137). There is also the question of momentum with snowball sampling; generating a diverse sample for a hidden area such as *Intersexuality* takes time, due to rapport and trust building. As a funded doctoral student I had to complete my interviewing within an allotted timeframe, to allow sufficient time for transcription and in-depth data analysis. Unfortunately, this meant I had to decline late requests for interviews that a few months earlier I had been seeking. Ideally I would have liked to have a sample more diverse in terms of age and social visibility, I recognise that there are missing voices, but when looked at from the perspective of the genealogy of *Intersex* I understand why at this moment in time it has not been the case for my study.

Diversity of Sample

Black and brown people remain invisible within the highly sensitive, hard to access research topic of *Intersexuality*. As explained in the Introduction to Section One, *Intersex* research is on the whole dominated by a white, North American context (with respect to both the researchers and the research participants), due in part to the fact that *Intersex* activism emerged from this demographic. Having partially shifted this trend by being a Black researcher, I made a concerted effort to do the same with my research sample; diversity also being an indicative feature of sound feminist research (Reinharz and Davidman, 1992). This included attaching the link to my Facebook profile page which included my photograph in online recruitment requests, as well as overtly sharing my wish to fill the lack of representation in *Intersex* research when approaching Black and Brown people with *Intersex* conditions. This strategy did prove fruitful, although unfortunately my timescale worked against me. The *Intersex* forums of which I was a member also had a dearth of Black and Brown people and it took time to build trust and eventually locate potential participants from Africa which could have led to snowball sampling. However, the interview phase of my project had to draw to a close. I could not extend it beyond nine months. Yet this has laid a very good foundation for future research.

Nevertheless, I was still pleased to have people who were non-white and/or living outside of North America in my study - from places such as Asia, the Middle East, Europe and New Zealand – who were diverse in terms of their sexual identity, gender identity and *Intersex* condition, including those who had undergone consensual or non-consensual surgery. Since my interview questions were deliberately broad to

guard against unethical and intrusive insensitivity, I am unable to precisely clarify and quantify all of the nuances of my participants' identities. Being mindful of the words of Morgan Holmes (2008), who cautions would-be researchers that individuals diagnosed as *Intersex* who have undergone genital normalising treatment could understandably be reluctant to allow further access to their 'already overaccessed bodies' (Holmes, 2008:64), I chose instead to empower interviewees by giving them the opportunity and the space to decide how and whether to answer and/or elaborate upon my broad interview questions. I also wanted to ensure that my questions did not trigger any negative associations of institutional modes of formal questioning. In retrospect, a multi-method approach may have held the solution, comprising a questionnaire structured to systematise information related to the diversity of my participants, which could have potentially helped to supplement my interview questions.

My Sample

Brief description	In their words
<p>Autumn</p> <p><i>Intersex</i>, attracted to women, testicular gonads removed as a baby</p> <p>Age: 50</p> <p>Resides: USA</p>	<p>Uh, well I identify as Intersex...and if you are asking how do I identify sexual orientation, uh, I consider myself attracted to women primarily.</p>
<p>Bo Laurent</p> <p><i>True hermaphrodite</i>, assigned male at birth,</p>	<p>When I was ten my parents took me aside and they told me that uh...I had been born with an enlarged clitoris and the clitoris is something that would have been a penis if you were</p>

<p>subsequently reassigned female at eighteen months</p> <p>Lesbian, Married</p> <p>Age: 58</p> <p>Resides: USA</p>	<p>a boy, but if you're a girl you don't need one. So they had it removed when I was an infant. And that was all the explanation they ever provided me.</p>
<p>Bridget</p> <p>Complete Androgen Insensitivity Syndrome</p> <p>Age: 19</p> <p>Resides: Iceland</p>	<p>[M]ostly female.</p> <p>I've always been Intersex and I don't know anything else so...so it doesn't bother me.</p>
<p>Clara</p> <p>Woman, Mosaicism, Turner Syndrome</p> <p>Age: Unknown</p> <p>Married</p> <p>Resides: USA</p>	<p>I identify as a woman but I also understand that my body is not strictly female...that, it's a mixture or maybe not even a mixture so much as, I don't have any reproductive system to speak of, because everything was taken out a long time ago.</p> <p>I'm mosaic, I have a Y chromosome in some of my cells...and so I ended up with a smaller jaw because that's one of the things that happens in Turner Syndrome and, apparently it doesn't affect the size of your teeth though...</p>
<p>Courtney</p> <p><i>Intersex, XX, pseudo-hermaphrodite</i></p> <p>Age: 54</p> <p>Resides: USA</p>	<p>I identify as Intersex; not male or female.</p> <p>I'm XX. I have a uterus. I have menstrual periods and everything...but my genitals appear to me to be... and other people, when, before they were cut, appeared to be in the middle...</p>
<p>Dana Zzym</p> <p><i>Intersex, hermaphrodite, disabled</i></p> <p>Age: 50 – 60s</p> <p>Divorced</p> <p>Resides: USA</p>	<p>I have...a very small penis...uh...uh...I have testes but I also had a, a vaginal opening of some sort...</p>

<p>Darryl</p> <p>47 XXY Klinefelter's Syndrome</p> <p>Age: Unknown</p> <p>2 children, divorced</p> <p>Resides: Middle East</p>	<p>I...see myself as masculine man... I'm 47 XXY Klinefelter.</p>
<p>Gavan Coleman</p> <p><i>Intersex</i>, Klinefelter's Syndrome, XXY</p> <p>Age: 30 – 40s</p> <p>Resides: Germany</p>	<p>Uh, well I'm definitely Intersex...so I don't identify as 'male' and I wouldn't identify as 'female' even if I was wearing all female clothes and had make-up on me. I would just say I was Intersex and I would like to be treated as 'Intergender' you know, I wish I were gender- neutral as a kid, let's put it that way, so...but how do I identify, the question? Yes I identify as Intersex...I think best describes me...</p>
<p>Hiker Chiu</p> <p><i>Intersex</i></p> <p>[Congenital Adrenal Hyperplasia, is unsure]</p> <p>Age: 48/49</p> <p>Resides: Asia</p>	<p>I remember that my mother told me that 'You were born, like, both,' and [...] when I was forty-two.. I was trying to write my own story as an Intersex [...]. So, I...take my medical record out and read [...]. So, I...found that I was born with...uh, ambiguous genital, genitals...so, it was written in the medical records...</p>
<p>John</p> <p>Male, <i>Intersex</i> person, 46 XY, Hypospadias, Chordee</p> <p>Age: 56</p> <p>Married, 3 children</p> <p>Resides: USA</p>	<p>I identify as a...male, Intersex person, and I say male specifically because I've had it tested at least three different type of karyotype tests to confirm it is 46 XY. However I was born with a uterus and...ovo-testicles, which is a mixture of ovaries and testicles, all of which had been removed last March [2014]...but I still consider myself Intersex. I still have a couple of the other Intersex conditions such as hypospadias and chordee.</p>

<p>Jools</p> <p><i>Intersex</i>, Transgender, Female, Assigned <i>male</i> at birth</p> <p>Age: 50 - 60s</p> <p>Resides: Confidential</p>	<p>Uh...how do I identify...I identify as [...]</p> <p>Intersex...Transgender...Female...but assigned male. Does that make sense?</p>
<p>Katherine</p> <p><i>Female</i>, Lesbian, Congenital Adrenal Hyperplasia, Disabled</p> <p>Lives with her partner</p> <p>Age: 50s</p> <p>Resides: UK</p>	<p>Female...lesbian and someone born with an Intersex body.</p>
<p>Kitty</p> <p>Gender-fluid, Pansexual, <i>Intersex</i>, Androgen Insensitivity Syndrome</p> <p>Age: 32</p> <p>Resides: Iceland</p>	<p>[laughs] Uh, ... gender-fluid... pansexual, Intersex.</p>
<p>Leidy Tatiana</p> <p><i>Intersex</i> person, <i>hermaphrodite</i> person</p> <p>Age: Unknown</p> <p>1 son</p> <p>Resides: Latin America</p>	<p>I identify as Intersex person, because like, being activist in Latin America and defend the rights of these Intersex people I have taken this autonomy, and since I know I've had this biological composition with whom I feel great and proud because I am happy to be an Intersexual person or a hermaphrodite person as it was called earlier.</p>
<p>Mani Bruce Mitchell</p> <p><i>Intersex</i>, gender-fluid, queer</p> <p>Age: 50 – 60s</p> <p>Resides: New Zealand</p>	<p>[G]ender-fluid, uh, queer in terms of my sexuality, uh...happy.</p>

<p>Peggy</p> <p>Androgen Insensitivity Syndrome</p> <p>Age: 50 – 60s</p> <p>Resides: North America</p>	<p>[W]hen I was eighteen and I got fuller information, uh, I...I...just conceptualised what I found as, my being, a girl with this condition, Androgen Insensitivity, who was mistakenly reared as a boy...</p>
<p>Saifa</p> <p>African-American, <i>Intersex</i> man, queer, transgender man, assigned female at birth, Androgen Insensitivity Syndrome</p> <p>Age: 30 – 40s</p> <p>Resides: USA</p>	<p>I don't really see myself as having a gender, like, you know, uh, so I do identify as African-American, uh, I do identify as Intersex. I identify as Queer. I think I'm just in a space of understanding [sighs] man-hood and masculinity...Uh, and to create my own...just to occupy... the space. Because I think for me, it's like...you know...whenever I'm, so speaking in <i>the world</i>, I'm definitely, identify as like, an Intersex man.</p>

Activist Work and Online Engagement with *Intersexuality*

Overall, what helped to build trust and generate interest and subsequent participation in my *Intersex* project, was my political activism, engagement with *Intersex* people and *Intersex*- related concerns and my transparency. After beginning my *Intersex* research at King's College London in September 2013, I organised and hosted two community events containing a strong *Intersex* component via my LGBTQIA+ Arts project *Freedom To Be*;²³ the first, an enactment of an *Intersex* monologue in a play about LGBTQIA+ identities on 5 April 2014, and the second, a book sale of the *Intersex* novel *Golden Boy* (2013) and interview with its author Abigail Tarttelin on 3

²³ For further details of all 'Freedom To Be' events please visit:

Facebook: <https://www.facebook.com/Freedomtobefestival>

Twitter: @lgbtqiasw19 #freedom_to_be

May 2014. I located and advertised my events on a number of *Intersex* online forums and was successful in my requests to become a member of *Intersex UK* and *Intersex and Trans Alliance*. As an outsider I knew that access to participants for my study, especially issuing from a sensitive research demographic, would be very challenging so I made the decision to be as transparent as I could be, not only in setting out my research aim and questions and intentions, but also with self-disclosure: why I wanted to pursue this subject matter in particular, my activism and past academic work. As most of my recruitment was done on Facebook via the *Intersex* online forums, in addition to uploading my personal and academic email address, I attached a brief biography and links to my *Freedom To Be* Facebook and Twitter community pages. It was slow moving at first so after careful consideration - and not without some reservations - I took the decision to personalise my Facebook page by uploading a profile photograph of me for the very first time, as well as keeping my page on a public (and no longer private) setting. As an activist I have always been wary about displaying personal information online. Previously, I had only used my page to facilitate the activation of my Facebook community page, which I restricted to posting details of my events and community news. Nevertheless, in the feminist spirit of exchange of information, trust and mutual interaction - plus appreciating that my participants would be committing to sharing a great deal of personal information with me, albeit with the added protection of confidentiality that my own sharing would not be subject to - on the same day I uploaded photographs of me interviewing Abigail Tartellin, an author whose award-winning book dealing with the life of an *Intersex* teenager had been well-received by the *Intersex* community.

Thereafter, I began to post numerous documents, articles, film clips, graphics and short stories on a daily basis to share my personal opinions and stance on current world events in general, and gender, sexuality, identity and *Intersexuality* in particular. I was inadvertently helped to do this by my friend Gemma. I had sent an article to Gemma that had been uploaded onto my university's website, dealing with her research topic: anorexia nervosa. I was taken aback when she emailed to say she already had it. When I enquired how, since it had only been posted that day, Gemma introduced me to *Google Alerts* which you can set up online to receive emails regarding the latest information on any topic from around the world. This proved an invaluable tool for my Facebook and Twitter posts which now contained very up-to-date information on *Intersex*, provoking interest and feedback. Additionally, I would post these updates on the *Intersex* online community forums of which I was a member and a number of these 'hot off the press' articles sparked much discussion and debate on their pages. As a result, by the time I began my fieldwork in November 2014, members of *Intersex UK* and *Intersex and Trans Alliance* were already familiar with me and my work. Here is a brief summary of some of the results of my online activity via Facebook:

- I received a number of friends requests from people with *Intersex* conditions on Facebook, members of *Intersex* Facebook forums and their friends.
- I received a number of friends requests from people right across the gender, sexuality and identity spectrum.
- One Black *Intersex* person contacted me curious to know if I also had an *Intersex* condition. I wondered if it was because there are fewer Black people who are 'out'

on Facebook.

- A few participants said in interview how much they enjoyed my Facebook pages.
- An *Intersex* person who declined to be a participant would regularly frequent my page. They would re-post articles they enjoyed (without attributing them) and re-post ones with which they disagreed with an accompanying title such as: 'Why (name of article) Is Wrong'.
- The moderator of a key online *Intersex* forum repeatedly messaged me to express appreciation for some of my posts and offered me an administrator role. I had to decline since I was already finding the daily management of my own social media platforms very time consuming: two Facebook pages, one Twitter page, one academic and one personal email account. Ultimately, I felt it was an important and gratifying step as an outsider/person without an *Intersex* condition as the majority of *Intersex* forums are private and closed to the public.
- My own friends and academic colleagues (formerly unfamiliar with the subject) also began posting articles that they now noticed about *Intersex* onto my page or commented on how moving they found some of the *Intersex* life-stories.
- One participant posted a photograph to my Facebook page that their friend (a public figure for another activist group) had taken during our Skype interview (the friend had asked our permission). This meant the photograph was visible on three Facebook pages (the friend, the interviewee and mine). It received a lot of attention, accumulating 'likes' from a plethora of people including, members and friends of the *Intersex* community, my friends and colleagues, their friends and colleagues and members of other activist groups.

Bias

Researchers employing feminist methods have provoked the charge of bias for sharing personal information with their research participants. Their response to their critics

has been to state that feminist methodologies will always imply personal and political sympathies on the part of the researcher since they openly reflect an ideological conflict with sexism. Feminism challenges the legitimacy and hierarchy of dominant social structures; to be involved in feminism is to be concerned with emancipation and feminist research aspires to change the status quo by critiquing social policy and representing human diversity (Roberts, 1981; Francis, 2003). Sexist ideologies legitimise unequal relationships by normalising the harmful treatment of others and opposing actions towards equality; they exert a powerful influence on culture, philosophy, social theory and science. If you are part of the dominant group, then the continuation of this pattern is viewed as entirely 'normal' and any challenge to it as controversially denying its legitimacy (see Miller in Roberts, 1981). Strauss and Corbin (1990) state that *all of us* bring 'our biases, assumptions, patterns of thinking, and knowledge gained from experience and reading' to our work (Strauss and Corbin, 1990: 95). Similarly, feminists maintain that the sensory, emotional and affective relations of researchers feature in how they engage with, understand and produce what becomes termed as 'research' (see Fraser and Puwar in Page, 2017). For the reason that these aspects of non-feminist research are frequently not made explicit and so remain obscured, feminists assert that non-feminist methodologies are skewed in an androcentric, male-oriented way, foregrounding the world view, experiences and concerns of a patriarchal society (Roberts, 1981).

The Semi-Structured Life World Interview

In order to explore the individual life experiences of people with *Intersex* conditions, I selected to use the semi-structured life world interview (Kvale, 1996). Qualitative methods are frequently used to better comprehend the social experiences of research participants and their discursive constructions of their lives. What is more, qualitative interviewing is recommended as a method which helps people make explicit their perceptions, feelings and understandings of a situation that has hitherto been implicit (Arksey and Knight, 1999). The purpose of the semi-structured life world interview is to obtain descriptions of the interviewee's life world with a view to understanding and interpreting meanings of the research phenomena (Kvale, 1996). The interviewer introduces the topic and the interviewee chooses specific instances from their lived world to talk about how it is they experience and live in relation to the phenomena under discussion (Kvale, 1996, Arksey and Knight, 1999).

Nevertheless, in *Qualitative Interviewing as an Embodied Emotional Performance*, Douglas Ezzy (2010) observes that textbooks on qualitative interviews are replete with masculine metaphors of conquest: probing, directing and questioning; this is hierarchical and places the interviewer firmly in control of the course of the interview. Drawing from Jessica Benjamin's work with psychoanalytic theory, feminism and sociology, Ezzy contends that the ideal of the rational, autonomous individual epitomised in contemporary social organisation is a 'distinctively masculine' way of being human and argues instead for Benjamin's 'intersubjective view' (Ezzy, 2010: 164). This viewpoint moves beyond domination, submission and conquest to mutual, relational dependence and communion, allowing for the Self and Other to meet as

equals. It argues that the performance of the dispassionate researcher role can emotionally distance the researcher from the research participants, making it harder to hear their voices and experiences, whereas understanding that the Self is dependent on the Other for one's own sense of Self, and so listening with openness to and validation of the Other, can allow the Self to be transformed by the emotionally framed story which is co-created by the communion of interviewer and interviewee. This approach runs in parallel with the feminist aim of *connecting with* rather than dominating over others and marks a refusal to perpetuate the interviewer/interviewee hierarchy which rationalises inequality and does not necessarily benefit either party (Oakley, 1981).

The 'proper' interview within a patriarchal society conforms to the dominant, masculinist, positivist paradigm which values objectivity, detachment and hierarchy (Oakley, 1981; Jaggar, 2008). The interviewer is analogous to a miner whose task it is to unearth the buried valuable nuggets of data or meanings from participant experiences (Kvale, 1996). It is incumbent that the 'miner' interviewer not contaminate or pollute the knowledge conveyed by the interviewee by asking leading questions, so as to preserve 'the precious facts and meanings' to be purified by transformation - from oral to written words - during transcription (Kvale, 1996:3). The interviewer and interviewee are depersonalised: the interviewer is constructed as neutral and without opinions, whilst the interviewee is constructed as a passive, subordinate, data-producing machine. Information extraction is more highly prized than information yielding; feelings and emotions are an irrelevant distraction (Oakley, 1981).

Feminists reject positivist methods as a product of patriarchal thinking which separates the researcher from the researched, believing that this skews knowledge in an androcentric way (Reinharz and Davidman, 1992; Roof and Wiegman, 1995; Stanley, 1996; Wilkinson and Kitzinger, 1996; Jaggar, 2008). They recognise and engage with the 'double subjectivity' in the research process. The interviewer is analogous to a travelling reporter who journeys to a different country reporting on what is heard and seen, asking questions of the local inhabitants who 'tell their own stories of their lived world' (Kvale, 1996:4). The 'traveller' interviewer metaphor recognises the interactional impact of the interviewer upon the potentialities of meanings supplied by the interviewee, which are subsequently unfolded and re-moulded in the process of transcription (Rubin and Rubin, 1995; Kvale, 1996; Wilkinson and Kitzinger, 1996). Hence, it is the travelling reporter's interpretations of the stories received, which formulate 'new narratives' to be told to the people of the traveller's country, as well as to those in whose country the traveller sojourned (Kvale, 1996:4). This is in line with a constructivist framework which holds that researchers interpret and define reality, rather than independently observing it *out there* (Reinharz and Davidman, 1992). This indicates that not only can interviewees 'extend and alter' the interviewer's understanding of the phenomena under investigation, resulting in new narratives gained from new knowledge, distinctions and dimensions of the subject matter (Kvale, 1996: 100), but also that the very act of journeying can lead to 'new ways of self-understanding' and a re-thinking of certain normalised values and customs by the traveller in their own country (Kvale, 1996: 4).

In many ways feminist research methods produce an uneasy tension between disbelief and trust (Reinharz and Davidman, 1992). On the one hand, there is a stance of scepticism, suspicion and resistance towards dominant doctrine, ideological assumptions, socialisation and non-feminist scholarship. On the other hand, trust involves the casting aside of conditioned responses and instead allowing ourselves to be totally receptive to the Other in our attempts to understand from a marginal or boundary-dwelling perspective (see Stone in Reinharz and Davidman, 1992). With respect to the controversial idea of believing the participant, feminist researchers are advised that, commensurate with the principles of communion and relating, they should approach the project with the intention of believing and accepting the interviewee. If it should transpire that the interviewer questions or disbelieves the testimony given, the feminist approach encourages the researcher to either question the interviewee in the interview which then provides an opportunity for further discussion in the data analysis phase, 'look not for the falsehoods of their claims, but to the actual conditions of the women's lives and the way those conditions might generate the [feelings] the women express' (Andersen as cited in Reinharz and Davidman, 1992: 28, 29). This is reinterpreting the notion of participants as merely data providers - or as explained in 'Activist Work and Online Engagement with *Intersexuality*', as 'respondents' -and involves a commitment to forming a relationship with participants and making them feel valued as individuals (Oakley, 1981). Two extracts from my research diary in 2014 illustrate my own experience with acceptance, engagement and receptivity whilst interviewing.

(Participant's name) was so nice and knowledgeable. I could feel [their] kindness and goodness. And felt quite emotional talking to [them].

Interview with (participant name) had a very precious moment in it. I suddenly realised how vulnerable and exposed my participants are being in the hope that things will be better for the next generation via knowledge that they are imparting to me. I suddenly realised that I am being trusted with the knowledge to use it in a good way. The Very Best Way. It is a mission of trust... [People with Intersex conditions] are crying out for help. They have been overlooked appallingly.

Research Diary, 2014

Undertaking Highly Sensitive Research

Sensitive research has been defined as research that deals with the 'private' and 'stressful' (Dickson-Swift et al., 2008:2), and which potentially carries with it consequences and costs for all involved: the research participants, the demographic they represent and the researcher (Renzetti and Lee, 1993). *Intersexuality* is a highly sensitive research topic. It incorporates intimate aspects of a person's sex, gender, body and sexuality, which for many *Intersex* people has been a traumatic source of secrecy and shame due to a genital normalising treatment protocol imposed upon them at a very young age (Chase, 1998; Morland, 2001; Holmes, 2008; Preves, 2008). Areas that have been defined as sensitive in research are those for which

participation involves the disclosure of deeply personal and private experiences (Renzetti and Lee, 1993; Dickson-Swift et al., 2004, 2006, 2007, 2008). These can carry an emotional charge with the capacity to trigger profound emotional distress - such as guilt, shame, embarrassment - or fear of discovery and sanction (Renzetti and Lee, 1993). I believe my volunteering and fundraising work experience provided me with some valuable skills in this regard. For three years I worked as a listening volunteer and fundraiser for the Samaritans charity (2005–2009). They provide support and counselling to people who are anxious, depressed or suicidal. Before I was allowed to do this I had to undergo six months of rigorous training and complete a probationary period with a mentor. I was then based at their central London branch in Soho - which is predominantly used by sexual minority groups - supporting people on the telephone, by SMS, answering emails and letters and counselling people in person. I also worked as a volunteer and fundraiser for a sexual health charity called GMFA (Gay Men Fighting A.I.D.S) for two years (2010–2012). They also had an induction and selection process to ensure their volunteers were trained to interact sensitively and ethically with sexual minority groups.

It is important that in research preparation the researcher assesses the potential for risks and sensitivities at each phase of the research process and incorporates ethical methods therein. This involves understanding the kinds of ethical issues that can arise surrounding privacy, safety, confidentiality and respect, and then taking steps to implement them via respectful communication and treatment, full disclosure, consent and debriefing (Sieber, 1993). With this in mind, I ensured that all of my participants

were fully informed of the nature and purpose of the research and participated on the basis of fully informed consent. They were emailed an Interview Consent Form and an Interview Information Sheet. These were compiled by me after attending a very helpful lunchtime workshop entitled *Applying for Ethical Approval* led by the chair of the *Arts and Humanities Research Ethics Panel* at King's College London. I then forwarded these documents to the *King's College London Ethics Committee* for review and clearance. On interview day, I reiterated to my participants that, as detailed in their Interview Information Sheet, they were welcome to use pseudonyms to protect and preserve their anonymity and that their real names and the organisations where they work would not be disclosed. Whilst a few selected anonymity, a large number selected to use their real names, a request I respected.

Dickson-Swift and colleagues have written extensively on the subject of sensitive research (see Dickson-Swift et al., 2004, 2006, 2007, 2008). They note that there are facets unique to undertaking this form of research project which are not to be found in other types of research, extend beyond what is reviewed by an Ethics Committee and impact all who are involved (Dickson-Swift et al., 2007). For example, in order to mitigate potential hierarchical issues of power, the reciprocal sharing of life stories has been used to establish rapport, enhance respect and validate research participants' stories and for these reasons is presented as good practice by feminist theorists (Oakley, 1981; Cotterill, 1992; Stanley and Wise, 1991; 1993). However, unlike other research topics, the level of intimacy involved with this form of self-disclosure in a sensitive research project could lead to a researcher feeling

uncomfortable, exposed and vulnerable. Particularly, and as already mentioned, the confidentiality of the researcher is not guaranteed in interaction with their participants (Dickson-Swift et al., 2007). With respect to research participants, it may be their first time revealing difficult, hidden or unexplored aspects of their lives to another person, causing boundaries to become blurred and difficulties in differentiating the research project from therapy, which could also lead to emotional overload and/or burnout for the researcher (Coyle and Wright, 1996; Dickson-Swift et al., 2007; Dickson-Swift et al., 2008).

For this reason, self-reflexive journaling from the outset of the research project and debriefing sessions during supervision meetings have been advised as emotional risk reduction strategies for researchers engaged in researching sensitive topics (Dickson-Swift et al., 2008). Whilst I was not subject to this form of reciprocal life-story sharing by any of my research participants, I can vividly recall a situation that occurred at the outset of my study when an *Intersex* person contacted me via Facebook to ask if I could help them with problems they were facing as a result of their doctor's lack of knowledge about their condition. The person confided in me with a lot of detail wondering if I could provide clarity and even offering to send me photographs. I remember feeling unsettled at the time as I really sympathised and could feel their intense distress and desperation. I carefully advised them to contact a moderator of an *Intersex* forum who regularly gave advice on similar concerns and was relieved to discover a little while later that they had.

Cultural Sensitivity

In the development of an ethical protocol for the project, another approach I was able to use effectively was cultural sensitivity (Sieber, 1993). This can be compared to conducting preparatory reconnaissance work on the research group by becoming cognizant of their lifestyles, beliefs, needs and fears (Sieber, 1993). This preliminary information can be used in a number of ways. It can attune a researcher to some of the basic assumptions and views of the research population which is invaluable for preparation of an interview schedule and optimal comprehension during interviews. It is a useful way to keep abreast of current opinions circulating within the community, some of which the researcher may want to expand upon in the project. Moreover, it can be used to discern risk factors by highlighting any areas requiring extra sensitivity and/or discretion, thereby ensuring that all interactions with research participants are ethical and appropriate. Cultural sensitivity helped me at every phase of my research project. What I learned from my engagement with my research population and groups affiliated with them infused my research design, interactions with my research participants – in recruitment and interview – and data analysis. It was in communication with an *Intersex* person on Facebook that I became acquainted with the 'Guidelines for Intersex Allies' (as mentioned in the thesis Introduction) located on the *Organisation Intersex International* (OII) website. These guidelines prompted me to add the following footnote onto my Interview Information Sheet since I had become sensitised to debates about nomenclature within the *Intersex* community.

As explained in 'Brief Guidelines for Intersex Allies,' I recognise that not everyone born with a

mix of anatomical sex traits identifies or feels comfortable with the term 'Intersex,' and it is not my intention to exclude those who describe themselves differently or identify as 'DSD' (Please see: <http://oii-usa.org/1000/information-intersex-allies/> , accessed October 2014). On the contrary, I have chosen to use 'Intersex' in line with its political usage as a term which raises awareness of the naturally occurring diversity and variety of sex characteristics in human beings.

Two *Intersex* people wrote to me commenting positively on this footnote, one of them, who became one of my research participants, is quoted here:

I love "on the contrary, I have chosen to use 'intersex' in line with its political usage as a term which raises awareness of the naturally occurring diversity and variety of sex characteristics in human beings". Wow! Great wording!

Sensitive Interviewing

As interviews on sensitive topics have a greater likelihood of bringing uncomfortable and distressing feelings on the part of the interviewee to the surface, it has been advised to help off-set this with a post-interview debriefing (Edwards, 1993). This can include giving the interviewee an opportunity to know a bit more about you as the researcher (Edwards, 1993). In addition to sending all prospective participants a Researcher Information Sheet containing a brief biographical account of my research aim, objectives and intentions, activism and previous academic work, I used my

introductory and closing remarks in interview in a way that reflected the debriefing method. This is outlined below.

Pre-interview

- Warm welcome, thanks and introductions.
- A very brief, easy to understand summary of my research topic.
- An approximate interview duration time (60 minutes) and reminder that it will be recorded.
- Explanation to say that if there is a question that they do not feel comfortable answering, to please let me know and we can omit it. Also, if they change their mind regarding the entire interview it can be terminated at any time.
- Reiteration that the interview is strictly confidential, false names can be used and that they can choose a name they prefer if they wish to.
- Asked if there was anything that they would like to ask me before we begin.

Post-interview

- Asked if there was anything else they wanted to say or add.

What I discovered was that pre-interview the majority of participants were eager to get the interview underway and that it was post-interview when I was often questioned as to how I became interested in the project, what I hoped to do with the research information and offered further information by email. Interestingly, only two participants asked whether I had an *Intersex* condition.

My Interview Schedule

My interview schedule originated as seventeen questions formatted on a PowerPoint slide that reflected nine key themes from my research aims and research questions (see 'First Draft of Interview Questions' in Appendices). My completed interview schedule comprised a list of twenty-eight questions designed to shed light on key areas of *Intersex* experience (see 'Final Interview Schedule' in Appendices for the content, sequence and style of my interview questions). As already demonstrated being culturally sensitised to the *Intersex* community was a great benefit; it was how I became more keenly aware of the current controversies, debates and deficiencies in research. This knowledge factored into the following questions:

How do you identify?

Do you use the term 'Intersex'?

Have you ever felt discriminated against for being *Intersex*?

Where have you received the least (support from)? How could this have been improved?

Have you read any books, literature, on-line information on *Intersex*?

Are there any that you recall as being particularly helpful or unhelpful?

Please explain.

How would you improve upon the information that is currently available on *Intersex*?

The first two questions arose from controversies relating to nomenclature in the *Intersex* community. There are some individuals who reject the term 'Intersex' preferring instead 'Disorders of Sex Development', whereas for others 'Intersex' is

very much a part of their identity (see Chapter Eleven). The interview questions relating to discrimination and support arose from the almost daily online postings to *Intersex* forums by members who felt that they had been or were currently being unfairly treated during medical encounters or received a lack of support and understanding from their peers and/or loved ones. The last three questions regarding information in the public domain about *Intersex* were influenced by online conversations about, and my own reading of, *Intersex* authors, where dissatisfaction with certain fictionalised novels containing *Intersex* characters, and what were perceived as spurious academic research or sensationalised newspaper reports had been expressed. I piloted my interview schedule with a friend who belongs to the LGBTQ community since, as people with *Intersex* conditions belong to a hard to access group, I thought it would be wise to keep the ones who volunteered to be interviewed for my actual sample. My finalised questions were approved by the *King's College Ethics Committee*.

To abide by ethical guidelines I had been very careful not to include questions that could be construed as prurient or insensitive. I kept my questions open-ended and broad so that participants could answer with as much or as little detail as they felt comfortable with (or not at all, as previously explained in 'Diversity of Sample'). However, on reflection this approach had its drawbacks. In interview some replies to the question, 'How do you identify?' were as follows:

Participant: Uh, I think this is a complicated question.

Participant: Myself? That's a hard question...

Participant: How do I identify? In any way? In general?

And, some answers to the question, 'Can you tell me your experience of living as an *Intersex* person in a world which strictly divides people into female OR male?'

included:

Participant: No. That just is way too broad...I don't have a simple answer for that.

Participant: The biggest thing for me, there's loads of comments here, uh, and you'll have to remind me of the question...

Int: [laughs]

Participant: Uh...what has my experience been? I basically...to answer that question I'd be answering...uh...I'd be...how can I put it? I'd be...telling you the whole story of my life.

Whilst I was tempted to omit the above questions after receiving these responses, I quickly found that a way to deal with the situation was to pre-empt it. Accordingly, during the interviews I began to verbally acknowledge the broad range of some of my questions before asking them. What I found was that this helped the participant to relax knowing that they had extra time to mentally prepare to answer, as is discernible in the following two examples:

Int: OK. Uh, now a bit of a bigger question here, can you tell me your experience of living as an Intersex person in a world which strictly divides people into female OR male?

Participant: Uh, well, yeah, that's kind of a *big* question...

(Participant then proceeds to answer the question with a lot of detail, 400+ words in transcription.)

Int: Great. Uh, the next question, it's a bit of a broader question...

Participant: OK

Int: Can you tell me your experience of living as an Intersex person in a world which strictly divides people into female OR male?

Participant: I can!

Int: [laughs]

(Participant proceed to answer the question, 200+ words in transcription.)

Whilst interviewing it became clear that a lot of my participants were very comfortable with answering *Intersex* related questions and revealing intimate details of their experiences without hesitation. This came as a surprise to me and I recorded in my research diary that all of my participants were 'very relaxed'. When contemplating possible reasons for this I thought of the large number of activists and/or public figures - people who are very vocal about *Intersex* - who comprise my sample. Many had undergone years of therapy to deal with their traumatic *Intersex* related experiences (medical, at school or in the home), and, as a result of their healing, quite a few now provide support and assistance to newcomers to the *Intersex* community.

All of this indicates that they are (and have been) talking about *Intersex* very regularly. Subsequently, it is my belief that they balked at questions which they perceived as too broad, unsure of how or where to begin their answer. What this taught me is to be less afraid of causing offense with my interview questions and to be more direct and specific with my interview schedule, confident that my volunteering and activist work combined with my academic background had already provided me with the competence required to formulate respectful interview questions and secure in the knowledge that by agreeing to participate in an *Intersex* research project my participants are survivors who feel they are ready to talk (this is discussed in more detail in Chapter Eleven). As noted by one feminist researcher, a person's ability to retell a traumatic story is an indicator that they have already survived the worst of the pain (Reinharz and Davidman, 1992).

Interviewing

Interviewing commenced in November 2014 and ended in August 2015, a total of nine months. With respect to duration, the shortest interview was thirty-one minutes in length, while the longest continued for one hour and twenty minutes. My first two interviews I scheduled on the same day and quickly realised after completing the second one that it would be far too taxing for me to conduct more than one per day. Whilst it was very rewarding to reach this stage in my project and finally sit down with an *Intersex* person to hear their thoughts on different aspects of *Intersexuality*, I found that it was also very hard work. There are a lot of things that need to happen simultaneously and seamlessly during the interview. First, I believe it is very

important to show appreciation to your participant at the outset of the interview, that they are willing to talk to you – a stranger in the majority of cases - about a subject as intimate and personal as *Intersexuality*. Second, recognition of this should ensure that you create a comfortable space where they feel the necessary level of confidence and trust in you, the project and the interview process. For me, this occurs during the pre-interview stage (see 'Sensitive Interviewing') where I explained with enthusiasm my motivations as a researcher, the research project and the interview format. I was very aware that during this pre-interview stage, the participants - the majority of whom had not seen me in person before - were using this time to in fact gather their initial impressions of me through my voice, appearance, bearing and more. Third, during the interview questioning stage, I found that I had to sustain a high level of attention for the duration of the interview. I was not only listening to the answers to my questions, but equally how they were being answered, to help me to gauge the level of comfort (and/or discomfort) with questions related to an especially sensitive research topic. This is a two-way enterprise, for while answering certain questions I noticed some participants also gauging my reactions to their responses. The level of intensity involved in interviewing was for me encapsulated by one participant who noticed and remarked that I blink a lot (which I do!). Connected to this, is my fourth point which involves being alert to the pace of the interview, where it might be necessary to ask the participant to elaborate or to subtly encourage them to move on. The latter was a conundrum for me as I had a few very talkative participants. On the one hand, it is a relief when engaged in sensitive research that your participant feels at ease to contribute in this way. On the other hand, when you have twenty-eight questions to ask and have only asked ten of them after a considerable amount of time

has passed in the interview, it can be hard to know what to do for the best. In the end, I simply let the participants talk, reasoning that this is an area where they are so often silenced. It may have helped to have fewer interview questions (although for those who did not talk as much the interviews felt far shorter), but on reflection, and as mentioned in the preceding paragraph, this could once again be tied to the overall process of coming to terms with and/or 'coming out' as *Intersex* which has for many involved therapeutic counselling sessions. In fact, one of my talkative participants mentioned having had a great deal of therapy and due to this had grown accustomed to speaking in detail on *Intersex* and other related personal matters.

Conducting Interviews Using Skype

Although an 'in person' encounter is frequently advocated as the optimum mode of interviewing in qualitative research, recent studies have increasingly promoted the advantages of other interview formats, such as Skype calls (Hanna, 2012; Deakin and Wakefield, 2014; Holt, 2012; Bryman, 2016). Researchers involved in these studies assert that the advance of internet technology has surmounted problems often associated with face-to-face interviewing. From a practical point of view, interviews via Skype afford busy research participants (and researchers) greater freedom and flexibility with scheduling that obligations connected with travelling to a face-to-face appointment do not permit (Hanna, 2012). The low cost, ease of access and minimisation of ecological concerns associated with Skype interviews are also recommended (Holt, 2010). Some researchers have even cited the convenience of Skype interviews for encouraging people to agree to participate in a research project

who might have otherwise declined (Bryman, 2016). Skype interviews are not only advantageous as a means to reach geographically hard to access participants, but equally, those who are less physically mobile, socially isolated, can only be interviewed outside of office hours (9am-5pm) or are living in areas deemed 'dangerous' (Hanna, 2010; Holt, 2012; Deakin and Wakefield, 2014: 605). There are ideological benefits too. Many marginalised groups have been subjected to a 'professional gaze' – interviewed by professionals, officials and community workers who have entered their homes asking questions of their lives and lifestyles (Holt, 2010). By not 'intruding' on a research participant's home, a researcher avoids reproducing this professional gaze and hence minimises the intensity of a surveillant and judging Other (Holt, 2010). This is appealing from a feminist research methods perspective which is alert to issues of power; a participant can be empowered by the ability to speak from a location of their choosing without the imposition of the researcher's physical presence (Hanna, 2012). This can also enable increased freedom over their social space by furnishing them with the ability to move around their home/location of choice to another room in a way that is not permissible during a face-to-face interview encounter (Holt, 2010). Notwithstanding these benefits, there are drawbacks to Skype interviews. Identity verification has been pinpointed as an issue for researchers to be wary of (Deakin and Wakefield, 2014). Also, Skype interviews presuppose a level of technological expertise from research participants and that they have access to the internet, in addition to possessing Skype friendly apparatus (Deakin and Wakefield, 2014), the absence of which could eliminate or privilege certain groups, thereby calling into question the 'representativeness' of a research sample (Deakin and Wakefield, 2014).

When thinking about this issue in regard to my study, I noted how the *Intersex* community has been predominantly computer/internet based from its outset. Bo Laurent, its founder was a computer software engineer who singlehandedly built the first online internet platform for *Intersex* people (Torassa, 2002). This meant that all who sought knowledge and community regarding *Intersex* had to go online to find it. All of the *Intersex* people I met in person or in *Intersex* forums possessed the equipment to be online, although not all of them were Skype users. One of my participants ventured onto Skype for the very first time to interview with me. Another interviewed via Facebook messenger which has all of the same features as Skype. Essentially, my sample represented people who had some association and/or involvement with the *Intersex* community, which meant that they also had to have access to the internet and an electronic device with which to access the internet with.

I was very dependent on Skype for conducting interviews with participants from many different countries of the world. On securing the first few interviews, the initial challenge was navigating and negotiating time differences/zones. Also, certain countries contain states or cities with the same name as those in other countries, so it was vital for me to double-check all of these details. I soon grew adept at including in my emailed or Facebook messenger confirmation the agreed interview date and time in both my and the participants' location, as on a couple of occasions I had found myself sitting alone at night in a private room in the university library due to a misunderstanding as to how many hours someone is ahead or behind in a particular time zone. Due to these time differences some of the calls took place very late at

night, and, as I live in shared accommodation, talking loudly on an international Skype connection in the middle of the night could not only compromise participant confidentiality, but also be discourteous to my fellow housemates. For these reasons, in addition to reserving a private room at the library, I was able to request the use of a private office in my department whenever there was one available. I also took the opportunity to schedule an interview when staying at a friend's house for the weekend as they had a spare room suitably placed for interviewing.

As noted above, Skype calls grant research participants added flexibility and freedom. A few of my interviewees walked with their laptops to another room or outside in the garden during their interviews, two showed me their new puppies, one introduced me to their partner, another to their friend and a few participants mentioned that they have disabilities, including physical and/or mental health issues, so I imagine a Skype call at home was welcomed. One participant who was travelling was able to have their interview with me in their hotel room whilst visiting another city for an event. All of these factors led me to believe that Skype interviews are well-suited to *Intersex* research since they afford agency to interviewees who are divulging very sensitive and personal stories. Their ability to speak about their experiences in spaces that they both feel secure in and at a comfortable proximity from the interviewer, empowers them in the research setting, something which is less possible with other interview formats.

The interviews were not without technical difficulties and surprises. In one Skype interview the participant could see me on the screen, but I could not see them. The Facebook messenger interview had to be conducted as a phone call as there were problems with the camera. In the middle of another Skype interview I suddenly disappeared from my participant's screen. When this could not be rectified, I offered to remove them from my own screen as well, in case this felt uncomfortable, but they said it was not a problem and continued answering the interview questions unperturbed. Whilst reflecting during my data analysis of that participant's transcript, I wondered whether not seeing me on the screen had actually helped them, as it was an interview where the participant revealed a lot of very intimate details. Another potential participant, whose first language is not English, wrote to me worried about their language proficiency in an English-speaking interview. We briefly considered conducting the interview via Facebook messenger instead, typing questions and answers rather than speaking them. In the end, the participant resolved it in a novel way. They requested the questions in advance and then unexpectedly sent me a link to a filmed video of them answering each question in their language, complete with accompanying English subtitles!

Data Analysis

My data analysis was a cyclical process and reflexive activity which progressed alongside my data collection and writing (Coffey and Atkinson, 1996). There were numerous stages to my data analysis comprised of different strategies. My first phase began during the interview and transcription stages. If the participant mentioned

something that stood out in a particular way, perhaps because it was completely unfamiliar to me, had been said by other participants and I could observe a pattern was developing, or conversely, that it vehemently disagreed with what the majority of interviewees (or research population in general) had to say, I would make a brief note of the comment in my research notebook. Comments were noted either when the interview had concluded or during transcription when I would pause the recording to write them down. For the second phase of my analysis I selected two interview questions that were most directly tied to my research aim and questions (see 'Second Phase of Data Analysis' in Appendices) and compiled a table with a column for each question and inserted interviewee answers for both (in their entirety) into their respective columns.

Next, I used open coding techniques from grounded theory to organise this section of the data. Open coding is a tool that helps in the arranging, examining, conceptualising and categorising of data (Strauss and Corbin, 1990). It is a way of beginning to make analytic sense of the stories and statements, and to develop an emergent theory (or theories) to explain them (Charmaz, 2014). My main provisional codes from the two interview questions were as follows:

- The Problem with Gender
- Freedom:
 - Conformity/Acceptance/Societal Pressure
 - It Starts from Birth/Early
- All Wonderful

- Psycho-social support:
Mental health, well-being vs. trauma
- Organisational support and education
- Onus on the self/the *Intersex* person

For all of the data - in its entirety - I developed spidergrams in PowerPoint. Rather than using them as a clustering technique where the researcher writes down a theme, circles it and then uses it as a nucleus with which to brainstorm by writing their ideas on spokes issuing from the circle, I used them as liberating, non-linear, visual creative writing devices (Charmaz, 2014). I have always used spidergrams (an amalgamation of the words 'spider' and 'diagrams') for writing projects as I find that it helps to counter writer's block by bringing a feeling of lightness and creativity to my writing assignments. For my spidergrams, the name of each participant was the body and any pertinent themes issuing from their transcripts were the legs (see 'Spidergram Example' in Appendices). I kept a tally on the spidergrams of how often a theme was repeated by different participants, for example, if a theme was mentioned by participant one, I would write the theme and alongside it #1, if it was mentioned again by participant three, I would again write the theme and alongside it add #2.

The themes were inspired by insights I had gained from a variety of sources. They incorporated sensitising concepts from the literature and direct engagement with the *Intersex* community either in online forums, or in person when attending conferences and informal events directly related to *Intersex*. Any observations of these

engagements and interactions were recorded in my research diary and field notebook, (including my brief notes from interviewing and transcribing as mentioned above).

What also informed these themes was attendance at a number of events, talks and presentations on gender, sex, sexuality and culture more broadly (see 'A Cross-section of Events, Talks and Presentations I Attended on Gender, Sex, Sexuality (and more)' in Appendices).

I worked through my interview transcripts by closely reading each line and from this I formulated codes which became my themes that I wrote onto my spidergram legs. After this phase I comprised a list of categories - both frequent in appearance (besides which I had placed a hashtag) and also any wild cards - and then sub-categories of their properties and dimensions (Strauss and Corbin, 1990). From these categories and sub-categories I compiled a two-page list called 'Emerging Themes'. When complete, this list was comprised of fourteen main themes with thirty accompanying sub-categories. I also attached the words 'Links to' below a category and inserted the name of another category, if I felt that it overlapped, cross-referenced, or was in some way associated with, or even directly opposed to another category (see 'Emerging Themes List Example' in Appendices).

Next, I exported my 'Emerging Themes' list onto a table I formatted in Word and created columns for my categories and sub-categories which I then populated with indicative data. This helped me to verify the themes with actual data. I used evidence in the data which supported, problematised or challenged the listed

categories in some way (Corbin and Strauss, 1990). I selected a Word table so that I could easily highlight specific areas of text in colour. I used the same or a similar colour (for example dark green and light green) when there was a correlation or comparison in the data between certain categories and sub-categories. In this way, I created an easy to reference colour-coded scheme, so that when the table was fully populated I was able to quickly compare each category and sub-category across columns. The use of colour helped to make patterns visible; it also provided me with evidence of difference and variation.

Working from the above table, I was able to compile another Word table comprised of data themes and core categories. The data themes were a selection of words, terms, expressions, questions and phrases from the data in the first Word document. The core categories were words, terms and statements that could help to reveal, emphasise and elaborate them. This was an enhanced sifting process. It helped me to think, re-think, organise and compartmentalise large amounts of the data into smaller, more manageable, themed segments (see 'Data Themes and Core Categories' in Appendices).

I then transferred these to a third table in Word where I converted my core categories into chapter headings. They did not necessarily become data chapters in the final thesis, but this helped me to systematically differentiate between them. Researching both the properties of my data themes and core categories enabled me to define my chapter headings and sub-headings in increasingly theoretical terms. This step also

helped me to think more deeply about what theories would be most useful in interpreting, examining and explicating my data. It was the theories unearthed at this research stage which ultimately informed my data analysis writing (see 'Chapter Heading and Sub-headings' in Appendices).

I found that writing and submitting early drafts of data chapters to my supervisor, whilst still in the process of data collection, and presenting my preliminary data findings at two conferences and as part of my MPhil/PhD upgrade examination report greatly helped my data analysis overall. The invaluable feedback I received from all of these activities provided me with new lines of enquiry and fresh perspectives which helped to direct, inform and inspire each phase of my data analysis.

Case studies

Another complementary data analysis approach I decided to use to document my data was participant case studies and biographies. Case studies appear as cameos at the start of each of my four data chapters and I have devoted an entire chapter to brief biographical portraits of each of my seventeen participants (Chapter Seven). The work involved in compiling, drafting and writing both of these sections contributed another worthwhile layer of analysis. Case studies have been referred to as a key tool of feminist research due to the way that they can effectively portray the minutiae of a target population's characteristics and experiences (Reinharz and Davidman, 1992). They can illustratively depict a variety of diverse phenomena important to a particular group through a combination of analysis and description. In addition, post-colonial

feminists have criticised 'imperialist research projects' in Europe and North America for constructing an 'essentially truncated life' of cultural others, arguing that this type of representation erases specificities and experiences and obscures the complexities and layers of particular sites and contexts; they charge that this does not occur when research groups are privileged as being the norm or referent (see Mohanty and Spivak in Page, 2017). When accessing narratives they advocate for methodological strategies that are attentive to both the micropolitics of subjectivity and struggle in addition to the macropolitics of global economic political systems, infrastructure, institutions and processes, whilst moving between them to generate theoretical categories from within the situation and context under analysis, rather than dealing with cultural others as 'already constituted groups' connected by a single notion of oppression and powerlessness (see Mohanty in Page, 2017). It is for these reasons I employ case studies and biographical portraits of my participants which help to make visible the dimensional variations and conditions surrounding *Intersex* experience. They are also a valuable structural tool for highlighting areas to be drawn upon within the data chapters. In tandem with the feminist project of demystification, case studies and biographies of research participants can be used to humanise aspects of a phenomenon that people may only know in theoretical terms, whilst concurrently informing how these are tied to larger social structures and processes.

Conclusion

When reflecting on my methodological choices it was gratifying and surprising to witness how my work as a researcher, activist and volunteer unexpectedly intertwined

in the many decisions involved in designing and researching my project. This mix has been both beneficial and challenging. Introduced to *Intersexuality* by chance triggered the activist impulse in me to pursue what I could see was a little known and under-researched area. Organising community events dedicated to *Intersexuality* was something I knew I could do, having been involved in similar activist related activities. Similarly, adopting feminist research methods which support disrupting power hierarchies in society by refusing to replicate these when representing and interacting with my participants, and advocating for social change on behalf of marginalised groups by demystifying their situation (to themselves and others), were in alignment with my own core values. Likewise, following ethical guidelines for a highly sensitive research topic also made sense to me, having worked for several years with charities which conscientiously promoted the same. The questions surrounding speaking for others were a challenge to me throughout the research process. This is a very delicate issue. As a Black woman, I completely understand why it is important to have another Black woman speaking on my behalf in research and have felt the familiar jarring feeling when this has not been the case. However, I also understand that there are Black women who speak that I do not relate to at all. And, I have also experienced when someone who is not a Black woman speaks 'for me' and they have succeeded in doing so in a very respectful way, that just 'felt' right. Thinking about why this might be, I believe that it is something to do with a person's stance on, genuine feelings towards and understanding of societal discrimination, exploitation and systemic inequality. For me, these elements are critical when 'speaking for' a marginalised and oppressed group; they are discernible and can be gauged in a person's work. Assisted by its convergence with my activism and volunteer work, it is

my hope that my many research choices (as outlined in this chapter) result in a contribution to the under-researched topic of *Intersexuality* which is 'spoken' in a tone that is both respectful and right, and that it succeeds in helping to promote real change for *Intersex* people and impelling more researchers who are *Intersex* to also 'speak'.

Chapter Seven: Introducing the Participants

This chapter contains brief biographical life-histories of my seventeen research participants. They appear in alphabetical order and I have endeavoured to include the participant's name, age, country of residence and preferred pronouns, and to provide information regarding their *Intersex* condition and how they have experienced living *Intersex* from childhood to adulthood. It was not possible to do this in a systematic way in every case as already explained (see 'Diversity of Sample' in Chapter Six). At the end of each biography I have added what the participant shared regarding *Intersex* support and improving the quality of life for *Intersex* people and the extent of their involvement with the *Intersex* community. These biographical portraits will be expanded upon in the four data chapters that follow. Essentially, they are intended to personalise and introduce my data by placing the people who made the research possible at the centre of the analysis.

Autumn

Pronouns: she/her

Autumn is fifty years of age, she is a Christian who lives in San Diego, USA.

Autumn's karyotype is XY. She uses *Intersex* 'as a term and an identity' and is 'attracted to women primarily'. Autumn had testicular gonads removed as a baby, ('when I was like...100 days old, three and a half months old...'). Autumn was assigned and raised as a girl and became aware of her *Intersex* condition as a teenager when she began hormone therapy.

Autumn's *Intersex* condition was a family secret; she explains how her parents 'dealt with it very old school, what they call [...] "the concealment paradigm", which is where you just try to gloss it over, you know, bury it, you don't deal with it'. Her father was a physician, her mother a nurse and she has two older brothers. Autumn described her upbringing as 'very traditional, mid-western, United States, Catholic, Conservative...'. An insight into this is given by Autumn who remembers when she had to begin hormone therapy. Her mother 'broached the subject' by telling Autumn that she needed to see a doctor in order to start menstruation. Looking back, Autumn reflects:

[W]hich of course was never gonna happen, I was never gonna have a period. But that was her way of saying 'OK, you're at that age and so we're gonna take you to the doctor and get you on hormones...'

In her forties, after her mother died (in 2004), Autumn started the journey of retrieving her medical records to find out about her *Intersex* condition. This search was prompted both by a need for more comprehensive information regarding her medical history and to ascertain if there was a link between her existing hormonal regimen and a lifelong lack of a romantic and/or sexual life. Autumn was helped in this endeavour by the academic Alice Dreger who 'volunteered to help me get my medical records, uh, 'cause I was born in the mid-west in the Chicago area and she is [...] the professor at North-western'. Autumn is now on a weekly testosterone injection protocol and has found that this has 'made much more of a difference as far as [...] my own sort of internal recognition of where my attractions lie...'.

With regard to what support for *Intersex* people in society would look like, Autumn says

[F]or parents to get support earlier in life [...] when they come to an understanding that they have an *Intersex* affected child. Uh, so that they, are...become comfortable with raising an *Intersex* child...

Autumn served for two terms (a total of four years) as a board member for an organisation that organises annual meetings for *Intersex* people.

Bo (formerly known as Cheryl Chase)

Pronouns: she/her

Bo is fifty-eight years of age and lives in California, USA.

Bo was assigned *male* 'with a micropenis, complete hypospadias, undescended testes and a strange extra opening behind the urethra', following a three day deliberation after birth (Chase, 1998: 193). However, at eighteen months Bo's parents were advised by another team of medical experts to re-assign Bo as *female*, reading and relabeling Bo's anatomy as 'vagina, urethra, labia, and outsized clitoris'. Following their advice, Bo's name and birth certificate were changed, Bo underwent a clitorrectomy, her parents moved town and raised Bo as a girl. Bo's *Intersexuality* was kept a secret, even from Bo.

Bo remembers medical examinations as a child which involved having fingers, in addition to instruments, inserted into her vagina and anus and being photographed naked from eight years of age until she began to menstruate. At eight years of age, Bo underwent abdominal surgery to remove the testicular portion of her gonads which were 'partly ovarian and partly testicular in character'. At ten years of age, Bo was told by her parents that she had been born with an enlarged clitoris which had been removed in infancy. At nineteen years of age, Bo 'first got hold of [her] medical records' and discovered that she was a 'true hermaphrodite' and additional information pertaining to her original *male* sex assignment and clitorrectomy.

In her early twenties Bo came to identify as a lesbian. In 1992 she moved to San Francisco, and as a result of meeting transgender and gender activists, began to explore 'the cultural politics of intersexuality' (Chase, 1998: 196). A key moment occurred while at a *New Woman* conference weekend retreat amongst post-operative transsexual women. These women shared their stories, swam and sunbathed naked. It was there that Bo resolved to bring a similar type of 'healing experience to Intersex people' (Chase, 1998: 197). In 1993, Bo became the founder of the *Intersex Society of North America* (ISNA) the first movement and community for *Intersex* people, an act which 'caused [Intersex] to become widely used [...] I was the most famous Intersex person in the world'. ISNA began as a P.O Box number advertised in *The Sciences*, in response to an article by Anne Fausto-Sterling.

With regard to what support for *Intersex* people in society would look like, Bo says, 'Intersex shouldn't be treated as something freakish or shameful uh...that needs to be hidden or surgically erased'.

ISNA was dissolved in 2008, its funds, assets and copyrights were transferred to Accord Alliance (2008 - current).

Bridget

Pronouns: she/her

Bridget is nineteen years of age and lives in Iceland.

Bridget has *Complete Androgen Insensitivity Syndrome* and identifies 'mostly as female'.

Bridget knew about her *Intersex* condition from an early age as her family have always been open about it. Bridget explained, 'because my Mum, she like...gave me parts and bits'. At three years of age she recalls, 'I was like "I can't have kids! Did you know that?"' When Bridget was nine months old her testes were removed and at 'eleven or twelve years old' she began hormone replacement therapy. Bridget related, 'I was sick a lot...yeah. And I'm still sick a lot and I haven't had a doctor for almost two years because the system here is completely fucked up...'. Bridget attended her first *Androgen Insensitivity Support Group* conference at nine years of age, and remembers, 'It was horrifying, I didn't speak any English!' [laughs].

With regard to what support for *Intersex* people in society would look like, Bridget says, 'I think it would be nice that people...like... everybody knew about it, but didn't care because it wasn't important'.

Bridget's cousin Kitty is also a participant in my study.

Bridget is the Co-Founder and Vice-President of *Intersex Iceland*.

Clara

Pronouns: she/her/hers

Clara is a published author and a Christian, she is married and lives in Atlanta, USA.

Clara identifies as 'a woman but I also understand that my body is not strictly female...that, it's a mixture'.

Clara's karyotype is XYXO, she has *Turner Syndrome* and is Mosaic, the latter means 'I have a Y chromosome in some of my cells'. Clara explained how she does not have a 'reproductive system to speak of, because everything was taken out a long time ago'. Clara also has a small jaw which is a symptom of *Turner Syndrome*.

Clara's mother was a nurse and took care of all of her childhood medical treatment.

For this reason Clara only remembers 'going to the doctor's one time when I was young'. It was the dentist who made reference to Clara's small jaw, but she was not diagnosed until adulthood. Clara had ovo-testes when she was young and so required hormones to start puberty. Due to *Turner Syndrome*, Clara has significant medical health issues such as heart malformations, kidney malformations and thyroid problems; she has to take a number of different medications daily including estrogen, testosterone, progesterone and thyroid medication.

Clara would like to explain her *Intersex* condition to her friends of twenty-five years; they know of her surgeries and medical issues but are unaware of their underlying cause. She would also like to tell her Church but is concerned of how they would

react since, 'the attitude of most people is that it's only the genitals that have any meaning as far as sex goes'.

With regard to what support for *Intersex* people in society would look like, Clara says, 'I would like to see a better acceptance of people who are Intersex who are uncomfortable being entirely male or female.'

Clara writes and gives talks and presentations on *Intersex*.

Courtney

Pronouns: them/their/they

Courtney is fifty-four years of age and is a qualified and practising medical doctor who lives in California, USA.

Courtney's karyotype is XX, they identify 'as Intersex; not male or female'.

As a result of Courtney's birth, both parents trained and qualified as endocrinologists.

Courtney's father is a professor, a 'reproductive endocrinologist gynaecologist' and

Courtney's mother, who died three years ago, 'went to nursing school when she was fifty and got her Bachelor's in Nursing and went on to get a Masters in Pediatric Endocrinology Nurse Practitioner'.

Courtney explained how they 'found out that I was Intersex when I was about eleven'.

Courtney was given a textbook by their father and told, 'This is what you are, you're a pseudo-hermaphrodite'. Courtney remembers, 'I was eleven reading a textbook! And

that's how I first saw it'. Courtney's *Intersex* condition was kept a secret from family and friends. Their mother had an emotional breakdown after Courtney's birth and their older brother had to stay with family friends. Courtney grew up without knowing there were other *Intersex* people like them. They explained that even in adulthood their father kept this a secret and did not tell Courtney that there was an *Intersex* community near to Courtney's home although he knew about it for twelve years. Courtney's older brother did not know about their *Intersex* condition until Courtney emailed him last year (2013).

Courtney has a uterus and menstrual periods; phenotypically, up to the age of eighteen their genitals 'appeared to be in the middle' due to a 'fused labia...so it looked like a scrotum, an empty scrotum and I have a large clit[oris]'. Courtney's father operated on Courtney at eighteen years of age, in order to make 'my labio-scrotum appear to look more like a vulva with labia [...] And that's the first time I had access to my vagina...'

It was marching with the *Intactavists*²⁴ at San Francisco Pride Parade in June 2013 which inspired Courtney to 'come out'; 'that's when I really, I felt empowered to finally like, you know what, I'm gonna start talking about this'.

²⁴ 'An 'Intactavist' is a protestor who is against the circumcision of children and 'believes that every child, regardless of their gender or parents' beliefs, has the right to their intact genitals, as they're born. Someone who believes forced genital cutting on any child violates human rights. Someone who raises awareness and educates about the functions and value of the prepuce (male foreskin, female clitoral hood) to change public opinion thereby protecting the next generation'.

'What is an intactavist?', *Bloodstained Men*, Bloodstained Men Development, (2014-2016) <http://www.bloodstainedmen.com> [accessed February 2017]

With regard to what support for *Intersex* people in society would look like, Courtney says, 'the general public needs to be educated. Everybody needs to be educated [...] about us'.

Courtney is an activist and *Intactivist*.

Dana

Pronouns: they/them/theirs

Dana lives in the USA and identifies as *Intersex* 'biologically and gender-wise'.

Dana is unsure of the exact name of their *Intersex* condition, but described it this way:

I have [...] a very small penis...uh...uh...I have testes but I also had a, a vaginal opening of some sort [...] so it could have been an extremely severe...uh...hypospadias type condition...

Dana refers to themselves as 'an *Intersex* genital mutilation survivor' who underwent 'at least two surgeries, probably a couple more but I'm not sure' in childhood at 'age five, six years old'. Dana relates how the trauma of these procedures was heightened due to waking up during one of the operations and being 'alone most of that time' since they were performed in another state, far from where Dana lived. All of this created acute feelings of isolation and trust issues, precipitating mental, emotional and

physical problems, including clinical depression and childhood *Post Traumatic Stress Disorder*. Dana described growing up with parents who were not loving or kind, and brothers who kept their distance due to some of the physical issues Dana had to deal with. Dana was often punished for being lazy until an examination revealed scar tissue on their bladder, the result of childhood surgery. Dana required further 'corrective surgeries to uh get rid of some of the pain' caused by the earlier surgeries, explaining how they had 'damaged my water so I've leaked all my life'.

It was after their divorce in 2007, that Dana began searching on the internet and found the term *Intersex* and started therapy. Dana 'found out...uh...for sure...that I was Intersex at forty-nine'. Therapy has given Dana the ability to 'come out' as *Intersex* and talk about it to others. Dana's father died recently and their mother has not spoken to Dana since they 'came out'.

Dana is involved in online activism for many groups, including *Black Lives Matter* and joins local protests in Denver or Boulder with the *Intactivists* and 'some of the queer groups'.

With regard to what support for *Intersex* people in society would look like, Dana says, 'They can acknowledge us and give us human rights and civil rights'.

Dana is an *Intersex* activist and ‘an Associate Chairperson of the OII USA group’ who gives talks about *Intersex* at universities and churches. In 2012, Dana was invited to give a talk at The White House Health Conference in Philadelphia.

Darryl

Pronouns: *male*

Darryl lives in the Middle East. His karyotype is 47 XXY *Klinefelter’s Syndrome*.

Darryl says, ‘I...see myself as [a] masculine man’.

Darryl has three sisters and his mother died when he was twenty-one years old.

Darryl was diagnosed with *Klinefelter’s Syndrome* late in adulthood, but related how during puberty ‘my breasts grew and I had, you know, no hair’. Darryl experienced sexual harassment and bullying at school due to his breast growth, and so arranged for a doctor, who was also a family friend, to help him ‘come up with an excuse’ to not participate in sports at school, so that he would no longer have to undress in front of his peers. Darryl was successfully removed from sports classes from ages thirteen to eighteen and ‘got into guitar and piano and... played in a band’ instead. Darryl, as explained in the following extract, went into therapy from eighteen to twenty years of age to try to ascertain why he:

[W]as physiologically not developing the way guys develop and I didn’t understand [...] I thought, whatever I’m going through, I’m psychosomatic [...] because I wasn’t diagnosed until later.

Darryl eventually had a mastectomy, but, because his *Intersex* condition remained undiagnosed (while living in the United States), he did not receive medical insurance to cover the costs ('I had to pay privately because it was cosmetic...'). It was later after Darryl's marriage, when living in the Middle East and attempting to have children, that investigation into fertility issues revealed *Klinefelter's Syndrome*. At the time Darryl recalls, 'I found out all that information but I forgot it, put it in the back of my mind and went on trying to have children'. Darryl and his wife had children ('as a result of donor sperm and as a result of adoption'), yet it was not until after Darryl's divorce ('about two years, three years' ago) that he began examining *Klinefelter's Syndrome* more, to, 'try to find out who I am'. Darryl is a full-time father who looks after his two children, 'on a twenty-four [hour], seven-day a week basis'.

With regard to what support for *Intersex* people in society would look like, Darryl says, 'We all as *Intersex*, we all need to feel that empowerment inside in order to get support from other people, we need to be proud of who we are'.

Gavan

Pronouns: they/Gavan

Gavan is an Irish musician who lives in Germany.

Gavan identifies as 'Intersex' and 'would like to be treated as 'Intergender''. Gavan has *Klinefelter's Syndrome* and was diagnosed as XXY at seventeen. Gavan also had breast tissue removed at seventeen and no facial hair up to the age of twenty-six.

Gavan is now 'reaching forty' and takes 'a very small amount of testosterone'.

At twenty-two years of age, Gavan was introduced to the word *Intersex* while watching a documentary on Channel Four about *Intersex* (with 'XXY's in it') and recalls, 'I just totally got them. I was like 'Oh God! That word, now that hits a bell'. Gavan credits Gavan's mother, referring to her as 'The Rock, The Medical Genius and also Healer', for supporting Gavan through a very difficult childhood and adolescence of bullying ('she was able to...you know, de-stress me and shit'), due to Gavan's *Intersex* condition:

Without my mother, let's put it this way...my fucking brilliant friends wouldn't have the pleasure of [...] me as a friend of theirs...d'you know what I mean. [...] I should have been dead a long time ago, you know...It was so difficult for me in my childhood. I was bullied everyday...

With regard to what support for *Intersex* people in society would look like, Gavan says,

[D]octors you know, they need to be very seriously informed and go and get educated on these issues. If they don't know they should simply [...] admit that they don't know and send...uh, their patients to actual experts, and most of these experts of course will be affiliated with the *Intersex* movements in the world.

Gavan is an *Intersex* activist who regularly talks about *Intersex* on YouTube. They started the Facebook group *Intersex and Trans Alliance*. Gavan also features in the documentary film *Intersexion* (2012).

Hiker

Pronouns: s/he

Hiker lives in Taiwan. Hiker's native language is Chinese.

S/he was born in 1966, has a female I.D card and identifies 'as Intersex'.

Hiker's medical records do not list Hiker's precise *Intersex* condition. S/he believes it is 'pretty close to CAH'²⁵ because s/he has '...uh, much more testosterone than normal girl [...] But I, [ss] don't have to take any medicine...' S/he also explains:

I remember that my mother told me that 'You were born, like, both,' and [...] when I was forty-two.. I was trying to write my own story as an Intersex [...]. So, I...take my medical record out and read [...]. So, I...found that I was born with...uh, ambiguous genital, genitals...so, it was written in the medical records...

Hiker has siblings and is the youngest in the family. Hiker's *Intersex* condition was kept a secret from family and friends; s/he explains, 'in my family my body issue is almost pretty much like a taboo'. When Hiker was 'fourteen or fifteen' s/he was

²⁵ Congenital Adrenal Hyperplasia

disturbed when an examination of Hiker's medical records revealed the word *pseudo-hermaphrodite* written in English, Hiker says, 'I didn't really want to learn more about it because I'm monster and I didn't want to be a monster at all...'. As a result of that first introduction and discovering that 'I couldn't have baby [...] another very difficult for me', Hiker 'pushed the issue out, very, very deep' and did not revisit it again until 2008.

In 2008 when Hiker was forty-two years old, s/he watched the movie *XXY* (2008) and became aware of the word *Intersex*. As a result of the film Hiker researched on the internet and connected with other *Intersex* people through the online *Intersex* community groups *Organisation Intersex International* (OII) and *Bodies Like Ours*. In 2012, Hiker went to San Francisco, USA and met with leading OII members Curtis Hinkle (founder), Hida Vilorio and David Strachan. This proved a life changing event for Hiker; s/he recounts:

I feel nothing to be shameful after that journey to US, and it change my life totally and I never feel shame to talk about myself, I see myself as a *gift* to this world.

Inspired and empowered by the US trip, Hiker decided to 'come out' at the Pride Parade in Taipei, Taiwan in 2010, ('the biggest [Pride] in Asia') by joining the *Global Movement Intersex Free Hugs* campaign. Hiker designed a large board with the words *Free Hugs* on it and brought it to the Parade. S/he also posted a video on YouTube and related, 'after I came out I became famous in Taiwan'.

With regard to what support for *Intersex* people in society would look like, Hiker says:

[E]ducation I think is the base. And [...] if we have, like a law... to protect. Because [...] we don't have a common and normal and comprehensive education about Intersex people.

Hiker is the translator of the OII International website for the Chinese speaking community.

John

Pronouns: he/him/his

John is fifty-six years old and lives in the U.S.A.

John has a 46 XY karyotype and identifies as a 'male, Intersex person'.

John was 'born with a uterus and...ovo-testicles, which is a mixture of ovaries and testicles' in addition to hypospadias and chordee. From birth John underwent seven different operations to correct what his mother (his sole caregiver at the time) was told by doctors were 'undescended testicles'. John now believes that he and his mother were lied to by medical professionals, because despite these series of invasive surgeries they were never told that he had a uterus or ovo-testicles. Instead, at twelve years of age they were told that John's undescended testicles carried a high

risk of cancer and that he would not live 'much past fifty'. John recalls, 'it was a very depressing point when I reached fifty'.

When John went to enlist in the navy and declared that he had undescended testicles, he was advised to have them removed before joining. John returned to his childhood surgeon who dissuaded him from surgery claiming that it would cause scar tissue; a claim which John now believes was made to prevent the discovery of his uterus, which could have led to the surgeon being sued.

In 2006, at forty-eight years of age John found out that he had a uterus, but only 'discovered the Intersex connection' after undergoing internal examinations in 2013 when his uterus became inflamed and started bleeding. After enduring six months of 'debilitating pain' culminating in five hours of surgery, John's uterus and ovo-testicles were removed in March 2013. John believes that if the information regarding his internal organs had not originally been hidden from his mother, he could have taken preventative steps to avoid these physical issues much earlier.

John is married to Laura and explained, 'I couldn't have kids of my own but I have adopted two kids and I have a step-son'. John and Laura are both students on Masters programmes.

With regard to what support for *Intersex* people in society would look like, John says:

I think [Intersex people] need to come out and talk about it and educate the people around them. The more people know about it the less likely they're going to have an issue with it and they're going to be more comfortable with it.

John is member of a number of different online *Intersex* groups and provides support garnered from his own experience of living *Intersex*.

I'll go in there and I'll read parents' concerns and I'll [...] tell them what my experience was and hopefully they can learn from my experience.

Jools

Pronouns: not *male*

Jools identifies as 'Intersex...Transgender...Female...but assigned male'.

Jools used to be quite religious and has received a lot of support and understanding from the Anglican church.

Jools had surgeries and 'gender reinforcement' as a child, the latter to avert 'any 'non-male behaviour'.

Jools's *Intersex* condition was kept a secret; regarding the multiple childhood surgeries, she recalls never being 'told anything about them, or what they were, or

what they were for'. At approximately sixteen or seventeen years of age, Jools relates how she, 'discharged myself from having anything to do with doctors'.

It was not until the late 1990s, aged 'about forty-two', when watching a documentary that Jools 'began to understand the significance of what those surgeries had been about'. Jools' says that her mother is still very traumatised by what happened in Jools' childhood.

With regard to what support for *Intersex* people in society would look like, Jools says:

Yeah I think that people should accept that some people are born this way and that...that they...they should be given the freedom to grow up the way they want to, and they should be able to live without having to conform, to somebody else's expectations of what men and women should be like...

Jools has been 'open about being Intersex for about ten, ten years maybe, nearly fifteen years'. Jools has been involved in *Intersex* activism and advocacy for ten years and feels very strongly 'that people need to be informed' about *Intersex*.

Katherine

Pronouns: she/her

Katherine is in her fifties and lives in the U.K with her partner.

She identifies as 'Female...lesbian and someone born with an Intersex body'.

Katherine has *Congenital Adrenal Hyperplasia*, and adds, 'so I am disabled and I have to have medication and I have to balance life'. Katherine believes her *Intersex* condition gave her athleticism and 'phenomenal strength as a female'. She describes her parents as 'very loving and caring', although, with regard to her *Intersex* condition, they were unable to 'address stuff directly'.

Katherine recalls her interactions with the medical profession as a child as 'pretty damn grotty' and specifically remembers being 'endlessly paraded in front of doctors and nurses'. As an adolescent, both confused about her identity and a recipient of discrimination from the lesbian community, Katherine says that she engaged in self-destructive behaviour. It was involvement with disability activism twenty years ago that proved to be a turning point for Katherine; this brought with it the realisation that, 'I feel rubbish [...] because you guys have treated me rubbish. It's not because I'm rubbish [laughs]'. Katherine has found a lot of support from other disabled friends and her partner.

With regard to what support for *Intersex* people in society would look like, Katherine says, 'I think starting from birth, we need a huge revolution in the medical system'.

Katherine regularly presents workshops and gives talks on *Intersex*.

Kitty

Pronouns: she/her/they

Kitty is thirty-two years of age and lives in Iceland.

Kitty identifies as 'gender-fluid...pansexual, Intersex'.

Kitty has *Androgen Insensitivity Syndrome*, had 'surgical intervention as a child' and understood that she was *Intersex* at twelve years old, when it was explained to her by 'my endocrinologist'. Kitty is half-British; she grew up in Iceland and lived briefly in the U.K in childhood, returning to Iceland when her parent's divorced. Her father is British and lives in the U.K.

Kitty is on a programme of hormone replacement therapy. She credits the *Androgen Insensitivity Syndrome Support Group (AISSG)* which 'helped me a lot in just understanding, uh, why my body was different from other people's'. Kitty has 'been out as an Intersex person for more than a decade'.

Kitty's cousin Bridget is also a participant in my study.

With regard to what support for *Intersex* people in society would look like, Kitty says

I think we need to see, like, a lot more support for Intersex youth...uh, but I think sort of surrounding a lack of knowledge, or lack of understanding around Intersex issues, that there aren't very many people who are qualified to deal with support, and uh, we don't really have the... ability to, uh, demand it.

Kitty is the President of *Intersex Iceland*.

Leidy Tatiana

Pronouns: feminine

Leidy Tatiana lives in Colombia and identifies 'as Intersex person [...] or a hermaphrodite person'.

Leidy Tatiana's mother was the first person to identify her *Intersexuality* at birth, but did not pursue any surgical procedures, instead adopted a 'neutral parenting method' and gave Leidy Tatiana the gender-neutral name 'Alexis'. Up to the age of thirteen Alexis 'grew up as a boy', until their body began to change. In open communication with and the support of her mother and grandmother Alexis then decided to live as a woman and became 'Leidy Tatiana Marquez'. This was formalised at a registry office when Leidy Tatiana turned eighteen years of age.

Leidy Tatiana has a fifteen year old son, Nicolas Esteban Angel, referring to him as 'my great treasure, for whom I fought'.

With regard to what support for *Intersex* people in society would look like, Leidy Tatiana says, 'education is the basic tool to generate understanding'.

Leidy Tatiana is head of the *Intersex* Colombia Foundation. Leidy Tatiana is a well-known *Intersex* public figure in Colombia and Latin America, who presents public

lectures on *Intersex* both at home and abroad engaging with ‘doctors, psychologists, lawyers, teachers [and] families’.

Mani Bruce Mitchell

Pronouns: them/they

Mani lives and works as a psychotherapist in New Zealand.

Mani identifies as ‘gender-fluid, uh, queer in terms of my sexuality, uh...happy’

Mani has siblings and their dad was an amateur photographer.

Mani had surgery as a child, but did not find out about their *Intersex* condition until they were in their early forties, ‘because nobody when I was a child talked to me and this information was hidden from me as an adult’. Mani only knew that they had been in hospital and that ‘things had happened’. But the word ‘Intersex’ wasn’t part of it.’ It was after Mani’s mother died they found some medical documents with information pertaining to their *Intersex* medical history.

Mani lets their facial hair grow and says that ‘people uh...read me as a guy. [...] of course if I’m wearing bulky clothing they don’t notice that I have breasts’, adding how ‘of course “female” in Western culture is supposed to remove facial hair so [discrimination is] around that’.

Mani was present at the start of the *Intersex* movement, ISNA, recounting how, 'in the last twenty years I've been part of, visibilising something and *literally* bringing something out of the dark into a space'.

With regard to what support for *Intersex* people in society would look like, Mani says:

Well I...[Intersex] fits alongside, human rights movement[s] in general...So I think, all countries strengthening human rights protocols, 'cause it's interesting lots of countries, 'Oh yes, we're into human rights!' but it sits down here, fairly low on the priority.

Mani is a well-known public figure in the *Intersex* community, was the clinical background support person for the first ever *Youth Intersex Retreat* and has been involved in a number of films about *Intersex* including the documentary film *Intersexion* (2012).

Peggy

Pronouns: 'feminine'

Peggy does not 'enshrine any particular label as my quote "identity"'.

Peggy has *Androgen Insensitivity Syndrome* (AIS).

In childhood Peggy was told by her father that she was a boy with 'something different about me anatomically', and that surgery would 'make me like other boys'.

At thirteen Peggy had a mastectomy. At 'around age sixteen' a pediatric endocrinologist explained AIS to Peggy without using the term 'Intersex'. It was not until eighteen years of age that Peggy began reading medical books in college, including endocrinology books and books by John Money, which she found to be very helpful sources of medical information ('that was where the real explanation was'), adding that at the time there was 'really nothing else'. As a result of this research, Peggy then conceptualised herself as 'being, a girl with this condition, Androgen Insensitivity, who was mistakenly reared as a boy' and deeply regretted the mastectomy at thirteen years of age, wishing instead that someone had explained that people with AIS 'could be sexually active women'.

Peggy thinks very highly of the work of John Money and 'read everything, almost everything that John Money wrote'. Peggy disagrees with the *Intersex* movement, she believes 'they demonised John Money' and does not value their publications or opinions. For Peggy the *Intersex* movement 'is coming from people who do not have an in-depth knowledge of the medical aspects of Intersex and it doesn't reflect the actual needs of Intersex people'.

With regard to what support for *Intersex* people in society would look like, Peggy says, 'I think mainly if you are talking about healthcare professionals, they could do a better job'.

Peggy is the author of two articles in medical journals and features as a participant in *Intersex and Identity: The Contested Self* by Sharon Preves (2003).

Saifa

Pronouns: he/him

Saifa lives in Atlanta, USA and has *Androgen Insensitivity Syndrome* (AIS).

With regard to his identity Saifa says:

[W]hen I'm in my *house*, [...] I don't really see myself as having a gender, [...] so I do identify as African-American, uh, I do identify as Intersex. I identify as Queer [...] in *the world*, I'm definitely identify as like, an Intersex man, 'cause I mean, in this gender binary system, like, I identify more with men [...]. But I think even in that category, it feels very limited to me.

Although Saifa had testes removed as a baby, he 'was spared from genital surgery'.

Saifa was assigned *female* at birth but decided to transition to *male* as an adult. He has undergone a mastectomy and now takes testosterone injections ('like, every week or two'). Eight of Saifa's relatives have AIS 'on my mother's side of the family'.

It was 'probably around nineteen' years of age when Saifa discovered he was *Intersex*. Prior to this he knew he had *Testicular Feminisation Syndrome*, recalling

how, 'my mum tried to explain it to me [...] I don't remember how she explained it actually...it wasn't enough information for me to, uh, kind of be like, "Oh, I really understand!"'

Saifa maintains that 'being, you know...poor...being Black in the United States', has more of a daily impact upon him than being *Intersex*. He explained it this way, 'because I think the *Intersex* trait contributes to me looking younger than I am [...] I get profiled as a young, Black man'.

With regard to what support for *Intersex* people in society would look like, Saifa says:

It's gonna take non *Intersex* people who are willing to be allies. I think it's gonna take so much more than *Intersex* people sharing our stories because we've been doing that for *years*, right? So I think it's gonna require ally-ship to really help advance this issue.

Saifa is Board member and President of *Advocates for Informed Choice*, which is 'a legal rights organisation dedicated to protecting the bodily integrity of *Intersex* infants'.

Conclusion

This concludes the biographies of my seventeen participants. Chapters Eight to Eleven will be structured differently. Each chapter opens with an in-depth case study of one my participants, chosen for the scope of its illustrative and exemplifying capacities. The case study will be examined in more detail with an analysis that incorporates more research data and theory to explicate a range of features, properties and dimensions of living *Intersex*.

Chapter Eight: Intelligibility and Living *Intersex*

Hiker's story

Hiker was born in 1966 and was raised as a girl in Taiwan.

At six years of age Hiker had surgery for their *Intersex* condition. They are unsure but believes that they may have Congenital Adrenal Hyperplasia (CAH). Hiker explains how s/he was always the tallest person in school until s/he reached ten years of age and abruptly stopped growing and soon became the shortest.²⁶ This was very distressing for the young Hiker so their parents took them to the doctor who put Hiker on a course of injections. The injections did nothing to alter Hiker's short stature and instead served to exacerbate their distressed emotional state.

But after several, uh, many injections, I don't know what the inject-, what the doctor inject, uh, me, but they are many injections but it seems useless because, there's no...no change at all, in my body. So I kind of feel, like a...like, uh, very, very confused about myself...

Puberty brought with it feelings of isolation, helplessness and 'difference from others' as Hiker did not experience any breast development or begin menstruation like many of the girls of their age. Hiker had no one to talk to about these complex feelings, 'comprehensive sex education' was something which was not discussed at school or in the family. Hiker recounts how it was the lack of menstruation, rather than the breast

²⁶ Premature growth and bone aging, which results in short stature as an adult, is a common feature of CAH (see 'Some Intersex Conditions' in Chapter One).

development, which elicited feelings of terror since their mother - without fully understanding Hiker's *Intersex* condition - had repeatedly told Hiker 'You are going to be a mother in the future, you have to be good! And be the mother of your child!'

Hiker then wrestled with questions pertaining to their identity. Hiker reasoned that if they were unable to bear children, then they could not be a woman, and if this were true then ultimately nobody would love them.

I don't know that, uh...what, what am I, really.
 Because, my...in my mind, uh, if you, if, woman
 cannot, uh...have children, it is, is is a woman?
 And that's my question. And if I cannot, if I
 cannot have chi-, children, how can I get married
 after...when I grow up? So it...it feels very
 terrifying, because it seems that, if you cannot
 have children and then nobody will love you.

Hiker explains how these potentially anxiety and depression inducing feelings threatened to engulf them, and so, in order to cope they 'pushed the issue out, very, very deep'. Encompassed in this was a decision to no longer believe in love. Hiker reasoned that such thoughts would be useless as there would be no hope of ever finding anyone to reciprocate their love. Hiker remembers how this affected their behaviour when a boy attempted to express his love for Hiker and s/he did not know 'how to react to him...'

Living with an *Intersex* condition is to be faced with 'daily issue[s]' says Hiker, which surfaces when s/he has 'to use the toilets' or 'go to the...places that is, uh, binary'. Hiker mentions receiving unsolicited advice from women who are older than them, who upon learning 'Oh, you are a woman! A girl', when Hiker presents their *female* I.D card or other official documents for inspection, will then proceed to instruct Hiker on 'how to be a woman'.

[S]he will give me some suggestion like to eat something to grow my breasts bigger or something like that! ... Very funny and uncomfortable...

Hiker reports how s/he is regularly asked 'Are you a boy or girl?' due to their androgynous appearance and short stature (1m 44cm/4ft 72in). This has made the area of how to dress a particularly fraught one.

Uh...because uh, I'm very small, but I look like...uh, somewhere in-between male and female, so that make...uh, very hard to dress, because when I dress in 'female' clothes, it looks very much like, uh, a male...a man [laughs] who wear woman's clothes and it...makes me very nervous...so in the past, I even, uh...feel very sensitive to wear...the colour...like the pink colour...uh, the colour that belong to [laughs], uh, female. Or, uh...so it's very weird, you know? Like I'm a girl, but I couldn't wear a girl, uh, dress, very well, 'cause it looks, uh, pretty weird and it makes me feel nervous.

Interestingly, when attending high school Hiker felt protected by the obligation to wear a school uniform which was separated according to the *male* and *female* binary. Owing to this differentiation no one would ask, 'Are you a boy or a girl?' because it was self-evident, as Hiker explains, 'when you wear "female uniform", *you are a "female"*'. However, this protection was lost once Hiker left school and began employment where s/he was frequently questioned about wearing skirts, high heels or make-up by their manager. These inquiries made Hiker 'very nervous' as at that time s/he was also grappling with mounting identity concerns.

I don't very, very understand myself at the time, also, I just feel very uncomfortable...and I feel very, very depressed and I couldn't really...you know, I couldn't really stand for to...to work in, in that kind of environment because you have to be...you have to play a 'female role'...

The situation at their place of employment soon became intolerable, serving to heighten and increase Hiker's feelings of isolation and alienation in society. As a result of this, Hiker decided to terminate their employment and began to work from home doing translation work, reasoning that this way they could escape the expectation and/or requirement of having 'to play a "good female role"'.

Nevertheless, this move could not curb public curiosity about Hiker. Hiker explained that s/he lives in an area of Taiwan which, although a city, is more comparable to an agricultural countryside dwelling, where their neighbours regularly gather outside to

socialise under a tree or in front of the local temple. S/he is careful to refrain from indulging in overly personal conversations with their neighbours fearing they may have been tainted by and hold some of the many misconceptions held against *Intersex* people since s/he lives in an area that is 'conservative and traditional'. Yet these attempts at discretion do not deter Hiker's curious neighbours.

[A]nd it *did* happen that people were chatting about my gender...and make me nervous actually...and they send a girl... send a woman to ask me, if I am a woman or a man...They did, they did ask me that. For them it may be very curious, but for me it may be very nervous...'Yes I am a woman! Yes I am woman!' And... she ask me 'Do you mean it? Is it real?' [laughs] She couldn't believe it... But... I kind of face this kind of issue everyday

Hiker says that their voice has been of great value in allaying concerns at crucial moments in public when their sex and gender could potentially have been called into question. For this reason Hiker feels 'lucky' in possessing a 'feminine voice' which makes them intelligible and therefore able to 'pass' as *female*, particularly at airports, granting Hiker the freedom to travel. In contrast, Hiker shared how their friend with CAH, who identifies as *female*, is completely unintelligible as such since phenotypically they present as *male*. According to Hiker, this friend who possesses a 'very, very male' voice is afraid of ever travelling abroad.

[O]ne of my Intersex friends in China [...], she is CAH...but she...because many, many Intersex people in China doesn't have chance to get any treatment, because they can't. They live in countryside and the... lack of the medication and hospital... something like that... and information too. So, uh, they just grow up...and she grow up, just like a man, you know...totally looks in appearance to be like a man and you couldn't really tell [laughs] that this person is a girl at all! So, just kind of, after...like sixteen or seventeen forced to change herself to live as a boy and then she can living like that... but...the difficulty is that, that, her I.D card is still female, so... she couldn't like... go abroad...because she afraid...she's afraid to...uh, it's hard to pass Customs because [...].she have to...like, uh, uh...buy a fake I.D card...to, to, like fit in...with his [laughs] *her* appearance, because is like a male. Also her voice, is very, very male! Me? I'm very, very lucky because I have...like, uh, much more feminine voice, when I went to...when I pass Customs, I can use my voice, uh, to...pass...Some of my friends, couldn't do that. And she identify herself as a girl, as a female, but she couldn't... you know, she couldn't live in that way.

Hiker's experiences with 'the gender system' has led them to believe that it makes people suffer and that this could be remedied if people were to learn and understand about the development of *Intersex* bodies. In this way, society could better accommodate *Intersex* variation, and with respect to travelling abroad supply identification cards tailored to meet the needs of *Intersex* people.

And it...so it's very difficult for us. If people learn about that...uh, actually they are...there are people, uh, that has XX..XX but would develop like...uh, a male...but uh, although she develop like a male, she could be...still identify herself as female [...]. So, sometimes that, it's very difficult for us...my friend in China really hope that, if everyone can have...like male and female I.D card...[laughs] [...] at the same time. Then we can use them whenever we need it [...] Because there's *no card for Intersex*, you know and nobody understands...uh...Intersex people could have this kind of...uh...*variation*...

Hiker says that s/he welcomes 'positive curiosity' which motivates people to learn about diversity in human beings and that opens their eyes to see that the world is not only *male* and *female*.

Chapter Four demonstrated how sex and gender intelligibility was at the heart of the David Reimer case which sanctioned the current medical management of *Intersex* people in Western societies. David's sex reassignment, authorised by John Money was based upon his construction as incomplete, defective and unintelligible as a human. The issue of intelligibility originates with Judith Butler's (2004) analysis of the Reimer case in *Undoing Gender*. Butler outlines how the conditions of intelligibility for humanness are comprised of norms and in a binarised society it is gender norms that make people intelligible or knowable as humans. In other words, gender norms function as the framework for accepted intelligibility; a powerful regulatory regime which forcibly defines and bestows coherent personhood. Butler theorises that for those who find themselves outside of this framework of accepted intelligibility, gender norms convey a sense of aberration and freakishness and, in so doing, render their bodies unintelligible.

Hiker's story illustrates some of the ways that sex and gender norms function to either define or deprive personhood to people with *Intersex* conditions by either bestowing humanness and intelligibility, or conveying certain bodies as unintelligible and freakish. Exclusion from the norms governing human recognisability positions individuals as liminal subjects. For Hiker, living *Intersex* and navigating this disciplinary framework has entailed regularly confronting the sex and gender policing gaze of others regarding their clothing and comportment, as well as surmounting personal challenges at puberty regarding their credibility as a woman if s/he could not reproduce and

whether this would deny them romantic love and intimacy available to those defined as intelligibly human.

It is for all of the above reasons that I have selected to use Butler's theorising on intelligibility and humanness to inform my analysis of several aspects of living *Intersex* which emerged in my data. There were numerous accounts in my data of how sex and gender norms exert considerable internal and external disciplinary pressure and harms upon *Intersex* people and how they have even been used to lure some *Intersex* people into having surgical procedures with promises – frequently unrealised - of obtaining a coherent sex and gender, and therefore personhood. In this chapter I shall be giving particular attention to what Butler (2004) has identified as:

- 1) The operation of a disciplinary framework which both questions and asserts intelligibility.
- 2) The role of an 'already speaking' language saturated with gender norms.
- 3) The world of feeling, being and desire as experienced by those who could in fact be said to 'exceed the norms'.

The Disciplinary Framework

A prominent theme to emerge in my data is the impact that a disciplinary framework has upon *Intersex* bodies and how this is implemented by 'experts'. Jools and Peggy, who were both recipients of surgical normalisation management and treatment, recall the pressure to conform to the idealising gender norm of *male/boy* in childhood:

I tried to live as a male, I'd had what's called 'gender reinforcement' through my childhood, to try and avert me from any 'non-male' behaviour, and to try and reinforce male behaviour. If I'd known what the situation was and if I hadn't had to do that, I would have lived a very different life.

Jools

Well when I was a small child, I was just told that I was a boy, but, I had something different about me anatomically...and...I was also told that someday I would have a surgery that would make me like other boys. [...] I look back and I was thirteen years old and I had had mastectomy and I thought that was a big mistake and I became very regretful about that ...If when I was thirteen someone would have explained the medical details of AIS²⁷ to me...and had explained to me that people with AIS could be sexually active women...I would have chosen to live as a girl then and I would have not had mastectomy...which would have been a big improvement in my life then and all times thereafter.

Peggy

Incorporated in the gendered disciplinary regime is coercive surgery and hormones and the imposition of normalised gendered behaviour, as well as beguiling promises of coherence as a gendered being and with it the achievement of 'real' or 'natural' personhood (Butler, 2004). Jools and Peggy say they were not provided with

²⁷ Androgen Insensitivity Syndrome

comprehensive information about their *Intersex* conditions and both speak of their wish to have been better informed in order to have made very different decisions earlier in life and to have had the opportunity of living a life at variance with what was imposed upon them under the regime of the disciplinary framework. In connection with coercive medical management, Butler queries, if normalised gender is so malleable why does it have to be 'forcibly imposed and behaviourally appropriated?' (2004: 66).

The Lure of a Coherent Gender

The lure of a coherent gender and therefore personhood is a powerful one. Hiker's story depicted someone who had been repeatedly told that a woman equals motherhood, and so when Hiker failed to menstruate in puberty this brought terrifying feelings of anxiety and depression, because s/he then wondered what type of a person/woman s/he was and whether anyone would ever love them. Puberty was referred to as an unusually challenging time by the majority of participants for a variety of reasons, including: its very late or early onset, undergoing bodily changes that are embarrassingly different from your peer-group, not having others to relate to or communicate with, and unique hormonal concerns. These replies were all given in answer to the question, 'At what ages would you say an *Intersex* person needs the most support and why?'

Around, first I'd say, around puberty, like, sort of the age around puberty, maybe a little bit before that, especially if they've always known, a little before that, because your body is going to be

doing different things and you need to be able to talk to someone about, I mean, most non-Intersex kids they have like, their entire age group to talk about these things with, like the changes your body goes through during puberty.

Kitty

[W]hen they're in their teenaged times, as Intersex...uh, that's uh...I think that's possibly the most important time [...] 'cause that's the time when most kids are...becoming young adults and puberty business coming and obviously, that's hormones for most of the kids anyway going all over the place...uh, and, you know, for Intersex people, not all of them have hormone issues, but, uh...the ones that do, like, yeah...like for me, I wasn't...you know, going with them at all...uh, they were swimming and they had flippers on, they were flying ahead of me...basically, you know...so I'd say the teenage times are the, probably the most important.

Gavan

In adolescence is much needed because the sexual life begins to grow. He begins to like a man or a woman, begins to develop their estrogen or androgen, both the male and female life. A great support during adolescence. That is the point where you need to take strength this person and live like a normal, happy person and that suits the society and not feel bad and can be accepted by [...] their family and friends without having some kind of discrimination.

Leidy Tatiana

Bridget: Uh, I would, I would say...well, in my case it would be...uh...the...puberty. Because, then you're like...going through *some serious shit* and you're on hormones. And, you have *no idea what's happening*...So, yeah...that would be, that would have been a lot better if I would had like, support from other kids going, through the same rollercoaster...

Up until the age of eighteen Courtney had a 'fused labia' which resembled 'an empty scrotum' and no vaginal access. In interview, Courtney revealed how they selected to have surgery in adolescence in order 'to have sex':

I could've been cut at birth. They could've taken my clit at birth. Luckily my dad had good advice from his mentor and they...he said 'No, don't do anything, don't do anything...' and when I was eighteen, the reason I got surgery at eighteen, is that I wanted to have sex! [laughs] ...

Courtney

The operation of societal norms is discernible here, dictating and restricting 'normal' sexual activity to penile-vaginal intercourse, an impossibility for many *Intersex* people, leading them to seek out surgery. Sarah Creighton, a gynaecologist specialising in pediatric and adolescent gynaecology in London, UK, writes how patients who have *Intersex* conditions are often 'deeply influenced' by the constant societal pressure declaring that difference is bad and 'all must aspire to a "normal" appearance' (Creighton et al., 2009: 253). Creighton has noticed how these aspirations toward "normality" drive and inform decisions regarding genital surgery in the belief that it

can solve 'a whole range of problems' which may or may not be associated with their *Intersex* condition (Creighton et al., 2009: 254). A key concern for *Intersex* patients, says Creighton, is sexual intercourse and the majority pursue vaginal reconstruction surgery despite the lengthy and sometimes multiple procedures, risks of scarring, vaginal dryness, soreness and pain, with the conviction that it is a 'cure' for their *Intersex* condition (Creighton et al., 2009: 257). When writing about vaginal surgery for *Intersex* people with atypical vaginas, independent scholar and *Intersex* person Iain Morland (2009) says that although the surgical treatment is elective it cannot be called 'patient-centred', insofar as the patients are capitulating to heterosexual norms and medical authority, and therefore cannot be said to occupy the treatment's 'centre' (Morland, 2009: 203). Courtney shared the aftermath of their vaginal surgery:

[T]he surgery was botched and the hole wasn't made big enough so...it was just a disaster [...] it was offered, 'Yeah you can always have surgery to fix it!' and like, [...] I declined...

Courtney

Creighton states that it is 'unrealistic' to believe that surgery can create 'a vagina that functions as if no surgery has been necessary', adding that this expectation is 'partly the fault of clinicians' who imply or say that surgery is the treatment for *Intersex* conditions (Creighton et al., 2009: 257). As previously mentioned, Peggy recalled being told how surgery 'would make me like other boys' while Kitty was 'reassured' as follows by an endocrinologist:

Int: Can you tell me how [Intersex] was explained to you and by whom?

Kitty: Uh,... this was explained to me by my endocrinologist... who reassured me that I was a real girl I just had different parts and some of them had to be taken out [...] had been taken out.

Here we see that Kitty was told by her endocrinologist that the 'different parts' of her had necessarily to be surgically removed so as not to interfere with her 'real girl' status. Correspondingly, Butler reflects on a similar narrative of coherent gender, ergo personhood, in the David Reimer case (see Chapter Four). David Reimer was frequently pressurised by medical professionals - including John Money - to undergo vaginal surgery and live as a woman. David repeatedly refused but remembers being told: "it's gonna be tough, you're gonna be picked on, you're gonna be very alone, you're not gonna find anybody" (Butler, 2004: 71). Butler explicitly calls this bribery since the doctors implied that without surgery David would have outsider status: be bullied, alone and without love or companionship. However, this is not about love, states Butler, rather it is a 'seduction to subjection,' and compliance to a 'regime of reason established by the norms of sexology' (2004: 73, 74). On this point, Katherine reflected as follows:

I've never ever wanted to be anything other than myself, but I wanted other people to be happy with who I am really, and it took me a long time just to actually just get to the point of actually, other people are never going to be happy with

who you are, whatever you are, it's about yourself isn't it really?

Katherine

The disciplinary framework is not limited to the medical gaze. As Hiker's story evoked sex and gender policing is implemented 'through a plurality of gazes', often involving people in the workplace, neighbours and peers (Butler, 2004: 67). Bullying at school was repeatedly spoken of during interviews. Specifically, getting undressed for sports class was overwhelmingly remembered by participants as a source of dread, discomfort, abuse and humiliation, due to the phenotypical manifestations of certain *Intersex* conditions being visible to their classmates. John and Darryl recount their experiences:

Int: Do you feel under, have you ever felt under pressure to hide that you're Intersex?

John: Yes. Some of the physical conditions that I have...make...my particular condition stand out, especially in, say a locker room setting for example...as a kid I was terrified of gym class because I'd have to get undressed and take a shower with all the other guys and...I didn't look like all the other guys. I had conditions that changed the way I look in the genitalia area and...that was...even to this day I'm very uncomfortable in dressing, undressing in a locker room setting...at any given time [...] so yes it's very hurtful in that respect I'd guess you'd say...

My breasts, they come over and feel me, they came over, because my boobs, I had breasts in those years. They were trying to feel me up, so...I... had to get out of gym [...] I hated it. I hated being humiliated because I wanted so much to be a man, a boy, and there I was looking like a girl. So...I...so it was really hard. And so what I did, was I went to my doctor and I got a phony excuse, so I could get out of gym, and from the age of thirteen 'til the age of eighteen I was no longer in gym...

Darryl

The psychological effects of sex and gender policing in childhood are long-lasting.

John explains that getting undressed in a public space as an adult now in his fifties still elicits 'uncomfortable' feelings.

Hiker's story referred to the disciplinary gaze of airport officials and how this affected both Hiker and their friend with CAH. The fear that Hiker's friend has, preventing them from ever travelling abroad, is not unfounded. Mani, who 'hates going through airports', explained how they were currently providing support to an *Intersex* person who had been raped when attempting to go through passport control.

I travel a lot so...you know, my legal documents are all 'female,' and I *hate* going through airports, you know. I am always *hugely relieved* to come out the other side of immigration, you

know, passport control because I never totally know what's going to happen... [...] you know, I've been asked pretty horrible questions, that's as far as it's gone, *for me*. This past weekend I've been supporting someone, I won't identify the country at the moment, where...you know [sighs] someone...an Intersex person was stopped by immigration officials...uh...and taken aside. This person ended up being... having all their clothes taken off and they were raped by the officials.

Mani

Sex and gender norms incite 'aberration and freakishness' (Butler, 2004: 70). My data demonstrates that set against the grid of intelligibility *Intersex* bodies are unintelligible and therefore make them uniquely vulnerable to any number of emotional, psychological, physical and sexual harms from their peers and/or institutional/organisational staff. As Mani later adds:

It's interesting, we're starting to get, more accurate information about the mental health status of Trans and Intersex people in our community and you know, the stats are horrific, like over 60%...people feeling suicide, depression, anxiety...all the things that weigh up above the standard population *of course*...There is a consequence to, not feeling OK about yourself and how you're being treated [...] being different in our world is not easy. And if you have a body

that's not...uh...the same as everybody else's, it does put you at risk.

Mani

The 'Already Speaking' Language

Language is an integral component of the disciplinary framework that constitutes a grid of intelligibility. It is a key part of the regulatory power which authorises and 'set[s] out in advance' what we can be or become (Butler, 2004: 58). Language is 'saturated with norms' (Butler, 2004: 69). Accordingly, if sex and gender norms define intelligibility for humans it would follow that a normalising language would function to convey the self-same 'aberration and freakishness' reserved for the bodies of those situated 'outside of the framework of accepted intelligibility' (Butler, 2004: 70, 73). Owing to this, language can be said to hamper, restrict, delimit and predispose us as we speak. This 'already speaking' language (Butler, 2004: 69) was very apparent in my data as illustrated here by Courtney and John's descriptions and opinions of *Intersexuality*:

Kids need to know that they are not normal...that they are Intersex [...] We need more people, more Intersex people to come out and explain their specific conditions because it's such a wide variety of conditions, some, the AIS women with XY chromosomes look perfectly normal. When they're in the locker room they look like girls, so I think, everybody needs to understand that there's a lot of different types of Intersex. Some

people look normal, some people don't look normal. We all have, we all have different, you know effects of it, because of it.

Courtney

[W]hat I consider Intersex now, is something that is, is, just like any other...birth defect, you...you're dealt a hand and you have to deal with that.

John

Courtney and John's comments on *Intersex* as 'not normal' and a 'birth defect' inadvertently echo a medical discourse that reads *Intersex* bodies as abnormal and defective, because they diverge from the norm. Fundamentally, these excerpts are indicative of the difficulties of using a language at odds with *Intersex* to delineate *Intersexuality*, for medical discourse is aligned to the dichotomously sex and gendered grid of intelligibility (Holmes, 2008). Courtney and John are bound by the limiting, confining and obscuring parameters of normalising language even though they do not subscribe to the stigmatisation intrinsic to it. This is evident in their following remarks that acknowledge people with *Intersex* conditions as people who need to be 'recognised as part of society' and *Intersexuality* as a medical condition 'just like any other'.

Nobody knows what Intersex is! It's just now kind of coming in, you know, into the, into the

culture...People just need to know more about us. [...] I feel for little Intersex kids man! 'cause it's a tough life. There's no way around it. It's a hard life. It's difficult. And the way... it's gonna be made better is if we are recognised as part of society because really, people don't know about us.

Courtney

I don't consider [Intersex] a burden.
I don't consider [Intersex] a blessing.
It's something that just like any other medical condition I had to deal with...

John

Section One examined how language is employed in medical settings to legitimise genital surgeries on *Intersex* babies and infants (see subheading 'The Construction of *Intersex* Patients', in Chapter Four). Condemnation of corrective rhetoric and the motives it obscures was emphatically expressed by Gavan.

I mean, babies who are born Intersex, quite often ... they've got ambiguous genitalia and the doctors are still gonna either cut them up or sew them up, whatever, you know...and they're making babies transsexual essentially, at the start [...], or it's female genital mutilation, whatever way you want to look at it. [...] So that's what we're dealing with, and they want to 'correct babies that were not born fucking properly'. How dare they say that!

Gavan

Significantly for my analysis, Butler (2004) evaluates how David Reimer develops a discourse of self-reporting and self-understanding. Since the purpose of the intense scrutiny endured by David in childhood and adolescence was to garner evidence for or against a 'true' sex and gender, in adulthood David fully understands that toys, games, clothes, behaviour and utterances can all function as evidence for or against a particular sex and gender. What this suggests is that when David is responding to interview questions about his sex and gender identity as an adult, he is in fact speaking to the 'apparatus of knowledge' previously applied to his body and person (Butler, 2004: 67). Butler contends there must be 'enormous anxiety' at work in a world which seizes upon the multifarious variables of body, dress, appearance and more to sate the desire for an unequivocal 'truth' of sex and gender (2004: 70). Yet it is from out of this disciplinary framework that David's intelligibility, humanness and personhood is not only directly questioned, but is asserted and emerged.

Writing on the David Reimer case, American gender and feminist theorist Bernice Hausman (2000), argues that John Money was not wrong to identify the use of gender narratives as crucial to the development of a child's gender identity, but what should have been analysed in more detail is how coercive gender narratives can incite rebellious and creative responses; and how the attempts of clinicians to 'feminise' David with certain gender narratives prompted David to fight back with his own 'arsenal of stories' (2000: 126). Mani, one of the earliest members of the *Intersex* movement, similarly noted the power of young *Intersex* people who have pushed the boundaries of language and the contribution this has made to the *Intersex* community and their identity formation.

[T]he language has become more nuanced since I started this journey and a lot of that is coming from the youth, who are, who are really pushing out the boundaries [...] language is so important and one's sense of identity so, you, you know I think that emerging visibility, strength of the Intersex community is because we now have language around this we have actual images for people to reflect on...

Mani

Likewise, in the following extract Kitty confronts the narrative of *Intersex* as inherently flawed and set apart from the 'true' categories of *male* and *female*, by re-situating *Intersex* instead as alongside 'women and men', and as such, reasserting a narrative of *Intersex* as a healthy variation of sex.

Int: Uh, are there common misconceptions about Intersex people?

Kitty: Uh, yeah sure there's lots of them, there's a common misconception that [...] there is something medically wrong with us from birth, and uh, which a lot of the time is not the case, I mean, sure some of us face health issues but, uh, without there necessarily being anything wrong, just like, women and men face health issues.

Correspondingly, a number of participants shared what they perceive as advantages of *Intersexuality* which creatively, and even rebelliously, repudiates *Intersex* as a transgression of sex and gender.

Uh...for example...uh, I don't *sweat*. Well, I sweat a little, so, it's like... and it doesn't smell, so it's awesome. I don't get pubic hair...and...well, menstruation is, is an unknown thing for me. So...*yeah!* It's fun!

Bridget

Oh! Many people say that uh...Intersex people look much, much, more younger than...their age [laughs]

Hiker

[B]ut, uh, yeah, the advantages are being infertile [laughs] ...in your twenties! [laughs] [...] I did have some great times [laughs]

Gavan

Exceeding the Norms

When considering the predicament of the unintelligible subject, Butler determines that they occupy a 'world of feeling, being and desire' that is both complex and distinct from the norm (2004: 69). This understanding stems in part from the othering action of the norm, for, with respect to David Reimer, the norm posited a gendered ideal that he is aware he was supposed – but failed - to live up to, and so in the moments before the mirror his humanness is called into question. David however recognises his worth lies elsewhere and is not solely determined by 'what I have between my legs' (Butler, 2004: 71). The norm is supposed to inaugurate humanness and intelligibility,

yet crucially David is indicating he recognises a worth that surpasses the norm, and in so doing, does not require its validation. By proclaiming this from a place of unintelligibility David Reimer 'exceeds the norms' (Butler, 2004: 72). There are many parallels with Butler's discussion of exceeding the norms in my data as exemplified here:

I've always thought differently from men or women, peers, you know, boys or girls [...] so the advantages are, in that you don't think, for me it's I don't think the same way as most men or women do, which gives me different insights, different understandings...uh, but also, it's kind of...I think, it's given me different relationships, different qualities.

Jools

[I]t's taken a long time to come to this, but I think, it's, it's...sort of a gift because I feel like I can see things from a perspective that's not female and not male, but I understand both of those perspectives.

Courtney

I'm not male or female, I don't have a body that's completely male or female and the more I have reflected on this I, I don't... my actual *brain works differently* [...] and it's really interesting to have understood that. And you know, I am comfortable in many aspects of the male world and there's parts of the female world. But where I am most comfortable is around other Intersex,

gender-queer people! And it's interesting 'cause I'm around people who think and respond to the world in a similar way to I do.

Mani

I have come in touch with the sexuality of both sexes, inside me when I am with somebody in a sexual act, in a sexual relationship. I can identify and feel...that connection. I can feel it. [...] I can experience one. I can experience the other. I can experience both at the same time and I cannot explain that. I don't know what it's like to experience sex as being a total male. I don't know what it's like to experience sex as a total female, I never have, I'm not total one or total the other, I'm both. [...] I'm getting both at the same time and it's the best moments of my life.

Darryl

These themes appear as a leitmotif in several other participant interviews. In speaking this way and asking to be known without entering into intelligibility - ergo whilst outside the accepted intelligibility - *Intersex* people are showing that there is indeed an understanding to be had that *exceeds the norms*. In conjunction with this, a number of participants spoke of their gratitude for the 'blessed', 'extraordinary' life and 'wonderful' mission that *Intersexuality* has bestowed upon them.

But then I think, anatomically, I understand what it means to be both a woman and a man, so I think I've been blessed *in a way* just...uh, just to

be able to have different experiences along the gender spectrum [...] uh, *and* increasingly to tell my story about being Intersex and receive such compassion and understanding from people. So I think that's really...I've been fortunate in that regard.

Saifa

[L]ook at the extraordinary life that I have had that, uh...astounding people I have met...uh...I have a very *rich* life now. I have people that I love literally, all around the world. Not very many people get to be involved in something like I have. [...] would I wish this experience on anyone? No. But as being an Intersex person I can say this now, it's been amazing. And of course, I can't imagine what it would be like not to be an Intersex person, that's...*that has not been this life.*

Mani

My experience of living as Intersex person is wonderful. I am a human rights activist and more depth to the Intersex community, live a normal social environment, I have no problems of discrimination [...] I am very happy to be so, I'm happy to get across to people "who I am" and the mission that I have in this life, I feel good knowing that I am doing a good job.

Leidy Tatiana

It gave me uh...a really meaningful mission in my life. I was able to accomplish some work that was really important and changed a lot of

people's lives and I might not have had that in my life if I wasn't born Intersex.

Bo

Conclusion

Hiker's story demonstrates some of the ways people with *Intersex* conditions navigate a world which uses sex and gender norms as the benchmark for intelligible humanness. As a result of these norms *Intersex* bodies are incomprehensible, resulting in many unwanted intrusions into their lives. The range and severity of these intrusions is apparent in my data where surgical alteration, physical abuse and prescribed gendered behaviour are condoned as part of a disciplinary framework designed to convey *Intersexuality* as a freakish aberration. This creates extraordinary pressures in puberty for a young *Intersex* person whose body is often developing at a different rate and in a different way from that of their peers. The lure of intelligible 'normality' can lead to acute feelings of alienation at puberty and this is why it was singled out by participants as a time where the most support is needed. My data also shows how language is an integral and therefore inescapable part of the gendered grid of intelligibility. A dimension of this is that its usage caused participants to inadvertently echo a discourse describing *Intersexuality* as abnormal and defective. Yet it is equally evident how this predisposing language 'saturated with norms' is being defied. My data contained numerous instances where participants celebrate the unique complexity of *Intersexuality*, despite enduring episodes of abjection, and speak

of their remarkable distinction from sex and gendered norms and the advantages this has brought to their life course.

Chapter Nine: Parental Secrecy and Shame

Courtney's story

Courtney is fifty-four years of age. They are a qualified medical doctor who lives and practices in California, USA. Courtney's karyotype is XX. They have a uterus and menstrual periods and up to the age of eighteen their genitals 'appeared to be in the middle'. Courtney explained, this was due to a 'fused labia...so it looked like a scrotum, an empty scrotum, and I have a large clit[oris]'

Courtney's *Intersex* condition influenced the direction of the professional life of their parents who both specialised in endocrinology. Courtney's mother (now deceased) attended nursing school as a mature student at fifty years of age and became a Pediatric Endocrinology Nurse Practitioner. Courtney's father, who was working as an intern when Courtney was born, decided upon a career in obstetrics and gynaecology and became a reproductive endocrinologist gynaecologist and professor.

Nevertheless, Courtney shared how their birth had a very 'traumatic' effect upon the family. Courtney's mother experienced a breakdown ('she was just a mess') and was unable to care for either Courtney or their older brother. The latter was sent to live at the house of a friend for a few weeks whilst their mother received outside assistance.

Int: ...What advice would you give to parents of Intersex children?

Courtney: Don't keep secrets number one. And don't keep secrets from the siblings. The whole family has to be involved. It's traumatic. It's traumatic for the parents. My parents lied to me, they said they weren't traumatised. It turns

out they were so traumatised that my brother had to get sent away to a friend's house for a few weeks because my Mum was unable to take care of me and she had to have people come in and deal with her...She was just a mess. No secrets. Don't lie...I mean, don't say 'Yeah we were fine, we just wanted a healthy baby.' No, you wanted a healthy boy or girl. Nobody wants an *Intersex* baby. Everybody says 'I don't care what it is, just so long as it's healthy'. Bullshit...

Courtney described the extent to which secrecy about their *Intersex* condition has impacted their life and relationships. As a baby, Courtney's parents would not allow anyone to change their diaper for fear they would see Courtney's *Intersex* genitals. Their mother did not tell her best friends, lifelong family friends or even her son about Courtney's *Intersex* condition. Courtney recounted how they are only now telling their mother's close friends and that they emailed their older brother about their *Intersex* condition just last year (2013).

There needs to be more honesty and openness from parents, from the get go...my brother didn't know I was *Intersex*! My older brother, until last year when I sent him an email. My brother didn't know...So it's the secrecy and, that needs to go away. The shame, the stigma, the secrecy. All the secrets, that's the biggest thing, secrets are damaging. [...] My mum kept it secret even from her best friends. My mum died three years ago and I'm telling her best friends that she knew for fifty, sixty years. They never knew...Nobody was allowed to change my diapers when I was little except Mum and Dad because they didn't

want anybody to see my crotch.....it's very, very isolating.

Courtney remembers their first introduction to *Intersex* at eleven years of age when their father gave them a textbook to read with a chapter bookmarked on *pseudo-hermaphrodites* and said, 'This is what you are'. At this point in their life Courtney says they knew it applied to them because their genitals 'looked different than anybody else's', but they did not actually understand what it *meant for them*, explaining that it takes a very long time 'to come to grips with' *Intersex*. At twelve years of age, after being subjected to extreme verbal and physical bullying on a daily basis at school, when undressing in front of peers for gym class ('It was hell'), Courtney stopped attending school altogether and instead spent their time 'smoking a lot of pot and partying'.

Well, yeah, when I began junior high which is 7th grade here...we had to go to gym school and go to the locker room and get undressed and that's when I first had bullying for having different genitals. People called me 'he-she', 'pin dick', people...I...it was only a couple of girls who bullied me but that's all it takes to [...] they...kicked me in the crotch...punched me in the boobs, called me names and I stopped going to school. I basically just skipped school through junior high and high school. I stopped going to school because I was getting bullied. It was hell. I just said 'Fuck it, I'm not going'.

Speaking of their parent's reaction to the numerous phone calls from school on the matter of their truancy, Courtney says, they 'didn't understand that it had anything to do with my genitals. They were like clueless. They didn't get it [...] I was a pot-head and they just thought I was a bad kid'.

Courtney was encouraged by their parents to keep their *Intersex* condition a secret from others, whilst paradoxically being told 'it's not a big deal'.

I was brought up to not tell anybody about it. I was told it, it's not a big deal but don't tell anybody about it because it's too complicated for anybody to understand. So that's how I grew up. It has to be a secret. You don't tell anybody

This pressure negatively impacted their opportunities for intimacy in romantic relationships. Courtney recalls being 'a bitch' and 'mean' to a boy who liked them because the 'secrecy, shame, [and] all that stuff' created barriers to learning how to date, relate to people and have boys be close to them.

[B]ecause it's made me defensive of people becoming close to me...any chance of intimacy...intimacy...if somebody's interested in me...I have to...my whole life I've been 'No, no, no, I don't want to have a relationship' and so...it's been like that my whole life.

Courtney explained how this behaviour has affected their 'whole life' which has been an 'extremely lonely' and very isolating existence. As recently as two years ago they still remained under the influence of parental pressure convincing them 'to be closeted' and to keep their *Intersex* condition a 'secret from everybody'. Courtney believes that this need for concealment has even steered their sexual object choice.

I've had two partners, briefly, two females. One was a... actually a transgender male to female and the other one was a lesbian and...I'm not...I'm not really that attracted to women! [laughs] But I thought if this is the only way I'm gonna, gonna have a relationship. So I have had a total of two relationships, for maybe a total of five years out of my life [...] So I've been... it's a very...I've been very lonely. It's extremely lonely...

Even as an adult in their forties Courtney's father did not want them to talk about their *Intersex* condition, for twelve years he kept secret the location of the local *Intersex* community.

I moved out here twelve years ago and the woman, the *Intersex* woman who was in charge of [Intersex Society of North America] lived in the town I moved to and my Dad knew all about her, knew all about *Intersex* organisations, never told me that they even existed! I didn't know that there were others out there...I never knew...I never knew. And so, when I was...I was...how old was I? Forty... forty-two, when I first came across my first...it was online or something, *Intersex* group...and that was *Intersex* Society of North

America, ISNA. I...my Dad knew all about this, he never told me that there were groups. He didn't want me to hook up with other Intersex people and talk about it.

Int: What did he think...what did he think was gonna happen?!

Courtney: I don't fucking know! [laughs] He's fucking crazy!

Courtney eventually found and joined an online Facebook group for *Intersex* people and made some 'great friends'. However, the transformative moment occurred years later, in June 2013, whilst marching with the *Intactivists* at San Francisco Pride Parade. It was there that Courtney was inspired and empowered to 'come out' and finally start talking about their *Intersex* condition to their brother, other family members and friends. When asked what advice they would give to an *Intersex* child Courtney advised:

Love yourself. Don't be ashamed. Don't feel like a freak. Explore your body...you know, love it, get into it. Don't...don't be ashamed. And...you don't need to advertise it but when you feel comfortable talking with somebody about it, talk, tell people, tell 'em, they'll get it! People get it. If you tell them and explain to them, they get it.

Previous studies on *Intersex* have importantly centred on the ways in which medicalisation harms people with *Intersex* conditions, including how normalising surgery fosters a culture of secrecy and shame (Preves, 2008; Liao and Boyle, 2004b; Gough et al., 2006). However, a distinct component of this to surface in my data, as depicted in Courtney's story, is the role of *parental* secrecy and shame, and the multiple ways it was communicated and enacted towards my interview participants as children, as well as their subsequent appraisal and framing of it as adults. On closer scrutiny, these findings on parental secrecy and shame show it takes many diverse forms, including deceit, silence, evasion, subterfuge, traumatic breakdowns and denial. Moreover, it has a very wide reach, with the ability not only to detrimentally affect the *Intersex* child, but also tainting relationships with other children in the family, close friends, work colleagues and even relatives sharing the same *Intersex* condition.

Accordingly, what these findings suggest is that the significance of this area must not be overlooked. As participant Hiker asserted, parents of *Intersex* children are 'the first one[s]...in the closet'. This statement acknowledges both the support required to get past the stigmatisation of your new child's identity, as well as the courage and determination needed to 'come out of the closet' by openly facing and resisting attempts to dehumanise and erase your child. All of this is compounded by research which, as evoked by Courtney's experience, attests that parental adjustment and adaptation to a child's *Intersex* condition profoundly dictates how the child in turn accepts their *Intersex* status (Liao and Boyle, 2004b). Yet in spite of these formidable hurdles, Arlene Istar Lev (2006b) has found there to be a silence throughout the

therapeutic literature and community – incorporating social work, counselling and family therapy – concerning the therapeutic issues and needs of *Intersex* people and their families. Consequently, it becomes apparent that my findings relating to parental secrecy and shame could have important implications for the development of much needed support in this area (Gough et al., 2006). It is within such a context that this chapter presents in detail some of the issues emerging from parental secrecy and shame, as highlighted in Courtney's story and shared by many other participants in my study; specifically, it will consider the ways it permeated self-image, family dynamics and social bonds, and will contrast these experiences with the accounts of participants who did not grow up in such an environment.

Disclosure to Family, Friends and Work Colleagues

My data shows that being in possession of medical expertise does little to alleviate parental secrecy and shame. Autumn's father, who like Courtney's was 'very intelligent [...] a practising physician', did not want his medical colleagues to discover he had a child with an *Intersex* condition, in spite of working in a field that deals directly with *Intersexuality*. Subterfuge played a significant part in Autumn's family dynamic of secrecy as is evident when her father arranged that she attend her endocrinology appointments in Los Angeles and not where they resided in San Diego. For Autumn, preserving the 'family secret' involved travel to another city on a school day with her mother, employed as a nurse, who euphemistically referred to these outings as 'Shopping Trips' (see Chapter Eleven).

When psychologists Gough et al. (2006) interviewed ten parents of *Intersex* children to explore how they made sense of and lived with it, they found disclosure to friends and family to be an area of difficulty. As related by Courtney, their mother died without telling Courtney's brother or her best friends about their *Intersex* condition and she feared the latter seeing Courtney's genitals as a baby. Consistent with this finding, Gough et al. reported that underpinning parental anxieties surrounding nappy changing was that friends 'inured to the two-sex system' would see external genitalia marked as 'other' on the child which would cause upset and be perceived as monstrous (Gough et al., 2006: 500).

The Impact of the Pre- and Post-Natal *Intersex* Scenario

Some of the emotional reactions experienced by new parents of *Intersex* babies have been listed as devastation, disbelief, grief, anger, shame and guilt (Gough et al., 2006; Lev, 2006b). When considered in the light of a typical pre- and post-natal *Intersex* scenario, the breakdown of Courtney's mother, as recounted in their story, and her subsequent temporary inability to care for both of her children is unsurprising. Previous studies have reported that medical teams retain exclusive control during the pre- and post-natal scenarios, relegating parents to playing a marginal role in the decision-making process for their *Intersex* child (Beh and Diamond, 2000; Hester, 2004). Parents also receive a lack of full disclosure and support, all of which raises serious ethical questions concerning irreversible infant surgeries (Beh and Diamond, 2000; Creighton and Minto, 2001; Hester, 2004; Lev, 2006b; Preves, 2008). John, who is fifty-six years of age, revealed how his mother remained completely unaware

of his *Intersex* condition until he told her last year (2013). This was in spite of him having to undergo 'at least seven different surgeries' before the age of seven which his mother was informed was to correct her son's undescended testicles.

I know it really upset my mother when she found out...because she went back to the memories of...birth... shortly after birth and how the medical profession lied to her and that really hurt her...because she, she was completely unaware 'til I told her...

Int: and you told her as an adult didn't you?

John: Yes [...] Last year.

With respect to the pre-natal scenario, despite there being numerous baby books and information featuring a host of pre- and post-natal medical conditions and complications, *none* of them discuss *Intersexuality* (Lev, 2006b). Additionally, there are no protocols in place for medical and health care professionals - in the fields of obstetrics and genetic testing - for discussing chromosomal anomalies related to *Intersex* conditions and their impact upon pre-natal parents (Lev, 2006b).

Consequently, at birth a baby with a visible *Intersex* condition is usually removed from the mother for medical diagnostic examinations in order to determine their 'true sex' assignment (Kessler, 1990; Lev, 2006b; Preves, 2008). The following excerpt from the novel *Golden Boy* by Abigail Tarttlin (2013) helpfully provides an illustrative, fictionalised account of a new mother experiencing difficult and distressing feelings at the birth of her *Intersex* baby Max.

When Max was diagnosed, I couldn't do anything but weep silently. I remember listening to doctors murmur to Steve about surgery. I nodded over and over again, hearing no real words, just hoping they could fix him, asking what I did, why it happened. They couldn't tell us. [...]

The moment after Max was born, the nurse took him away from us. I knew something was wrong right then, because they usually put the baby on the mother's skin.

It was the young nurse who took him. She was about my age at the time, twenty-six, and her name was Anna. Anna, who had a brown ponytail, little silver hoop earrings, and a cheerleader-type zest during the labour, had only recently qualified. I wondered immediately if it was Anna who had done something wrong. As she cleaned the baby, she called the older nurse, Barbara, who was by my side. Anna waved her over like she didn't want to say anything out loud.

Barbara went to stand by her side and started to rub the baby and talk to him. They had their backs to me. He was still gurgling so I couldn't think what could be wrong. The doctor who had the forceps was still standing there, Dr Horvath, and he was talking to me, and then Anna came over and the doctor went to the baby. [...]

On the day of his birth, I remember I was on the bed, looking at the polystyrene tiles in the ceiling. Steve was holding me and I was shaking with fear and pain. My chest hurt. My stomach hurt. My ribcage felt broken, like every bone had caved in. I had failed the first task of being a mother. Something inside me had hurt my baby. I couldn't look as the doctor examined him.

'What is it?' Steve said, standing up, letting go of my hand.

The doctor turned around and took off some plastic gloves I hadn't seen him put on. He faced us both and spoke softly, but firmly – something about ambiguous genitalia. He said he was going to take Max and do some tests.

Excerpt from *Golden Boy* by Abigail Tartellin
(2013: 184-185)

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When newborn *Intersex* babies are taken away for various tests their mothers are questioned so medical professionals can decipher possible causes for the baby's *Intersex* condition. However, when probing the mother with questions - which can even include those related to chemical exposure, substance abuse or prescription medication - failure to communicate the reason for such questioning can engender parental feelings of distress, guilt or blame (Lev, 2006b). Added to this emotionally fraught scenario, parents reluctant to pursue surgery have been accused of child abuse, threatened with legal action or have even been ignored by medical professionals who have proceeded with genital normalising operations under the guise of 'surgical completion' for a 'developmentally incomplete' child (Kessler, 1998; Lev, 2006b; Preves, 2008; see also subheading 'The Construction of *Intersex* Patients', in Chapter Four). Finally, when parents are discharged from the hospital with their newborn *Intersex* baby, due to the absence of therapeutic support, education and resources, they are – as depicted in the case of Courtney's mother - ill-equipped to navigate the multiple family issues ahead (Lev, 2006b). In one study conducted with

twenty mothers of *Intersex* children, there were five instances of divorce while fourteen reported that marital harmony was strained (Kessler, 1998).

The Culture of Secrecy

The culture of secrecy is a hallmark of the medicalisation of *Intersexuality* (Preves, 2008; Dreger and Herndon, 2009; Reis, 2009; van Heesch, 2009). *Intersex* conditions and any associated surgical history are frequently hidden or even erased, requiring no further discussion or disclosure with those who are directly impacted by it (Creighton and Minto, 2001; Lev, 2006b). This conduct was repeatedly corroborated in my data, as explained here by Katherine, Bo and Jools:

Well when I was young, I knew I was different, but I didn't know the word *Intersex* at all [...] it was never explained by family [...] that word never came up.

Katherine

I think I was discriminated against when I was born...when my birth was treated as a disaster and my parents were not supported uh...by medical professionals and then again when they kept things secret from me and when they performed mutilating sexual surgeries on me.

Bo

Int: Can you tell me how [Intersex] was explained to you and by whom?

Jools: Well it wasn't. I found out about it [...] I had surgeries as a child and...I was never told anything about them, or what they were, or what they were for...

Kipnis and Diamond (1998) highlight 'physician deception' as the practice of withholding information from *Intersex* people from childhood and into adulthood (Kipnis and Diamond, 1998: 57). The rationale for this is the same as for surgical normalisation: by eliminating all signs of anatomical or physiological difference any associated social problems are also potentially removed. Thus, in cases where parents are informed their child has an *Intersex* condition, they are warned that revealing this to the child could have severe consequences to its psychosexual health. This hypothesis is based on the *Optimal Gender Rearing* (OGR) model established by John Money in the 1950s, which states that in the achievement of gender congruent parenting the history of a child's *Intersex* condition should be kept secret, thereby eliminating any problems related to gender development (see subheading, 'The Optimal Gender Rearing Policy (OGR)' in Chapter Four). By contrast most of the participants in my study believed that, as stated by Peggy, 'Intersex is not an impediment to fitting into society' and that the difficulty lies in a medical protocol which reinforces a culture of shame and secrecy.

The Repercussions for Peer-support and Community

In recounting their story, Courtney spoke of how their father, a reproductive endocrinologist gynaecologist, had refrained from disclosing the existence of the local

Intersex community, thereby thwarting any attempt by Courtney to ‘hook up with other *Intersex* people and talk about it’. Parents of *Intersex* children have revealed that physicians are very reluctant to connect them with other parents in similar circumstances and have reported receiving reactions of incredulity at the idea of discussing their child’s genital variation with other parents and not medical professionals alone (Kessler, 1998), this may explain the actions of Courtney’s father who is professionally employed within the medical sphere. In the following excerpt, Kitty details how a doctor overtly attempted to prevent her and her mother from seeking members of the *Intersex* community:

Int: What made you decide to join the *Intersex* online group?

Kitty: Originally being told that I was the only person like me and that I would probably never meet someone else like me. Or that if I would meet someone else like me they would probably be [ss] a psychological state that would not be beneficial to me making contact with them.

Int: Who were you told that by?

Kitty: My doctor.

Int: Doctor.

Kitty: So yeah, we were basically told I wouldn’t meet anybody else and that the few other people out there would be psychologically not stable, not advisable for me to make contact, so me and my mother sort of pressured the doctor until he eventually gave us some information which we then sort of followed, this was like, late 1990s [...] early days of *Intersex*.

Int: OK. Yes.

Kitty: So, yes, we searched out other people, and found them, and there was a lot of them, and basically everything we’d been told was wrong.

For Saifa, the potential for community which was lost due to parental secrecy and shame, included people with *Intersex* conditions who were also his relatives. Rather than presenting a unique opportunity for peer support and sharing, Saifa speaks of 'the impact of shame and stigma' upon his family dynamics:

Saifa: Uh, Intersex is a really interesting topic in my family because eight people in my family have AIS... we were all born with

Int: *Really?*

Saifa: ...yeah, a really high frequency on my Mother's side of the family. We were all born with AIS, which stands for Androgen Insensitivity Syndrome, uh, so, all of us have different varying response [ss] so I have, uh, three uncles and a cousin who were assigned male and my sisters and my other cousin were assigned female at birth. Uh, so I think AIS is one of those traits where it really depends on how sensitive you are to testosterone as to whether you'll be reared as male or female [...] So I would definitely encourage parents to really, sort of be a resource for each other [ss] I kind of feel like, uh, having an Intersex child can feel so isolating, basically [ss] my mom's experience and you know, other parents I've talked to you know, who have Intersex children...

Int: Even though there were a lot in the family?

Saifa: Yeah! I mean, that just shows the impact of shame and stigma, you know?

Empathising with the Plight of *Intersex* Parents

In the data it was interesting to note the level of awareness and understanding exhibited by participants of the difficulties their parents had been subjected to.

Courtney spoke of trauma, Saifa referred to isolation and Autumn recognised her mother was 'just doing the best she could'. Likewise, Hiker recounts the 'very, very difficult' predicament of being a parent of an *Intersex* child.

[B]ecause when I came out my parents pass away and I couldn't really talk to them when they alive because whenever I want to discuss them about this...my body's issue, my parents... you know, just started to cry...so I I couldn't, we couldn't really start, you know this issue successfully so I didn't really get many many information from my parents but uh I did I do really believe now that they are very supportive to me you know because being *Intersex* parents is very very difficult. Because they are the first one who begin to in the closet [ss] they have to you know nobody nobody because recently I met some some of our neighbour in the past and my father's colleagues he had and nobody know about my body, you know, even though I have my surgery when I was six. I was old [laughs] not very small but.. uh nobody know about my surgery and about my body issue. So, I think it's very difficult for parents to hide the truth, it's very high pressure...my parent's couldn't tell to me about this issue my [ss] because they feel sorry for giving me this body....

Hiker

Hiker's statement is helpful in summing up the plight of parents of *Intersex* children who, as already indicated in this chapter, are faced with the prospect of either 'coming

out' or hiding the truth from their family, friends and work colleagues. This is the result of being misinformed about their child's *Intersex* condition and receiving inadequate support, exacerbated by self-blame or guilt for their child's body. Under these circumstances is it not hard to see why - encouraged by an OGR model endorsing secrecy for the psycho-social well-being of their child - parents select to 'hide the truth' from family members, friends, work colleagues and their *Intersex* child.

This behaviour by parents can present a quandary for the *Intersex* child. Growing up with parents who were visibly distressed by questions concerning their *Intersexuality* and who actively concealed all references to it from family members and friends conveys a profound message to the *Intersex* child who in adulthood may find it unbelievably difficult to broach a subject which has - due to shame and secrecy - been off-limits within the family for their whole life. This could explain a trend in my data (as expressed in previous comments by Courtney and Hiker) which showed that a number of participants began the process of finding out about their *Intersex* condition and/or 'coming out' as an *Intersex* person, only after one or both of their parents had died. Practical matters associated with the bereavement of a parent can unexpectedly lead to discovering or obtaining childhood medical documents as experienced by Mani:

So, it wasn't until after my mum died and I got some documents, that I started the journey and putting this jigsaw together.

Mani

Parents can have a hard time processing feelings of anger brought about by their mistreatment by medical professionals, guilt for the pain and hurt their child is undergoing and/or resentment for the responsibilities involved in rearing an *Intersex* child (Lev, 2006b). Empathy, not wanting to cause undue distress, fear of straining or breaking familial ties can all play a part in the pattern of consciously or unconsciously waiting until after parents have died to investigate an *Intersex* condition in more detail. Some of these difficulties and sensitivities were discernible in interviews with participants whose parents were alive.

[M]y mother doesn't speak to me anymore because I 'came out' [...] It's hard for Intersex people to come out because there's a lot of shame and...issues around that...you know, how they were brought up in the families....

Dana

And my only parent, is still, has always been in denial about it. I think she was very damaged by things that happened when I was young, and uh, traumatised...

Jools

Family Communication and Open-ness

Two participants had a very different experience with their parents. Bridget spoke of how from a very early age her mother talked to her in stages about her *Intersex* condition and that the family stance was one of open-ness and not secrecy:

Bridget: [...] But my family are like 'It's a family matter and you can tell whoever you want to.' But, my rule is, kinda just, 'Hi, I'm Bridget,' and if you're my friend 'I'm Intersex,' but if you're just random stranger then it's just 'Hi, I'm Bridget'...
 Int: Yeah.
 Bridget: ...it's like, I don't wave it around! But like, it ain't a secret.

Likewise, Leidy Tatiana explained how her mother handled her *Intersex* condition at birth:

[T]he situation of my Intersexuality was given since I was born, when my mom called the doctors and said this person is a hermaphrodite [...] She took no decision about an operation or surgery. She simply said that 'this person is born and perhaps take a decision later, but I do not want you to hurt,' and I was very young. Since childhood I had medical check-ups and all things pertaining to good health. Luckily my mom gave me a neutral parenting method, where once my name was Alexis, this name is woman and man at the same time in that neutral

method where I had my female dolls and male dolls.

Leidy Tatiana

Leidy Tatiana also related how her mother gave her the gender-neutral name 'Alexis', and supplied Alexis with the autonomy to grow up as a boy up to the age of thirteen without 'psychological pressure'. Incorporated in this approach were words of positive affirmation ('my mom told me that I was someone important and valuable in life'), in addition to open communication and collaborative decision-making between Alexis, their mother and grandmother when significant bodily changes occurred at puberty.

I started having some physical changes, where I was in first grade high school when I started having my periods of menstruation, I started to have my training body, hips, breasts, and an early decision was taken together with my family, because the circumstances were changing, fortunately I had the support of my mother and grandmother in which, they said, we go to the doctor to see what's happening [...] and more exams said this person is really a hermaphrodite, is forming as a woman, is 80% female and 20% male [...] I made the decision to say, 'I've never felt like a man and these changes are favourable to what I really feel inside me and make the change as it should be'. My grandmother worked as a judge in a city, we moved to

another city, and the man uniform change it to the female uniform.

Leidy Tatiana

One important question raised by the data is why Bridget and Leidy Tatiana's family dynamics and experiences were so very different from the majority of my interview participants where secrecy and shame was the norm. On further inspection, it is possible to conjecture that age, culture and the internet may be important factors. At nineteen years of age Bridget was the youngest participant in my study, born in an era where *Intersex* activism and the internet exist. Unlike Saifa's family situation, Bridget works alongside her older cousin Kitty (who also has an *Intersex* condition and is a participant in my study) as a visible and vocal advocate of *Intersex* rights in Iceland. What is more, *Intersex* information and support can be accessed today in unprecedented ways. The significance of this is noted by Mani and Darryl:

Mani: And if you analyse the whole uh...Intersex movement [...] because Cheryl Chase who started this whole thing...you know, is...was...is a computer geek! You know she was right there in the early days of *knowing* the power of the Internet. And she knew how to use it and that's how we all got connected in the...you know, there was this tiny handful of people around the world and suddenly [ss] we're talking to each other.

Int: Wonderful

Mani: Yeah! Quite extraordinary.

Twenty, thirty years ago we wouldn't be sitting here having this interview, so the fact that we're having this interview today shows that there is a lot out there to support us...

Darryl

In 2000, ISNA's website was frequented by 1,000 visitors per day, and in 2005 they estimated their total outreach - since their emergence in 1993 - via media coverage to be thirty million (Morland, 2009). These resources about *Intersex* were not available to the pre-internet generation who are a majority in my study, or their parents, and their impact in counteracting secrecy and shame cannot be overlooked, for Bridget explained that her mother also faced intimidation at her birth.

OK. So. First of all, when I was born, people didn't have to scare my mum because... [puts on a scary voice] '*I was Intersex!*'

Bridget

Additionally, social status, position and power could equally be determining factors in enabling the positive rearing of *Intersex* children. This is not an area that I had set out to explore in my interviews and so unfortunately the data on this is somewhat limited, but it was a theme that emerged during my interview with Leidy Tatiana.

Leidy Tatiana explained that her grandmother - who was closely involved in her development - worked as a city judge and links this to being able to move to another city and pursue her chosen identity. It may also have helped to expedite any legal requirements. Nevertheless, mobility such as this may be nullified in the presence of strong religious beliefs or political views held by the family. The influence of these and pressure they can exert were discernible in interviews with Autumn and Clara.

I came from a very traditional, mid-western, United States, Catholic, Conservative upbringing [...] and, so that['s] definitely is a layer of the story [...] you know, and how it's dealt with, and quite frankly, they dealt with it very old school, what they call the uh, what is now sort of referred to as 'the concealment paradigm', which is where you just try to gloss it over, you know, bury it, you don't deal with it...

Autumn

I have to confess that I've received the least support from the Church and I think it's due largely to the fact that we haven't, I haven't addressed my own Church in [a] way that's completely open with them for fear of rejection. And I would rather, with my husband, work on them rather than simply leave. Even though, were they to know my entire background they might well say, sex is determined strictly by this one parameter and you need to start living as a male or you have to be a eunuch and eunuchs

can't marry or whatever, who knows, they might actually say 'No big deal...'

Clara

How Well-Intentioned Parental Secrecy and Silence Loom

My data unequivocally supports the view that secrecy and silence, however well intentioned, is always counterproductive. Attempting to protect a child from the challenges presented by *Intersexuality* by raising them 'in total ignorance' is condemned by Autumn as 'most disturbing' and 'unsettling' for many *Intersex* people.

[I]f you see this as a source of...you know, a challenge for your child that you're trying to prevent them from experiencing, don't...you need to get away from that type of thinking because you can't prevent your child, you can't, you know, try to raise your child in total ignorance of what is happening to them [...] They need to be informed and there is a right time to share information incrementally, little by little [...] I think, what I've learned from, uh, you know hearing the many stories of other *Intersex* friends...the thing that's the most, the most disturbing and it's the most unsettling is the feeling that we had information *withheld from us...*

Autumn

For children with *Intersex* conditions who have either been subject to surgical normalisation, repeated medical scrutiny of their genitals (sometimes involving

humiliating non-consensual staff demonstrations or photography) or are simply aware that their genitals are different from their peers, as Lev writes, 'what they do not know looms large in their fears and imaginations' (Liao and Boyle, 2004b; Lev, 2006b: 39; Reis, 2009). My findings suggest that secrecy and silence are presences which can subconsciously pervade the psyche of an *Intersex* child. Moreover, this may begin before the child fully understands they have an *Intersex* condition, as vividly portrayed here by Mani:

Int: ...have you ever felt under pressure to hide that you are Intersex?

Mani: ...Well of course, I didn't *know* that's what I was as a child. But, *absolutely* that was the message I was given. So, I had to hide my physical body, *literally*...uh...and I wasn't allowed to talk about this, you know, and I took that message into my bones, it's interesting, even though I didn't really understand it. And I...you know, I...remembered things like... as a kid I could hold a towel up, you know, in one hand and get dressed inside the towel? Like, it's, it's an extraordinary feat [laughs] when I think about it now...

Int: Yes.

Mani: ...but you know, I lived through that, I learnt to be ashamed of my body, I learnt to hide it...

Secrecy and silence do not erase the issue of *Intersex*; rather, they temporarily push it underground, only to find that it resurfaces in strained and/or severed familial and personal relationships, mental health issues and sexual problems. In interview Dana spoke of their experiences with dealing with all of these problems, and how when it

came to deciphering their root cause, that they were faced with the task of having to 'figure it out' by themselves.

Dana: I found out...uh...for sure...that I was Intersex at forty-nine.

Int: Forty-nine. Can you tell me how this was explained to you and who explained it?

Dana: Well...I had to figure it out for myself...uh...'cause I knew I had surgery...uh...as a kid. But I didn't know what that was about. And...after my divorce, in 2007. I was kind of... went through all my mental health problems and some of my sex problems were because of surgery I had as a child...

If questions regarding their *Intersex* bodies, surgeries or genital examinations are met with parental discomfort and anxiety or medical evasion (Kessler, 1990) and condescension this can foster feelings of anger, betrayal, humiliation and unspeakable shame. Such feelings can in turn create trust issues with parents and deter *Intersex* individuals from seeking future medical care or therapeutic counselling (Lev, 2006b), as well as hindering any development of peer support (Liao and Boyle, 2004b). As Dana continues:

[S]o...it's really difficult...for people to talk about it...or come out about it. It's difficult to find somebody who, in the therapeutic community, the therapist community, who knows anything about it. It's hard for anybody who's Intersex to go to the doctor 'cause...a lot of us have been brutalised [...] medically, surgically and otherwise...

Dana

In their article *Intersexuality and Discrimination: Silence as Family Violence*, Isabel Lima et al. (2015) outline the family's value-laden role as an arbiter of socially constructed standards of normality. The family is a discipliner and regulator of individuals, state Lima et al, for it defines and legitimises ways of being and what is normal. Foucault (1998) referred to the family as 'an agency of control' and parents/relatives as 'chief agents' who anchor the deployment of sexuality in accordance with the juridical law (1998: 108, 110). Correspondingly, Howard Waitzkin (1989) observes that patterns of sexuality and child-rearing within the family render it 'an important institution for ideologic reproduction', since it reinforces the personality characteristics and attitudes which are a requirement of an acquiescent and fully participating population (1989: 222). Commensurate with these objectives, parental silencing of *Intersexuality* reproduces what is considered 'normal' and 'abnormal' within a status quo based upon a binary system, and, although stemming from a need to protect their child from discrimination, it inadvertently serves to reinforce societal humiliation of and violence towards an *Intersex* child (Lima et al., 2015).

Parents as Facilitators

By contrast, my data showed that participants were unanimous in advocating parental honesty, open-ness and age-appropriate disclosure without shame or secrecy.

But if we could talk in age-appropriate ways so that children knew that their body wasn't ugly or terrible and then we gave children the languaging and the skills...how to manage

different situations as they were growing up. The most important thing, is to have that...channel of conversation [...] with the child [...] you know, and you go where the child is, so if the child wants to talk about it, you talk about it and then they'll be periods of time where the child doesn't wanna talk about it at all, as...that's how kids are. And so, you know, you are guided by and listen very carefully to what it is your child wants and needs. And if the child feels safe that they can talk about whatever's inside then...isn't that what we desire with all our kids around everything?

Mani

[T]hey don't need to be given the science lecture. It's more an emotional thing at the start. D'you know like?

Gavan

[B]ut first of all, I'd give them information about their own condition and their own medical options, that a child can understand. So it would have to be explained in language a child could understand. And also I'd give them advice about how to... get along in society with the medical condition...how to, how to deal with social situations...uh, how to explain being *Intersex* to other people. Because I remember when I was a child, I sometimes did have to explain my situation to people and I just did not have the vocabulary.

Peggy

These comments reflect a view of the ideal parental role as one of a facilitator who equips their *Intersex* child with the information, emotional support, language and social skills required when dealing with different social situations and people, in a world in which the child is different (Roen, 2009). This includes facilitating the child's relationship with their own body to be one of pride and pleasure and the child's readiness for bodily intimacy with others in adulthood (Roen, 2009).

I think it's really important that children are taught about difference from the earliest age, whether it's different families, different gender identity, different bodies, you know, different culture, just, you know, give a broad vision so that they feel, actually there's a lot of difference, but they can be who they are within that...

Katherine

As detailed in the introduction to this chapter, in order for parents to support their child in this way, Mani and Clara share that it is essential that they too receive the right support and resources.

If mum and dad are struggling [...] then, mum and dad, family will need more support [...] but right at the moment most agencies wouldn't have any idea how to support parents around this...[...] because most agencies, are ill-informed. Many agencies...uh...you know, nobody has ever challenged their homophobia, their transphobia, you know. These things exist inside institutions not because that's what people want, just

because nobody has ever thought about it and, yeah, challenged the dominant, narrative, discourse that's out there in society [...] comes back beautifully to your earlier question around education and training, so if we've got social workers if we've got counsellors that will be interacting with the family [ss] got the skills and knowledge, no problem.

Mani

The main thing that would have helped was a doctor and a psychologist sitting down with me and my whole family and saying, here are the issues with your body, here are the likely outcomes of it and here are your options, in terms of just staying Intersex, this is what...the surgery that it would take to make you capable of vaginal intercourse as a male, this is what, the surgery that would be required to make you capable of vaginal intercourse as a female and of course with the understanding that vaginal intercourse isn't required for sexual intimacy, not with everyone anyway, and...that you have all these choices, all these options and you don't need to hide who you are or... tell us, [...] what you think you're parents want to hear.

Clara

As already mentioned, an important source of help, advice and support is from other parents of *Intersex* children, as spoken of by Saifa and Kitty.

I think parents really need to get support for, for themselves, you know, to be in community with

other parents who are also going through the same issues. So I would definitely encourage parents to really, sort of be a resource for each other... I kind of feel like, uh, having an Intersex child can feel so isolating, basically my mom's experience and you know, other parents I've talked to you know, who have Intersex children...

Saifa

Int: What advice would you give to parents of Intersex children?

Kitty: Seek out other parents, like number one, two and three, do not get isolated [...] Try to make sure that your Intersex child meets other Intersex children growing up so it's something that, like, they don't experience this feeling of isolation, they'll always have this, sort of, 'Oh yeah, I met this person and this person and this person and we went to the park and had fun and they're like me'. Also, like, get in contact with adult Intersex persons and... talk to them, learn from them, like, what their life experiences were and what they feel could have gone better and, sort of, try to follow that. Get information from multiple sources, like, if you feel uncomfortable with what your doctor is saying, like, try to reach out to support groups that are out there and get their recommendations, and don't keep stuff a secret from your kid like. Raise your child knowing. A lot of people found it difficult in the past to sort of, suddenly be told at a slightly more advanced age that, 'You are different', whereas if you're raised with this knowledge, always knowing, never having this moment of being revealed that all these people in your surroundings knew so much more about you than you did yourself. So tell them at a young age, get them together with their peers,

and their peers are other Intersex kids. Get to know other Intersex parents so you have a basis for support and get to know Intersex adults who like, have been through this before and talk to their parents if possible.

Conclusion

This chapter has exposed the many and varied dimensions of parental secrecy and shame and their ramifications for *Intersex* children as rendered in my data. As vividly introduced by Courtney's story, it has shown that parents are largely unprepared for the birth of an *Intersex* child, and owing to this, can experience the post-natal scenario as an overwhelming and traumatic ordeal, which without therapeutic care and professional/peer-support, can leave an indelible imprint of shame, guilt and more. My data has demonstrated the ways that these negative feelings adversely affect parents' relationships with close friends, work colleagues, the family unit and most especially the *Intersex* child and how the latter subsequently comprehends and lives their *Intersexuality*. The profound impression this leaves with the child became clear when an associative sub-category in my data revealed that many *Intersex* adults wait until one or both of their parents have died – often most of their adult lives - in order to find out more information pertaining to their *Intersex* condition, and that those who do not wait often experience strained or broken relationships with their parents. My participants insist that children are able to receive information about their *Intersex* condition from an early age and can work with parents and primary caregivers to make decisions about their bodies at the key formative stages of their

lives. There was a trend of empathy manifest in my data for the plight of parents along with the understanding that there is an urgent need for professional training and comprehensive support to enable them to successfully act as facilitators for their *Intersex* children.

Chapter Ten: The Medicalisation of *Intersexuality* in Practice

Autumn's story

Autumn is fifty years of age and lives in San Diego, USA.

Autumn's karyotype is XY. Her 'Intersex difference' was apparent at birth when she was medically described as having 'ambiguous genitalia'. This diagnosis resulted in the removal of Autumn's testicular gonads as a baby aged '100 days old, three and a half months' and she was assigned and raised as a girl. Although Autumn spoke of being 'spared' medical intervention as a young child or a teenager ('unlike a lot of Intersex kids'), she nevertheless revealed some of the unique challenges she has had to face which made *Intersex* a 'confusing' and 'frightening' phenomenon for her.

Firstly, as a young person, Autumn remembers feeling like an "outlier" or an "outsider" when observing the lives of her peer group and how they were unfolding very differently to hers, this led to feelings of disconnection.

[A]s you would expect, you know...girl-, you know, girlfriends of mine were meeting, having boyfriends, having dates, having a romantic life and uh, you know, and then of course getting their periods, you know, you go through all these different... all these different phases, and you know, one thing that we talked about, uh, in the Intersex community is, a sense of missing, feeling that you've missed these milestones... these kind of very typical milestones in life, uh, you know that sort of plot your way... you know,

growing up, uh, and uh, so, you know, for me, I use that term of kind of feeling disconnected...a little bit, uh, from other people's...you know, from, sort of, quote unquote, normal...: I would say the Intersex experience is one of struggling with that sense of feeling like an outsider...

Secondly, Autumn shared that her upbringing was 'old school' within a 'very traditional, mid-western, United States, Catholic, Conservative' family environment which she believes added an important layer to her experience of growing up with an *Intersex* condition. Autumn has two older brothers. Her parents were both medical professionals: her mother was a nurse and her father a physician. In spite of this, her *Intersex* condition remained a 'family secret' which was never dealt with openly. In fact, Autumn says, 'we really didn't even start dealing with my situation until I was a teenager and needed to get on hormones', at which time her father organised for Autumn to attend endocrinology appointments at a medical facility in Los Angeles - and not where they resided in San Diego - 'for the sake of family privacy'. Autumn's mother, who was tasked with handling the topic of *Intersex* with her, 'broached the subject' of these treatments by saying that Autumn needed to see a doctor to help her to begin menstruation, something which was anatomically impossible for Autumn, and, (as noted in Chapter Nine) referred to the endocrinology appointments in Los Angeles as 'shopping trips'.

[S]o we, we, my dad made arrangements for us, for me to go to an endocrinologist up in Los Angeles and my mother would take me out of school on a school day and she'd call these '

Shopping Trips: We were going to L.A. to go shopping, they were really, it was a trip to go to the endocrinologist...it was truly bizarre. You know looking back it was very bizarre how she handled it, but it was also just her way, she was just doing the best she could, you know...it was like her way of trying to make it seem like...'No big deal'...

Autumn says that her *Intersex* condition and experiences were 'shrouded in secrecy and never talked about'. As noted in the extract above, retrospectively Autumn recognises the good intentions for this, yet at the same time the effects upon her whilst growing up were profound. Autumn admitted to feeling 'socially vulnerable' as a teenager. She became increasingly aware of unwanted feelings of difference causing her to wonder 'what other friends of [hers] are having to do this?' when she did not see her life experiences – for example, her regular endocrinology appointments - reflected in the lives of her peers. Moreover, Autumn disclosed how her parents' handling of her *Intersex* condition instilled in her at an early age 'bad habits' of concealment and covering up her truth, inhibiting openness and honesty. As a result, Autumn carried her *Intersex* secret with her into her forties and says that she would have said she was 'all girl' and 'all female', rather than 'being willing to admit to being *Intersex*'. It was the process of 'coming out' as *Intersex* which exerted an internal pressure upon her to pursue her truth, including being more open to her family and friends.

Another significant component for Autumn of having had surgical intervention as a baby is the physical impact. Autumn states, 'I was meant to have testosterone 'cause I had...I had testicular gonads that were removed as a baby...' and points to this as having created lifelong consequences, detrimentally affecting her moods, energy levels and sexual interests. It was in her forties, when trying to understand why she had never been partnered and/or sexually active, that Autumn began to wonder whether this could be attributed to a hormone deficiency. Feeling increasingly stifled and dissatisfied by her life circumstances, after her mother died in 2004 she embarked on a journey of self-discovery ('to know more about what happened to me') which involved the retrieval of her medical records to learn about her *Intersex* medical history. With the help of supportive doctors who uncharacteristically allowed her to experiment with testosterone, Autumn now feels that at fifty years of age she is finally in a better place on a hormonal protocol of weekly testosterone injections.

I really haven't been partnered and I think it's been, for me, an issue pertaining to the hormone ...uh, the lack of hormone in my profile [...] for the last ten years or so I've been experimenting and tweaking with different, you know, different hormones regimens. [...] I've always wondered if, if, the, the lack of hormones and not being at the right dosage of hormones has affected why I haven't had a romantic life, you know? [...] I haven't been partnered and I haven't been sexually active.

And I didn't want that to be the case.

This new regimen of hormones has 'made much more of a difference' in helping Autumn to clarify an attraction to women. However, she revealed that there are many people with *Intersex* conditions who similarly 'struggle with, you know, low libido and issues of sex-...you know, their... sexual life is less than satisfying...' and that this is derivative of a lack of the right hormones or not being on the correct dosage. Hormones are a very potent part of our lives, states Autumn, comparing the constant monitoring of hormonal levels - to prevent feeling as though your life is engulfed by a medical condition - to that of a diabetic. Autumn adds that medical limitations in this area make it a very precarious experience.

It's all essentially... and unfortunately...it's all kind of trial and error... and so, you know, you can't really go to a medical professional who will tell you '*This* is what you need. *This* is what you should be on'.

As a member of the online *Intersex* community who now assists newcomers, Autumn relates that many share their battles with obtaining testosterone from doctors who are frequently only willing to provide prescriptions 'if you're living as a man'.

People are talking about trying to get the hormones, trying to get uh, trying to get their doctor to sign off on testosterone, because that's what our bodies produce but so many...so much of the time doctors think 'No, you're a woman, you're living as a woman, we don't give women testosterone, because that's not what...you know ...' and so, you know, society is just *finally*

starting to learn, like yes women do have testosterone, they *need* testosterone and especially Intersex women it's...You know, I've been lucky to have doctors that have allowed me to experiment...

Autumn served for two terms (a total of four years) as a board member for an organisation that organises annual meetings for *Intersex* people. Her life experience and those shared by others have led her to believe that medical interventions are 'devastating' and that rather than focusing on altering people with *Intersex* conditions, medicine should be dealing with them as they are. This includes taking into account their specific symptoms and circumstances, being more embracing of *Intersex* identities and 'more informed about what Intersex people need medically'.

We know these procedures were damaging to us and we're trying to get you to understand that we're not attacking the medical community, we're, we're trying to present, you know, sound evidence-based findings that, that, uh, that, that will prove our point. We've had, we've had things done to us that, excuse me, that uh, have been, that have been uh, uh, damaging and so we need to change the, we need to change those protocols and interventions of the past, to make it better for, for the future.

Section One examined how people diagnosed as *Intersex* find themselves at the disposal of a medical protocol which renders treatment and interventions upon their bodies as predictable and necessary in their quest to recover and assign a 'true sex'. Encapsulated in Autumn's story are a number of key themes found throughout my data regarding the medicalisation of *Intersexuality* and its accompanying 'true sex'/truth discourse, as raised by the following questions:

1. Is *Intersex* simply a temporary and erasable issue of the genitals? If so, can genital surgery performed on *Intersex* babies and small children be rightly viewed as a harmless and forgettable medical encounter with malleable and not fully formed subjects?
2. Is the current way of managing *Intersex*, based upon recovery of a 'true sex', compromising medical expertise and knowledge of *Intersexuality*?
3. What do the routine removal of testes and an accompanying testosterone divestment strategy for assigned *females* reveal about the operation of sex and gender normalisation in biomedical practice?
4. Is *Intersex* a medical emergency and a rare, freak occurrence that is to be wholly confined within the medical sphere?

Is a Child Merely a Malleable, Forgetting Subject?

Autumn's story demonstrates that although undergoing surgery as a baby aged 100 days old, the effects to her life have been profound. Or, as another participant stated, 'my entire life-history affects the things that happen to me now...' (Peggy). The

process of medicalisation has an impact which is indelibly imprinted upon the emerging self of an *Intersex* child (Roen, 2009). As an infant of eighteen months old Bo, who was originally assigned *male*, was re-assigned as *female* and underwent a clitorrectomy to remove her 'outsized clitoris'. Bo remembers successive medical examinations as a young child which were very invasive and traumatic (see Bo's biography, in 'Chapter Seven). At eight years of age, Bo underwent abdominal surgery to remove the testicular portion of her gonads which were 'partly ovarian and partly testicular in character' and sums up the impact of her experience here:

I first got hold of my medical records when I was nineteen. But I uh...had people examining my genitals and taking naked pictures of me uh, I remember starting from age eight. And there wasn't any good explanation for that [...] Well, the...uh...mutilating sexual surgery certainly affects my day-to-day life. Deprived me of sexual function and affects my relationships. [...] I think I would have been better off if I was born in a place with no medical care.

Bo

Many of my participants spoke of mental, emotional, physical and sexual struggles in adolescence and adulthood stemming from surgical practices which treat *Intersexuality* as a temporary condition of infancy that can be erased without harm to patients constructed as 'malleable', 'forgetting', and 'not yet become' subjects in order to place them into their 'true sex' category (as explained in Chapter Four).

I think for a lot of female people I know born with Intersex bodies, they, it's about them feeling confident as females, because they've been so messed about and I think the common experience of abuse as a child through the medical profession, you know, as we know a lot of stuff around sex abuse can disassociate you from your body [...] so many people I know with my condition, you know, you're endlessly paraded in front of doctors and nurses, you know, they all had a little look and everything, you know, and, and that's, that's really, you know, shouldn't be done now and it's still being done, but that sort of stuff has a huge impact...

Katherine

Uh...the problem with [medical professionals] is they think of Intersexuality as a physical condition of infancy that is eliminated by their intervention and therefore there aren't any Intersex people. Back when I first sought them out they referred to me as 'formerly Intersex', or 'formerly hermaphroditic'...so what they need to understand is that uh, Intersexuality is a lifelong condition...

Bo

Because I've found that the medical profession is very much geared towards treating 'men' or 'women' and isn't, kind of, really very understanding, uh...of how to deal with people who don't fit those two categories...clearly...so what it tries to do, it tries to push people into one category or the other and actually Intersex

bodies are quite unique, they need different care from males or females...

Jools

John and Clara expressed how the medicalisation of *Intersexuality* in some cases incorporates denying that it exists at all.

Well, I think they need to start introducing more information in the medical profession itself. Obviously from what I've researched and the people that I've talked to and the doctors that I've talked to, they're not doing that. This is a taboo subject. It's very hush hush and hardly any of the medical profession will...acknowledge that they, that this even exists, let alone a problem.

John

There's also...Intersex treatment which doctors tend to...like, I've had doctors stand there and talk to each other as though I wasn't even there ... some doctors don't seem to want to...admit that Intersex even exists so all of your problems have to be from something else. Which also I think tends to push you into the...outsider category...

Clara

Jools, who was assigned *male* at birth experienced multiple surgeries in childhood, but was kept in ignorance of them and also had to undergo *male* gender behaviour reinforcement (see Chapter Eight). After finding out about *Intersex* in adulthood, Jools transitioned to *female*. Similarly Peggy and Dana, despite surgery and an initial *male* assignment, are no longer living as *male*. What these examples effectively demonstrate is that, irrespective of medical prediction, predeterminism and intervention, the *Intersex* child will wish - and eventually may seek - to become the sexed, gendered and/or sexual subject that they choose to be (Roen, 2009). In the following extract Jools shares her thoughts on decision-making and autonomy on behalf of *Intersex* children.

[W]ell, my advice would be to allow...to be open and honest with the child because...children, people think that children can't accept these things, but they can and I think, just so that they know that they are different and in a sense, that they're special...that they're unique and that they should not feel ashamed of the way they are and that the parents should be open to listening to the child...what the child wants and what the child needs to live their life, that, I think the child and, and, not to impose their ideas of what a child should grow up like, like, most parents will have no idea what an Intersex child should grow up like. Most doctors don't. They all think that they should grow up as a boy or a girl in a particular way and they all think that if something doesn't look right or doesn't fit they should intervene and make it so that it does, but

actually the only person that knows what is right for an Intersex person, whether as a child or an adult, is that person. Nobody else [...] and if they're not old enough to, they should just wait and see what happens and see what the child decides is best for them and, uh, at an age at which they can make those decisions for themselves...

Jools

The Never-Ending *Intersex* Treadmill

Imagined normativity overlooks the detrimental impact of medicalisation upon the child, including the emotional trauma and physical pain of repeated surgeries, unforeseen complications, genital scarring, loss of genital tissue and sensation, medical objectification in examinations and/or evasion in consultations (which can result in a long-term mistrust of medical professionals) and, as Autumn's story portrays, the influence upon the child's family dynamic which keenly affects an *Intersex* child's self-image and development. Katherine and Mani shared how medicalisation affected their lives.

Luckily in terms of physicality and surgery, I've got over all the, you know, potential side-effects of that, so that's not a day-to-day thing anymore which is great, that was much more when I was younger [...] I think for quite a long time my experience in the world was very harsh, so you

get that internalised stuff going on and then, you know, I engaged in quite a lot of self-destructive behaviour...because... I had a lot of conflict with identity, I think, but that was, I would say, that was pretty much induced by outside... It's interesting these days, because there's a lot more interest in people with Intersex bodies, in terms of human rights and different things, and through a sort of slow process it's like, I've been able to talk about it [...] I feel I've worked through a lot of my trauma.

Katherine

Yeah, well, I look at my life and my first forty years was...pretty empty and certainly, many, many things that make a, a quality life were missing. But I mean I had no way of *knowing* that, I had no way of engaging with that, so I've chosen not to be very, uh, looking backwards...other than learning, there's been a whole lot that I've learned about myself and learned about my parents and...that's been wonderful. But I'm a very forward focused person, so, you know, certainly reflect on the past, but it's what...how does that inform the moving forwards, how does that make moving into the future different, that's been very much...and I think...I have that way of looking because I work with some extraordinary therapists and counsellors, myself and you know, these were frameworks that I learned from then...and now, I'm hugely grateful for that...

Mani

Infant surgery is rarely a one-off affair once set in motion. No one can accurately predict the changes that may occur to an *Intersex* child during puberty. A common phenomenon with some surgical interventions is increased ambiguity in adolescence and post-adolescence *Intersex* youth (Spurgas, 2009). Moreover, what is referred to as 'the *Intersex* treadmill' (see Chase in Spurgas, 2009), has been used to describe - what has frequently become - the lifelong medical management of *Intersexuality*. It involves repeat surgeries and regular medical examinations that are supplemented with hormonal, steroidal and psychotherapeutic drugs and therapy. All of these stages have been verified by my participants. It would appear then that fitting into a normative category for *Intersex* people can be a never-ending pursuit. Rather than erasing difference, at every medical encounter the growing child will be confronted with their *Intersex* difference in order to 'pass' as their assigned normative category and what this in turns means is, the risk of psychological distress will always be present.

Is the 'One True Sex' Discourse Compromising Medical Knowledge of *Intersexuality*?

A persistent refrain in my data was that despite encountering 'extremely compassionate and understanding' medical staff (Autumn), there is a surprising *lack* of knowledge possessed by 'experts' in biomedicine who were expected to know much more about *Intersexuality* than they in fact did. This is expressed below by Bridget, Kitty, Dana and John.

Bridget: ... Mmm, I think that, I think that people are obviously nice...uh, *the doctors*. They just aren't *informed*...properly, and the system is completely [sighs]...What was the question again?

Int: Uh, how could it have been improved?

Bridget: Uh...listen to us. Because...if you don't *know* a lot about this condition, then, how about listening to people who actually are *going through* that condition and have *studied it* a lot more than you have!

I'm thirty-two and I've never met a doctor who actually knows what he or she is doing, [imitates a chipper voice] 'Oh well I've never met a person like you before, but I'll try!'

Kitty

[I]t amazes me how little [doctors] know about Intersex bodies. [...] So support would mean [...] teaching psychiatrists, therapists and doctors, uh...anything on Intersex issues 'cause I've had to teach every one of them that I've ever seen about Intersex issues. Uh...so...improvements are there, making all those people go back and require certification at the Board levels on the issues would be helpful.

Dana

[A]nd then I went to the OB-GYN for a hysterectomy [...] Obstetrician slash Gynaecologist [...] and that conversation started out quite priceless [laughs] - he looked at me

and goes 'You're kidding right?' and he looked at my wife thinking she was actually the one he was going to treat and we had to physically say 'Look, no, this isn't a joke, there's the CAT scans' and...he went along with it but he disagreed with me right up to the day of surgery that it was the uterus that was causing my problems... so I researched it very intensely... and after the surgery he came back into my recovery room and said 'You know, you're right, you were right, that's what it was, it was inflamed and it was bleeding and obviously that was the cause of your pain' [...] and...I even had issues with an endocrinologist, who in my opinion should have known more about this condition than anybody and she flat out came right out and said 'I don't know anything, I can't help you' [...] I don't know anything about this.' I was just flabbergasted. She was from UCLH Medical Centre which is [an] upstanding Medical Centre [...] and she knew nothing of it...felt the need to charge me \$290 to tell me that! [...] but she, she couldn't help me [...] and very few doctors can, it's a very difficult realisation to find out that there's nobody really studying this or specialising in this. There are very few doctors in our country that...or anywhere that I know of that really specialise in this [...]. There's a select few, here and there that I read about, but they're a very select few...

John

Nevertheless, there was one participant in my study, from the pre-internet generation (see 'Snowball Sampling' in Chapter Nine) who found John Money's work to be a helpful source of information, 'about the social aspects of *Intersex*', at a time when 'there was really nothing else' and despite there being comparably much more social

science literature on *Intersexuality* in recent times, including publications written by members of the *Intersex* movement and activist academics, does not think 'too highly' of them.

Uh...well...going back to the 1990s when I first got in contact with the...uh, Intersex movement. I thought very highly of the works of the late Dr John Money, and I disagreed with a lot of the people within the Intersex movement because they demonised John Money. [...] when I needed help most, was when I was a young person. And that was when I found the books written by John Money at that time, very helpful. I found uh, endocrinology books helpful as sources of, sources of medical information. I found the John Money books helpful as sources of...information about the social aspects of Intersex. At that time there was really nothing else...I don't think too highly of most of the books that have come out recently about the sociology of Intersex.

Peggy

Clara was in the minority as expressing appreciation for her nurse practitioner who is both 'lovely' and also 'well versed on Intersex'.

I was just going to say that I have a lovely...nurse practitioner, where I go for my gynaecology stuff,

who, she's well versed on Intersex and willing to listen and...like she'll ask 'Do you really need the vaginal examination this time or do you, do you care about it, do you want me to go ahead and do that. If nothing's changed we don't have to do that if you don't want to. She's very, very good about it.

Clara

A specialist team equipped to deal with cases of *Intersexuality* needs to consist of at least four medical experts: the original referring doctor (obstetrician or pediatrician); a pediatric endocrinologist; a pediatric surgeon (urologist or gynaecologist) and a geneticist. Yet in spite of the wealth of knowledge represented across these disciplines and medicine's overall advanced understanding of the complexities of bodies - as multilayered phenomena comprising organic, genetic, somatic, behavioural and psychological factors - the primary concern of surgeons, pediatricians, endocrinologists, cytologists and psychiatrists remains surgical correction of atypical anatomies for the recovery of one category, namely, a 'true sex', as opposed to recognising and acknowledging the presence of a nonconformist and/or multiformed sexed body (Grosz, 1996). This raises fundamental questions concerning the degree to which the current case management of *Intersexuality* compromises a genuine in-depth study of *Intersexuality*.

Relatedly, it is possible to discern how truth discourses from the medical sphere influence participant narratives of self-discovery, especially with regard to how crucial

it was for them to find and recover the 'truth' of their being which was previously confused, called into question or denied.

Int: ...So, uh, what does being Intersex mean to you?

Hiker: Uh, being Intersex...It's me! I finally find the truth of my being, because in the past, I, I, couldn't really...I was very confused about myself. And I, I didn't really know how to fit into the society. And I didn't know what, uh, how, how, uh, what I feel so depressed. But I, after I learned that, I feel release and I 'Oh! It's me!' and there are other people there...uh, uh, and I think it's OK for me, too! [laughs]

John: There are very few doctors in our country that...or anywhere that I know of that really specialise in this [...]. Most of them equate it to transgenderism and I try to explain to them that, you know what, I didn't choose it this way, this is something I was born with and I'm not, I'm not seeking to change gender, I'm seeking to recover my gender [...] and...at the time I was doing all of this, my gender was in question. I didn't really understand which gender I was, I was kind of in the middle. I had the internal sexual organs of a female and the external sexual organs of a male...

Int: Yes

John:... that's, that's a... a very...difficult realisation...but it happened and I had to deal with it...

These participant narratives of self-discovery supply evidence of how the medicalisation of *Intersex* pervades the psyche of those with *Intersex* conditions. It is possible to see parallels with their need to know and recover the 'truth' of their being - that purportedly resides in the area of sex - with a biopolitical discourse that affixes intelligibility and personhood to a 'true sex' category.

The Routine Removal of Testes in Assigned *Females*

As in Autumn's story, the routine removal of testes from those assigned *female* at birth repeatedly appeared elsewhere in my data as a cause for concern. Bridget, Kitty and Saifa shared their thoughts on this particular medical policy:

It's like, because my testes were removed. I get a lot of sickness thingys, I'm really tired all the time. I get ear infections really easily and that is ... kind of... because my immune system... something made, something easier to... have more infections or something [...] because of the medicine²⁸ I'm taking.

Bridget

Int: ...Is there anything that could have improved the quality of your life as an Intersex person [...]?
 Kitty: Yes, well, I think not having been subjected to unnecessary surgery, uh, would have improved the quality of my life and not being dependent on hormone replacement therapy would be a plus.

²⁸ Hormone Replacement Therapy.

Saifa: I mean, uh, you know, the [ss] is that medical providers think that women should not have testes...right? Uh, and it says that my testes would be, were, cancerous...And you know, of course my mum, who's my mother and concerned [ss] 'They're cancerous? They should be removed'. Right? [...]

Int: So... were they...cancerous?

Saifa: No, they weren't [...]. They kept referring to them as ovaries. Uh, and so, you know upon, later, sort of research on my own...they were testes. And then when I got a hold of my medical records, they were also referred to as testes as well.

In the above excerpts, Bridget correlates her tiredness, regular ear infections and frequent bouts of ill-health to her body's immunity caused by the removal of her testes, Kitty laments to now being dependant on hormone replacement therapy and Saifa (a transgender man) believes his mother was deceived into having his testes removed with the false information that they were cancerous and specifically links this deceit to a medical stance opposing testes in assigned females. As mentioned in Section One, many people with *Complete Androgen Insensitivity Syndrome* – if given the preference - opt to retain their testes and benefit from a process called aromatization where testosterone is converted into estrogen by the body with the help of the enzyme aromatase (see 'Five *Intersex* Conditions' in Chapter One). This process is believed to forgo the need for an artificial hormone replacement - and any associated negative physical reactions it might induce – and prevent all of the other problems related to energy, well-being and libido that Autumn suffered for the first

forty years of her life. Furthermore, the insistence of referring to them as ovaries and not testes explicitly invalidates and erases their existence in bodies assigned *female*.

The Testosterone Divestment Strategy

Autumn's story foregrounds a predicament that many assigned *females* face concerning access to the hormone testosterone. It highlights how medicalisation of *Intersexuality* upholds and reinforces a stringent binary division of the sexes as recounted here by Kitty:

Having access to...this one is a big one for a lot of people, having access to hormone therapy which doesn't match your uh, passport gender descriptor, so like, if your registered gender is female, having access to testosterone, and that's something that I've not been able to access... A lot of people with my form of Intersex they use testosterone because it affects them...they feel, health-wise, better using testosterone...whereas where I live that's a huge issue [ss] like you don't give somebody hormones for their opposite gender marker.

Kitty

Depending on your doctor and location, testosterone is frequently denied to those who are deemed as possessing – as Kitty says – the 'opposite gender marker' (phenotypical *females*) to testosterone producers (phenotypical males). Notably, none of the assigned *males* in my study who shared the fact that they take testosterone mentioned any problems with being prescribed it – as Gavan stated, '*I've chosen to*

take a very small amount of testosterone' (italics added). It would appear then that this testosterone divestment strategy is meeting a culturally gendered societal demand and not a medical one, for as stated by Autumn, women both produce and require testosterone. Up to the time of puberty, *male* and *female* children alike produce steady levels of both androgens (which testosterone is a type of) and estrogens, and except for during ovulation, both hormones are produced by adult *males* and *females* in comparable amounts (Kessler and McKenna 1978). The adrenal glands, ovaries and fat cells produce androgens in the *female* body which is required for over two hundred functions.²⁹ A key role of androgens in *females* is its conversion into the hormone estrogen. A deficiency of testosterone in women results in impaired sexual function and well-being, fatigue and a loss of bone density (Davis, 1999). Therefore, this testosterone divestment strategy reflects social intentions based on the binary division of the sexes by giving credence to the pervasive and erroneous view of testosterone as a uniquely *male* hormone inextricably linked to masculinity and virility.

As Autumn's story revealed there are marked health improvements for those who have sympathetic medical care providers. Conversely, for those who do not, there is a greater likelihood of debilitation of health brought about by testosterone depletion - as expressed earlier by Bridget and here by Saifa:

Int: OK. Is there anything that could have improved the quality of your life as an Intersex person...?

²⁹ James, Simon, 'Androgen', *Healthy Women*,

<http://www.healthywomen.org/condition/androgen> [online] accessed September 2017

Saifa: [sighs] Well you know, given that I decided to transition, like now I'm dependent on testosterone...and I think the one regret that I do have and the one *wish*, is that...I wish that, when it came time, when they were thinking about removing my testes, I wish that, they did not. That they would have explored ways for me to get, keep my testes so that I could develop, uh, in a way that felt good for me and so that I wouldn't be dependent upon testosterone. ' Cause I have to take injections like, every week or two, depending. So, I'm just like 'This sucks!' So I think this is the one regret that I do have, that my, my potential capacity for reproduction, although I was, was infertile, *but still*, my god, I think I wasn't given the opportunity to develop and now, you know, because if I don't take the testosterone I'm at risk of early on-set osteoporosis. Uh, so, you know, I think for me, although I was spared from genital surgery, uh, I just think it's very important that doctors be committed to exploring other options.

Is *Intersex* a Medical Emergency?

When asked what advice they would give to parents of *Intersex* children, the majority of the participants in my study advised that there is no urgent need for surgical procedures simply because the child happens to have an *Intersex* condition; instead, they all encouraged restraint. This can be seen in the following excerpts from my interviews with John, Katherine and Clara, who all urge parents to take their time, gather information to familiarise themselves with their child's *Intersex* condition and then make any surgical decisions without feeling pressurised to do so by medical staff.

When a doctor comes in and says your child is born with ambiguous genitalia, they need to take

it upon themselves to give the doctor his marching orders...In other words: OK, I understand what that is, and we're not going to do anything about it right now. Unless he has issues, or she has issues with urination or any kind of physical health problem that, that we got to correct, other than that, they're not going to be corrected...OK...If we had that sort of information available when I was born, I wouldn't have had the problems I had [...] I have a lot of scar tissue...I have a lot of issues that, that came about...

John

It depends what their condition is, I have to say, but I think find out about the condition, don't rush into anything, unless you have to do any of the physical stuff because of, you know, there is a medical need, just wait a minute. I think that would be my, just wait a minute, you don't have to rush, there's no hurry, get the information, don't feel pressured...

Katherine

My advice to parents of Intersex children is number one, it's not an emergency. I'm ignoring certain cases of CAH³⁰ where there's a medical emergency, but Intersex is not an emergency and you don't have to decide anytime soon, which means, in terms of making the body male or female.

Clara

³⁰ Congenital Adrenal Hyperplasia

Whilst recognising that some forms of *Intersexuality* do require medical assistance, my data endorses the view that *Intersexuality* is not inherently life-threatening and therefore should not mandate surgical intervention as though invariably constituting a medical emergency.

This treatment of *Intersex* as a medical emergency not only reflects non-empirically driven social prejudice, but also has a profound impact on the perception of the condition of parents and others involved in the decision-making process. When analysing the representation of parents with atypically sexed newborn babies in psycho-medical texts, psychologist Katrina Roen (2009) notes that they are habitually constructed as tragic and/or in a tragic situation in order to justify and normalise surgical intervention. This psycho-medical construction serves two purposes. First, it presents surgical intervention as something that parents may seek - rather than resist, and second, it presents surgical technologies as the solution to, not simply the child's 'anxious' future, but also parental anxiety; in short, as in the best interests of all parties concerned. For Roen, this is a reductive misrepresentation of a very complex and ambivalent time. Pointing to research that analyses the retrospective responses of parents with *Intersex* children to early surgical decisions, it contains parents who were not only concerned for their child's future, but also doubtful of and even appalled by the recommended clinical procedures, and, as a result, feeling caught in a bind. This research portrays the anxious state of parents as a *discursive effect of the clinical encounter* and not of *Intersexuality* per se (Holmes, 2009). For

these reasons, Roen believes there should be available alternative constructions of parents in these clinical settings, ones that reflect the complex dynamics and wider possibilities of the situation. As explicated in my data, these representations would include parents who need time to work through their own feelings, learn about their child's medical condition and critically evaluate all of the treatment options on offer. In this way, psycho-medical texts would not be misrepresenting parents of *Intersex* children by positioning them as only anxious, distressed and therefore welcoming surgery (Roen, 2009).

The Framing of *Intersex* as a 'Rare' and 'Freak' Occurrence

The framing of *Intersex* as rare perpetuates an exhibitionist discourse of the exceptional body by portraying *Intersexuality* as a freak occurrence and people with *Intersex* conditions as 'freaks'. This in turn serves as a mechanism to advance the belief that an *Intersex* body is one which inspires fascination (to be paraded, photographed, displayed or experimented upon) or horror (to be concealed in shame), disregarding the existence of the person. Resistance to these narratives was frequently displayed in my data:

I'm not a phenomenon, I'm not a monster, I'm not rare in society, I am a normal person who [is] simply born with... something different and beautiful.

Leidy Tatiana

If people would not consider us freaks...People just don't know that we are out here!

Courtney

[T]here's a lot of people who think we're...we're just, uh...you know, just freaks of nature and...[...] here in the United States, we were...like...side-show freaks at circuses and...uh...things like that. [...] nobody ever talked about those things so I think, just because nobody ever talked about it we were just rare and freak...

Dana

Yeah, Intersex shouldn't be treated as something freakish or shameful uh...that needs to be hidden or surgically erased.

Bo

As noted above by Bo, not only does treating *Intersex* 'as something freakish' sanction unnecessary surgery, but it can also, as Gavan and Autumn explain, deter a person with an *Intersex* condition and their parents from connecting with the *Intersex* community, believing that they are a solitary outcast or misfit, and in so doing, foster feelings of acute isolation.

[D]octors told me that 'You're one in a million,' you know...and you're fucking...that sentence there, itself to you, from a doctor [ss] and you believe them [...]. That's very difficult psychologically. You know, there's a lot of stabs that they do that are psychological...

Gavan

[A] very common narrative in my experience and many other Intersex people that I know is, we all feel, we think we're the only one on the planet. You know, you go through this whole phase where you're the only one, there's no one else out there like you and so you're reluctant to share your story [...] now that I know there are so many other Intersex people around the world, uh, I, I definitely feel as normal as anybody

Autumn

Conclusion

My data vividly portrays the range, scope and impact of the medicalisation of *Intersexuality*. It shows that rather than simply outgrowing surgeries that have taken place in 'malleable' infancy, early surgical encounters greatly impact those who have experienced them and they carry it with them when growing and developing into adolescence and adulthood. Autumn's illustrative story describes a fifty year battle with hormones and the negative effects this produced on her health, well-being, energy levels and potential for intimate relationships. In addition, it depicts a family life of concealment and secrecy and a disconnected relationship with peers that shaped Autumn's self-image and behaviour. All of these things stem - directly and indirectly - from the removal of her testes as a baby of 100 days old.

Correspondingly, my data testifies to adverse mental, emotional, sexual and physical affects in adolescence and adulthood stemming from childhood surgeries, with a minority even having to embark on a process of transition from their medically assigned 'true sex'. This indicates that the medicalisation of *Intersex* in practice does

not begin and end with surgery in infancy or childhood, but potentially touches every significant area throughout the lifespan of an *Intersex* person. These testimonies can also explain two trends in my data. The first is participants' urging of new parents of *Intersex* children to learn about their child's condition without feeling pressurised into surgery deemed an emergency. The second is a questioning of the depth of medical knowledge of *Intersexuality* that selects to alter bodies in the pursuance of a 'true sex' rather than starting from a position which, paraphrasing Autumn, deals with them *as they are* - embracing their bodies, anatomies and identities. The data shows how a language of surgical 'correction' and the framing of *Intersex* as a rare, freak occurrence can increase the likelihood of genital surgeries by parents of *Intersex* children. This language and framing of *Intersex* also marginalises and works to erase the category of *Intersex* entirely by inhibiting a person from seeking others in the community, leading to psychological harm and isolation.

Chapter Eleven: Transforming the Medicalisation of *Intersex* and Living *Intersex*

Dana's story

Dana lives in Fort Collins, Colorado, USA. They identify as *Intersex* both 'biologically and gender-wise' and as a *hermaphrodite*. Dana is a navy veteran who has a disability which requires them to use a walker and a cane. Dana was assigned and raised *male*. They are unsure of their specific *Intersex* condition having only discovered it at forty-nine years of age; they described it in these terms:

Int: Yes, what is your *Intersex* condition?

Dana: You know, I don't...100%...know 100%, because by the time I found out I was... you know, as I said I was forty-nine, uh, so...we believe it was some kind of...uh...I had a little bit of...mixture...between the two, male and female. I have [...] a very small penis...uh...uh...I have testes, but I also had a, a vaginal opening of some sort [...] it could have been an extremely severe...uh...hypospadias type condition...

Dana recounted a life full of fear, the result of multiple childhood surgeries ('from age five, six years old') coupled with parents who were 'not really kind and loving'. An especially traumatic episode occurred when Dana woke up during one surgical operation. Most of their surgeries occurred in a different state to which Dana lived and they remember being 'alone most of that time'.

It took me a long time to be confident.

Uh...because...the first, probably the first forty-

nine, fifty-two years of my life...I was scared of my own shadow. Uh...it took me a long time to, you know, get over that...uh...because my surgery I had was, a,...was...you know, stemmed from age five, six years old. It was at least two surgeries, probably a couple more, but I'm not sure...I woke up during surgery, and my surgery happened in a different state from where my parents live. I was alone most of that time...uh...so I have a lot of trust issues, I have a lot of fear issues because of all that. My parents treated me differently [...] they were not really kind and loving parents...uh...so I have a lot...I have a lot of issues and I grew up with those...uh...and no matter what I did I always had these thoughts of whether I was a boy or a girl.

Dana says that the 'good times' in childhood were marred by 'physical and emotional problems' connected to their *Intersex* condition. They included being raised as *male* but unable to 'stand to pee', as well as a lifelong battle with incontinence, the result of childhood surgeries. These all had a negative impact on Dana's relationship with their family. At home on the family farm Dana's brothers distanced themselves from Dana who was frequently punished for laziness by their parents and treated differently from their siblings. The accusations of laziness, which Dana says were supported by their doctors, were eventually disproved when scar tissue – known to cause incapacitating physical symptoms - was located on Dana's bladder. The toll of these childhood experiences soon became apparent in adulthood. In 2007, while reflecting on the reasons for their divorce, Dana began an investigation into their childhood surgeries, mental health problems and sexual difficulties to see whether they were all connected.

I started looking things up on the internet, kind of explained what the surgery was to myself and I came across the term 'Intersex' and...that started...things started falling into place and I just started therapy with my therapist.

This process revealed to Dana that they are an 'Intersex genital mutilation survivor' who is living with the effects of clinical depression, childhood Post Traumatic Stress Disorder and 'a few other things that go along with that' on a daily basis. Dana says that discovering they were a person with an *Intersex* condition also involved a reassessment of living as an assigned *male*, which they ultimately felt had never worked because they were 'forced to live it'. In trying to decipher what living *Intersex* might mean for them and only understanding the availability of the binary categories of *male* and *female*, Dana rejected *male* and began living as a woman for 'a little over a year'. When this transition proved unsatisfactory, Dana researched online and their connection with the *Intersex* community brought with it the affirmation that Dana could in fact live the additional option of *Intersex*.

Well, once I figured out I wasn't a woman...I knew I wasn't a man. I really started checking every Intersex book I could find...and started, trying to figure out what that meant and then I started going online and trying to find some sort of community and somehow it just kind of manifested that it was OK to be living as a Intersex person...internally. You know, I mean, 'cause initially it was like a foreign term because I only knew of 'male' and 'female'...

Dana credits talking about *Intersex* in therapy with 'learning how to talk about...

[Intersex-related] issues' with other people. This has proved to be a site of immense liberation and subsequent politicisation for Dana who says that previously they were 'a ball of fear'.

I do a lot of activism around being Intersex [...] giving talks at universities and churches and a few other places, and sometimes I go [to] different places in the United States and give talks [...] I hand out business cards [...] because I am out there, everywhere. Every one of my friends knows that I'm Intersex, everywhere I go I put my business cards in like the little [ss] where you can draw things for a free lunch or whatever [...] a bunch of my clothes say 'I'm Intersex and Proud' just things like that and I go out everywhere as an Intersex person, being out..

Dana's newfound confidence and pride in being 'out' as an *Intersex* person and an advocate for *Intersex* rights, is not only apparent in their frequent public talks and presentations, but also in their day-to-day choice of clothing and public bathroom usage. Dana spoke of how they 'mix and match' their clothes ('men's clothes, women's clothes, it doesn't matter to me...I just wear whatever I want to wear') and how they enter the women's bathroom with three days beard growth or the men's bathroom wearing a dress. Dana is unconcerned by any 'dirty looks' and ignores the 'few bumps' they have received, unless it feels as though their life might be in danger.

Dana: and uh...and I'll, and I'll say...you know, when they ask me 'Why are you in the bathroom?'

Int: Yes.

Dana: ...then I'll say 'Well, why are *you* in this bathroom?' and sometimes [...] and sometimes I get ladies who go outside and check the bathroom door, you know, sign and I'll still use the bathroom...

Int: Yes.

Dana...I confuse them! [laughs]

Dana is currently serving as 'an Associate Chairperson of the OII USA group' and is a member of twenty different *Intersex* groups on Facebook. Whilst Dana would like more people with *Intersex* conditions to 'come out', they recognise the importance of not pressurising anyone to do so.

I don't pressure anybody to come out, because at some of my lectures, you know, people come up and tell me they're *Intersex*. I don't tell them they have to come out. I would...I would like more *Intersex* people to come out...but no-one's ever told me I had to come out and be *Intersex*.

When asked if there was anything that could have improved the quality of their life

Dana replied:

Well, yeah...I think, uh...not cutting me... would have been nice [...] my parents being told not to cut me and to...just to love me and...you know...treat me just like any other child and...not to let anyone pick on me would have been the

best option...uh...I...I think that would have been
the best thing for me...

In 2012, Dana was invited to give a talk at The White House Health Conference in Philadelphia. In 2016, Dana successfully filed a suit against the United States State Department for refusing them a passport to attend an *Intersex* Forum in Mexico City; it transpired that Dana's passport application was rejected because they did not select *male* or *female*. If the State Department does not appeal Dana's suit against them they will be forced to make their sex and gender classifications more inclusive.

Dana's story portrays a person moving out of a world of 'shadows, secrecy and silence' filled with guilt, pain and pathology into 'therapy, survival, recovery or politics' (Plummer, 1995: 50). It is a 'coming out' story: a classic theme in my data. Primarily associated with the lesbian and gay experience, 'coming out' tells the definitive story of sexual suffering, surviving and surpassing (Plummer, 1995). Cheryl Chase (1998), the founder of ISNA (now Bo Laurent), has compared 'coming out' as gay in the 1950s to 'coming out' as *Intersexual* in the 1990s. To be gay was pervasively depicted as an illness, sin and crime, and so it was instead promoted by gay activists as 'gay is good'. Similarly, with a burgeoning politicised self-understanding, Chase pledged to affirm that 'Intersex is good' and not a shameful and diseased state of being (Chase, 1998: 195; Kessler, 1998). It was the management of *Intersexuality* that was monstrous, claimed ISNA, who used *Intersex* as an act of defiance to positively affirm a group identity that was institutionally created to be erased. This section will look at four data themes on the subject of 'coming out' and transforming the medicalisation of *Intersex* to living *Intersex*:

1. 'Coming out' and being 'out' as *Intersex* (the benefits and the difficulties).
2. Internal identity politics and controversies (community and nomenclature related).
3. External identity politics and controversies (LGBTQ identity politics and intersectionality).
4. The transformative power of love in healing and living *Intersex*.

'Coming out' as an *Intersex* person

As demonstrated in Dana's story, 'coming out' is a compelling story of a metamorphosis, involving major change, epiphany and significant transformation. It usually includes four key aspects - not necessarily sequential - namely the *personal*, *private*, *public* and *political* (Plummer, 1995). The *personal* refers to clarifying who one is in self-conversation; the *private* concerns speaking to others in delimited spheres, namely, family, friends and/or therapists; the *public* can refer to the increasing numbers of people who are told or who eventually find out, and the *political* is when your story is used as a means for social change (Plummer, 1995). With regard to the *personal*, a number of participants mentioned how their self-understanding and self-conversation was clarified by watching documentary programmes or films about *Intersex*, the impact of which directly contributed towards their process of 'coming out'.

Channel 4 had a documentary about Intersex at one point, and I saw that, I think they were XXY's in it, who were actually transsexuals at the time and I completely understood them. I just totally got them. I was like 'Oh God! That word, now that hits a bell,' [...] it was in the 90s or could have been early 2000s...

Gavan

Hiker: I saw the movie and I learned the word 'Intersex' [...] when I was forty-two. I saw the movie 'XXY' [...] So that's, that's why I started to

[be] aware about the word 'Intersex.' Then I, then I googled this word, but then I found 'OII'

Int: Yes

Hiker: And, and, and started to, uh, connect with other Intersex uh, uh...I met on Internet [...] it's very similar to my own experience, so that's how I...uh, identify myself as an Intersex gradually.

[A]nd it wasn't until, uh, I watched a documentary in the late 1990s, that I kind of, understood...or I began to understand the significance of what those surgeries had been about.

Jools

These examples show that 'coming out' stories are not only to be told, but also consumed – read, heard or watched – by others. Consuming the stories of others serves a variety of purposes: it can enable and empower individuals, as well as provide rich source materials to help them to learn, assemble, produce and craft their own stories (Plummer, 1995).

'Coming out' was spoken of as a very positive experience which can produce many benefits for *Intersex* people, both personally and as a community.

I think before I came out for sure, like I was 'Oh!' I was scared about how people would receive the information, like I think it was a very...it wasn't an easy thing to talk about. You know, but I found that the more people I talked to, the

more that I talked about it, I found so much more compassion and so much more understanding and people really wanting to hear that story, you know...

Saifa

But, uh, over the course of the last, like, fourteen years, I've come out, uh, upwards of one hundred, or to a few hundred people [...] and it's never been an issue [...] I've never had a truly bad reaction.

Kitty

[S]o the online groups were to connect with others...yeah, absolutely and also my main concern, when I really first joined was, was, children that were maybe getting bullied. That was my first initial thinking, like, 'Jesus, if there's somebody like me out there who's thinking that they're nothing and they're worthless and that there's something very majorly wrong with them and that they're never gonna get a girlfriend and all that sort of stuff', I thought, I could go on and tell them 'Look at me now.' D'you know what I mean?

Gavan

Being 'out' as a person with an *Intersex* condition is a way to resist the retreat into secrecy imposed by biomedicine. It counteracts the dominant story of *Intersex* as a shameful, hidden pathology to be concealed.

Int: What does being Intersex mean to you?

Bridget: [...] So it doesn't bother me, it's like, I can give people fun facts at parties and stuff [laughs] [...] Because...mainly the doctors are like, 'you don't have to talk about it, you shouldn't talk about this, this is a secret...'.

Correspondingly, Autumn rallies *Intersex* children to 'tell your story' and reach out to the *Intersex* community, recommending this as a powerful means of combating isolation, erasure and personal struggles, not only at an individual level, but collectively as a community:

Int: And, what advice would you give to an Intersex child?

Autumn: Uh, I would basically say, you know, 'You're not alone, you do have a community out there, uh, lean on them when you need, uh, when you need help, when you're struggling, and, and, and there is somebody who has certainly been through what you're going through, so don't feel that you're alone and that nobody else knows what you're, what you're dealing with', and then also to encourage them to *be involved*, to come forward to tell your story, to share, you know, to share your, your Intersex story as, as an advocate on, you know, social media, you know, start giving presentations or telling your story at school, uh,

you know, whether it be a genders class or a biology class and uh, that's part of the solution as to how the situation gets better in the future for, for *everybody*. It's...again, it becomes, we, we're gonna continue to feel invisible, if we are invisible. You have to, in order to change society you have to be willing to be visible and come forward.

As can also be seen above in Autumn's comments, there was a tendency on the part of some participants of placing the onus for societal change - via 'coming out' - on the *Intersex* person. This veered towards a respectability politics narrative of being/setting an example, making a good impression and bearing the responsibility for educating others.

And after I came out, uh...yes I still feel pressure sometime, because...uh... like uh... because uh, when I come out and uh, they are many, many media...that talk about me and have my picture, so sometimes [laughs] there are people on the street or on the bus will recognise me, but, but most of the time, the response is positive so I feel like I'm very, very lucky one. And uh, but sometimes I still feel uh, nervous, because I believe there are still people feel uh, uh, mmm...like, *have fear* about Intersex people, so I was...still...I have very like uh, I have to pay attention to people's *reaction*...because uh [...] you have to be very careful about...everything. And I'm the only one who come out here, so...very, very important, people have very good impression of me...

Hiker

Int: Yes. Are there any ways you think that Intersex people could be better supported in society?

John: Well I think they need to come out and, I think they need to come out and talk about it. Instead of harbouring bitterness towards the medical profession which I don't, I'm not bitter towards them I'm just disappointed in them. I think they need to come out and talk about it and educate the people around them, the more people know about it the less likely they're going to have an issue with it and they're going to be more comfortable with it.

I am happy to move forward and be an example of life for many people who feel that the Intersex perhaps be bad.

Leidy Tatiana

We all as Intersex, we all need to feel that empowerment inside. In order to get support from other people we need to be proud of who we are and be...and have that, know that the power inside us is stronger than anything going on outside and around us and we need to present that outward, release that outward. Once we release that out, we will get support from other people.

Darryl

My data depicts 'coming out' and being 'out' as a very difficult process. Institutional stigmatisation, marginalisation and repression - the result of mistreatment faced as a child in the medical, familial and/or educational realms - produce acute long-term effects which to combat takes time, tremendous perseverance and support. A genuine understanding of this offers as explanation as to why moral critiques of *Intersex* individuals who remain closeted combined with heroic 'coming out' narratives are likely to be received as another potentially damaging layer of *Intersex* oppression.

Some Difficulties with Being 'Out' as an *Intersex* Person

Dana related rejecting their original *male* assignation, transitioning to live as a woman (for over a year) before online researching, joining the *Intersex* community, understanding what *Intersex* meant for them and settling upon an *Intersex* identity. This process has importantly helped Dana to clarify where they do and do not 'belong' with regard to their identity.

Dana: ...I belong outside binary terms of 'male' and 'female'. Uh, I don't belong in those boxes in any way, shape or form. Uh...that...yeah...I just don't belong, uh, to those terms. I can live my life, uh, without the restrictions...I don't...I don't have to conform [...] the world tries to make me conform, you know, I get... you know, I always get, no matter what happens I get mis...mis-gendered. And so people will say 'Sir' and I'll say '*No*' and they'll say 'Maam' and I'll say '*No*' and they'll say 'What...' and I'll say 'Exactly, I'm...I'm neither!'

Int: [laughs]

Dana: so... [laughs] and I'll say 'herm' or 'Mx' ...
you know the new term 'M-X'...?

In Dana's story they related that although they would like more people with *Intersex* conditions to 'come out', they never pressurise anyone to do so. It is not something that everyone has the ability and/or emotional, mental and psychological resources to do. In the following excerpts participants share how self-acceptance of *Intersexuality* is very challenging.

So the term 'Intersex' comes in as a part of that process and then there's this whole journey of 'what does that mean?', 'what does that mean for me?' 'what does that mean for my identity?' and, you know, it's a process, it's a journey, it's still going on now.

Mani

Int: At what age did you understand that you were Intersex?

Courtney: Did I under-...? I found out that I was Intersex when I was about eleven. I understood it about five years ago [laughs]. I'm fifty-four [laughs].

Int: Big, big gap.

Courtney: It's...yeah...it's hard to...to come to grips with. It takes a long, long, long, long time.

As articulated by Courtney, self-comprehension of *Intersex* for a person with an *Intersex* condition can take a very long time. It may incorporate emotionally,

mentally and psychologically overwriting a medicalised past or coming to terms with a new, late diagnosis in adulthood, before a person feels able/in a position to talk to anyone else about it. These factors could explain the age range in my study. At nineteen years of age, Bridget was the youngest, whilst a third were over fifty years of age. It is also worth remembering that there are very real, material dangers in being 'out' with any difference in a discriminating world. It can compromise personal safety and weigh oppressively on top of an already unusually tough life trajectory. Darryl discloses his fears within the context of coming/being 'out'.

I think the one thing I would like to add [...] is, that, I'm scared, I'm really, really scared to go out and face it. I only found out late in life and I lived a lie a lot of it and I never came to...realise my dreams and... the world has won and part of that is so much fear and afraid. I'm so afraid to...to expose myself like that to the world. I think anybody that does, takes a lot of guts, I mean there are, there's a lot of phobia out there and there is hate crimes out there for people like us and it's a scary place. It's safe to be inside and it's safe to walk around and be what everybody wants me to be and it's safer that way and it takes a lot of guts and it takes a lot of brave...a hero, bravery, for somebody to do...open...and be themselves and be who they are, the way God created them and be Intersexed in the world and be accep-...and let everybody know it and I'm afraid [...] and I, this interview makes me want to be more brave, to try to find a way to be more brave and to...and to try to... not let the world win in the end.

Darryl

Darryl helpfully foregrounds the complexities of public and political resistance for an *Intersex* person. Unlike the majority of participants in my study, Darryl is not an *Intersex* activist. He is a single parent raising his two children full-time in the Middle East, a region without a visible *Intersex* community or well-known *Intersex* public figures. As previously described by Mani and Courtney, negotiating living *Intersex* is a lifelong venture which Darryl has only recently embarked upon due to a late diagnosis, received when investigating infertility issues (see Darryl's biography in Chapter Seven). Notwithstanding these potentially fear-inducing hurdles, Darryl replied to my request for interview participants posted on an *Intersex* online community forum, and arguably simply taking steps to research, find, contact and join the *Intersex* community can be understood as an act of resistance amongst 'a plurality of resistances' (Foucault, 1998: 96).

Appropriating and Contesting Stigmatising Nomenclature

Counter-discourses, counter-identifications and reverse discourses are all implicated in the dynamics of reconstituting identity. Activists who advocate for renaming a particular group do not do it because they believe a label will magically remove their material oppression, rather, it is to challenge the ideological structures which naturalise and normalise – thereby tacitly condone - the subordinate status and oppression of the group in question (Cameron and Kulick, 2003). This is in evidence when individuals reappropriate stigmatising labels, using them instead as implements for resistance, self-affirmation and group solidarity, and in so doing, act to subvert the

discursive positions originally mapped out for them by a classifying authority (Cameron and Kulick, 2003; Mills, 2003).

The Nomenclature *Hermaphrodite*

The reappropriation of *hermaphrodite* in ISNA's first newsletter *Hermaphrodites With Attitude* and using the term *Intersex* to mobilise an international, political 'pan-intersexual identity' were successfully deployed as strategies for resistance and to birth the *Intersex* movement (Chase, 1998, see Chapter Five). The majority of participants in my data did not like or use the term *hermaphrodite* in a personalised way. As noted here by Clara, it is familiarity with some of its 'confusing and insulting' connotations which has resulted in the outright rejection of the term *hermaphrodite* by many *Intersex* people:

I use the term 'Intersex', I think that's probably my preferred term. I don't mind the medical term 'hermaphrodite'. It's just too many confuse it with the mythological term or with the biological term, but biological term it means you can reproduce as either male or female. The medical term is simply that you have a mix of ovarian and testicular tissue. And then of course you know, the mythology... is, are the Greek mythology, it's just confusing and insulting to some people, I don't mind it...

Clara

Although Clara is accommodating of the term, Hiker, by contrast, shared feelings of terror evoked when retrieving their medical records as a teenager and discovering the word *hermaphrodite* written in English (Hiker's native language is Chinese):

Int: OK. And at what age did you understand that you were Intersex?

Hiker: Uh...it's a complicated question, uh...I had aware-, I had my medical record when I was teenager, maybe it's about fourteen or fifteen, but I didn't understand what does it mean...

Int: OK

Hiker...and uh...uh, on my medical record, it, uh, it was written, like, *pseudo-hermaphrodite*, uh, it's not *Intersex*, so, uh...I, and also, my medical record was writ-, written in English, uh, handwriting, so it's very difficult to, uh, uh, to tell, what does it mean [...] so I tried to check dictionary and find the word *hermaphrodite*, and it terrifies me, because it...it just looks like a monster for me. Yeah, so I didn't really like...I didn't really want to learn more about it because I'm monster and I didn't want to be a monster at all...

As exemplified in Hiker's situation, twentieth century usage of *hermaphrodite* included physicians using it privately when writing up the medical records of *Intersex* people and also in communication with other specialists, but not directly in consultations with the *Intersex* person or their parents (Kessler, 1990). Holmes states that this was to minimise any confusion about the issue, which could potentially undermine a course of action that had the singular intention of revealing a 'true sex' (Holmes, 2009). Nonetheless, a minority in my data, and as expressed by Dana, are happy to be

referred to as a *hermaphrodite* (or *herm*). Reclaiming *hermaphrodite* in this way functions as a political and conceptual resistance strategy.

The Nomenclature *Intersex*

Whilst the term *Intersex* is preferred by most of my participants, they recognised that there are many negative and/or erroneous associations with the term. Many of these surfaced in answer to my interview question regarding common misconceptions held about *Intersex* people.

Int: Are there common misconceptions about Intersex people?

Darryl: I think that...people misunderstand it. They think hermaphrodite. [...] when I tell somebody that I'm Intersex they say, [...] 'Oh do you have a penis? Do you have a vagina?' That's the first thing they think of. [...] I don't know what to say. I feel again...in a way like...they just... made me feel inferior or they made me feel like I'm a eunuch.

Sure. There's the idea that people have two sets of genitals, uh, or that everybody who has an Intersex anatomy must also have some unusual gender identity.

Bo

Uh, yeah sure there's lots of them, there's a common misconception that all of us are somehow stuck in between and that must be a

horrible state of being, being stuck in between the two sexes and not knowing what you are.

Kitty

[T]here's lots of misconceptions. I think people have very, kind of, uh, [...] unrealistic ideas about what people who are Intersex are. It's very sexualised by some people...For me it's not a particularly kind of sexualised thing, [...] I think people think that people who are Intersex are in some way exotic...uh...different, you know, uh,...I think, I suppose Intersex people are different, but not...uh...but it's not particularly exotic...

Jools

Intersex Education

Education and providing opportunities for interaction with *Intersex* people were given as important ways to combat misconceptions about *Intersexuality* in society.

I think just general education...uh...for the first time, Intersex is now taught as a component in our medical schools, so that's huge getting it in, but it's still an elective paper, but it's only people who are really interested that do the paper. I would like to see that as part of the *core curriculum*...

Mani

Courtney: [N]ot many people know about people like us and it's just, people need to be, the general public needs to be educated. Everybody needs to be educated. Sexual minorities, other sexual minorities need to be educated about us. [...] People just need to know more about us.

Int: Yes, yes

Courtney: They need to meet us and, and, and we need to say 'Yay you know what? I'm Intersex...

I think we didn't have very good, we didn't have positive education about Intersex people in the past because, we have some, we have like...misconception and bias and, uh...but that's OK because we were...uh...like uh...we were uh, ignorant in the past. I think it's acceptable because human being are keeps...uh, developing our uh, understanding [...] I think we should see it as a way we learn, we gradually learn, uh, have more...knowledge about Intersex people and we should have, we should give Intersex people, uh, a space...uh, to help all human being learn about Intersex [...] for me, for myself when I saw other Intersex people, the first one I saw...the first few one I saw Intersex people I saw are in US, US and when I met them I feel so good, because in the past I didn't know anyone, anyone...

Hiker

Intersex as a History and an Identity

My findings give credence to the privileging of the term *Intersex* by participants for its association with a collectively medicalised history. The term *Intersex*, defined by Bo in interview as, 'somebody whose sex anatomy has been problematised by someone

else', was utilised by ISNA as a tool to assemble and provide peer support for *all* who shared the medicalising trauma of being born with bodies surgically 'corrected' for violating cultural understandings of *male* and *female*. In regard to this, Kitty and Mani explained as follows:

Uh,...Intersex to me means [...] a shared history with uh, other, uh, lots of other people, uh [...] It also means... well that's part of the shared history, it also means a medicalised background... and having been raised with a medicalised understanding of my body and how it functions.

Kitty

Yeah, yeah I do use the term Intersex and I use it with great *affection* and it has a lot of meaning for me. And, and part of that is historical reference because of [ss] having a name and claiming that, owning that and it's *historic*. I know...OK...so the term that was given, medical term, when I was born was 'hermaphrodite', 'hermaphroditism', you know that was replaced by the word Intersex. And I think what happened, because it's still a medical term, is Intersex people did with that...what...*men* did with the term homosexuality, in the fifties and sixties, highly pathologised, stigmatised word and the guys took it out and went 'No,' you know, 'we're homosexuals,' the whole 'out and proud' thing...

Mani

Contrary to expectations, it was interesting to observe in my data that *Intersex* is not easily adopted by those who are currently happy to use and/or organise around it. This can be seen in the following excerpts from my interviews with Katherine and Peggy.

I actually like the term 'Intersex body' now [...] But yes, Intersex is fine, but I wouldn't necessarily use it as an identity, but it's a way of understanding my being and more my history actually...

Katherine

Well there are a lot of labels that could apply to me... and...but I don't enshrine any particular label as my quote 'identity' [...] so you might say...'Are you Intersex?' and I say 'Yes, I'm Intersex', but I wouldn't say, 'That's my identity', and that excludes anything else as my identity.

Peggy

Holmes observes how *Intersex* is not only a sign that is constantly under erasure, but it always bears 'the trace of an agenda from somewhere *else*' (Holmes, 2009: 2). This could explain why accompanying the growing visibility and development of ISNA were issues related to naming that became the site of intense contestation (see Chapter Five). The nomenclature *hermaphrodite*, *Intersex* and *DSD* are each divisive and controversial in some way (Reis, 2009), owing to what is viewed by some as untoward emphasis on:

- Disordered/exceptional/monstrous identity (*Hermaphrodite*)
- Radical/queer politics and identity (*Intersex*)
- Medicalised/pathologised bodies (*DSD*)

Due to these viewpoints I anticipated (and received) a variety of perspectives expressed in my data concerning nomenclature and identity. In the excerpt below, Darryl speaks of the 'rebellion inside' of him at his first encounter with the word *Intersex*.

Int: Do you use the term Intersex?

Darryl: ...Yes. Nowadays I do [...] I went to the website KSA, Klinefelter's Syndrome Associates in the United States and started reading up all about it and saying 'Wow! That's me! Oh My God!' And all the therapy I had gone through trying to figure out what was wrong with me 'There's nothing wrong with me!' It's what's *right* with me, it's really what's right with me, not what's *wrong* with me, but I could finally say 'These are all the same issues I had'. Everything was making sense, and then came along this word, and the word was 'Intersex' and I said 'Wait a minute, that's not Me...' You know for a minute it turned me off, it started that rebellion inside of me, 'What am I now?' 'Am I a man or a woman?' 'Am I one or the other?' I'm genetically, I know I'm both, but I've been a man, I got married, I'm trying to have children, what is going on here? I'm...and I saw that...I saw this word 'Intersex' and I thought, 'Wow, that's not Me'. I rejected it immediately...

Dana's story showed that for them *Intersex* was a welcome departure from the assignation of *male* which they were 'forced to live'. Conversely, for Darryl, who sees himself 'as a masculine man', a key cause for concern with *Intersex* is what it means for this and the other identities that he – diagnosed as *Intersex* later in life – had already grown accustomed to. This is discernible when he says, 'I know I'm both, *but* I've been a man, I got married, I'm trying to have children, what is going on here?' (italics added). It is possible to view this remark as a reaction to a perceived threat to heteronormative identity and ergo social status. It is the stance captured by this 'but' which has also caused dissent within the *Intersex* movement.

***Intersex* and LGBTQ**

Many objectors to the use of the term *Intersex* as an identity category have expressed a desire to identify as 'perfectly ordinary, heterosexual, non-trans men and women' without any concomitant need for 'building intersex communities or culture' (see Koyama in Spurgas, 2009: 104). They object to being categorised as 'queer' and aligned to radical LGBTQ identity politics and movements. In interview, Gavan stated, 'I'm definitely *Intersex*', but raised concerns regarding fitting both 'the LGBTQ world' and 'the stereotypical kind of *Intersex* picture', and Leidy Tatiana was keen to draw a distinction between *Intersex* and LGBTQ.

I don't fit into the LGBTQ world, even though the way I talk and the way I look would say 'Oh you must be gender *queer* or you've got gender dysphoria'. [...] I don't fit the face of *Intersex*, you know, the general face that's been given out

there, [...] this large, big faced, definitely androgynous type...person that you can stereotypically go, that person must be a lesbian or she is a lesbian or whatever. It could be a guy...like an Intersex guy, that looks like a female, but that's just a stereotypical kind of Intersex picture and I don't fit that and I'm not gonna go to LGBT meetings to meet, uh, lesbians, gays and bisexuals because that's not my thing, you know.

Gavan

[W]e are including as LGBT and Intersex really are not LGBT because we are not gays, lesbians, bisexuals and transgender people; are not because our situation is biological. And because our sexual preferences can vary. There [are] Intersex people who like women or men, some taking female identities, others take male identities, but that has nothing to do about a transgender, precisely because we do not make a transition gender, we make a reconstruction of our life from the point of view genetic, chromosomal and biological.

Leidy Tatiana

These sentiments regarding *Intersex* not fitting in the LGBT/Q world flow, in varying degrees, in both directions as experienced by Jools and Katherine.

[U]h, and also there was a lot of pressure, 'cause of my being transgender as well, there was a lot of pressure not to come out as...not to, not to

say I was Intersex by people in the transgender community, as well as people in the Intersex community.

Jools

I was doing a workshop about Intersex and there were comments from other people, who didn't want to go to the workshop, commenting that it was distasteful and you know, so that was a bit, a little bit odd, but it wasn't a big deal, but it was quite interesting, and that was from the LGBT community [...] that was gay men, and that was like, OK [laughs].

Katherine

Adverse reactions to *Intersex* such as these within the LGBTQ community could be, as observed below by Saifa and John, due to an associated dearth in well-known public figures, iconic representation and community, caused by the unique secrecy and 'deeply rooted shame and stigma' that *Intersex* bears in comparison to its LGBTQ counterparts.

[P]eople are like 'Oh!...' They can look at certain icons to understand trans and say 'Oh, Laverne Cox, Janet Mock, Caitlin Jenner, that's trans...' [...] People can look to that for a rudimentary understanding of trans. Uh, and I still feel that [...] we're still on that learning curve! And we're gonna be on that learning curve for a while, because I think with *Intersex*, it's [ss] so much deeply rooted shame and stigma, that people have to...uh...confront, in order to...identify as

Intersex or, acknowledge that they have uh, an Intersex trait that they're living with.

Saifa

[P]eople are probably less prone to come out of the closet for Intersex than they are for being gay or bisexual...and we really don't have a community that represents us...as a whole...[...]
It's really difficult to communicate with other people with the same conditions because a lot of people don't want to talk about it.

John

Nevertheless, participants did appreciate the ways in which LGBTQ and *Intersex* are connected, especially in regard to societal perceptions and the ending of oppression.

But in the past, I believe that...everybody, almost everybody couldn't really...tell the difference between Intersex, gay, lesbian or transgender people...uh... many people think they're, uh, pretty much the same, they couldn't tell the difference.

Hiker

I think homophobia will be, in the end, at the end, it will be over when Intersex is really, truly taken on-board, understood, people go 'Oh my god! There is no real gay! It's just people, people with people', you know...

Gavan

At this point, it is worth remembering that ISNA's original platform was, according to its founder, built on the disruption of 'heteronormative systems of sex, gender, and sexuality' (Chase, 1998: 190). This focus allowed for the constitution of an *Intersex* identity which, due to its strategic interaction with LGBTQ activism and theorising, was overtly queer insofar as its articulation defied 'the attempted production of normatively sexed bodies and gendered subjects through constitutive acts of violence' (Chase, 1998: 189, see Chapter Five). This is a stance still favoured by Curtis Hinkle, the founder of the current largest global advocacy group for people with *Intersex* conditions, *Organisation Intersex International* (OII). Hinkle, who sees an LGBTQ alliance as fruitful and sensible has stated that 'all of us, intersex, transgendered, transsexual and gays, lesbians and bisexuals are deprived the privilege of normalcy' within a heterosexist binary (Hinkle as cited in Spurgas, 2009: 108).

Intersex and Intersectionality

In Dana's story, they mentioned that they have a disability requiring them to use a walker and a cane. Below Dana reveals how their disability intersects with their *Intersex* condition.

I'm also disabled so, you know, sometimes I have to use a walker, most of the time I use a cane. So, uh, people open doors for me and let me in line and things so...I don't...I think people see that before they see anything else...

Dana

Legal and critical race theorist Kimberlé Crenshaw's (1991) highly influential theory of 'intersectionality' originally addressed the oppression Black women face due to the intersection of race and gender and how this double bind is routinely elided in feminist circles (with their focus on white women) and anti-racist circles (with their focus on Black men). This double omission presents Black women with a 'difficult political dilemma', says Crenshaw, for alliance with either group – however well-intentioned – denies fundamental aspects of the ways they are oppressed (as distinct from white women and Black men). Essentially, this inhibits the development of a fully actualised and empowering political discourse on their behalf. If intra-group differences are conflated or ignored, this can lead to tensions (at least) and strengthen the self-same power relations to be challenged (at most), due to certain identities that are not being recognised 'fall[ing] into the void' (Crenshaw, 1991: 1282). As demonstrated in Section One, categories marking difference/other have profound meanings and carry material consequences. What this suggests is that whenever there are coalitions the multiple differences/dimensions of identity should be acknowledged and grounded, and the ways they are to be expressed politically need to be readily negotiated (Crenshaw, 1991).

In the following extracts participants reveal how race, age, sex, sexuality, gender and having a disability, intersect with their *Intersex* conditions to provoke additional discrimination and prejudice from others (Saifa and Mani) and highlight profound intra-group disparities within the *Intersex* community (Katherine).

[W]henever I've been discriminated against, I think the Intersex piece is definitely operating in the background, because I think the Intersex trait contributes to me looking younger than I am. But I think because of how that affects me physically, in addition to my race, I get profiled as a young, Black man. Uh, which I think, definitely affects my quality of life. [...].

Int: So you uh, so you've faced, racial profiling?

Saifa: Mmm hmm. [...] And even when I'm read as a stud, you know, or a gay man, it's sort of like, being exposed to homophobia. You know, so I think it doesn't come without, uh, you know, 'cause I'm just trying to be like a Black, queer, Intersex person in the world right? But then, interacting with *folks* I definitely kind of like, rightly or wrongly, sort of [ss] are impacted. I am impacted by people's prejudices...

Saifa

Int: [...] have you ever felt discriminated against for being Intersex?

Mani: Oh yeah! I mean, particularly once I came out and made the decision to...just let my facial hair grow. Uh, and that's complicated, so some of it is being read as being 'female' and of course 'female' in Western culture is supposed to remove facial hair, so it's around that. Some people know me for my queer identity, so that's sort of a general homophobia, so homophobia, transphobia, so...yeah, absolutely...

I mean obviously for me there's big links with disability, you know, people with my condition,

you know, if it's found in utero, people are offered abortions and stuff, you know, that's very connected for me but I know a lot of people with Intersex bodies they don't identify as disabled at all and they haven't got a condition which is disabling in the same way. You know, often people find only when they're older that they have an Intersex body, so again, it's these huge differences and I think that's one of the real challenges moving forward, because I don't see it as there is one Intersex community, at all. I don't think there is. I think a lot of work potentially needs to be done on people understanding more and working within their own condition.

Katherine

Genuinely inclusive identity politics can promote strength, growth, solidarity, community and intellectual development (Crenshaw, 1991). This is shown by participants in the following accounts.

Courtney:... 2013 when I first came down in March my first SF Pride parade, San Francisco in June and I marched with a bunch of Intactavists. In the parade and that's when I really, I felt empowered to finally like, you know what, I'm gonna start talking about this, I'm old, I'm getting old, you know, what do I, what do I have to lose? Nothing [...]

Int: Where have you received the most support from?

Courtney: Uh...my fellow Intactavists. I would say my fellow Intactavists. I don't know any other

Intersex people in real life so [laughs] it's my, [...] Intactivist friends...

Int: Yes, yes...where have you received the most support from [...]?

Katherine: Well I did have very loving parents...who, although they didn't address stuff directly, they were very loving and caring and, you know, I had good attachments from there...The disability movement, my disabled friends, that's huge and then...my current partner [laughs] [...] I think people really misunderstand [the] social model of disability, these days, they don't see it, they just think, they're stuck a little bit on thinking disability is negative still whereas the social model is very encompassing and I think, actually a lot of people with Intersex bodies would find it helpful [...] Very much, very much, because I think on my journey, you know, when I got very involved with the disability activism, sort of twenty odd years ago, that was a real turning point for me, because actually, it was, actually, yes this is why I feel rubbish. It's because you guys have treated me rubbish. It's not because I'm rubbish [laughs]. It's because you say I'm rubbish...

Int: Where have you received the most support from?

Bo: Mmm...well when I was, uh, starting my activism I went and talked to...other activists and found that in general they were *really* generous with practical advice and uh... support and uh, that was really helpful for me [...] I remember there was one person who was active in co-housing...

Int: OK

Bo: [U]h, there were the people who founded the Turner Syndrome Society, uh, there were lots of people at National Gay and Lesbian Task Forces Annual Skills Building Conference Co-creating Change [...] uh...there was...uh...there were people who were involved in fund-raising who taught me how to do fund-raising, uh...there were people involved in uh [...] publishing who helped me to write professional articles and get them published...

Int: Yeah, so right across the board...no specific identity or group...

Bo: ...nope, so many I can't begin to name them all.

Intersex and Community

Dana's story shows how the private and personal stages of 'coming out' can often be combined with public and political ones. Since the majority of my participants are, like Dana, now activists, it followed that 'coming out' for them included public and political phases incorporating a large amount of community participation and therefore involvement in community concerns. There was a strong sense of ambivalence when participants commented on their relationship to the *Intersex* community, as illustrated in Autumn's comments below.

Int: ...And where have you received the least support from and how could this have been improved?

Autumn: Well, sometimes, believe it or not, it's been from the Intersex community itself, because uh, I've served in a leadership role in a support

community, and, uh, you know, as Intersex people we're still human beings and human interaction can be challenging at times, and we can, you know, we sometimes get our own ideas about what the best way to do something is, and uh, and that can sometimes lead to conflict. And uh, so I, I, I sometimes feel that, you know, the biggest challenge for Intersex people is sometimes the Intersex community or other Intersex people. [...] ...whatever your issue in life, most people feel good about knowing there's others out there. It's not like, perfect, 'cause like I said before, Intersex people are still people. And, you know, as long as we're human we're gonna have challenges at times dealing with each other, you know, getting along, agreeing on how things should be done, but uh, it's good to have...like we like to say, it's good to find your tribe. You know, it's good to find your people, find your community and to have people who are there for you, to support you.

For Autumn, experiencing a lack of support, challenging interactions and conflict is mitigated by 'knowing there's others out there' like you and feeling good about finding 'your tribe.' This is understandable in light of the pervasive and entrenched narrative of *Intersex* as a rare and freak occurrence which, as already shown, can produce acute feelings of isolation and alienation (see Chapter Ten).

The *Intersex* community contains people from diverse countries and backgrounds with a wide range of conditions and accompanying experiences, so grouping and labelling them all together would invariably lead to problems. The proportion of information

and coverage accorded to each *Intersex* condition surfaced in my data as a concern.

This is illustrated below with regard to Androgen Insensitivity Syndrome (AIS). Peggy spoke of wishing to gain 'an in-depth knowledge of the medical aspects' of AIS, whereas Clara felt that AIS was disproportionately controlling the narrative of the community.

I think that, a lot of the information on Intersex currently is coming from people who do not have an in-depth knowledge of the medical aspects of Intersex and it doesn't reflect the actual needs of Intersex people. Uh, uh, for people, I'll give you a couple of examples, for people with Androgen Insensitivity Syndrome, an important issue is having a very short vagina, too short for intercourse. And there are ways to lengthen it. Very little of the current literature out there by activists addresses that issue. There are some other minor issues with diagnosis of AIS uh, diagnosis sometimes happens in a scenario which is very unhelpful. But only people who have an in-depth knowledge of people with AIS can understand those situations or know about them. And people in, for example, OII don't have that knowledge, so they're not able to even be aware of those issues and they're not able to address them.

Peggy

And then within the Intersex community there's a struggle to control the narrative and the narrative is pretty much, at least the public popular narrative is more, the complete AIS narrative, XY chromosomes female, and there's

so much diversity in Intersex, so many possibilities that it's difficult to stick with any one narrative that works for everyone.

Clara

One axis of diversity is language, which was an issue for some and not all. Below

Hiker and Kitty respectively raise some old and current concerns.

Uh yes! Uh...2008...since 2008, after I found out what Intersex. I started Google and learn and try to read everything. But you know, it's very *hard* for me also, also a pressure for me because I had everything English. English is not my native language and I didn't really... I didn't really talk that much English [laughs] you know, in the past. I was forced to speak English... yeah, after I came out, after 2008 because uh... I, I, I, because we don't have any Chinese, you know, we don't have any Intersex information for Intersex people in Chinese...

Hiker

I think, a lot of information out there needs to be translated, like we have uh, we have a lot of information out there in various language bases and uh, I think a lot of that information needs to be translated to multiple language bases so that it is accessible to everyone...

Kitty

Overall, Mani sums up a common view held by my participants when candidly noting the problems within the *Intersex* community whilst acknowledging how extraordinary it is that ‘a group of traumatised, really badly injured people’ could come together.

[Laughs] [Y]ou know, it’s fascinating and it’s very complicated. Uh...*but*...there is a very strong... extraordinary all around the world now connected Intersex Advocacy community and, yeah, we’re ... different as people, we’ve had...uh...very different experiences, we come from different cultures, we come from different...you know...some are working-class, some are middle-class...uh...but we’ve found this place to be working together, which is...quite *extraordinary* and I think what unifies us is both our experience and our desire to change this medical model. [...] you know and it moves me [ss] Oh My God if this group of traumatised, really badly injured people can do this, then why can’t the rest of the world figure out...how to *hold difference*, how to actually reach across and find our common shared humanity. And I’m making it sound like it’s perfect, it’s not, there’s been lots of bumps in the road to get to this place.

Mani

The New Nomenclature Disorders of Sex Development (DSD)

Many participants in my study voiced their displeasure for the newest nomenclature *DSD*. ‘I absolutely hate ‘*Disorders of Sex Development*’ (Mani), ‘I totally reject *DSD* it’s an absolute insult, how dare they’ (Gavan). Here Leidy Tatiana connotes it with ‘pathologies’, ‘deformities’ and defects:

Common errors that occur about an Intersex person is to speak of "disorders of sex development" (DSD), is to speak of pathologies, is talking about deformities is talking about genetic defects. All these words that are used are sometimes a bit discriminative, maybe not because the doctor or the person who knows something about this situation wants it done that way, but if they are concepts and words to say them in a wrong way, they see the person bad, as a phenomenon or different as if it were not competent in society. And it really is something that we must begin to change and the word 'hermaphrodite,' formerly of discrimination....

Leidy Tatiana

Whereas *Intersex* is viewed by many as a non-normative identity which embraces the multiplicity, messiness and unintelligibility of *Intersex* bodies, the shift to *DSD* was, by contrast, interpreted as a return to pathologisation, control and disciplining of *Intersexuality* (see O'Rourke and Giffney in Holmes, 2009). What is interesting about the overwhelming rejection of *DSD* in my data is that on closer inspection it included participants – like Katherine - with *Intersex* conditions requiring genuine medical assistance. On the surface this appears to belie the original argument in favour of *DSD* that sought to steer the focus solely onto *medical* issues to improve *medical* care with the adoption of a medical term (Feder, 2009; Rosario, 2009). However, the widespread rejection of *DSD* more likely underscores the complexities of identifications. This is evoked by Clara, who summed up her feelings towards *DSD* in this way:

It would be nice to...not have the medical issues, you know I take...every morning, well I have a patch for estrogen [...] but I take testosterone every morning and I take...thyroid medication every morning and I take progesterone every evening. And...I take some other medications and they're all because...you know, the side-effects of having my, Intersex condition. [...] 'DSD', I'm not sure that was an improvement. Although I do use the difference of sex development at times, to try to explain things, rather than a disorder. I would be the first to admit that...my karyotype is XYXO, and that resulted in a lot of medical issues, and...that's what doctors call a disorder, and I'm over it OK, so if you want to call it 'I have a disorder,' that's fine, just, whatever.

Clara

As Clara notes, 'that's what *doctors* call a disorder' (italics added); a charge which has been levied by those who consider the new nomenclature as reactionary, assimilationist and who are suspicious of a term which they feel unnecessarily erases 'healthy' *Intersex* in favour of 'disordered' *males* and *females* (Spurgas, 2009). They hold that *Intersex* is accompanied by a variety of different sub-descriptors/categories which *already* identify any associated health-compromising conditions (see Chapter One); for example, in the above case of Clara, an 'Intersex' person with (or affected by) Turner Syndrome. *DSD*, as previously remarked upon by Leidy Tatiana, is felt by many to posit *Intersex* as the disorder, the defect and the disease (Spurgas, 2009).

My data shows that these controversies are not easily resolved, especially, and as analysed in Section One, when it comes to alliance building with medical institutions (see Chapter Five). Alliances are important, but as stated earlier, points of divergence need to be clearly delineated to prevent the harm of their being subsumed. These concerns were elucidated by Clara and Mani.

I think we can all agree that we don't like the idea of sex assignment surgeries on babies before they are old enough to participate in their, those sorts of decisions and forcing hormones on people is not a good idea if it's against, against what the child wants. But there are some medical considerations and it would be good to work with the medical community to make sure that, they're first of all doing no harm and we should have a good working relationship with those in medical practice. There's also the political side of it in terms of how closely we associate with LGBT politics, and the whole question of same-sex marriage and how that affects Intersex; whether we want Intersex markers as possibilities on a birth certificate or passport.

Clara

I think the most powerful thing that we can do is being visible, creating safe spaces for conversations and finding the people and communities who are our allies.

Mani

The Transformative Power of Love in Healing and Living *Intersex*

Love was overwhelmingly spoken of as something which could categorically transform the quality of life for *Intersex* people. When contemplating their life Dana recommended that their parents should have been more loving. Many participants agreed that love could provide support throughout childhood and has the power to heal the trauma of medicalisation in adulthood.

Well, the, the, the first thing is remembering what their child needs from [parents] and what they are fully equipped to give is *love*.

Mani

Int: Yes. Where have you received the most support from?

Clara: [laughs] My husband, actually, but...I think my husband reacted well in part because I had reached the, the attitude that, there was nothing wrong with me being *Intersex* [...] and, so when I, I started off figuring that look, I'm going to, just tell him everything and he'll run away and he'll go 'Oh you're weird, can't date you or anything' so I decided to just, after he reacted positively a couple of times, to just tell him everything and he called me and said that he cried and I went out and started looking at wedding dresses and a couple of weeks later he proposed, after we got it all out of the way and I knew I could tell him anything and he would still love me.

I: Yes. What advice would you give to parents of an Intersex child?

Darryl: Love. Just love them. I think the number one thing that is missing from the entire interview so far is [laughs] except in my relationships...my relationships require love and what I will say now about children is that, love is the number one part to help any child with any issue or any problem that they may have and if they're Intersexed, it really goes to the heart because love is so connected to being Intersexed so...I would say that...just show them a lot of love and let them...find other kids that are like them...

Int: [W]hat advice would you give to parents of Intersex children?

Bridget: Relax. It isn't a big fucking deal!

I: [laughs]. And, anything else? [laughs]

Bridget: Uh...don't talk too much to the doctors. They don't know anything. Talk to support groups and...be like, 'It's your kid! It's beautiful! It's lovely!' You don't have to cut it up. You just have to love it.

Int: What advice would you give to an Intersex child?

Kitty: You're beautiful. You're perfect the way you are. Go and make some great friends and have fun.

Int: Where have you received the most support from John?

John: My wife, by far, my wife. This is my wife right here, her name's Laura [Laura appears on the Skype screen]. She's been my absolute biggest supporter and she's helped me research ...and...she accepts me the way I am and we have

a...fairly normal intimate relationship...and a very, loving marriage [they kiss].

Conclusion

This chapter has drawn on my data to articulate the many aspects involved in transforming the medicalisation of *Intersex* to living *Intersex* at personal and community levels and the ways that these are closely intertwined. The 'coming out' narrative is one that is usually associated with LGBTQ groups and has been successfully adopted by members of the *Intersex* community in their fight against pathologisation. Its profound influence can be seen in Dana's illustrative story and other participant stories that depict 'coming out' as a dynamic process that is liberating, defiant, fear-inducing, painful and formative. It requires much internal reflection, readiness, research, external assistance and support. These latter components are not only sourced from the *Intersex* community, but from other groups engaged in activism and in overcoming their oppression in addition to supportive therapists. 'Coming out' was frequently portrayed in my data as a well-received and powerful endeavour which brings empowerment to self and others. Perhaps for these laudable reasons, there did appear to be a very high expectation by participants upon *Intersex* people to 'come out', educate others, be a sterling example and more, without questioning how this might further oppress the person with the *Intersex* condition and whether society should instead be held more accountable and responsible. 'Coming out' involves a process of immense metamorphosis involving many deeply held and received aspects of a person's identity. For example, with the help of a therapist and the online *Intersex* community, Dana rejected their *male*

assignment and transitioned to a woman before discovering and settling upon an *Intersex* identity which (for them) comfortably incorporates *hermaphrodite*. There were numerous identity related anxieties and debates in my data. These concerned nomenclature, proximity to LGBTQ networks, what *Intersex* means for a person's other identifying categories (such as masculinity) and how far to align with biomedicine for improved healthcare. Whereas, solidarity with other oppressed groups was largely depicted in my data as a safe, empowering and liberating space for participants needing to evaluate their feelings about *Intersex* before 'coming out', allying with the medical profession via the medical-friendly nomenclature *DSD* was, by contrast, viewed with much suspicion, despite it carrying promises of enhanced medical care. Finally, love was proffered by the majority in my data as the ultimate and ideal transformative power, with the ability to successfully sustain, heal and restore throughout the lifespan of an *Intersex* person.

Section Three: Supporting People Living *Intersex*

Section Three contains the Conclusions and Recommendations for my study. The Conclusions are comprised of a theoretical and empirical review based on the previous two sections and guided by my research questions. Following the Conclusions are my Recommendations. These have been distilled from my data to provide practical information, tools and resources on how people living *Intersex* can be better supported and what this will entail in practice. Covering educational and therapeutic resources and training and support, it includes everyone directly and indirectly involved in *Intersex* care.

Having examined in earlier chapters how dualisms based on mind/body and male/female have caused untold harm and injury to *Intersex* people, the Recommendations section offers a new paradigm. It advocates for a non-dualistic, non-dichotomous conceptualisation of human bodies. Theories of embodiment which have emerged from disciplines such as phenomenology, artificial intelligence, neuroscience, biology, psychology and the performing arts, have enhanced our understanding of how human physical experience of the world is a confluence of body, brain, mind, nature, culture and environmental interactions (Batson et al., 2012). Our thoughts, ideas and concepts are shaped by our bodily experience and our *being in the world* develops our thoughts and consciousness (Batson et al., 2012). Evidence in support of these theories has been mounting and attracting a lot of attention. I will show how they may hold tremendous possibilities for the way *Intersex* is conceptualised and managed in Western culture.

Chapter Twelve: Conclusions

My study set out to theorise and document the experiences of and challenges for *Intersex* people in dualistic societies. Its theoretical framework combines insights from the fields of Gender Studies, Feminist Theory, Feminist Post-structuralism and Queer Theory. As an empirical social science study it employed feminist research methods to examine the accounts of seventeen *Intersex* adults obtained from in-depth interviews conducted via Skype. It analysed how a group of internationally diverse *Intersex* people have conceptualised and navigated their *Intersex* difference throughout their lives and in a variety of personal circumstances and public situations.

My study has shown that living *Intersex* in Western societies is about how *Intersex* people have been forced to live dualistic interpretations of and expectations for *Intersexuality*. In the vast majority of cases living *Intersex* in a truly liberated sense has first involved re-living *Intersex*; re-living medicalisation, stigmatisation, shame and a host of other traumatic events and emotions. Nevertheless, my research also contains suggestions for how *Intersex* people can live *Intersex*, as *Intersex*. In recounting and recording these stories of *Intersex*, new ways to live *Intersex* can not only emerge, but eventually be realised.

The theoretical and empirical understandings gained from my study strongly suggest that *Intersex* deserves to occupy space in the world as *Intersex*, on its own terms. What this involves is a refusal to withdraw, an insistence on taking up space, not receiving the message that has been given regarding *Intersexuality* which constructs it

as defective, disordered and in need of surgical correction, and resistance to that message (Ahmed, 2017).

In this penultimate chapter I want to pull together the main insights from this study.

The chapter is organised around the core themes signalled in my research questions

and running through all of the chapters of the thesis, namely theorising,

comprehending, negotiating, medicalising and supporting *Intersex*.

Theorising *Intersex*

The understandings and negotiations of *Intersexuality* found in my empirical data interface with the key theoretical texts and dominant discourse on sex, gender and identity analysed in Section One of my thesis. Chapter One described how *Intersex* is the category tasked with filling the many incongruencies and overlaps of the *male* and *female* categories, and yet simultaneously how it has been forced to remain lesser known, invisible and even subjected to surgical procedures to fit those arch-categories. The primary aim is to silence, marginalise, stigmatise and remove anything which does not fit and *Intersex* does not fit. Therefore, it is not in the interests of a dualistic society to tolerate and accommodate *Intersexuality*. This explains why, in comparison to the plethora of readily obtainable information and support that those categorised as *male* or *female* can access about their bodies in schools, universities, medical and healthcare facilities, public libraries and therapeutic spaces, there is a dearth of resources for *Intersex* people about *Intersexuality*. This has resulted in the estrangement of *Intersex* people from their bodies and alienation from others, particularly during puberty.

The naturalisation and normalisation of the *male* and *female* categories which classifies some bodies as inferior, defective and abnormal was examined in Chapter Two (Karkazis, 2008). Our intelligibility as humans is based upon sex and gender norms (Butler, 2004). It is part of the project of the 'heterosexualisation of desire' which requires coherence, continuity and stability between sex, gender, sexual desire and sexual practice (Butler, 1990). This provides an explanation for why it is that people with *Intersex* conditions are subject to an injurious policing gaze at all levels of

society resulting in stigma and shame. Dualistic male/female categories are not based on scientific 'facts', but are volatile, historical, cultural and discursive notions. They, and their associated categories of sexual difference, namely, masculine/feminine, procreative sex/sodomy, heterosexual/homosexual (to name but a few), have historically functioned to organise, regulate, control and ultimately steer society in normative ways.

Chapters Two to Four catalogued how medicine has always had an important part to play in reinscribing cultural norms surrounding sexual difference (Wittig, 1992; Oosterhuis, 2000; Dreger and Herndon, 2009; Reis, 2009). It is this function which makes it indispensable to the maintenance of the social order. Medical examinations and confessional settings – observing, interviewing, probing and report-writing – individualise and normalise disciplinary processes. They encapsulate Foucault's theory of 'bio-power' and are a hallmark of the modern-day regulation of bodies.

Heteronormative discourses of sex and sexuality are an integral component of bio-power, inform the rhetoric surrounding genital surgery which is presented as the 'cure' or treatment for *Intersexuality*. An aspect of this concerns penile-vaginal intercourse which is promoted as 'normal' sexual activity and the optimum surgical outcome for *Intersex* patients. This medical rhetoric disregards the fact that for many *Intersex* anatomies this outcome is an impossibility and it completely submerges the existence of other forms of sexual intimacy.

Language is a constituent element in the conceptualisation and treatment of *Intersexuality* in dualistic societies. Chapter One identified that within the medical literature *Intersex* is referred to as a 'sexual disorder' (Grosz, 1996). Chapter Five critiqued this controversial word 'disorder' and its usage in the medico-psychiatric realm by analysing theory from Butler and Foucault and medical texts such as the DSM. For Butler (2004), adopting the word 'disorder' means internalising some of its pathologising aspects including the stigmatisation of being found ill, abnormal and out of order. For Foucault (1998), the power of a pathologised group to speak its own name and use the terms by which it was medically disqualified is always circumscribed by power's oppressive terms and limited by the parameters of the oppressor's discourse formation. Notwithstanding this, Oosterhuis (2000) believes differently. For Oosterhuis (2000), medical pathologisation, of which naming is an integral part, is a complex site of struggle which can coexist with medical acceptance, patient self-expression, self-comprehension and even catharsis. Historically, these factors have played an important part in public debate and acceptance of marginalised identities. They can create communities and subcultures that offer self-validation, transformation and collective resistance as depicted in Chapter Eleven.

Comprehending *Intersex*

Intersexuality takes a long time to come to terms with. Traumatic medical encounters in childhood, silence and/or evasion in the family home, and verbal and physical abuse at school, as evoked in Chapters Eight to Ten, can all relay a message of *Intersex* as abnormal, embarrassing, a problem that needs to be concealed and fixed.

Information provided very early in the life of an *Intersex* person is pivotal in helping them to make sense of and positively adjust to their *Intersex* condition. As shown in Chapter Nine, this only happens in a minority of cases. For the majority, notably the pre-internet information generation, comprehending their *Intersex* difference was a long and painful process filled with suicidal feelings, depression, anxiety, isolation and alienation throughout childhood, adolescence and in adulthood.

The process of self-discovery for *Intersex* people was usually initiated after the death of one or both parents, underscoring how deeply ingrained the stigmatisation of *Intersex* resulting from parental secrecy and shame can be. As articulated in Chapter Eleven self-discovery is a journey for information and self-understanding which entails retrieving medical records, internet searches, watching television programmes, documentaries or films directly or indirectly related to *Intersex*. This is a journey of communication and sharing which can incorporate therapeutic counselling sessions, reaching out to people in the *Intersex* community and exchanging life-stories. Within this process 'coming out' is featured as an important milestone. 'Coming out' can be influenced by close association with other minority groups engaged in activism, such as when marching together in LGBTQ Pride parades, or being a member of the disability movement or the *Intactavists*.

Conversely, the repercussions of a lack of information for an *Intersex* person are severe as substantiated in Chapter Eight. This was given as a reason for agreeing to surgeries that were later regretted. Participants spoke of being misinformed and/or misled about their *Intersex* condition and the full implications of surgery leading to

unrealistic expectations and outcomes. Chapter Ten attests to the extent of this misinformation upon the lives of *Intersex* people by directing attention to cases where participants transitioned in adulthood from their medically assigned sex and gender. This entailed pursuing alternative lifestyles and life-choices by adopting different identities and orientations to that which was institutionally imposed upon them. In light of this, very many participants spoke of the importance of comprehensive and candid discussions about *Intersex* from an early age where both medical staff and family members are present. The full range of options, choices, viable outcomes and possibilities for living with an *Intersex* condition (with and without surgery) would feature in these discussions and it should be made clear that penile-vaginal intercourse, which is the inducement for a large number of surgeries by *Intersex* people (see Chapter Eight), is not a prerequisite for sexual intimacy.

Language is how we learn to comprehend ourselves and others, but what if, such as in the case of an *Intersex* person, the available language is steeped with sex and gender norms and our sex and gender is non-normative? How can we express our *Intersexuality* in a language that is predisposing and restricting towards the full possibilities and capacities of what we can be, do and have? How can we think and feel positively about ourselves in a language designed to engender feelings of aberration, freakishness and monstrosity? Chapters Eight and Ten showed that *Intersex* people have a complicated relationship with language that issues from medical discourse. It leaves them no recourse but to express themselves and their condition in its limiting terms. Examples of this were discernible in participants' expressions of *Intersex* as not 'normal', a 'birth defect' and the process of self-

discovery as finding out the 'truth' of who they 'really' are. Nevertheless, the importance of language and speaking to an *Intersex* child using vocabulary they can understand was spoken of as critical since it can assist body-positivity and arm the child to skilfully navigate their difference in a variety of social situations.

As discussed in Chapter Five, the progression of the *Intersex* community in recent years has incorporated celebration of *Intersexuality* which has facilitated new modes of self-understanding, strength and pride. Each new generation of *Intersex* people have pushed the boundaries of language allowing for alternative methods of self-expression and self-reporting. As presented in Chapter Eight, a member of the pre-internet generation remarked upon the enjoyment that *Intersex* youth have in their non-normative identity. Many participants recognised how they 'exceed the norms' and waxed lyrical about some of the advantages and blessings of their sex, gender, body, sexual identity and sexuality. These include the unique experiences their *Intersexuality* has brought to them via youthful appearance, infertility in young adulthood, lack of menstruation and pubic hair, as well as the ability to feel, think and engage with life from more than one sex and gender perspective, and having an extraordinary life and mission. But how far can stigmatising language be pushed? The many conflicting answers to this question has caused ruptures within the *Intersex* community. This conflict was depicted in Chapter Eleven with many wholeheartedly embracing '*Intersex*' as a way to describe themselves or some aspect of themselves (identity, body, history), a few others self-identified as 'hermaphrodite' and a small minority felt at ease with 'Disorders of Sex Development'.

Negotiating *Intersex*

Anatomical and hormonal changes in puberty are already known to heighten issues of sex, gender, the body, sexual identity and sexuality. Chapter Eight revealed that for an *Intersex* person all of these aspects are magnified. Puberty was cited as an incredibly perplexing and troubling time to negotiate. Participants spoke of how *Intersex* bodies present different challenges during this already confusing and taxing phase of life. For an *Intersex* adolescent, puberty can start very early, very late or not occur at all, requiring assistance with hormonal therapy and regular trips to an endocrinologist. Moreover, bodily changes for an *Intersex* person can be at odds with those experienced by members of their peer-group. Dealing with the phenotypical characteristics of hypospadias or an enlarged clitoris, coping with the absence of menstruation (for an assigned *female* with Androgen Insensitivity Syndrome) or facing breast growth (for an assigned *male* with Klinefelter's Syndrome). Adolescence is a time when many young people want to be accepted and not stand out or feel apart, so experiencing these changes can lead to unwanted attention, ridicule, harassment, embarrassment, feelings of isolation, depression and anxiety. To navigate through the awkwardness and alienation of the pubertal phase, some of my participants withdrew socially (as presented in Chapters Eight and Nine), refusing to form any romantic relationships or close attachments as a way of pre-emptively defending themselves from the hurt of rejection.

Chapter Eight detailed how living in a society where sex and gender norms make people intelligible as human exerts internal and external pressures on *Intersex* people who are regularly subject to sex and gender policing. This policing gaze can take the

form of constant questions, unsolicited advice on appearance and comportment, and verbal and physical abuse, the impact of which can last a lifetime. Bullying at school was repeatedly mentioned by those who recalled the fear and terror of having to undress for sports class in front of jeering peers. Being asked embarrassing questions regarding your appearance and 'true' sex and gender category, by work colleagues, neighbours or members of the public, and dealing with ever-present anxiety when using public toilets, undergoing medical examinations or encountering immigration officials at airports. These situations impact how vulnerable or at ease you are - emotionally, mentally, psychologically and physically - living in the world as an *Intersex* person and determine the spaces you occupy.

Medicalising *Intersex*

Chapter Ten brought into sharp relief how profoundly the medical management of *Intersexuality* affects an *Intersex* person. Those who have had surgical interventions in childhood remember invasive, intrusive and even abusive medical examinations, non-consensual photography sessions and humiliating demonstrations where their *Intersex* genitalia were on display for groups of medical staff. These left an indelible imprint on their lives. Many report mental, emotional, physical and sexual problems, self-destructive behaviour and identity conflicts in adolescence, grappling with feelings of emptiness and disassociation, internalised trauma, depression and anxiety leading to an inability to form or maintain romantic/intimate relationships, marital problems or divorce. When contemplating their childhoods there is a great sense of loss. *Intersex* people say that pushing them into one category or another is part of a belief system

which holds *Intersex* to be a temporary condition of the genitals and lacks the understanding that it is a lifelong concern. Once initiated, the current medical management is rarely the one-stop, quick fix procedure that it is claimed to be, but requires repeat surgical procedures, medical examinations and years of hormone therapy.

Cartesian dualism with its mechanistic world view pervades Western societies and structures biomedical treatment and practice. It reduces the body to disordered organs, systems and symptoms by privileging it as a diagnostic tool to be controlled, regulated, monitored, diagnosed and treated by medical experts (Zola, 1976; Grosz, 1994). Cartesian dualism constructs patients as passive, body-objects and disregards their relationship to the full potential and active capacities of their bodies. Medical practitioners wield absolute authority over their body-object patients, which for *Intersex* people results in a closing down of alternative avenues of knowledge formation about *Intersexuality* for these are denigrated as merely fringe perspectives (Karkazis, 2008). Eventually, *Intersex* adults become estranged, alienated and dissociated from their bodies due to multiple intrusive medical examinations and surgical techniques, and exclusive medical control can prevent them from reaching out to other people like them in the *Intersex* community.

Chapter Ten also showed that an aspect which dovetails with these experiences is poor medical expertise overall and a lack of professionals who specialise in *Intersexuality*. There were reports of incompetence, ineptitude, and even case

management experienced as experimental. This has resulted in emotional and physical distress due to misdiagnosis and mistakes and a complete loss of confidence in medical professionals. A few mentioned the great deal of time and money wasted in substandard and amateurish consultations, including those held within prestigious medical institutions. This entailed having to personally pay for medical treatment that should rightly have been covered by health insurance as a consequence of physical symptoms of an *Intersex* condition failing to be accurately diagnosed. These failings are in alignment with societal discourse which elevates and sustains the dominant classifications of *male* and *female* as 'natural', 'normal' and inevitable biological categories. *Intersex* case management betrays the status of *Intersex* in the medical sphere. *Intersex* is a threat to a dualistic society and this is evoked by the injurious experiences reported in my study. It is not studied to ascertain how *Intersex* people can live with, embody and integrate their *Intersex* condition in society for optimum physical, psychological and emotional health and well-being. Rather, *Intersex* is managed as an abnormal, defective and disordered anomaly which is to be quickly, quietly and completely erased. It is this limited focus that is compromising the scope of medical expertise and knowledge of *Intersexuality*.

Those who have had surgical interventions as babies, such as the removal of their gonads, report that these have been devastating. Removal of the gonads eliminates the body's capacity to produce the hormone testosterone which has a detrimental impact on moods, energy levels and libido. This was reported in Chapter Ten as having a disastrous effect on an *Intersex* adult's romantic and sexual interests, desires and relationships, in addition to their overall well-being. It is a medical protocol that

creates a predicament for assigned *females* who seek to off-set all of these problems with a prescription for regular testosterone injections, but are refused by their medical providers. Societal discourse states that testosterone is a *male* hormone that is only to be administered to assigned *males*. It exposes anxieties and fears that were apparent in nineteenth century medical discourse on *hermaphrodites* who were portrayed as perverse, degenerate, women who masqueraded as men to lure wives away from their husbands and therefore were a threat to the social fabric. It was believed that surgery could treat *hermaphrodites* by removing their capacity for deviant sexual behaviour and conclusively cure them with heterosexual, opposite-sex desire and activity within the confines of heterosexual marriage, touted as the primary indicator of success.

The 'one true sex'/truth of sex discourse also promotes a binary ideology of sexual difference which undergirds the insistence of placing the 'disordered' *Intersex* person into one of only two available true categories - that they 'in truth' belong to. It legitimises the routine removal of gonads and testes in *Intersex* people who are assigned *female* by referring to them in medical consultations as ovaries (and not testes or gonads) that have an increased risk of becoming cancerous which is not always the case. This is reinforcing heteronormative norms that require sex, gender, the body, sexual desire and sexual behaviour to cohere. These regulatory sex and gender norms prescribe that the anatomies, roles, behaviour, desire and activity of those categorised as *males* and men or as *females* and women are to be dualistic and asymmetrical. The one true sex/truth of sex discourse is what advanced medicine's professional reputation in the hegemonic social sphere.

Chapter Ten exposed how *Intersexuality* is constructed as a freak and rare occurrence. There was a lot of resistance to this in my data. The freak discourse and discourse of the 'exceptional' body was shown to have multiple injurious effects on an *Intersex* person. It is used as censure; that *Intersex* is something to be concealed, managed and confined within the medical sphere, which also acts as a deterrent. Parents and primary caregivers who are likely unaware of the frequency of *Intersex* births are deterred from connecting with other *Intersex* affected families and the *Intersex* community, heightening their feelings of isolation and shame. The disciplinary framework, to which sex and gender norms are integral, are designed to convey *Intersexuality* as a freakish aberration of sex and gender, which secures the position of the categories *male* and *female* as 'natural', 'normal' and inevitable. Chapter Ten revealed how this rare and freak discourse condones the use of surgery presented as 'repair', 'corrective' and 'reconstructive'.

Another mechanism which justifies normalising surgeries is how the birth of an *Intersex* baby is case managed as an emergency event. Participants expressly commented in Chapter Ten how *Intersex* does not invariably constitute a medical emergency, but is often stage managed in this way. Participants advised parents to resist medical pressure by waiting and learning about their child's *Intersex* condition, and to not make any emergency decisions unless there is a genuine health concern. Taken together with the participants' accounts on parental secrecy and shame in Chapter Nine, it becomes clear how the pre- and post-natal medical emergency scenario can be a traumatising ordeal for parents of *Intersex* children. An ordeal that results in an emotional, psychological and physical distancing by the parents from

other family members, relatives, friends and work colleagues, in an effort to keep their child's *Intersexuality* secret. An *Intersex* person first learns about their *Intersex* condition and how to adjust to it from their parents and primary caregivers. The culture of secrecy in *Intersex* case management means that typically parents receive a lack of full disclosure, therapeutic support and educational resources. They are likely to have been ignored, misinformed, deceived, threatened with legal action and worse, and so are ill-equipped to manage the task of raising an *Intersex* child. My data revealed the cumulative effects upon *Intersex* children and adults to be strained and/or severed familial ties, mental health issues, poor body image, anxiety, trust issues, shame and difficulties in forming romantic and intimate relationships. It can hinder the *Intersex* person from accessing future medical care and therapeutic counselling and from seeking peer-support from the *Intersex* community. The secrecy and shame of parents which descends on an *Intersex* child remains for a lifetime.

Supporting *Intersex*

My participants' suggestions about how people diagnosed as *Intersex* can be better supported covered a number of areas which were primarily discussed in Chapters Nine and Eleven. They suggested that support needs to start before an *Intersex* child is born. It begins with providing information to the parents and primary caregivers of *Intersex* children that is derived from multiple sources and these include *Intersex* support groups. Parents should be wholeheartedly encouraged to contact other *Intersex* parents for peer-support and information sharing, as having an *Intersex* child

can be a very isolating experience, and they should likewise ensure *Intersex* children grow up meeting other *Intersex* children for recreational activities.

In addition, parents and primary caregivers of *Intersex* children were advised by participants to raise their child knowing that they are *Intersex*. A home environment of open-ness and honesty should be fostered which starts with the parents and primary caregivers and extends to include the whole family. Participants unanimously agreed that *Intersex* children should be shown a lot of love and that this importantly incorporates talking to them in age-appropriate and child-friendly ways to assist with supplying them with the language and skills that they will need to navigate society. It was emphasised that information should never be withheld and under no circumstances should there be secrets or lies.

To assist with the above, participants recognised that a variety of agencies and institutions will require *Intersex* training. It was suggested that psychiatrists, therapists and doctors need to be taught about *Intersex* related issues and maybe even require special certification on *Intersexuality*, as there is a pressing need for more specialists in *Intersexuality* overall. There needs to be a recognition that many *Intersex* people have studied *Intersexuality* in depth and are therefore excellent sources of knowledge and information that can be central to any professional *Intersex* training enterprise. *Intersex* teaching must involve rooting out any homophobia and transphobia in professional agencies and institutions which will equip their staff to interact with the parents and families of *Intersex* children with skill and knowledge. It

also ensures that *Intersex* emerges against a large backdrop of the many differences in society - families, genders, bodies and cultures - so that *Intersex* children can feel free and comfortable to live, grow and be who they choose to be within it. Ultimately, everybody needs to be educated on *Intersex*. They need to meet *Intersex* people and interact with them which in the long run may result in more empathy and support of them.

Participants emphasised that the only person who knows what is right for an *Intersex* person, is the *Intersex* person themselves. *Intersex* people are not freaks and should not be treated as though they are. This means that there should be no mutilating sex assignment surgeries performed on *Intersex* babies and children, and they should not be coerced into taking hormones. There should be a greater willingness to listen to what the *Intersex* child wants and needs to live their life, and if the child is too young, wait for them to grow and reach an age where they can decide. Essentially participants stressed how vital it is to listen to *Intersex* people and not impose ideas upon them, for they are the ones who are living *Intersex*.

Chapter Thirteen: Recommendations

The empirical evidence provided by my study has demonstrated the multifarious ways that the medical case management of *Intersexuality* in dualistic Western societies is failing and harming the *Intersex* people who inhabit them. Documenting and theorising the experiences and challenges of *Intersex* adults in my research has

exposed and delineated how the male/female dualism sanctions the social abjection of *Intersex* people and how the mind/body dualism grants surgical access to their bodies. Healthcare for *Intersex* people is not based on health and this is the reason it negatively impacts them. The final chapter of my thesis will propose ways that *Intersex* people can be better supported. Combining empirical data from my study with theories of Embodiment it will advocate for a new paradigm and offer some practical recommendations.

The Embodiment Paradigm

Theories of embodiment show how inaccurate, damaging and disempowering the mind/body dualism is to the way people think, live and behave in general in Western societies. It creates and proliferates disembodied and fragmented subjects who become mechanical automatons to fit increasingly alienating lifestyles. For *Intersex* people this translates to experimental and irreversible infant surgeries, the consequences of which have been duly depicted in my data. Drawn from multiple fields, including philosophy, neuroscience, psychology, biology, phenomenology, artificial intelligence and the performing arts (Batson, Quin et al., 2012), these theories answer some of the pointed questions raised by my study regarding the relationship of human organisms to their bodies. They propose that a person experiences life as an ensemble, an interconnected and interlinked whole. Rather than existing as merely a taxi for the mind, they describe the body as a combination of a person's inner constitution and external circumstances, which is not a fixed state

or truth, but a series of dynamic processes that change over time. In short, we are embodied and embedded in our societies.

German-American philosopher Susanne Langer (1895-1985) theorised that everything we conceptualise as issuing from our minds are derived from aspects of the processes of our bodies (see Langer in Cromby, 2015). This challenges Cartesian dualism with the assertion that psychological capacities cannot be separated from bodies. For Langer, intellect is a high form of *feeling*, whilst the mind describes a phenomenon of the highest *physiological* processes. What this means is, the mind is not a metaphysical ultimate reality which remains distinct from physical reality, rather, it constitutes feelings which are a phase of the body and differentiates their emergent and fluctuating properties into psychological categories. Feelings shape and make our experience before any logical reflection precedes, they are the raw material of experience and organic life (see Langer in Cromby, 2015).

In a similar vein, Portuguese-American neuroscientist and neurologist Antonio Damasio (1994) states that our minds are a reflection of the interplay of both brain and body during evolution, individual development and the current moment. In *Descartes' Error: Emotion, Reason and the Human Brain*, Damasio (1994) writes that the body continuously provides the ground reference for the living organism and that feelings are an inextricable part of this since they offer the living organism cognition of its visceral and musculoskeletal state. When interrogating the Cartesian hypothesis which pits mind/reason/logic against body/feelings/emotions, Damasio (1994)

emphasises that feelings are cognitive, they *mind the body*: they are the first to influence the brain and cognitive structures in human development, they modify our comprehension of objects and situations, whilst retaining a primacy that subtly pervades our mental life.

Theories of embodiment indicate that genital reconstructive surgeries performed on *Intersex* babies and infants carry more complex considerations and serious repercussions than originally thought. Consistent with my empirical data, they suggest that although *Intersex* babies and infants may appear unaffected by the surgical encounter and any subsequent medical examinations, consultations, screenings, tests and treatment - which are highly likely to continue as they develop into childhood, adolescence and adulthood - each medical encounter and/or procedure will constitute a significant and ever-present part of their lived experience. As feminist philosopher Rosi Braidotti (2011) says, the body is a *living memory* endowed with the capacity to affect and be affected; it endures by undergoing continuous internal modifications following encounters with other living organisms and forces.

Nevertheless, biomedical science, with its inordinate focus on the biological, physiological, chemical and biomechanical functions of human organisms, directs comparatively less attention towards embodiment (Damasio, 1994; Eccleston, 2016). Danish physician Halfdan Mahler, who served for three terms as Director-General of the World Health Organisation (1973-1988) describes the biomedical approach in this way:

Most of the world's medical schools prepare doctors, not to take care of the health of the people but instead for a medical practice that is blind to anything but disease and the technology for dealing with it; a technology involving astronomical and ever-increasing prices directed towards fewer and fewer people...The medical empire and its closely related aggressive industry of diagnostic and therapeutic weapons sometimes appear more of a threat than a contribution to health...

as cited in
Fulder, 1997: 15

If a medical professional has been taught by their institution to view the body as a series of biomechanical functions and parts, it is easy to comprehend how they might overlook how their medical interactions, procedures and treatment contributes towards their patient's mental, psychological and emotional state and well-being.

Notwithstanding the pervasive biomedical perspective, the fact that *Intersex* is invalidated in dualistic cultures which only recognise *male* and *female* as 'true' sex categories will undoubtedly create problems for people with *Intersex* conditions. *Intersex* difference is cast as undesirable in body parts which have become saturated in normative cultural meanings of identity and within this dualistic cultural context it is the intention of well-meaning parents, caregivers and medical staff to surgically erase these marks of difference in order to alleviate the potential for harm it can cause in

such a world. Therefore, while genital surgery is available it will always be viewed as a viable option with or without full medical disclosure, informed consent and physical and psychological risk, as innumerable surgical procedures concerned with bodily appearance already bear out. We are not yet in a world where *Intersex* has the privilege of the dominant *male* and *female* categories. What this suggests is, that phenotypical differences due to *Intersex* conditions will always carry with them the potential for physical and psychological injury. How can this be practically addressed and ameliorated?

Recommendations for Supporting People Living *Intersex*

1. Mind/Body Dualism and Embodiment Theory Education for All Medical Health Practitioners

The core curriculum for medical health professionals (and all associated domains of healthcare, therapy, social work and well-being) needs to include critical social science problematising of the mind/body dualism and theories of embodiment. This education would enable practitioners in training to learn about critiques of the centuries old domination of the mind/body philosophy in Western culture and the ways that it currently permeates and functions in medical environments, as well as in society at large. It would examine how the mind/body dualism colours interactions between medical staff and their patients, particularly in the use of medical language when promoting complex surgical decisions. This education would support an appreciation of how, in contrast, theories of embodiment conceptualise people as whole, unified and integrated beings, and show the ways that this more textured understanding of

human organisms and existence could encourage patients to relate to their bodies and their medical experience in more positive and meaningful ways.

Since mechanistic language is an integral part of the mind/body philosophical epistemology and is used when promoting complex surgical decisions, it should also feature in this training. One approach that has been favoured by critics of mechanical metaphors is the use of organic metaphors. An illustrative example is provided by contemporary psychology. It has been observed how this field is dominated by computer metaphors, with cognitive therapy for mental health problems referred to as strategies for *debugging the software* and psychiatric drug treatment as *mending the hardware* (Cromby, 2015). Critics have instead proposed organic metaphors, such as comparing an emotionally distressed person who has experienced a traumatic event to a tree that has been hit by a car; although with treatment the place of impact will get smaller year on year as the tree grows, it will always differ from other trees that escaped collision (Cromby, 2015). This alternative organic metaphor sensitively communicates how humans are *living creatures* who are biologically complex, fragile, finite and unique organisms (Damasio, 1994). It can foster empathy and sensitivity in medical settings, two qualities which could profoundly change the management of *Intersexuality* for the better. Additionally, using language in this way importantly articulates the limitations of biomedicine; that it cannot provide quick and permanent fixes.

2. Education and Therapeutic Resources for Parents and Primary Caregivers of *Intersex* Children

The need to make easily obtainable and accessible education and therapeutic resources to parents and primary caregivers of *Intersex* children was a recurrent theme in my data. Even before an *Intersex* child is born all expectant parents should be provided with comprehensive information about *Intersexuality*, sourced from a wide range of diverse views and perspectives, and not just one dominant narrative. They can be compiled from the wealth of knowledge, experiences and testimonies of *Intersex* people, parents of *Intersex* children and adults and *Intersex* activists. This valuable information is to be found in the empirical data and theorising of *Intersex* academics from many fields (sex, gender, identity, psychology, bio-ethics, to name a few) and medical and healthcare staff who are recommended by *Intersex* people. This expert knowledge can be made available for pre-natal and post-natal classes, discussion groups, talks, presentations, activities and workshops.

3. Institutional Education and Training on *Intersex* for All

To considerably improve the quality of life of an *Intersex* person in society, education and training needs to be provided at an institutional and structural level. *Intersexuality* needs to be taught in schools (to teachers and children) and hospitals, to staff who are authorised to see people undressed or naked; such as those who work in prisons, at airports, for the police and other emergency services, as well as people who conduct smear tests and other intimate tests for sexual healthcare. This education and training could be authenticated by certification which attests that a particular environment is *Intersex* friendly. Accreditation could include the censure

that there will be zero tolerance for assault, bullying and discrimination of *Intersex* people.

4. Practical Support and Assistance for those Living *Intersex*

Practical support was another refrain in my data. Coffee mornings, monthly meet-up groups or 'away days' can be arranged for parents and their *Intersex* children to meet with other parents of *Intersex* children and *Intersex* people of all ages. Some of these gatherings can be used for *Intersex* film and documentary screenings, the review and exchange of books and helpful resources, sharing advice on interacting with institutional staff at hospitals or schools, providing practical assistance with how to manage getting undressed for sports classes and navigating key milestones in the life of an *Intersex* person, such as puberty. Support can include providing contact details for members of various *Intersex* communities and diagnosis specific groups. Members of these groups could volunteer to accompany parents and caregivers to medical consultations or provide advice on how to navigate them. An *Intersex* mentor can be made available either on the phone or in person. Lists of supportive institutions and medical staff (currently provided by many *Intersex* online forums and websites) can be shared. Parent-friendly and child-friendly teaching aids on *Intersex* can be used to educate *Intersex* children, family members, relatives, friends, teachers and employers. All of the above can be supplied to parents at the pre- and post-natal stages.

Final Word

Whether it is in terms of male/female, mind/body, opposite sex desire/same sex desire, heterosexual/homosexual, people in Western societies are constantly encouraged to see themselves and others in dualistic terms, cut off from what is typed as their 'other' or 'inferior' side. As shown in this study, where dualisms are present so is the concomitant evaluation of one in relation to the other, laying a firm foundation for discrimination and oppression. My thesis has described how dualisms enforce and enable separation, division and social hierarchies. The world is perceived in fragmented, ruptured and disembodied modes of difference as barriers are fabricated between the mind and the body, and society and the individual. There exists cooperation, integration, interdependence, fusion and various forms of partnerships on many levels between living organisms and their environment. Nevertheless, dualistic separation sanctions a plethora of schisms that occur at great cost to potentially invaluable opportunities for collaboration and innovation. Grosz sums it up in this way:

Dualism...is also at least indirectly responsible for the historical separation of the natural sciences from the social sciences and humanities, the separation of physiology from psychology...Dualism...this separation...has its costs. Since the time of Descartes, not only is consciousness positioned outside of the world, outside of its body, outside of nature; it is also removed from direct contact with other minds and a sociocultural community. At its extreme, all that consciousness can be sure about is its

own self-certain existence...Consciousness
becomes, in effect, an island unto itself.

Grosz, 1994: 7

Such alienating cultural tendencies are amplified by ideological forces that lionise individualism, self-sufficiency, moral autonomy and personal responsibility. For British psychologist John Cromby (2015) this is characteristic of a neoliberal agenda which rallies choice and individual obligation as excuses for social inequality in areas such as health, education and social care. It commends those positioned as overcoming or controlling their environments. However, the word 'individual' - often used as code for self-contained, separate and independent - is nowhere to be found in its absolute sense in nature or society (Koestler, 1967). It is derived from the Latin word 'individuus', which is closer in interpretation to the word 'indivisibility' (Koestler, 1967). This more accurately describes the condition of human experience where the individual's existence is indivisible from the environment which incorporates the actions and behaviours of others, and where self-assertion works in dynamic equilibrium with integration.

Another insidious component of dualistic separation and oppression is that it forces people to conceptualise, treat and speak about themselves in disembodied and disempowering ways. As articulated by Tamsin Wilton (2000), the mind/body dualism is a 'core dilemma of human self-awareness' and a radical form of disintegration.

There remain, clearly, inconsistencies and gaps in our understanding of the relationships between bodies and whatever animates them. We lack even a basic vocabulary, for all available words seem both inadequate and pregnant with excess implication. Words such as personality, persona, ego, mind, self, will or identity are firmly located within a psychological paradigm which is itself complicit in the Cartesian problematic. Soul, psyche, anima, spirit or essence belong properly to religion or spirituality. 'Subjectivity' or 'agency' are technical-sounding enough not to embarrass social scientists, but are difficult to identify with. Who among us can feelingly lay claim to a subjectivity? And how to describe the interplay between this whatyoumaycallit and the body? Phenomenologically, we appear to ourselves to inhabit our bodies, the 'certain grounds of our daily experience' (Shildrick, 1997: 168) they feel as if they contain 'us'. Like Koestler's ghost in the machine, we walk 'with' our legs, see 'with' our eyes ... and – things get complicated here – think 'with' our brains. This radical dysintegration, (sic) long predating Descartes, seems to be a core dilemma of human self-awareness.

Wilton, 2000: 240

We might ask, how can individuals feel powerfully integrated and whole if they are constructed as disembodied subjects roaming a Cartesian theatre-like world with bodies as taxis for their minds (Cromby, 2015)? These images of the self as a 'ghost in a machine' with mind and body as two mutually exclusive entities, forged of different substances and residing in separate spheres, inform how people in Western societies view, behave and treat themselves and others (Paechter, 2004; Cromby,

2015). Within these societies it is routine practice to pursue genital surgery for *Intersexuality* - despite the mutilations and scars - rather than to accept and address the unique needs and requirements of *Intersex* people in more empathetic and sensitive ways; “[t]hey can’t conceive of leaving someone alone”, says Chase (Chase as cited in Butler, 2004: 64).

This raises some difficult questions. Why has the philosophical epistemology upon which *Intersex* medical case management is based, instated in the seventeenth century, not been exposed as unsound, inaccurate and harmful, and updated with theories of embodiment instead? Could this have something to do with how lucrative the *Intersex* treadmill is (Spurgas, 2009)? Is the privatisation of medical treatment enabling a culture of surgery and hormones as routine treatment for *Intersexuality*? I suggest that the answers to these questions should form the basis for further *Intersex* research.

Bibliography

Ahmed, Sara, *Living a Feminist Life* (Durham: Duke University Press, 2017)

Ahmed, Sara, and Anne-Marie Fortier, 'Re-imagining communities', *International Journal of Cultural Studies* (2003) 6 (3) 251-259.

DOI: 10.1177/13678779030063001 [online] accessed January 2016

Ang-Lygate, Magdalene, 'Waking from a Dream of Chinese Shadows'
in *Representing the Other*, eds. Celia Kitzinger and Sue Wilkinson
(London: Sage Publications, 1996) pp. 53-56.

Arksey, Hilary, and Peter Knight, *Interviewing for Social Scientists: An Introductory Resource with Examples* (London: Sage Publications Ltd, 1999)

Atkinson, Rowland, and John Flint, 'Accessing hidden and hard-to-reach populations: Snowball research strategies', *Social research update* (2001) 33 (1) 1-4.

Batson, Glenna, Edel Quin and Margaret Wilson, 'Integrating somatics and science', *Journal of Dance and Somatic Practices* (April 2012) 3 (No. 1-2) 183-193.

DOI: https://doi.org/10.1386/jdsp.3.1-2.183_1

Beh, Hazel Glenn, and Milton Diamond, 'An emerging ethical and medical dilemma: should physicians perform sex assignment surgery on infants with ambiguous genitalia?' *Michigan Journal of Gender & Law* 7 (2000) 1-63.

Bhopal, Kalwant, 'Gender, identity and experience: Researching marginalised groups', *Women's Studies International Forum* 33 (May-June 2010) 188-195.

DOI:10.1016/J.WSIF.2009.12.005 [online] accessed December 2014

Braidotti, Rosi, *Nomadic Subjects: Embodiment and Sexual Difference in Contemporary Feminist Theory* (New York: Columbia University Press, 2011)

Bryman, Alan, *Social Research Methods* (Oxford: Oxford University Press, 2016)

Burman, Erica, *Deconstructing Developmental Psychology*
(London: Routledge, 1994)

Butler, Judith, *Gender Trouble and the Subversion of Identity*
(New York and London: Routledge, 1990)

Butler, Judith, *Bodies That Matter* (London and New York: Routledge, 1993)

Butler, Judith, *Undoing Gender* (Oxford and New York: Routledge, 2004)

Cameron, Deborah and Don Kulick, *Language and Sexuality*
(Cambridge: Cambridge University Press, 2003)

Carabine, Jean, 'Questioning Representing the Other' in *Representing the Other*,
eds. Celia Kitzinger and Sue Wilkinson
(London: Sage Publications, 1996) pp. 165-169.

Carby, Hazel, 'White women listen! Black feminism and the boundaries of sisterhood'
in *The Empire Strikes Back: Race and Racism in 70s Britain*
(London: Hutchinson, Centre for Contemporary Cultural Studies, 1982).

Charmaz, Kathy, *Constructing Grounded Theory 2nd Edition*
(California and London, Sage Publications, 2014)

Cixous, Hélène, 'The Newly Born Woman', in *Literary Theory: An Anthology Second Edition*, eds. Julie Rivkin and Michael Ryan
(Malden, MA and Oxford: Blackwell Publishing, 2004)

Chase, Cheryl, 'Hermaphrodites with attitude: mapping the emergence of intersex political activism', *GLQ: A Journal of Lesbian and Gay Studies* (1998)
4 (2) 189-211. DOI:10.1215/10642684-4-2-189
[online] accessed November 2013

- Coffey, Amanda and Paul Atkinson, *Making Sense of Qualitative Data: Complementary Research Strategies* (California and London: Sage Publications, 1996)
- Colapinto, John, *As Nature Made Him: The Boy Who Was Raised As a Girl* (London: Quartet Books, 2000)
- Conway, Gerard S., 'Disorders of sex development (DSD): an overview of recent scientific advances', *Psychology & Sexuality* (2014) 5 (1) 28-33.
DOI: 10.1080/19419899.2013.831213 [online] accessed June 2016
- Cotterill, Pamela, 'Interviewing women: issues of friendship, vulnerability and power', *Women's Studies International Forum* (1992) 15 (5/6) 593-606.
DOI:10.1016/0277-5395(92)90061-Y [online] accessed November 2014
- Coyle, A. and C. Wright, 'Using the Counselling Interview to Collect Research Data on Sensitive Topics', *Journal of Health Psychology* (1996) 1 (4) 431-40.
DOI: 10.1177/135910539600100402 [online] accessed November 2014
- Creighton, Sarah M. and Catherine L. Minto, 'Managing Intersex: Most vaginal surgery in childhood should be deferred', *British Medical Journal* (2001) 323 (7324) 1264-1265.
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1121738/>
[online] accessed December 2014
- Creighton, S.M. and L. M. Liao, 'Changing attitudes to sex assignments in intersex', *BJU International* (2004) 93 (5) 659-664.
DOI: 10.1111/j.1464-410X.2003.04694.x [online] accessed January 2014
- Creighton, Sarah M., Catherine L. Minto, Lih Mei Liao et al., 'Meeting between experts: evaluation of the first UK forum for lay and professional experts in intersex', *Patient Education and Counseling* (2004) 54 (2) 153-157.
[http://dx.DOI.org/10.1016/S0738-3991\(03\)00202-7](http://dx.DOI.org/10.1016/S0738-3991(03)00202-7)
[online] accessed October 2013

- Creighton, Sarah M., Julie A. Greenberg, Katrina Roen et al., 'Intersex Practice, Theory and Activism: A Roundtable Discussion', *GLQ: A Journal of Lesbian and Gay Studies* (2009) 15 (2) 249-260. DOI: 10.1215/10642684-2008-136 [online] accessed October 2013
- Crenshaw, Kimberlé, 'Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color', *Stanford Law Review* (July 1991) 43 (6) 1241-1299.
- Cromby, John, *Feeling Bodies: Embodying Psychology* (Basingstoke: Palgrave Macmillan, 2015)
- Damasio, Antonio R., *Descartes' Error: Emotion, Reason and the Human Brain* (New York: G. P Putnam, 1994)
- Davis, S R., 'The therapeutic use of androgens in women', *The Journal of Steroid Biochemistry and Molecular Biology* (April-June 1999) 69 (1-6) 177-184. DOI: [https://doi.org/10.1016/S0960-0760\(99\)00054-0](https://doi.org/10.1016/S0960-0760(99)00054-0)
- Deakin, Hannah and Kelly Wakefield, 'Skype interviewing: reflections of two PhD researchers', *Qualitative Research* (2014) 14 (5) 603-616. DOI: 10.1177/1468794113488126 [online] accessed November 2014
- Diamond, Milton, 'Sexual identity, monozygotic twins reared in discordant sex roles and a BBC follow-up', *Archives of sexual behavior* (1982) 11 (2) 181-186. DOI:10.1007/BF01541983 [online] accessed December 2016
- Diamond, Milton and H. Keith Sigmundson, 'Sex reassignment at birth, ' *Archives of Pediatrics and Adolescent Medicine* (1997) 151 (3) 298-304. DOI:10.1001/archpedi.1997.02170400084015 [online] accessed December 2016

Diamond, Milton and Hazel G. Beh, 'Changes in the management of children with intersex conditions', *Nature Clinical Practice Endocrinology and Metabolism* (2008) 4 (1) 4-5. DOI:10.1038/ncpendmet0694
[online] accessed December 2016

Diamond, Milton, 'Human intersexuality: difference or disorder?', *Archives of Sexual Behaviour* (2009) 38 (2) 172-172.
DOI:10.1007/s10508-008-9438-6 [online] accessed December 2016

Dickson-Swift, V., Erica L. James and Sandra Kippen, 'Do University, Ethics Committees Adequately Protect Public Health Researchers?', *Australian & New Zealand Journal of Public Health* (2004) 29 (6) 576-82.
DOI: 10.1111/j.1467-842X.2005.tb00254.x
[online] accessed November 2014

Dickson-Swift, Erica L. James and Sandra Kippen et al., 'Blurring Boundaries in Qualitative Health Research on Sensitive Topics', *Qualitative Health Research* (2006) 16 (6) 853-71. DOI: 10.1177/1049732306287526
[online] accessed November 2014

Dickson-Swift, V., Erica L. James and Sandra Kippen et al., 'Doing sensitive research: what challenges do qualitative researchers face?', *Qualitative Research* (2007) 7 (3) 327-353. DOI: 10.1177/1468794107078515
[online] accessed November 2014

Dickson-Swift, Virginia, Erica Lyn James and Pranee Liamputtong, *Undertaking Sensitive Research in the Health and Social Sciences: Managing Boundaries, Emotions and Risks*, (Cambridge: Cambridge University Press, 2008)

Downing, Lisa, 'A Disavowed Inheritance: Nineteenth-Century Perversion Theory and John Money's "Paraphilia"' in *Fuckology: Critical Essays on John Money's Diagnostic Concepts* (Chicago and London, The University of Chicago Press, 2015) pp. 41-68

Downing, Lisa, Iain Morland and Nikki Sullivan, *Fuckology: Critical Essays on John Money's Diagnostic Concepts*

(Chicago and London, The University of Chicago Press, 2015)

Dreger, Alice D., "'Ambiguous sex": or ambivalent medicine? Ethical issues in the treatment of intersexuality,' *The Hastings Center Report* (1998a)

28 (3) 24-35. DOI: 10.2307/3528648

[online] accessed December 2013

Dreger, Alice D., *Hermaphrodites and the Medical Invention of Sex*

(MA: Harvard University Press, 1998b)

Dreger, Alice D., and April M. Herndon, 'Progress and politics in the intersex rights movement: Feminist theory in action', *GLQ: A Journal of Lesbian and Gay Studies* (2009) 15 (2) 199-224. DOI: 10.1215/10642684-2008-134

[online] accessed November 2013

Drescher, Jack, 'Queer diagnoses revisited: The past and future of homosexuality and gender diagnoses in DSM and ICD', *International Review of Psychiatry* (October 2015) 27 (5) 386-395.

DOI: <http://dx.doi.org/10.3109/09540261.2015.1053847>

DSM II Behaviorism and Mental Health, 'The Diagnostic and Statistical Manual of Mental Disorders (DSM-II)', *Behaviorism and Mental Health* (2015) 44.

<http://behaviorismandmentalhealth.com/wp-content/uploads/2015/08/DSM-II.pdf>

[online] accessed September 2017

Eccleston, Christopher, *Embodied: The Psychology of Physical Sensation*

(Oxford: Oxford University Press, 2016)

Edwards, Rosalind, 'An Education in Interviewing: Placing the Researcher and the Research', in *Researching Sensitive Topics*, eds. Claire M. Renzetti and Raymond M. Lee (California and London: Sage Publications, 1993) pp. 181-196

Ezzy, Douglas, 'Qualitative Interviewing as an Embodied Emotional Performance', *Qualitative Inquiry* (2010) 3 (16) 163-170.
DOI: <https://doi.org/10.1177/1077800409351970>
[online] accessed December 2016

Fairclough, Norman, *Discourse and Social Change* (Polity Press, 1992)

Fausto-Sterling, Anne, *Sexing the Body: Gender Politics and the Construction of Sexuality* (New York: Basic Books, 2000)

Feder, Ellen K. 'Imperatives of normality from "Intersex" to "Disorders of Sex Development"', *GLQ: A Journal of Lesbian and Gay studies* (2009) 15 (2) 225-247. DOI: 10.1215/10642684-2008-135
[online] accessed June 2013

Feder, Ellen K. and Katrina Karkazis, What's in a name? The controversy over "Disorders of Sex Development", *The Hastings Center Report* (2008) 38 (5) 33-36. DOI: 10.1353/hcr.0.0062
[online] accessed September 2016

Follette, William C., and Arthur C. Houts, 'Models of scientific progress and the role of Theory in taxonomy development: A case study of the DSM', *Journal of Consulting and Clinical Psychology* (1996) 64 (6) 1120-1132.
<http://dx.DOI.org/10.1037/0022-006X.64.6.1120>
[online] accessed December 2016

- Foucault, Michel, *Herculine Barbin* (New York, Pantheon Books: 1980)
- Foucault, Michel, *The will to knowledge: The history of sexuality: Volume One*
trans. Robert Hurley (London: Penguin, 1998)
- Francis, Becky, 'The creation and dissemination of feminist research in education:
facts or fictions?', *Disseminating Qualitative Research in Educational Settings*
ed. Christina Hughes (Maidenhead: Open University Press, 2003) pp. 55-65.
- Fulder, Stephen, *The Handbook of Alternative and Complementary Medicine: The
Essential Health Companion, 3rd Edition* (London: Ebury Press, 1997)
- Gatens, Moira, *Imaginary Bodies: Ethics, Power and Corporeality*
(London and New York: Routledge, 1996)
- Gough, Brendan, Nicky Weyman, Julie Alderson et al., 'They did not have a word':
The parental quest to locate a 'true sex' for their intersex children',
Psychology & Health (2008) 23 (4) 493-507.
DOI: 10.1080/14768320601176170 [online] accessed December 2013
- Grosz, Elizabeth, *Volatile bodies: Toward a Corporeal Feminism*
(Indiana: Indiana University Press, 1994)
- Grosz, Elizabeth, 'Intolerable ambiguity: freaks as/at the limit' in *Freakery: Cultural
Spectacles of the Extraordinary Body* ed. Rosemarie Garland-Thomson
(New York: New York University Press, 1996) pp. 55-66.
- Gunaratnam, Yasmin, and Carrie Hamilton, 'Introduction: The Wherewithal of
Feminist Methods', *Feminist Review* (2017) 115 1-12.
- Guth, Lorraine J., et al., 'Relationships, sexuality, gender identity, gender roles,
and self-concept of individuals who have congenital adrenal hyperplasia: a
qualitative investigation', *Journal of Gay & Lesbian Psychotherapy* (2006)
10 (2) 57-75. http://dx.DOI.org/10.1300/J236v10n02_04
[online] accessed November 2013

Hanna, Paul, 'Using internet technologies (such as Skype) as a research medium: a research note', *Qualitative Research* (2012) 12 (2) 239-242.

DOI: 10.1177/1468794111426607 [online] accessed November 2014

Harper, Catherine, 'Intersex', *Dr Catherine Harper*,

<https://drcatherineharper.wordpress.com/research-portfolio/intersex/>

[online] accessed October 2017

Harris, Cheryl I., 'Whiteness As Property', *Harvard Law Review*

(June 1993) 106 (8) 1707-1791.

<http://www.jstor.org/stable/1341787>

[online] accessed June 2017

Hausman, Bernice L., 'Do boys have to be boys? Gender, narrativity, and the John/Joan case', *NWSA Journal* (2000) 12 (3) 114-138.

<http://www.jstor.org/stable/4316765> [online] accessed December 2016

Hawkesworth, M., 'Confounding Gender', *Signs* (1997) 22 (3) 649-685.

<http://www.jstor.org/stable/3175248> [online] accessed January 2015

Hester, J. D., 'Intersex(es) and Informed Consent How Physician's Rhetoric Constrains Choice', *Theoretical Medicine and Bioethics* (January 2004) 25 (1) 21-49.

DOI: <https://doi.org/10.1023/B:META.0000025069.46031.0e>

Hill Collins, Patricia, *Black Feminist Thought: Knowledge, Consciousness and the Politics of Empowerment* (New York: Routledge, 1991)

Holt, Amanda, 'Using the telephone for narrative interviewing: a research note', *Qualitative Research* (2010) 10 (1) 113-121.

DOI: 10.1177/1468794109348686 [online] accessed January 2015

Holmes, Morgan, *Intersex: A Perilous Difference*

(New Jersey: Rosemont Publishing and Printing Corp, 2008)

Holmes, Morgan, 'Straddling Past, Present and Future' in *Critical Intersex*, ed. Morgan Holmes (Farnham: Ashgate Publishing, 2009) pp. 1-11

hooks, bell, *Ain't I A Woman: Black Women and Feminism* (Boston, MA: South End Press, 1981)

hooks, bell, 'Sisterhood: Political Solidarity between Women', *Feminist Review*, No. 23, Socialist-Feminism: Out of the Blue (Summer, 1986) 125-138. <http://www.jstor.org/stable/1394725> [online] accessed January 2015

Ismail, Ida, and Sarah Creighton, 'Surgery for intersex', *Reviews in Gynaecological Practice* (2005) 5 (1) 57-64. <http://dx.DOI.org/10.1016/j.rigp.2004.10.004> [online] accessed December 2013

Jaggar, Alison M., 'Love and knowledge: Emotion in feminist epistemology', *Inquiry* (1989) 32 (2) 151-176
DOI: <http://dx.doi.org/10.1080/00201748908602185>

Jagose, Annamarie, *Queer Theory: An Introduction* (New York: New York University Press, 1996)

Karasic, Dan, and Jack Drescher, 'Sexual and Gender Diagnoses of the Diagnostic and Statistical Manual (DSM). A Reevaluation', *Journal of Psychology and Human Sexuality* (2006) 17 (3-4) 1-5.
DOI: http://dx.doi.org/10.1300/J056v17n03_01
[online] accessed February 2017

Kahan, Benjamin, *Heinrich Kaan's "Psychopathia sexualis" (1844): A Classic Text in the History of Sexuality* ed. Benjamin Kahan, trans. Melissa Haynes (Ithaca and London: Cornell University Press, 2016)

- Kaplan, Charles. D., Dirk Korf and Claire Sterk, 'Temporal and social contexts of heroin-using populations: an illustration of the snowball sampling technique', *Journal of Mental and Nervous Disorders* (1987) 175 (9) 566-574.
- Karkazis, Katrina, *Fixing Sex: Intersex, Medical Authority, and Lived Experience* (Durham: Duke University Press, 2008)
- Katz, Jonathan Ned, *The Invention of Heterosexuality* (New York: Penguin, 1995)
- Kessler, Suzanne J., and Wendy McKenna, *Gender: An Ethnomethodological Approach* (New York, Chichester, Brisbane, Toronto: John Wiley & Sons, 1978)
- Kessler, Suzanne J., 'The Medical Construction of Gender: Case management of Intersexed Infants', *Signs* (1990) 16 (1) 3-26.
<http://www.jstor.org/stable/3174605>
 [online] accessed December 2016
- Kessler, Suzanne J., *Lessons from the Intersexed* (New Jersey: Rutgers University Press, 1998)
- Kipnis, Kenneth, and Milton Diamond, 'Pediatric ethics and the surgical assignment of sex', *Journal of Clinical Ethics* (1998) 9 398-410.
- Kitzinger, Celia and Sue Wilkinson, 'Theorising Representing the Other' in *Representing the Other*, ed. Celia Kitzinger and Sue Wilkinson (London: Sage Publications, 1996) pp. 1-32.
- Kitzinger, Celia, 'The myth of the two biological sexes', *Psychologist* (2004) 17 (8) 451-454.
- Koestler, Arthur, *The Ghost in the Machine* (London: Hutchinson, 1967)

- Kosofsky Sedgwick, Eve, 'How to bring your kids up gay', *Social Text* (1991) No. 29 18-27. <http://www.jstor.org/stable/466296> [online] accessed Nov 2013
- Kosofsky Sedgwick, Eve, *Epistemology of the Closet* (California: University of California Press, 2008)
- Kvale, Steinar, *Interviews: An Introduction to Qualitative Research Interviewing* (California: Sage Publications, 1996)
- Ladau, Emily, 'Why People-First Language Doesn't Always Put the Person First', *Think Inclusive* (2015), <https://www.thinkinclusive.us/why-person-first-language-doesnt-always-put-the-person-first/> [online] accessed September 2017.
- Laqueur, Thomas, *Making Sex: Body And Gender From The Greeks To Freud* (Cambridge MA and London: Harvard University Press, 1990)
- Lev, Arlene Istar, 'Disordering gender identity: Gender identity disorder in the DSM-IV-TR', *Journal of Psychology & Human Sexuality* (2006a) 17 (3-4) 35-69. DOI: http://dx.DOI.org/10.1300/J056v17n03_03 [online] accessed December 2016
- Lev, Arlene Istar, 'Intersexuality in the family: an unacknowledged trauma', *Journal of Gay & Lesbian Psychotherapy* (2006b) 10 (2) 27-56. DOI: http://dx.DOI.org/10.1300/J236v10n02_03 [online] accessed November 2015
- Liao, Lih-Mei, and Mary Boyle, 'Intersex,' *The Psychologist* (2004a) 17 (8) 446-447.
- Liao, Lih-Mei, and Mary Boyle, 'Surgical feminizing: The right approach?', *The Psychologist* (2004b) 17 (8) 459-462.

- Lima, Isabel Maria, et al., 'Intersexuality and Discrimination: Silence as Family Violence' in *Sexuality, Oppression and Human Rights*: 101. eds. Júliá Tomas and Nicol Epple (Oxford: Inter-Disciplinary Press, 2015) pp. 101-112
- Mak, Geertje, *Doubting Sex: Inscriptions, Bodies and Selves in Nineteenth-Century Hermaphrodite Case Histories* (Manchester: Manchester University Press, 2012)
- Malatino, Hilary, 'Situating Bio-Logic, Refiguring Sex: Intersexuality and Coloniality' in *Critical Intersex*, ed. Morgan Holmes (Farnham: Ashgate Publishing, 2009)
- Marcus, Sharon, 'Queer theory for everyone: A review essay', *Signs* (2005) 31(1) 191-218. DOI: 10.1086/432743 [online] accessed October 2016
- Martín Alcoff, Linda, 'The Problem of Speaking for Others' in *Who Can Speak? Authority and Critical Identity* eds. Judith Roof and Robyn Wiegman (Urbana and Chicago: University of Illinois Press, 1995) pp. 97-119
- Meyer-Bahlburg, Heino F. L., 'Gender Assignment in Intersexuality', *Journal of Psychology & Human Sexuality* (1998) 10 (2) 1-21. http://dx.DOI.org/10.1300/J056v10n02_01 [online] accessed December 2016
- Mills, Sara, *Michel Foucault* (Oxon: Routledge, 2003)
- Minh-ha, Trinh T., *Woman, Native, Other: Writing Postcoloniality and Feminism* (Bloomington and Indianapolis: Indiana University Press, 1989)
- Money, John, and Anke A. Ehrhardt, *Man & Woman Boy & Girl: The Differentiation and Dimorphism of Gender Identity From Conception To Maturity* (Baltimore and London: John Hopkins University Press, 1972)

- Money, John, Joan G. Hampson, and John L. Hampson, 'Imprinting and the establishment of gender role', *AMA Archives of Neurology & Psychiatry* (1957) 77 (3) 333-336. DOI:10.1001/archneurpsyc.1957.02330330119019 [online] accessed December 2016
- Money, John, 'Ablatio penis: normal male infant sex-reassigned as a girl', *Archives of Sexual Behavior* (1975) 4 (1) 65-71. DOI:10.1007/BF01541887 [online] accessed December 2016
- Money, John, 'Gender: history, theory and usage of the term in sexology and its relationship to nature/nurture', *Journal of Sex and Marital Therapy* (1985) 11 (2) 71-79. DOI: <http://dx.DOI.org/10.1080/00926238508406072> [online] accessed December 2016
- Monro, Surya, Daniela Crocetti, Tray Yeadon-Lee et al., *Intersex, Variations of Sex Characteristics, and DSD: The Need for Change. Research Report* (Huddersfield: University of Huddersfield, 2017)
- Morland, Iain, 'Is intersexuality real?', *Textual Practice* (2001) 15 (3) 527-547. DOI: 10.1080/09502360110070439 [online] accessed December 2013
- Morland, Iain, 'Thinking with the phallus', *The Psychologist* (2004) 17 (8) 448-450.
- Morland, Iain, 'Between Critique and Reform: Ways of Reading the Intersex Controversy' in *Critical Intersex*, ed. Morgan Holmes (Farnham: Ashgate Publishing, 2009) pp. 191-213
- Morland, Iain, 'The injured world: Intersex and the phenomenology of feeling', *differences* (2012) 23 (2) 20-41. DOI: 10.1215/10407391-1629803 [online] accessed December 2015
- Morland, Iain, 'Gender, Genitals, and the Meaning of Being Human' in *Fuckology: Critical Essays on John Money's Diagnostic Concepts* (Chicago and London, The University of Chicago Press, 2015) pp. 69-98

- Oakley, Ann, 'Interviewing women: a contradiction in terms' in *Doing Feminist Research* ed. Helen Roberts (London: Routledge, 1981) pp. 30-61
- Oosterhuis, Harry, *Stepchildren of Nature: Krafft-Ebing, Psychiatry, and the Making of Sexual Identity* (Chicago: University of Chicago Press, 2000)
- Oudshoorn, Nelly, *Beyond the Natural Body: An Archaeology of Sex Hormones* (Oxon: Routledge, 1994)
- Paechter, Carrie, "'Mens Sana in Corpore Sano": Cartesian dualism and the marginalisation of sex education', *Discourse: Studies in the Cultural Politics of Education* (Sept 2004) 25 (3) 309-320.
DOI: <http://dx.doi.org/10.1080/0159630042000247890>
[online] accessed March 2017
- Page, Tiffany, 'Vulnerable Writing as a Feminist Methodological Practice', *Feminist Review* (2017) Volume 115 13-29
DOI: <https://doi.org/10.1057/s41305-017-0028-0>
online accessed June 2017
- Phoenix, Ann, 'Theories of gender and black families' in *Gender under scrutiny: New inquiries in education* eds. Gaby Weiner and Madeline Arnot (London: Hutchinson, 1987) pp. 50-61.
- Plummer, Ken, *Telling Sexual Stories: Power, Change and Social Worlds* (London and New York: Routledge, 1995)
- Preves, Sharon E., *Intersex and Identity: The Contested Self* (New Jersey: Rutgers University Press, 2008)
- Reis, Elizabeth, *Bodies in Doubt: An American History of Intersex* (Baltimore: John Hopkins University Press, 2009)

- Reinharz, Shulamit, and Lynn Davidman, *Feminist Methods in Social Research* (New York: Oxford University Press, 1992)
- Renzetti, Claire M., and Raymond M. Lee, eds. *Researching Sensitive Topics* (California and London: Sage Publications, 1993)
- Roberts, Helen, ed. *Doing Feminist Research* (London: Routledge, 1981)
- Roen, Katrina, 'But we have to *do* something': surgical 'correction' of atypical genitalia', *Body & Society* (2008) 14 (1) 47-66.
DOI: 10.1177/1357034X07087530 [online] accessed November 2013
- Roen, Katrina, 'Clinical Intervention and Embodied Subjectivity: Atypically Sexed Children and their Parents' in *Critical Intersex*, ed. Morgan Holmes (Farnham: Ashgate Publishing, 2009) pp. 15-40
- Roof, Judith and Robyn Wiegman, eds. *Who Can Speak? Authority and Critical Identity* (Urbana and Chicago: University of Illinois Press, 1995)
- Rosario, Vernon A., 'The Biology of Gender and the Construction of Sex?', *GLQ: A Journal of Lesbian and Gay Studies* (2004) 10 (2) 280-287.
<https://muse.jhu.edu/article/54591> [online] accessed December 2016
- Rosario, Vernon A., 'Quantum sex: Intersex and the Molecular Deconstruction of Sex,' *GLQ: A Journal of Lesbian and Gay Studies* (2009) 15 (2) 267-284.
DOI: 10.1215/10642684-2008-138 [online] accessed June 2013
- Rubin, Herbert J., and Irene S. Rubin, *Qualitative Interviewing: The Art of Hearing Data* (California: Sage Publications, 1995)
- Russett, Cynthia Eagle, *Sexual Science: The Victorian Construction of Womanhood* (Harvard University Press, 2009)

- Sarbin, Theodore R., 'On the futility of psychiatric diagnostic manuals (DSMs) and the return of personal agency', *Applied and Preventive Psychology* (1997) 6 (4) 233-243. DOI:10.1016/S0962-1849(97)80012-1
[online] accessed February 2014
- Schiebinger, Londa, *The Mind Has No Sex?: Women in the Origins of Modern Science* (Cambridge, MA: Harvard University Press, 1991)
- Sieber, Joan E., 'The Ethics and Politics of Sensitive Research' in *Researching Sensitive Topics*, eds. Claire M. Renzetti and Raymond M. Lee (California and London: Sage Publications, 1993) pp. 14-26
- Silverstein, Charles, 'The Implications of Removing Homosexuality from the DSM as a Mental Disorder', *Archives of Sexual Behaviour* (2009) 38: 161-163. DOI: 10.1007/s10508-008-9442-x
- Simon, James, 'Androgen', *Healthy Women*
<http://www.healthywomen.org/condition/androgen>
[online] accessed September 2017
- Simon, Lianne, 'Turner Syndrome Boys', *Lianne Simon* (2014)
<http://www.liannesimon.com/2014/01/31/turner-syndrome-boys/>
[online] accessed February 2017
- Smart, Carol, 'Disruptive bodies and unruly sex. The regulation of reproduction and sexuality in the nineteenth century' in *Regulating Womanhood: Historical Essays on Marriage, Motherhood and Sexuality*, ed. Carol Smart (London: Routledge, 2002) pp. 7-32
- Snow, Kathie, 'People First Language', *Disability Is Natural* (2017)
<https://www.disabilityisnatural.com/people-first-language>
[online] accessed September 2017

- Spitzer, Robert L., 'The Diagnostic Status of Homosexuality in DSM-III: A Reformulation of the Issues', *American Journal of Psychiatry* (February 1981) 138 (2) 210-215.
<http://ajp.psychiatryonline.org/doi/pdf/10.1176/ajp.138.2.210>
 [online] accessed December 2016
- Spitzer, Robert L., 'Sexual and gender identity disorders: Discussion of questions for DSM-V', *Journal of Psychology & Human Sexuality* (2006) 17 (3-4) 111-116.
 DOI: 10.1300/J056v17n03_06 [online] accessed December 2016
- Spurgas, Alyson K., '(Un)Queering Identity: The Biosocial Production of Intersex/DSD' in *Critical Intersex* ed. Morgan Holmes (Farnham: Ashgate Publishing, 2009) pp. 97-122
- Stanley, Liz and Wise, Sue, 'Feminist Research, Feminist Consciousness and Experiences of Sexism' in *Beyond Methodology: Feminist Scholarship as Lived Research*, eds. Margaret Fonow and Judith A. Cook (Bloomington, IN: Indiana University Press, 1991)
- Stanley, Liz and Wise, Sue, *Breaking Out Again: Feminist Consciousness and Feminist Research* (London: Routledge and Kegan Paul, 1993)
- Stanley, Liz, 'The Mother of Invention: Necessity, Writing and Representation' in *Representing the Other*, eds. Celia Kitzinger and Sue Wilkinson (London: Sage Publications, 1996) pp. 43-49
- Strauss, Anselm and Juliet Corbin, *Basics of Qualitative Research: Grounded Theory Procedures and Techniques* (California: Sage Publications, 1990)
- Tartellin, Abigail, *Golden Boy* (London: Orion, 2013)
- Thakker, Joanne, and Tony Ward, 'Culture and classification: The cross-cultural application of the DSM-IV', *Clinical Psychology Review* (1998) 18 (5) 501-529. [http://dx.DOI.org/10.1016/S0272-7358\(97\)00107-4](http://dx.DOI.org/10.1016/S0272-7358(97)00107-4)
 [online] accessed February 2014

- Torassa, Ulysses, 'Profile Cheryl Chase, Medical activist boy or girl? Advocate for Intersex children influences attitudes', *SF Gate* (2002)
<http://www.sfgate.com/living/article/PROFILE-Cheryl-Chase-Medical-Activist-Boy-or-2815701.php> [online] accessed September 2017
- van Heesch, Margriet, 'Do I Have XY Chromosomes?' in *Critical Intersex*, ed. Morgan Holmes (Farnham: Ashgate Publishing, 2009) pp. 123-145
- Van Meter, Karl, 'Methodological and Design Issues: Techniques for Assessing the Representatives of Snowball Samples', *NIDA Research Monograph* (1990) 98 (51.40) 31-43. DOI:10.1.1.152.3744 [online] accessed January 2015
- Waitzkin, Howard, 'A critical theory of medical discourse: Ideology, social control, and the processing of social context in medical encounters', *Journal of Health and Social Behavior* (1989) 220-239. <http://www.jstor.org/stable/2137015> [online] accessed November 2015
- Wilton, Tamsin, 'Out/Performing Our Selves: Sex, Gender and Cartesian Dualism', *Sexualities* (2000) 3 (2) 237-254.
 DOI: <https://doi.org/10.1177/136346000003002008>
 [online] accessed July 2017
- Wittig, Monique, *The Straight Mind and other essays* (Boston: Beacon Press, 1992)
- Zola, Irving, 'Medicine as an institution of social control', *Ekistics*, (April 1976) 41 (245) 210-214. <http://www.jstor.org/stable/43618673> [online] accessed May 2017
- Zucker, Kenneth, 'The DSM Diagnostic Criteria for Gender Identity Disorder in Children', *Archives of Sexual Behaviour* (2010) 39: 477-498.
 DOI: <https://doi.org/10.1007/s10508-009-9540-4>

Film

Dr. Money and the Boy with no Penis, BBC Horizon documentary (2004)

Intersexion, dir. Grant Lahood (2012)

XXY, dir. Lucia Puenzo (2008)

Appendices

References for Five *Intersex* Conditions (Chapter One)

Androgen Insensitivity Syndrome (AIS)

'What is Intersex and/or DSD?', *AIS-DSD Support Group* 2016

<<http://aisdsd.org/fact-check/>> [online] accessed December 2016

Koch, Christian A., 'Androgen Insensitivity Syndrome', *Medscape* 2015, WebMD LLC

<http://www.medscape.com> [online] accessed December 2016

'Androgen Insensitivity Syndrome (AIS)', *Intersex Society of North America*, ISNA 1993-2008

<http://www.isna.org/faq/conditions/ais> [online] accessed December 2016

Congenital Adrenal Hyperplasia (CAH)

'What is Congenital Adrenal Hyperplasia (CAH)?', *CARES Foundation* 2012

<http://www.caresfoundation.org/> [online] accessed December 2016

Pang, Songya, 'Congenital Adrenal Hyperplasia', *The MAGIC Foundation*

<https://www.magicfoundation.org/Growth-Disorders/Congenital-Adrenal-Hyperplasia/>

[online] accessed December 2016

'Congenital Adrenal Hyperplasia', *You and Your Hormones* 2013, Society for Endocrinology

http://www.yourhormones.info/endocrine_conditions/congenital_adrenal_hyperplasia.aspx [online] accessed December 2016

Klinefelter's Syndrome

'Klinefelter syndrome', *Genetics Home Reference* 2016, National Institute of Health, National Library of Medicine, U.S Department of Health and Human Services

<https://ghr.nlm.nih.gov/condition/klinefelter-syndrome>

[online] accessed December 2016

'What is Klinefelter's Syndrome (KS)?', *Klinefelter Organisation*
http://www.klinefelter.org.uk/about_ks.html [online] accessed December 2016

Swyer Syndrome

'Swyer Syndrome', *Genetics Home Reference 2016*, National Institute of Health, National Library of Medicine, U.S Department of Health and Human Services
<https://ghr.nlm.nih.gov/condition/Swyer-syndrome> [online] accessed December 2016

'Swyer syndrome', *Intersex Society of North America, ISNA 1993-2008*
<http://www.isna.org/faq/conditions/Swyer> [online] accessed December 2016

Turner Syndrome

'Turner syndrome', *Genetics Home Reference 2016*, National Institute of Health, National Library of Medicine, U.S Department of Health and Human Services
<https://ghr.nlm.nih.gov/condition/turner-syndrome> [online] accessed December 2016

'Turners syndrome', *The MAGIC Foundation 1989-2016*
<https://www.magicfoundation.org/Growth-Disorders/Turner-Syndrome>
[online] accessed December 2016

'Turner syndrome', *You and Your Hormones 2013*, Society for Endocrinology
http://www.yourhormones.info/Endocrine_conditions/Turner_syndrome
[online] accessed December 2016

'Treatment', *Turners Syndrome Support Society 2015*,
<http://tss.org.uk/index.php/what/treatment> [online] accessed December 2016

'Intersexion' – My Introduction to *Intersexuality*

I first came into contact with the topic of *Intersexuality* - outside of academia - in March 2013, completely by chance. It was the annual Lesbian and Gay Film Festival [LGFF] in Southbank, London. I had never attended before and so eagerly obtained a programme and with a friend marked down all of the films we wanted to see. Much to our surprise, when the booking lines opened, the vast majority of films were already sold out and we were encouraged to retry on festival opening day. Following this advice, none of the films we earmarked became available, I later found out that the LGFF is a very popular annual event in London and many complimentary tickets are first given to large LGBTQ organisations and leading LGBTQ figures in London. We were then notified of the films that had availability, one of them was called 'Intersexion'. I took my seat and – somewhat unenthusiastically - prepared to watch a film I had had no intention of seeing. The screening was 21 March 2013 at 15:30hrs and I had no idea that this film was going to alter the course of my life. 'Intersexion' is a documentary by director Grant Lahood, it is a compilation of interviews with *Intersex* people and their allies narrated by *Intersex* activist and person Mani Bruce Mitchell. I came out of the film screening spellbound. I had completed an MA in Gender, sexuality and culture just 6 months earlier and we had never spoken about *Intersex* people. Why the erasure? Surely *Intersexuality* is central to any gender, sexuality and queer theorising? From that point onwards, I could not stop talking about the film and went to see it again at the LGFF's Fringe Festival two weeks later. I was also in the process of creating and organising my own community project in 2013 called 'Freedom To Be – imagining multiple expressions of genders, identities, sexualities, bodies, emotions, freely being in the world'. 'Freedom

To Be's launch would be a five day Arts Festival, the first ever to be held in the London borough of Merton in Spring 2013. Due to the impact the documentary film had upon me, I devoted a day to *Intersex* Awareness & Education on 15 June 2013, which featured an interview with a mid-wife who had recently assisted with the birth of an *Intersex* baby and a screening of 'Intersexion'. This was preceded by an introduction read to the audience which had been emailed for the occasion by Mani Bruce Mitchell in New Zealand. I was now in regular contact with Mani since deciding *Intersexuality* was a cause I wanted to help with and the PhD research topic I now wanted to pursue. I sought Mani's input as an activist and *Intersex* person in regard to my direction. 'Freedom To Be' was placed on the official 'Intersexion' film website notifying people of its screening in Merton (see www.intersexionfilm.com/festivals/awards), and thereafter I began to know and be known by members of the *Intersex* community.

First Draft Interview Questions

Can you tell me your experience of living as an *Intersex* person in a two-sex world?

What was your first awareness of being *Intersex*?
How did you first become aware of being *Intersex*?

How do you think you are viewed by others?
How do you expect others to view you?

What does being *Intersex* mean to you?
Does it affect your everyday life?
If yes, how does it?

Intersex Interview Questions

Do you feel that you fit in?

Do you ever feel under pressure to 'reveal' that you are *Intersex*?
If yes, under what circumstances?

Do you ever feel discriminated against for being *Intersex*?
If yes, in what type of situations?

How do you explain yourself to others?
How does that feel for you?

How does being *Intersex* impact your thoughts, feelings, experiences about/related to your body, sex, sexuality and desire?

Final Interview Schedule

1. How do you identify?
2. At what age did you understand that you were Intersex?
3. Can you tell me how this was explained to you and by whom?
4. Do you use the term 'Intersex'?
5. What does being Intersex mean to you?
6. Can you tell me your experience of living as an Intersex person in a world which strictly divides people into female OR male?
7. Does being Intersex affect your every/day-to-day life? If so, how?
8. Have you ever felt discriminated against for being Intersex?
9. Are there advantages to being Intersex? What are they?
10. How do you expect people to react to your being Intersex?
11. Are there common misconceptions about Intersex people?
12. Do you think these can ever be remedied? If so, how?
13. Do/have you ever feel/felt under pressure to 'come out' as Intersex?
If yes, in what type of situations?
14. Do/have you ever feel/felt under pressure to hide that you are Intersex?
If yes, in what type of situations?
15. Do you feel that you fit into society? Please explain.
16. Are there any ways you think Intersex people could be better supported in society?
17. Have you read any books, literature or online information on Intersex?
18. Are there any that you recall as being particularly helpful or unhelpful?
Please explain.

19. How would you improve upon them/the information that is currently available on Intersex?
20. Is there anything that could have improved the quality of your life as an Intersex person, in the past, present, future?
21. Where have you received the most support from?
22. Where have you received the least? How could this have been improved?
23. What made you decide to join this Intersex online group?
24. Has it benefitted you? If so, in what ways?
25. What advice would you give to parents of Intersex children?
26. What advice would you give to an Intersex child?
27. At what ages would you say an Intersex person needs the most support and why?
28. That concludes the interview questions, is there anything else you wanted to say or add about the project?

Thank you very much for agreeing to be interviewed today.

Second Phase of Data Analysis

Research Questions:

- How does an *Intersex* adult comprehend and negotiate their sex, gender, body, sexual identity and sexuality in contemporary society?
- How far and in what ways do these understandings and negotiations interface with, ratify and/or challenge key theoretical texts, as well as dominant discourse on sex, gender and identity?
- In what ways does the current medical management of *Intersexuality* affect an *Intersex* person and how does this medical model interact with societal discourse on *Intersexuality*?
- Can people diagnosed as *Intersex* be better supported? If so, in what ways?

Two Interview Questions Selected:

Question Six: Can you tell me your experience of living as an *Intersex* person in a world which strictly divides people into female OR male?

Question Sixteen: Are there any ways you think *Intersex* people could be better supported in society?

Spidergram Example

Labelling / Identity / Language / Lived Experience # 6

- 'Uh, well I identify as Intersex...and if you are asking how do I identify sexual orientation, uh, I consider myself attracted to women primarily...but uh, if you're talking about an identity, uh I don't...'
- 'The concept of being 'Intersex,' you know, my understanding of what it meant to be 'Intersex' are different...'
- 'I didn't have [ss] certainly didn't have the understanding of it then as I do now.'
- 'a term and an identity'

p. 1, 3

Secrecy # 4 / 'the concealment paradigm'

- 'my experience was definitely treated with a lot of secrecy...'
- 'confusing...frightening...my mother, you know, we didn't really didn't talk that much about it...'
- 'you need to go to a doctor to help you get started on your period... which of course was never gonna happen, I was never gonna have a period'
[links with H's mother]

p. 2, 3, 17,19, 31

Parent's Discomfort / Role # 7

Parents who are Medical Professionals [link with C]

'my father was a practising physician here in San Diego and I think for the sake of family privacy, he didn't want other doctors in San Diego knowing that we had this kind of...you know, family secret...'

'Shopping trips' – 'We were going to LA to go shopping, they were really it was a trip to go to the endocrinologist'

p. 4, 21, 25, 30-31

Identity politics / Community # 3 [difficulties/differences]

'...and yet trying to forge an identity that you feel empowered to be...'

social awareness doesn't always equal change – p. 18, 24

'it's good to find your tribe' – p. 30

p. 6, 15, 16, 19, 21, 25, 28 – 30, 32

Autumn

Surgery # 4

Removal of Testes # 3

Hormone Challenges / Paternalistic Medicine # 5

Discriminatory Medical Paradigm / Testosterone Anxieties

- '...so my interventions were done when I was like...100 days old, 3 and a half months old...'
- 'I had testicular gonads that were removed as a baby'
- 'it's all kind of trial and error' / 'you can't really go to a medical professional who will tell you 'This is what you need. This is what you should be on'
- '...so much of the time doctors think 'No, you're a woman, you're living a a woman, we don't give women testosterone...' [links with K]
- To have a medical community that is more uh, embracing of, you know, Intersex identities

p. 2, 7 – 11, 22, 25-26

Terminology # 6

it's kind of like, 'being neither and both...'

'hermaphrodite'

p. 5, 14

Difference # 4/Outsider

- 'a feeling of disconnect'
- 'Like I'd look at other people, my friends, my peer group and they all seemed like their lives were kind of unfolding sort of typically...'
- 'all these different phases...a sense of missing, feeling that you've missed these milestones...'
- 'you're kinda outside the mainstream...'
- 'I definitely feel outside that binary system'
- Makes you socially vulnerable – p.18

p. 5, 6, 7, 18, 19, 20 –

Normal # 4

'you begin to realise there is no normal'

p. 6

A Cross-section of Events, Talks and Presentations I Attended on Gender, Sex, Sexuality (and more)

Date	Event title	Event description
January 2014	'Transculture at The Cinema Museum'.	A film screening.
February 2014	'Perspectives on Gender Identity and Trans Healthcare'.	Speakers included Dr. James Barrett, lead clinician at the Gender Identity Clinic in West London, Mr James Bellringer, surgeon specialising in genital surgery for transgender people, Sarah Brown and Natascha Kennedy, two transgender public figures.
February 2014	'Homosexuality in twentieth century Britain'.	A talk by historian Lucy Delap.
May 2014	Queer Theory.	Four week course held at King's College London.
May 2014	Feminist Research Methods.	Five week course held at King's College London.
May 2014	'Bodies with new organ: Becoming trans, becoming disabled'.	A talk by queer theorist Jasbir Puar.
May 2014	'FGM: Cultural practice, clinical dilemmas'.	Series of talks to help health care professionals and students understand and manage female genital mutilation (FGM) in the UK. Speakers included: Professor Janice Rymer, gynaecologist, Dr. Niall McCrae, lecturer in mental health, Dr. Comfort Momoh, FGM specialist midwife and Dr. Sridhar Venkatapuram, lecturer in global health and philosophy.
September 2015	'The Institute of Sexology'.	Exhibition by the Wellcome Trust investigating how sex research has shaped attitudes towards sexual behaviour and identity.

Emerging Themes List Example

Category:

Education

Sub-category:

The Role of Parents

School

Love, Support & Acceptance

Not Enough if Societies Systemic Faults are not Challenged

Intersex Rights are Human Rights

Links to Activism

Data Themes and Core Categories

Data Themes	Core Categories
<p>What is <i>Intersex</i>? What is being <i>Intersex</i>?</p> <p>Is there/what is the difference?</p> <p>Self-discovery of <i>Intersex</i> as a term and as an identity</p> <p>Hermaphrodite</p> <p>Medical terminology & medicalisation</p> <p><i>Intersex</i> as a shared history</p> <p><i>Intersex</i> as lived experience</p> <p><i>Intersex</i> activism</p> <p><i>Intersex</i> takes a long time to understand</p> <p>Rejection of <i>Intersex</i></p>	<p>Language, the power of language & terminology</p> <p><i>Intersex</i> history [hermaphrodite/medical]</p> <p>Identity & 'coming out'</p> <p>Seeking & finding community</p> <p><i>Intersex</i> community & <i>Intersex</i> activism</p> <p>Queer identity & queer activism</p> <p>Society & culture</p>
<p>Testes removal</p> <p>I had to find out for myself /</p> <p>Withholding of medical information</p> <p>Fear & distrust of medical staff</p> <p>Secrecy & shame</p> <p>Family secrecy & shame</p> <p>Invasive medical examinations</p> <p>Genital operations affected my sexual function & adult relationships</p> <p>Disassociation in the medical setting</p> <p>Parents who work in medicine but no extra help or support</p>	<p>Genital normalisation & surgery horror</p> <p><i>Intersex</i> medicalisation & pathologisation</p> <p><i>Intersex</i> rights are human rights</p> <p>Paternalistic medicine / 'the experts'</p> <p>Disciplinary framework / gender norms</p> <p>Lack of support & acceptance</p>

Chapter Headings and Sub-headings

Chapter Headings	Sub-headings	Links to	Includes
The discursive construction of Intersexuality	<ol style="list-style-type: none"> 1. Medical discourse 2. Paternalistic medicine: the 'experts' 3. Foucault's: one true sex/truth discourses 	<ol style="list-style-type: none"> 1. The medical construction of <i>Intersex</i> bodies 2. The power of biomedicine 3. Intersex as a medical emergency 	<ol style="list-style-type: none"> 1. Language: produces categories/ 'monstrous' beings/hermaphrodite 2. Lies: routine testes removal 3. Who are <i>Intersex</i> 'experts'? 4. Who am I really?
Gender norms / Impossible subjects	<ol style="list-style-type: none"> 1. Butler's: 'disciplinary framework' 2. Heteronormativity 1. Butler's 'exceeding the norms' 	<ol style="list-style-type: none"> 1. Un/intelligibility 2. The production of heterosexual adult subjects 3. Sex development is complicated 	<ol style="list-style-type: none"> 1. Mental health issues 2. Loneliness + isolation 3. Curiosity: polite + rude 4. Bullying + policing by others 5. Shame + secrecy (incl. parental)
Activism	<ol style="list-style-type: none"> 1. Queer Politics + Queer Theory 2. Intersectionality 3. Community Intersex + Activism 	<ol style="list-style-type: none"> 1. Coming Out + Self-discovery 2. Reverse discourse + Identity politics 3. Intersex rights are Human rights 4. Foucault's 'confessional': 'Is talking always good OR bad?' 	<ol style="list-style-type: none"> 1. Talking as opposed to secrecy + shame 2. Receiving support, compassion + understanding 3. Respectability Politics 4. Community & Imagined community
Education/ resources	<ol style="list-style-type: none"> 1. Parents 2. The internet 3. Self-discovery + Love 	<ol style="list-style-type: none"> 1. Puberty 2. Biology 	<ol style="list-style-type: none"> 1. Recommendations 2. Sex Education