# DIAGNOSING SEX

## Stories of Intersex, Relationships & Identity

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# Abstract

This thesis provides necessary insight into the stories of people with atypical sex development or intersex characteristics. It is one of the first sociological studies of its kind to take the UK as its only geographical focus, and therefore makes a valuable contribution to exploring the social understandings of intersex and its medical care provisions in a local context. In light of the contested pathologisation of these sex traits, this thesis pursues a greater understanding of participants' own accounts of the bodies, experiences and identities under question.

The study uses a two-tiered qualitative process of solicited diaries followed by in-depth interviews with nine participants. Starting with the broad themes of social relationships and identities, this research places an original focus on how feelings of loneliness are experienced, anticipated and understood by participants, as well as the framing of (in)authenticity in participants' approaches to sex classification, their engagement in and attitudes towards sexual activity, and their understandings of parenthood and experiences of infertility.

My research indicates that participants' understandings of their diagnoses are framed by notions of an idealised or 'normal' future. Normative expectations, including certain ways of being and life course milestones, are proffered as socially valuable at the expense of their alternatives. In some cases, this has led participants to feel an absence of control, and a sense that their lives or bodies are failing, unworthy or inconceivable. I show how the potential for stigmatisation and ostracism imposes a requirement to 'pass' as binary sex. Feelings of difference and deviance can lead people with atypical sex characteristics to feel like they do not 'fit' or 'belong'; that – despite their relationships – they are alone. These conclusions offer insight into how social and medical support can be improved, and provide valuable contributions to intersex scholarship, reproduction studies and broader sociological debates on personal, political and institutional relationships.

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This is dedicated to Grandma Hilda, who would love to have known I've written a PhD thesis.

# 1

## Introduction
## Approaches to Sex Variation

Two hundred faces watched as their university lecturer covered the basics of cell biology. The focus of recent sessions was genetics, including conversations on sex differences, in which students were taught the 'genetics of a woman' illustrated on the presentation slides by an XX karyotype. In this session their lecturer explored variations on chromosomal karyotypes and their related genetic conditions, joking to his class about one particular 'genetic mutation', androgen insensitivity syndrome (AIS). He listed the physical characteristics associated with women who have the condition – 'ambiguous' genitalia, the presence of a Y chromosome (typically XY) and internal testes – then pointed to his head and remarked mockingly: 'In their minds they think they're women, but they're not'.

Pandora sat in the large lecture theatre, her face was one amongst many but she still felt her skin burn up into an angry blush. She looked around to check whether the lecturer's description had revealed to other students that she was one of the women he had identified. She felt her 'disguise' was slipping, and feared that she would be found out soon. Already dealing with insecurities of not being a 'real' woman, Pandora sank further into her seat and waited anxiously until she could remove herself from the class. Once the lecture had finished, she ran home and cut deeply into her skin, just as she had on other occasions since receiving the diagnosis. This quieted the whirring panic temporarily and gave her a release from the feelings of despair.

<p style="text-align:center">***</p>

I begin this thesis with a story which was shared with me by Pandora, one of the nine participants in this research, to illustrate her everyday risk of exposure, shame and harm. This is Pandora's retrospective account and interpretation, so its veracity cannot be guaranteed. However, its importance lies in what it tells us about how Pandora heard it, how she felt, and what she then did. Many of us subscribe to the 'truths' relayed by Pandora's lecturer, and locate those living outside of binary sex classification as invisible, incongruous and suspect. These sex categories we live by were conceived by humans, and are maintained through social conventions. The sexed body, notes Gatens (1992, p. 132), is not 'the unproblematic biological and factual base upon which gender is inscribed', but itself 'constructed by discourses and practices that take the body as their target and as their vehicle of expression'. By exploring the experiences of people whose bodies are not incorporated by the dominant, dimorphic paradigm of sex, this thesis will advance a 'social model' of sexing bodies which locates the problem, much like the social model of disability, 'in the social environment, not in the individual' (Twigg, 2006, p. 55).

## Defining Intersex

Intersex people's bodies are not recognised as fitting into either of the discrete categories of male or female. These categories are medically defined by a number of physical criteria: genitals, chromosomes, hormone levels, secondary sex characteristics, and reproductive organs. People with intersex variations may be born with genitalia that are not easily defined by typical standards of male or female. Others may not go through pubertal changes, or experience unexpected changes as their bodies begin to develop characteristics which are not typical of their registered sex. Their chromosomes may not 'match' their genitals in the way that is expected, or they may not have XX or XY karyotypes, but instead X, XXY, or another variation. Expected reproductive organs may be missing altogether, or other organs may be present which are unexpected or deemed to be 'mismatching' due to genital appearance.

People with intersex traits may identify as men, women, both or neither and their sexual orientations are diverse. Their traits may have been discovered at birth, in adolescence, during adulthood, or they may never find out at all. They may have received surgery on their genitals and/or their reproductive organs, and they may have received hormone replacement therapy, or they may have had very minimal medical interaction. Intersex may be part of their identity, part of their history, or not even recognised as a label which describes their status, body, or condition.

The frequency of atypical sex development is difficult to quantify. The constitution and definition of 'sexual ambiguity' is debated and therefore interpreted in a range of ways, and often stigmatised, surgically erased and not always recognised or recorded. Some recent estimates report that approximately two per cent of infants are born with anatomy that clinicians may deem sexually ambiguous (Blackless *et al.*, 2000). However, the distinct differences between bodies which are considered indisputably male or female (or intersex) are illusory and compromised, and may therefore be better understood as a spectrum or continuum, rather than a dichotomy (Preves, 2003).

## The study

Over the last twenty years, intersex scholarship and activist discourses have emphasised ethical concerns with the pervasive medical approach to intersex, which assumes early intervention is necessary. Whilst some significant changes in the medical approach (e.g. Lee *et al.*, 2006) have started to appear in the last decade, intersex births are still persistently described or perceived as a 'medical and social emergency' (Özbey *et al.*, 2004, p. 388). Within medical protocol, corrective surgery and other interventions are described as serving the purpose of 'normalisation' and are often performed before the child is of an age to consent, with lasting impact on sensation, function and appearance of genitals. For many, these interventions illustrate the way in which intersex bodies are understood to be 'unacceptable, perhaps unlovable, and certainly unrecognizable as persons' (Holmes, 2008, p. 170).

The potential shame and social stigmatisation of conditions related to atypical sex can be difficult to manage in adolescence and adulthood, and present dilemmas of disclosure, privacy and sharing throughout the life course. Support networks may be challenging to negotiate, and trusting relationships may not always be easily formed. Sexual and romantic partnerships may feel intimidating due to these issues of trust, but also due to an invasive medical history,

insecurities about genital and physical appearance more generally, infertility, as well as other social and personal anxieties. Many adults with intersex traits also experience ongoing medical treatment, hormone therapy and surgical interventions (in some cases to repair those undertaken in their infancy).

Drawing on the stories of people with atypical sex development, this study builds upon existing intersex scholarship to explore the social consequences of intersex medical diagnoses, labels and treatment in the UK, and the personal and social negotiations which occur under everyday presumptions of binary sex. How and why is an intersex status often kept strictly confidential, how does this secrecy manifest and what are the potential impacts of 'keeping secrets' and 'hiding' identities and bodies? How is a personal sense of self developed and understood when a person's sex and body is in doubt, and in some cases altered to meet regulative ideals? How are these ideals constructed through expected life narratives, especially the timing and occurrence of particular, normative life events and anticipated futures? How much space is given to the lives and bodies which do not fit within these ideals?

Those with an atypical sex status are often socially marginalised, suffer significant mental, social, and physical repercussions following medical treatment, are not always able to access the medical support or clinical documentation they need, and speak of feeling misunderstood by medical professionals, family and other social networks. Research on intersex experiences in the UK in particular is meagre but urgently needed. In this study, seven people with atypical sex development and two parents of intersex children were asked to write in diaries about their experiences over a period of two months, then the same cohort were invited to attend in-depth one-to-one interviews to build on the themes explored in the diaries and discuss their experiences in person.

## Background

Media conversations about atypical sex variations are growing in frequency internationally. For example, many news publications, from Metro (Readhead, 2015) to CNN (Yan and Sutton, 2013) and Huffington Post (Bennett-Smith, 2013), reported the launch of a landmark lawsuit in 2013, led by the adoptive parents of an eight-year-old child. Pam and Mark Crawford sued the South Carolina Department of Social Services and doctors from the Medical University of South Carolina 'for performing an irreversible and medically unnecessary surgery on an infant in the state's care [at the time of the surgery]' (Advocates for Informed Choice 2013, p. 1). Their child, known publicly as 'M.C.', was born with intersex traits and, whilst in state foster care at the age of 16 months, underwent surgery to remove his penis and testicular tissue and to construct labia, 'potentially sterilizing him and greatly reducing, if not eliminating, his sexual function' (Advocates for Informed Choice 2013, p. 1).

Whilst this is the first lawsuit of its kind, recent legislative amendments and discussions at a government level have begun to materialise around the globe. A month after the launch of the M.C. lawsuit, in an unrelated episode, the Australian Sex Discrimination Amendment Bill 2013, which incorporates the protection of non-binary identities, was approved by Federal Parliament. For the first time internationally, 'intersex people are recognised fully and authentically in anti-discrimination legislation' (OII Australia, 2013). Two years later, a law passed in Malta which made it the first country to place a ban on non-consensual medical

interventions on intersex people, except in instances where strictly medically necessary. Then in January this year, the Chilean government presented instructions to medical professionals which directly opposes 'normalising' surgery on infants or children.

Whilst many news reports on atypical sex are centred on the US, attention has also been placed on medical practices in the UK. The recent UN Committee on the Rights of the Child (2016) criticised the UK for permitting 'medically unnecessary surgeries and other procedures on intersex children before they are able to provide their informed consent'. Unnecessary early corrective surgery is a pressing concern, but these debates often fail to address the problems with social and medical treatment of adolescents and adults. It was therefore especially encouraging to see the report acknowledging that surgery can also lead to 'severe physical and psychological suffering' and noting the 'discrimination and social stigmatisation' which affects many people with atypical sex development. The UK currently offers no legislation or state guidance on surgery performed on intersex infants or children, so in each case it is largely within the hands of the individual hospital or clinician to decide on the treatment and approach.

As many of these lawsuits, jurisdictions and anti-discrimination bills are in nascent stages but show promise for the future, this study comes at a time where debates around the bodily autonomy of intersex people in the UK are particularly necessary and pertinent.

## Thesis Presentation

This thesis is divided into ten chapters, and these broad concerns will be fundamental to the nine chapters that follow. I start with Chapter Two, which introduces the backgrounds of research participants in this study. I provide a brief overview of their medical encounters, diagnosis processes, social experiences and current situations with regards to their intersex status. This chapter illustrates the diversity of participants' experiences and provides an important foundation for later discussion.

Chapter Three reviews key literature relevant to the discussions in this thesis. I introduce the development of intersex studies as a field of research and the foundational works which have shaped it. I consider how feminist theory has approached sex variation over time and across differing frameworks; in some instances furthering a biological essentialist and dichotomous understanding of sex, and in others offering a socio-cultural constructionist theorisation of sex. I review literature which critically considers the role of medicine, relations of institutional power and the regulation of bodies, and reflect on how intersex studies fits within these conversations. I also discuss literature on the abjection of bodies, stigma and disgust, and reflect on the potential for critical disability studies scholarship to contribute to intersex approaches. Finally, I outline the development of intersex ethics as a political matter, and the recent transformations and scholarly developments which have led to this study.

In Chapter Four, I describe the methods used in this research, in particular the qualitative multimethod 'Diary-Interview' approach (Zimmerman and Wieder, 1977). I explain why this method in particular was selected, and expand on the feminist theoretical and epistemological approaches which have shaped my research design and understanding of the field. I consider debates on insider and outsider research, and how I have negotiated my role as 'outsider' in the study, reflecting in particular on how this role may have affected my relationship with participants. Following on from this, I also outline the significant issues I encountered with

accessing the intersex community and recruiting participants, and the ways I attempted to address these problems. I introduce my approach to the many complex ethical considerations in this study, which is influenced by Edwards and Mauthner's (2012) feminist ethics of care, placing an emphasis on the situational decisions made throughout the research process and my duties of empathy, respect and responsibility to participants. In closing, I detail the analytical approach taken to the data in the research and the reflexive processes which were employed throughout the writing of the thesis.

Chapter Five, the first of the analysis chapters, focuses on participants' experiences of loneliness in its various forms. I start by mapping out a sociology of loneliness, and argue that the theme of loneliness underpins a range of scholarly work on social relationships and the theorisation of what it means to be an 'individual'. Following Mills (1959), I position the personal and private experiences of loneliness within structural, public and social concerns. I illustrate how an intersex diagnosis can often lead to stigmatisation and the presumption of difference, and that these experiences have led participants to feel lonely and isolated. When a diagnosis is received in infancy, I show how social exclusion is often anticipated, and prepared for, from the earliest possible stage. I argue that some people with intersex traits experience an 'ontological loneliness', where regardless of their connections with friends and family, they feel like they do not correctly 'fit' into their social environments, and are not permitted to just 'be'. In order to find acceptance, participants described attempts to adapt and assimilate to their communities, deploying medical interventions, secrecy regarding their intersex status and medical history, and binary identification. I consider how, in some instances, participants find that support groups and networks can offer some reprieve from loneliness, and provide a temporary sense of ontological security.

Chapter Six is the first of two sections on passing, in which I expand on how the stigmatisation of atypical sex and experiences of ontological loneliness often lead people with intersex traits to keep their statuses private and hidden. I start with a discussion of Garfinkel's (1967) study of Agnes, which claimed at the time to be the first investigation into the passing processes of an intersex person. Following this, I develop my own understanding of passing and how it fits within other discourses of knowing, observing, authenticity, and stigmatisation. I proffer an approach to the data which observes the 'imaginary' (Gatens, 1996) of passing, in which I do not question the authenticity of bodies and identities, but instead focus on the experiences and understanding participants' draw from their own in/ability to 'pass'. I examine participants' differing notions of visibility and perceptibility, and use disability studies scholarship to critically reflect on the understanding that passing could be perceived as a form of betrayal. I develop this further by exploring the notion of a 'masquerade' and the construction of realness.

Drawing on Goffman (1963), I discuss how stigma symbols can be removed or hidden involuntarily. Reflecting on the early corrective surgery paradigm, I argue that a process of passing can therefore be medically or socially imposed, rather than personally actioned by someone with intersex traits. Chapter Seven explores the complexities of sex categorisation and our ability to 'know' sex. I develop critical perspectives on certainty and truth by engaging with Gilson's (2014) concept of 'epistemic vulnerability' and consider how personal mutability, vulnerability and an openness to revision and change may alter the way in which 'passing' is understood. I focus on the medical performance of certainty in the process of sex ascertainment and illustrate the ways in which some information is highlighted, whilst other details are

overlooked in order to present an impression of conviction and a relationship of trust. I consider whether this sense of certainty is necessarily in the best interests of people with intersex traits in all instances, and how an appreciation of epistemic vulnerability may change this approach. I expand on the personal and social ramifications of concealing an intersex status, and the feeling that one's identity is fraudulent. I show how some participants' negative experiences of disclosure have reinforced their desire for secrecy. In some cases, heightened measures of privacy were also demonstrated by family members and learnt from an early age. I reflect on how secrecy and 'closeting' (Sedgwick, 2008) may be tied to feelings of shame. In this sense, I illustrate how 'coming out' can be understood as a challenge to shamefulness. I observe how participants describe engineering environments where hiding is easier and secrets will not be revealed, and the delicate construction of stories, biographies, and purposefully placed props which help them to a build a profile of someone with a 'typical' sex status. In closing, I look to participants' notion of 'hiding' and being 'hidden', and further consider how knowledge is constructed in these conversations, and the extent to which participants feel a sense of control.

Chapter Eight discusses the way in which logics of normative time create expected pathways, futures and incremental milestones whereby some lives are located as successful and others as failing. I explore how medical constructions of intersex often assume normative sexual and romantic ideals, which can place limitations on the options available to people with intersex traits. I consider how the confines of 'straight time' (Freeman, 2007) affect decisions made by parents of intersex infants and people with atypical sex. I explore how the expectations of certain morphologies, abilities and experiences can be experienced as a loss when undelivered. I also reflect on the social barriers which prevent some intersex people from forming sexual and romantic partnerships, and how virginity is understood and experienced by participants as asynchronic in adulthood due to the expectation that particular milestones occur at specific times.

Developing Cacchioni's (2007) discussion of 'Discipline Work' (a form of 'Sex Work'), I illustrate how participants utilised specific methods – dilation, masturbation, vaginal surgery – to prepare their bodies for sexual activity with a partner. I examine the complex negotiations between pain, discomfort and pleasure, and participants' fluctuating attitudes towards sex. Finally, I incorporate the ways in which some participants are building lives and futures which steer away from straight time narratives. I illustrate their refusal to see their bodies as pathological, their exploration into unorthodox sexual practices, and their ability to re-write ideals of happiness and success.

Chapter Nine addresses intersex women's experiences and perceptions of reproduction and infertility. I discuss the temporal significance of discovering infertility alongside an intersex diagnosis before any attempts to conceive, and sometimes in infancy or childhood. In continuation from the previous chapter, I focus on participants' expectations and hopes for the future, and reflect on how these plans interact with infertility, and the extent to which infertility is experienced as a 'biographical disruption' (Bury, 1982) within their life narratives. I argue that, much like women who encounter their infertility in more 'conventional' circumstances, narratives of 'naturalness' and 'failure' still stigmatise participants' experiences and affect their disposition towards conceptive technologies and non-biological parenthood. However, some of the participants' accounts illustrate how competing narratives can, and do, co-exist. In addition

to the difficulties many participants face due to reproductive issues, I argue that infertility is not central to the lives of all women who are unable to conceive 'naturally'.

I conclude with Chapter Ten, which explores some of the central themes of the thesis and considers the practical and intellectual implications of my findings. In particular, I reflect on participants' expressions of a loss of control in three domains of their live: medical, social and embodied experiences. Finally, I acknowledge some of the limitations of this study and suggest new directions for future intersex scholarship which could build on the discussions in this thesis.

# 2

## The Stories
## Meeting the Participants

## Sophie

Sophie is 24 years old and lives with her boyfriend of five years. She started to complain of terrible stomach pains and vomiting at 15 years old. At this age, she had not experienced menstrual periods and she recalls that, unlike many of her peers, she had not developed secondary sex characteristics (e.g. breast development, growth of pubic and under-arm hair). Sophie attended a series of appointments with her GP and local hospital, in which doctors speculated about sexually transmitted diseases, menstrual cramps and constipation as the causes of her pain. Following a magnetic resonance imaging (MRI) scan, a benign tumour was found on Sophie's ovary (later understood to be a streak gonad). The tumour was surgically removed and Sophie was subject to further scans and tests which eventually led to a diagnosis of Swyer syndrome (or XY mixed gonadal dysgenesis). Those diagnosed with this condition will typically have XY chromosomes but experience sexual development which is recognised as typical for females, as well as having genital appearance deemed to be female. Whilst a uterus and fallopian tubes are usually fully-formed, the gonads (ovaries or testes) are 'dysfunctioning' or 'underdeveloped' and mainly composed of fibrous tissue, referred to as streak gonads.

Sophie's other 'ovary', also a streak gonad, was discovered to be malignant and consequently removed. She underwent six months of chemotherapy and started to administer low doses of oestrogen in order to induce puberty. Whilst receiving chemotherapy, Sophie spent a lot of time away from school. She found the diagnosis very difficult to talk about and still prefers not to share the details with others; her boyfriend is not aware of the full diagnosis.

Shortly after her diagnosis, a doctor informed Sophie that she had a 'minimally enlarged' clitoris and explained that there were medical interventions available to reduce its size. Sophie recalls feeling especially insecure and disgusted by the size of her clitoris at the time, so she agreed to reduction surgery. Due to complications in referring Sophie to a surgeon, there were significant delays in arranging the treatment. At a gynaecological appointment before the deferred meeting with a surgeon, Sophie was encouraged to reconsider the way she felt about her clitoris, and consequently decided against the surgery; this is a choice she is now relieved to have made. Sophie now feels much more confident and comfortable about her condition than she did in the years immediately following her diagnosis, and notes that Swyer syndrome is only a small part of her identity.

## Steve

Steve is 54 years old and specialises in disability and gender issues in a profession which advocates for individuals and communities who require support. He was born in 1960 with a penis, testicles, vaginal opening and cavity. Steve's parents were told by medical professionals that their son's 'ambiguous genitalia' indicated a form of 'hermaphroditism'; this is now

identified by Steve as partial androgen insensitivity syndrome (PAIS). Due to a *partial* inability to respond to androgens, it is common for those diagnosed with this condition to have genitalia which is considered 'ambiguous'. This ambiguity may manifest in a range of different ways. Regardless of phenotype, the gonads of people diagnosed with PAIS will be testes and they will not have a womb.

Steve's diagnosis was heavily stigmatised and treated with vigilant confidentiality by his family and medical staff. A medical consultant recommended that Steve's 'superfluous' opening should be 'sealed' in late adolescence, but his parents did not comply. Up until he was five years old, Steve had no visible body hair. He had an 'angelic, nondescript' face and a 'dumpy' body. Steve described how his penile development was affected by his condition, and at 14 years old his penis measured as one inch and was not visible when flaccid.

His parents kept the diagnosis private, and only four of his many relatives were aware of his condition before Steve discovered the diagnosis at 7 years old when attending regular healthcare appointments. Steve's sister, who is two years his junior, was surprised to accidentally learn of his diagnosis when she was 22 years old. Steve's career path was guided by his experiences of, and resistance to, medical care resulting from his diagnosis of PAIS. He also discussed his belief that his bisexuality may have been affected or steered by his genitalia and his diagnosis.

## Ian

At 44-years-old, Ian has just completed a year-long 'Access to HE (Higher Education)' diploma at his local college. He has struggled with ridicule and bullying about his appearance, dating back to his transition to secondary school at 11 years old. He did not experience the same pubertal development as his peers and describes presenting visible 'male and female characteristics', which he believes has led some people to incorrectly assume that he is transgender.

Following a suicide attempt, and feeling unsupported by his parents and desperate to find answers about his body, Ian moved to America at 23 years old. Ian visited a number of hospitals seeking a medical diagnosis, but found that most doctors did not identify a biological pathology, and instead suggested that there was psychological issue which was causing the insecurities about his appearance. Ian was eventually referred to an endocrinologist, who diagnosed him with a form of hypogonadism, which was causing his gonads to produce only half of the expected levels of testosterone of a male. Another medical professional presented Ian with a test result which indicated that he had a 46,XX/46,XY karyotype. Ian has since tried to confirm this result with varying degrees of success. A cytogeneticist (a specialist in chromosomes), advised Ian that it was likely the test result had been correct, but as cells leave the body over time as it ages, it is increasingly difficult to detect a minor cell line.

Ian's difficulty in finding a medical diagnosis and his attempts to 'prove' the credibility of his experiences have been time-consuming and disheartening. Ian has received very little emotional or psychological support throughout this experience, but he is now receiving therapy to help him to build social relationships and find ways of trusting others.

## Paula

Paula is 35 years old and as far back as she can remember, the hospital has been a continuous part of her life, involving regular appointments, waiting rooms, tests, measurements, and internal examinations. She recalls that, despite not being told about her diagnosis until later, the medical visits were something she never questioned. At eight years old, Paula remembers waking up one morning and being told that, without an explanation, she would be staying in hospital for a week. She believes that the series of tests she was given during this stay in hospital led to her acute phobia of hypodermic needles.

She returned to hospital for another stay when she was 11 years old. On this occasion, she was informed that her ovaries had 'gone funny' and were being removed to prevent illness in adulthood. Three years later, further surgery was recommended and Paula complied, despite feeling tired of receiving medical attention. At fifteen years old, she received a vaginoplasty procedure to create a vaginal opening and lengthen her vaginal cavity. During her stay, Paula was frustrated to find that hospital staff prevented her from reading her medical notes.

Paula identified her diagnosis at 18 years old by chance, when her mum was reading an article about someone with androgen insensitivity syndrome (AIS) in a women's magazine and recognised the symptoms and experiences as familiar. Whilst her parents had been given some information about Paula's condition, they had not been given a diagnosis, so this was the first time Paula and her mum were able to attach a name to her condition. For Paula, this also opened up the possibility of meeting other people with the same diagnosis and similar experiences; the magazine article led her to contact the AIS support group (AISSG), subscribe to their newsletters and later to attend their meetings.

After taking a long break from medical engagement and hormone treatment, at 32 years old, Paula decided to return to her GP to request to be referred to a specialist clinic for intersex conditions. At the specialist clinic, she discovered that at two years old her genotype had been tested and confirmed as 46XY, and at that time she had also been diagnosed with partial androgen insensitivity syndrome (PAIS) and testosterone biosynthetic defect. Paula feels like she has never been given full access to her own story and that important, personal information continues to be withheld. Paula's parents refuse to speak to her about her diagnosis and she believes this has contributed to her feeling ashamed and secretive about her body.

## Natalie

At 32-years-old, Natalie feels she is under-informed about her diagnosis and seeks to access further information, as well as potential medical treatment. She was diagnosed with complete androgen insensitivity syndrome (CAIS) at 21 years old during her first year of university. As with PAIS, individuals with CAIS have testes and no womb. As they have a *complete* inability to respond to androgens, genitalia will usually be deemed to be female, and diagnosis is therefore not usually made until puberty when the expected secondary sexual characteristics do not develop. When Natalie registered for the healthcare service in her university town, they took a routine blood test which indicated the presence of a Y chromosome. Natalie recalls that the karyotype did not concern her, but she was troubled by the identification of her reproductive organs as 'gonads' rather than ovaries. After receiving the diagnosis, she was significantly distracted from her university work and found it difficult to balance work life with hospital appointments and counselling.

Natalie was advised by medical professionals that her gonads would need to be removed once her counsellor confirmed she was psychologically prepared. Natalie felt there was some urgency to receive this treatment; she did not trust the healthcare she had received in her home town as they had not picked up on her condition, and she believed there would be significant delays in treatment if it was temporarily withheld. The counsellor maintained that Natalie was not ready for surgical treatment for the duration of her university education. She notes that this is why she has still not received the medical care she desires, eleven years after her diagnosis. Once Natalie returned to her home town, she discovered that, as expected, medical staff were not familiar with her diagnosis and consistently showed a lack of understanding of her needs.

Natalie was scheduled to receive a gonadectomy in May 2013 but the surgery was postponed due to her high blood pressure. Whilst she is concerned that her high blood pressure is in part a result of the stress and anxiety caused by the approaching surgery and will therefore remain an issue, she believes that losing body weight will also help with its reduction. She is very apprehensive about the surgery because she would need to travel to a city 150 miles away from home, with no friends or relatives nearby. She is also unsure whether removing the gonads is the best option for her, but feels she would be unsupported in taking alternative routes.

In search of answers to the many questions she has about her body, diagnosis and future, six months prior to our meeting, Natalie attended her first medical appointments specifically about her condition since around the time of her diagnosis.  She felt great apprehension about the internal examination, but was also keen to receive advice on the surgery, her long-standing depression, and on whether hormone therapy would be advisable.

# Pandora

Pandora is 22 years old and a sports and fitness enthusiast. When she was about six months old, her parents approached a doctor about two lumps they had noticed in her groin, leading to a diagnosis of complete androgen insensitivity syndrome (CAIS). Doctors surgically removed Pandora's gonads at this age; a procedure that Pandora was later told was hernia repair. Growing up, Pandora was aware that she would need to medicate in order to induce puberty but she did not discover the details of her diagnosis until she was 11 years old. One evening Pandora was told by her mother that she needed to attend a medical appointment the following day to check on the recovery progress of her hernia repair surgery, but in the car on the way to the appointment Pandora's mother told her that she did not have a womb. Whilst Pandora recalls that this disclosure was a very simplified version of her diagnosis, she was distraught with the realisation that her body was not as she expected.

At the appointment, an endocrinologist explained to Pandora the details of her diagnosis of CAIS. She informed Pandora that she had an XY karyotype and gave her a brief timeline of her medical history. She was prescribed hormone replacement therapy (HRT) to provide oestrogens that would have been produced by the testes which had been removed. Several other people were present during Pandora's appointment: medical students, a registrar and a nurse. Pandora was shocked and ashamed by the details of her diagnosis, and was especially troubled by the presence of medical staff who were not required.

After this appointment, Pandora was required to attend medical checks every six months to monitor the progress of her hormone treatment. She was asked to undress in front of doctors and other, often male, medical staff so that they could observe her development. She felt, and

continues to feel, great embarrassment and discomfort about clinicians viewing and touching her body.

Pandora was considered to be the 'fat kid' at school because her growth in childhood was affected by the removal of her testes. Prior to her diagnosis she took pride in this identity, and liked to think of herself as strong, tough and capable. Since her diagnosis Pandora has struggled with severe depression and begun self-harming shortly after she discovered her condition.

At 17 years old, Pandora underwent a procedure to determine the length of her vaginal cavity; following which, clinicians reported that her vagina was very short and would require 'work' to allow penetrative sex. She was given details of the options available to her, including dilation and vaginoplasty, which Pandora contemplated for two years before returning for further consultation. In 2012, she underwent keyhole vaginoplasty surgery without informing any friends or family, and was required to stay in hospital for eight days. After leaving the hospital, Pandora returned to her parents and informed them of the surgery, and took a ten month period of leave from her university degree to give her some time to focus on her psychological wellbeing.

## Siân

Siân is 28 years old and was diagnosed with Turner syndrome three days after her birth. Individuals with this diagnosis have only one chromosome (X), 'underdeveloped' ovaries which produce low levels of hormones, and are often shorter in height than typical. Turner syndrome can also affect physical appearance in a range of ways, and in some cases leads to health conditions, including heart, kidney, urinary tract and thyroid issues. Some people with Turner syndrome also have learning disabilities. Siân does not consider Turner syndrome to fit within intersex classification and does not personally identify with the label of intersex. Clinicians were not experienced or knowledgeable about the diagnosis at the time Siân was diagnosed so her parents researched the condition independently; however erroneous information led them to believe initially that Siân would be 'mentally retarded'. Siân first became aware of some of the consequences of her diagnosis at around 3 or 4 years old, when she was prescribed growth hormones and was required to inject these daily. For the first ten years of her life, Siân recalls that she understood her condition to be predominantly an issue of growth, whereby she was required to attend hospital appointments every six months.

During her childhood Siân struggled with hearing problems and recurring ear infections. She underwent two operations: one to insert grommets and another to repair a perforated ear drum. These problems left her hearing damaged, with around 25% hearing in her left ear and 60% in her right ear. The hearing loss had an impact on Siân's life and led to social misunderstandings due to mis-hearing or speaking too loudly, but a hearing aid has now improved the situation. She has since realised that the hearing problems are connected to Turner syndrome.

When Siân was ten years old, her parents explained to her the details of her diagnosis; at this time she learnt that she would need hormone therapy to induce puberty and that she was infertile. Discovering her infertility led Siân to feel differently about her diagnosis, becoming increasingly embarrassed and secretive. When Siân started school her parents begun to attend meetings and conferences held by a Turner syndrome support group, which Siân also participated in from the age of twelve.

Siân believes she bears physical features which are characteristic of women with Turner syndrome, including looking young for her age, but does not expect that this would be noticed by those without knowledge of Turner syndrome. Siân's parents have always been clear about their desire for her to live a 'normal' life, and encouraged her to achieve her goals. One of Siân's proudest achievements is her bachelor's degree because of the difficulties she initially faced at university, and the academic challenges some women with Turner syndrome encounter.

## Beth

Beth is 32 years old and gave birth to her first child, Imogen, seven months ago. Beth and her partner, Chris, were told that antenatal scans showed that their baby was healthy, but decided not to ask for Imogen's sex to be identified before she was born. Beth was not experiencing any labour contractions hours after her waters had broken, so she was taken to a maternity day assessment unit to be tested for group B streptococcal (GBS). After a 31-hour labour, Imogen was safely delivered into one of the hospital's labour rooms. Upon delivery, Chris was invited to identify and announce Imogen's sex to Beth based upon her physical appearance, and he declared that their baby was a boy.

Imogen was taken into the corner of the labour room to be checked by doctors but assessment took longer than her parents expected and a growing number of clinicians gathered, leading them to anticipate that there was an issue. Chris and Beth were told that Imogen's sex could not be determined through the appearance of her genitals so she would need to be taken to special care for monitoring and tests. In the meantime, her parents were advised against naming Imogen or registering her birth. Later that day, Chris and Beth visited Imogen in special care, and were told she might have an infection, but by the following morning Imogen had been transferred to intensive care and hooked up to equipment. Doctors confirmed that Imogen had an infection; this turned out to be GBS, which led to septicaemia. During this time Chris and Beth's attention was on Imogen's health, and their concerns about determining her sex were put on hold. Beth recalls, however, that the medical team did not know how to refer to Imogen and, to her annoyance, often used gendered pronouns. Friends and relatives who were aware that Beth had gone into labour wanted to know that everyone was healthy, and find out the sex of the baby. Beth and Chris decided to confirm that they were doing fine, whilst avoiding language that would indicate her gender.

Whilst Imogen was receiving medical treatment for septicaemia, clinicians began to liaise with an endocrine team to discuss the issue of her sex classification. They started to carry out some initial tests, and once Imogen was getting stronger, at around three days old they moved her to a different hospital where the team were based. The first test results revealed that Imogen had XX chromosomes, but further testing on other indicators of sex were still required before they would classify her as female. Next Imogen received an ultrasound to determine the status of her reproductive organs; this presented a uterus and a vaginal cavity (but there was no opening). Clinicians could not detect ovaries in the scan, but they were confident these were also present due to the hormones which had been observed in the blood tests. At this stage, it was confirmed that Imogen could be categorised as female. Beth recalls that Imogen's yellow name card in hospital was promptly changed to a pink one which stated her new name.

The next day, Beth and Chris were told that Imogen had been diagnosed with congenital adrenal hyperplasia (CAH), a condition unfamiliar to them both. Individuals with CAH are lacking the

cortisol hormone, which – due to its role in helping the body deal with physical and emotional stress – can be life-threatening when not present. Its absence also causes an increase in the level of androgen, which affects the appearance of genitalia (often deemed 'ambiguous') and causes conventionally 'masculine' secondary sexual characteristics and early pubertal development in children of all genders. CAH has an impact on the level of minerals in the body, often leading to low salt and blood sugar levels. Children with CAH are usually prescribed daily cortisol and aldosterone which will be necessary for their whole lifetime. After receiving this news, Chris and Beth's initial concerns with 'ambiguous' genitalia transformed into new considerations of different surgical options and a daily medication schedule. Beth was told that Imogen's vagina would need to be 'pulled' down to the surface, and that whilst she is likely to be able to conceive naturally in adulthood, she would probably need a caesarean section to deliver a baby. Twelve days after Imogen's birth, she was allowed to leave the hospital along with her parents.

Imogen was required to attend regular hospital appointments over the following 4-6 weeks as part of her weekly routine to check her medication levels were suitable for her needs and to monitor her responses. At seven-months-old, Imogen is now required to attend appointments every two months. Beth and Chris are currently making a decision about whether or not Imogen should receive vaginal and clitoral surgery.

## Nicole

Nicole is 51 years old and the younger of her two daughters, Emma, was diagnosed with Turner syndrome the day after her birth, 27 years ago. When Emma was born her skin was a grey-ish colour and her hands and feet were very swollen. A few hours after Emma had been delivered, clinicians raised concerns that there may be a problem, and sought assistance from a paediatrician, who informed Nicole that he would carry out some tests on Emma the following morning.

The next day, a consultant approached Nicole to enquire when her husband, John, would be visiting the hospital and she agreed to stay on an hour after her shift would finish in order to wait until he arrived so that she could talk to both parents together. Nicole waited anxiously for John to join her after work, and once he arrived they received Emma's diagnosis of Turner syndrome together. They were informed that this would affect Emma's growth, may cause some ear, nose and throat problems, and potentially lead to some issues with the heart and kidneys. They were also told that Emma did not have ovaries, so she would not menstruate or start pubertal development without medical assistance, and she was also infertile. They were told that in the hospital they were staying there had only been one other baby born with Turner syndrome.

Emma was not feeding well so she was taken to the baby unit. Meanwhile, Nicole and John were in a state of panic and shock following the diagnosis, and lacked privacy to discuss their discovery and comfort each other within the maternity ward. In hindsight, Nicole believes it was a significant mistake that they had not been informed about hormone replacement therapy at the initial stage of diagnosis because it would have given her hope that Emma could receive some assistance with some of the symptoms. That evening, Nicole and John were receiving visits from family, who they decided to tell about the diagnosis. They received mixed reactions: some were very supportive, others blamed Nicole for the condition. After John left the hospital in the evening, Nicole recalls that none of the hospital staff spoke to her until 10am the following

morning, despite her desire for support and comfort at that time. However, Nicole also describes the memory of a particular nurse who, on another occasion, took the time to talk compassionately to Nicole about Emma's condition and helped her to re-assess her fears.

Nicole was keen to find a support group for Turner syndrome and, after six weeks of looking, she discovered the Child Growth Foundation in London, who included Turner syndrome in their focus. Nicole has since become actively involved in a support group for girls and women with Turner syndrome and has dedicated much of her time to organising events and discussions for those diagnosed and their families.

# 3

## Literature Review
## A Background to the Medicalisation of Atypical Sex

## Situating Intersex

Over the last fifty years, intersex bodies have been medically observed and reported in acute detail, but it has only been in the last twenty years that intersex has blossomed as an area for social, political and ethical research. Despite being a relatively new subject of interest, a nascent body of literature has been established; now extending across multiple disciplines and beyond the academic arena. Important, intersecting links have been formed with various more established academic fields including the sociology of embodiment, gender studies, critical disability studies, bioethics and the sociology of health and illness, illustrating the breadth of significance for intersex treatment. As the field is still to some extent in its formative stages, the boundaries of what exactly we mean when we talk about intersex or atypical sex has not yet been crystallised. Indeed, much scholarly attention has been paid to the question of whether or not it would be possible, or even desirable, to characterise or reify the concept of intersex in this way.

Dreger and Herndon (2009, p. 200) contend that the definition of intersex is 'context specific' whilst Holmes (2002, p. 175) describes intersex as 'nothing more than a perpetually shifting phantasm in the collective psyche of medicine and culture'. She notes that in fact, 'no one is truly intersexed, but we are all, in our infinite differences from each other, intersexed' (p. 195). Along with many other scholars in the area (e.g Reis, 2009; Foucault, 1980a; Dreger, 1998b; Fausto-Sterling, 2000), Holmes places an emphasis on the historical and cultural contingency of social and institutional notions of (inter)sex. From this, she concludes that the pathological status of intersex is not an absolute or inherent consequence of particular combinations of morphological features, but the result of culturally situated standards of normality which are liable to change. In Kessler's (1990, p. 25) words, 'genital ambiguity is corrected not because it is threatening to the infant's life but because it is threatening to the infant's culture'. Much of the academic literature regarding intersex has therefore taken a historical focus to demonstrate the way in which perceptions of how – and whether – human sex can be identified and categorised have changed over time.

Reis's (2009) large-scale study of the history of North America's treatment of intersex provides a comprehensive overview of medical and popular literature relating to intersex, tracking the evolution of its medicalisation and ethical treatment. Reis notes that the binary system of sex was not conventionalised until the nineteenth century, around the time that the medical profession also gained its esteem (2009, p. 24). Reis places particular importance on chronicling the divergent ethical approaches to intersex and the way in which these approaches converge with broader changes in medical practice and, crucially, the changing eminence of the medical profession. Reis considers how certain disparaging perspectives and responses have persevered despite the various changes in methods of defining sex, as well as changes in our ways of

approaching and talking about atypical sex. In particular, the 'the mingling of fascination and fear', as Reis (2009, p. xv) calls it. Whilst Reis provides a detailed history of the conceptualisation of intersex, her monograph fails to redress the absence of intersex voices from historical record, as identified by Reis herself (2009, p. 152).

## Relating to feminism

In order to expose the perceived ethical inconsistencies implicated in the medical approach to intersex, some early scholarly focus (Holmes 1995; Chase 1994, 1997b, 2002; Coventry 1998, Ehrenreich and Barr 2005) looked towards the relationship between infantile surgery on intersex bodies and the female genital cutting practised by various communities and diasporic groups across the globe. It was argued that at that time many Western feminists were taking an uncompromising position on the immorality of female genital cutting but were not concerned about the analogous non-consensual surgical intervention taken against intersex infants, which was (and continues to be) sanctioned and performed frequently by Western medical practitioners.

Coventry (1998) maintains that 'clitoral surgery on children is brutal and illogical, and no matter what name you give it, it is a mutilation'. She believes that the wide condemnation of female genital cutting, but not of intersex surgeries, is symptomatic of an ethnocentric perspective which conceals the questionable customs which are part of the agitator's own cultural norms. Similarly, Chase (1998b, p. 205) argues that Western activists against female genital cutting

> consider Africans to have "harmful cultural or traditional practices,"
> while we in the modern industrialized West presumably have
> something better. We have science, which is linked to the
> metanarratives of enlightenment, progress, and truth. Genital cutting is
> condoned to the extent that it supports these cultural self-conceptions.

This debate illustrates a clear tension between hegemonic Western feminist activism at this time and the political interests of early intersex activists. For Chase (1998b, p. 208), feminism and intersex advocacy were at odds due to the 'widely shared feminist assumptions of properly embodied feminine subjectivity', which was compromised by the atypical bodies of intersex people. However, in the last two decades many gender theorists and feminist scholars whose work draws on queer theory and poststructuralist and postmodernist thought have fought to demonstrate the problems with gender essentialism, traditional understandings of female embodiment and the dichotomies that polarise and reify the interrelated nature/culture, sex/gender, man/woman and mind/body divides. Whilst Chase (1998b, p. 208) argued that scholarly work on intersex belonged with poststructuralists, she denounced feminism 'and many other identity-based oppositional social movements' as disinterested parties. Although Chase's suspicion may have been justified in the past (and of liberal, humanist feminism in particular), feminist scholarship now constitutes the majority of literature on intersex.

As Chase notes, feminist writing in the last fifty years has largely taken a constructionist perspective to gender, rooting back to the feminist theory of de Beauvoir (2010 [1952]) and, the anthropological and sociological work of Mead (1963 [1935]), Oakley (1972) and West and Zimmerman (1987). This approach makes an ontological distinction between sex (the biological and universal) and gender (the culturally and historically variable) and became a hugely

important principle for early feminist theory and activism, which Alsop *et al* (2002, p. 26) rightly name as 'one of the most fundamental assumptions in feminist theory from the 1970s on'. However, it has since been argued that the relationship between sex and gender is something quite different, and perhaps more indistinguishable. A model which was predicated on the writing of Kessler and McKenna (1978) and Wittig (1981, 1982), but expanded upon and popularised by Butler (1990, 1993) and others, contends that sex, like gender, is acquired, learned and constructed (Hood-Williams, 1996; Laqueur, 1990). Holmes (2002, p. 175) contends that categories of sex are 'as much a symbolic system of organisation as gender'. For this reason, the ontological distinction between male and female often made in second-wave feminist approaches has also been challenged. These changes in the theorising of gender have important consequences for intersex because the paradigm of gender/sex separation, which associates gender with culture and sex with nature, maintains the construction and innate validity of sexual dimorphism, concealing the governing practices which are required to 'correct' bodies which do not fit within these regulatory ideals. It is under these assumptions that intersex bodies are 'submitted, as it were, to the knife of the norm' (Butler, 2004, p. 53). Discourses of sexism tend to focus on socially-imposed gender-based oppression, largely against women. By highlighting the ways in which sex is also socially constituted, the current study intends to interrogate the oppression of intersex people which is founded upon an assumed sex difference.

## Re-thinking sex

Scholarship advocating the constructionist approach to sex – which includes a significant contribution to the social theory of intersex – proposes that it is through the discursive or relational practices of gender that we interpret sex difference in the first place; therefore often challenging the usefulness of the sex and gender differential altogether (Butler, 1993; Hird, 2000; Nicholson, 1994; Hood-Williams, 1996). Due to the way that sex is naturalised whilst gender is perceived to be a product of culture, critiques of the sex/gender binary closely tie in to the recent disassembly of the Western nature/culture dualism, most often associated with the philosophy of science and technology (e.g. Harding 1991, Latour, 1993; 1999, Law, 2008) as well as ecofeminist theory (e.g. Plumwood 1993). Harding (1991) emphasises the contingency of knowledge production in science, arguing that 'science produces information but it also produces meanings' (p. 42). In *Feminism and the Mastery of Nature* (1993, p. 38), Plumwood illustrates how detrimental the dualistic nature/culture framework can be for women, whose bodies are often interpreted as especially natural, passive and non-agentive. Plumwood argues that this can manifest as an obligation upon women not to intervene with the functioning of their bodies in any way, evidenced by the conflict which continues to surround issues of women's reproductive rights. In contrast, the intervention taken against intersex bodies is naturalised, normalised and enforced, and the narrative of finding a 'true' or 'natural' sex within the intersex body still perseveres (Preves 2003, p. 54-55, 112). However, both exemplify the ways in which the body is governed to conserve ideals of what is deemed to be natural and therefore superior.

Many critiques of the nature/culture division have also queried conventional understandings of what it means to be human or possess personhood, and how this relates to ideas of the subject. Butler (2004, p. 2) explores the dogmatic function of regulating boundaries of 'humanness', which she perceives to cause 'a differential between the human and the less-than-human'. With

respect to intersex, Butler (2004, p. 4) argues that 'the norms that govern idealised anatomy thus work to produce a differential sense of who is human and who is not, which lives are liveable, and which are not'. Similarly, Reis (2009) opens her monograph on the history of intersex treatment by asking 'What does it mean to be human?' (p. ix) and later details the transition whereby the status of an intersex person in the nineteenth century 'shifted from monster to person' (Reis, 2009, p. 24). She notes that this transition in fact marked a decline in ethical treatment, due to the way in which personhood granted intersex people subjectivity and therefore a (damaging) cerebral, character-based assessment, as well as one of the body. In contrast, Butler (2004, p4) argues, the intersex advocacy movement 'offers a critical perspective on the version of the 'human' that requires ideal morphologies and the constraining of bodily norms'.

Recent feminist theory and empirical research has challenged the medical and scientific ascendancy in Western approaches to gender, sex and the body. This broad move away from scientific discourse in feminist research can be seen in the social sciences across core methodological, epistemological and ontological approaches, challenging the 'discursive primacy of the universal, white, able-bodied, masculinist subject' (Shildrick, 2005, p. 15) and opening up the space for intersex advocacy in research. Ethical considerations of intersex treatment (e.g. Foucault 1980; Dreger 1998; Sytsma 2006) permeate most of the literature on intersex. This ethical discussion delineates varying degrees of offense and distrust to existing medical practices (Hester 2003, 2004; Callahan 2009; Roen 2008; Davis 2015) and often disputes whether the practitioners' priorities lie with the patient (Kessler 1998; Hester 2003), whether non-consensual surgical outcomes can have any kind of positive effect on people with intersex traits (Azziz *et al.* 1986; Holmes, 2002) and unravels how medical discourses tie in with larger structures of oppression and control (Foucault 1980b, Fausto-Sterling 2003, Butler 1993).

Feminist scholars writing on intersex argue that its institutional treatment holds particular relevance to feminist discourse, identifying traditional medical models of sex as a way to bolster a heterosexual imperative (Butler 1993, Kessler 1990, Fausto-Sterling 1993a, Feder 2009, Davis 2015) and perpetuate misogynistic and patriarchal values (Holmes 1995, Chase 1998b). Kessler's (1990) seminal article on the medical management of intersex which reported the findings of a series of interviews with North American medical specialists in intersex, brought to light the heterosexist beliefs held by doctors regarding gendered behavioural and physical expectations for children, claims which have since been supported by other empirical studies (Karkazis 2008, Feder 2009, Davis 2015). Similarly, Holmes (1995) has critiqued the gender regulation employed in the 'mutilations' of genitals which are founded upon the extent to which the appearance of the genitalia transgresses norms for a particular sex, i.e. the amputation or partial-removal of an enlarged clitoris which is identified as too 'phallic' and therefore blurring the discrete components of the sex binary. Furthermore, Chase (1998b, p. 207) considers the medical approach to intersex to be of particular detriment to women. She describes medical intervention as 'another form of violence based on a sexist devaluing of female pain and female sexuality'; whereby, as Chase describes, a girl growing up without a clitoris or ovaries is favoured over the prospect of a boy with a small penis. For these reasons, it is essential for this study to be situated within existing feminist theory with an incorporation of competing discourses of heteronormativity and prescriptive gender.

# Social structures of medicine

These ethical and epistemological commentaries on the medical model of intersex are prefaced by a formative body of work theorising relations of power in medical contexts. In particular, this study draws upon the notable contributions given by Foucault (1975, 1976, 1980b), Parsons (1975) and Freidson (1970, 1976).

Neither Parsons nor Freidson currently have a presence in intersex studies literature but the present study has been driven by these approaches, and thus consolidates these foundational theories into the existing discourse of intersex treatment. Freidson (1970) provides a critique of the institutional dominance of the medical profession by centring on the eminence of the establishment, which he calls 'professional dominance'. Freidson (1970, p. 277) argues that the medical institution 'by virtue of its authoritative position in society, comes to transform if not actually create the substance of its own work', allowing the institution to approach bodies as an evaluative 'moral enterprise like law and religion, seeking to uncover and control things that it considers undesirable' (p. 277). Thus, bodies deemed to be deviant or unhealthy are imputed as such and the divide between what is known to be natural or cultural becomes indistinct. Freidson (1970, (p. 223) contends that 'while illness as a biophysical state exists independently of human knowledge and evaluation, illness as a social state is *created and shaped* by human knowledge and evaluation'. Similarly, Butler (2004, p. 1) explains that 'the terms that make up one's gender are, from the start, outside oneself, beyond oneself in a sociality that has no single author (and that radically contests the notion of authorship itself)'. In the current research I believe that it is important to strive to understand the broader notion of the human world which engenders a multiplicity of meanings and sources of power, beyond the personal accounts of intersex people. Thus, the present study explores to what extent the self-determination of identity, selfhood and the body is understood to be possible or even desirable in the human world and, with particular emphasis on the subversion involved in sexual variance, investigates in what ways these three constructs relate and constitute each other within a context of institutional regulation.

Freidson's analysis takes influence from Parsons's earlier work (1951) which provides an analysis of the hierarchical dimension of the patient/physician relationship and the asymmetrical constitution of typical clinical interactions. Parsons (1975, p. 258) identifies those who are diagnosed as ill or unhealthy as becoming 'objects of manipulation'. One facet of this manipulation is an expectation for the sick to 'organise his [sic] behaviour and his life in such a way to save others from embarrassment' (Freidson, 1970a, p. 236). This is part of a broader contract, in which Parsons claims that the sick relinquish responsibility for their ill health but are still deemed accountable for the stigma or upset which it may elicit in others. This notion of blame, fault and accountability converge with Freidson's observations of eminence and professional dominance and are central to the treatment of intersex people and the feasibility of intersex identification.

In *Discipline and Punish* (1975), Foucault depicts modern institutional power, such as the clinic, as processes within a disciplinary regime, whereby the embodied subject comes to be known and controlled. In his exploration of discipline, Foucault problematizes the epistemology of the human body, contending that the body is recognised and materialised through discursive practices which are produced through the exercise of power/knowledge. This also

approximates much of the current post-structuralist writing on intersex which describes the bodies of intersex people not as evidencing pre-given or universal defects, but as bodies whose deviance is produced by the medical discourse (Butler 1990, 1993; Holmes 1994, 2009; Morland 2001). In agreement with Foucault, Butler (1993, p. 10) notes that 'there is no reference to a pure body which is not at the same time a further formation of that body' and, likewise, Shildrick (2005, p. 7) qualifies that 'morphology is not something given once and for all, but is a process without an end'. Foucault also identifies particular norms (or processes of 'normalisation') by which the body is disciplined. He (1996, p. 197) notes that 'medical power is at the heart of the society of normalization'. In the medical treatment of intersex, Foucault's processes of truth, regulation and control are combined to discipline the 'unruliness' of non-binary bodies and tie in closely with Freidson's explanations of professional dominance.

One of Foucault's later monographs, *History of Modern Sexuality* (1976, 1998 [1984], 1990 [1984]), locates sex, like crime, as an object of the scientific discipline and expands further on the particular norms deployed on the bodies and practices of modern social actors. Foucault's analysis is credited and utilized frequently within intersex studies. His notion of conceptual genealogy in earlier work (1970, 1972) has provided a useful framework for some intersex scholars to situate the pathologisation of intersex (Preves 2002), whilst others have incorporated his notions of normalisation and biopower (Malatino 2009, Feder 2009). Foucault's most prominent contribution to intersex literature, however, was his discovery, English-language translation and re-publication of Herculine Barbin's memoirs (1980a), prefaced by a commentary of his own. Barbin was a devout Catholic living in nineteenth-century France who, by current diagnostic standards, was intersex. Her medical treatment, including mandatory transition from female to male in adulthood, led to her committing suicide in 1868. Dreger (1998, p. 28) notes that 'Barbin shaped the biomedical treatment of human hermaphroditism for years to come' and that the publicity surrounding Barbin's memoirs, life and death 'instilled in medical practitioners an appreciation of just how troublesome and urgent—and potentially common—the problem of hermaphroditism was' (p. 28).

## Political development of intersex

Autobiographical accounts of the experiences of people who have been diagnosed as intersex generated the first platforms for intersex advocacy and indignation over a decade after the re-publication of Barbin's memoirs (Holmes 1994, Chase 1998a). *Hermaphrodites with Attitude*, a newsletter first published in December 1994 by the Intersex Society of North America (ISNA), a year after their formation in 1993, first introduced the term 'intersex' to a broader public outside of diagnostic practice (Holmes, 2009, p. 4) and put into print the personal narratives and political perspectives of people who had been treated for intersex/atypical sex conditions. The newsletter intended to provide 'a counterpoint to the mountains of medical literature that neglect intersex experience' (Chase 1998b, p. 198) and was the first time a public forum had been available for these personal ideas and experiences to be shared and explored.

The early 1990s marked a point where many people who had been treated medically for intersex conditions came to recognise for the first time that it may not in fact be their bodies that were the problem, but the way in which their bodies were understood by others (Chase 1998a). Many felt embittered by their non-consensual treatment, the loss of sensation and scarring caused by surgery, and the shame and secrecy they had stored for years (Chase 1994,

1997a, 1997b, 1998a; Coventry 1998; Holmes 1994). In 1996, the founder and Director of the ISNA (now Accord Alliance), Chase, produced a poignant 30-minute video called *Hermaphrodites Speak!* (Chase, 1997a)*,* which showed ten intersex people meeting for the first time to discuss their stories, having never before knowingly encountered anyone else who had similar experiences to their own. With a growing anger over their mismanagement and the facilities to find other intersex people, new options for dissent were emerging. Following on from Queer Nation and the Lesbian Avengers, direct action groups which were founded in New York the early 1990s to fight for the rights of LGBTQ people, some intersex activists took to the streets to spread their campaign.

In 1996, in what Chase (1998b, p. 200) calls the 'the first recorded instance of intersex public protest in modern history', an ad hoc assembly of 'militant intersexuals' picketed the American Academy of Paediatrics annual meeting in Boston under the name Hermaphrodites with Attitude, assisted by another direct action group, Transsexual Menace. The early 1990s, in part provoked by the AIDS crisis and resulting discrimination, became a period of reinvigoration for sexual identity politics; the protest led by Hermaphrodites with Attitude resembled - and was perhaps inspired by - action carried our three years prior by Transgender Nation (an offshoot of Queer Nation), whose members protested outside the American Psychiatric Association's annual convention to dispute, much like intersex activists, the pathologisation of transsexuality.

Following the advancement of intersex activism and the rising visibility of the personal accounts of intersex people, the intersex activist movement began to filter into the academic sphere, which slowly vitalized into a diverse body of literature throughout the 1990s. Because of its political urgency and greater social relevance, some academics writing on the area also made valuable efforts to share their work with a general audience. In 1993, biologist Fausto-Sterling published 'The Five Sexes' in *The Sciences* and 'How Many Sexes Are There?' in the *New York Times*, which provocatively critiqued the dimorphic model of sex and gender and suggested alternative, but 'tongue in cheek' (Fausto-Sterling 2000, p. 78), ways to taxonomise our bodies, i.e. 'herms', 'merms' and 'ferms' in addition to male and female (Fausto-Sterling 1993b). Fausto-Sterling explained to a general audience that 'society mandates the control of intersexual bodies because they blur and bridge the great divide' (1993b, p. 24). Her later book, *Sexing The Body* (2000), also brought intersex issues, as well as a broader challenge to scientific knowledge production, to a wider audience.

## Public engagement

More recently, the politics of intersex captivated the attention of the general public when a surge of national media interest emerged as a result of the controversy surrounding Caster Semenya. Following her triumph at the eight-hundred-metre race at the 2009 Berlin World Athletics Championships, other competitors raised doubts over the legitimacy of her female identity. Semenya was given compulsory sex-testing to determine whether or not she could legitimately compete in the women's race. Fervent media coverage followed the incident (e.g. Wheeler 2009; Moore 2009), some of which engaged in a broader analysis of intersex issues (BBC News 2009; Hanlon 2009) whilst other articles shared crass speculation over the visibility of her anatomy in her running shorts (e.g. Lawson 2009). The persistent presence of intersex in newspaper features (Navarro, 2011; Rogers 2011) and visual media (*Embarrassing Bodies*,

2011, 2012; *Me, My Sex and I*, 2011) reflects the continued widespread curiosity regarding gender, sex and bodies which do not meet customary expectations of 'normal' or 'healthy'.

The abundant news coverage of the Caster Semenya case also encouraged critical academic investigation, with particular focus on the language used in the reports (Kerry 2011), their function in regulating acceptable gender/sex identities and bodies (Amy-Chin 2010, Dreger 2010, Kerry 2011, Merck 2010) and the racist and/or imperialist nature of the accusations against Semenya (Kerry 2011, Merck 2010). Kerry (2011) introduces a concept of 'intersex imperialism' in which he contextualises the dispute over Semenya's sex as part of a debate which, he argues, has been ongoing for several decades, whereby the sex and gender of post-colonial citizens are racialised and othered. Amy-Chin (2010) describes Semenya's media reception as 'epistemic justice'; a structural prejudice which forces bodies to fit within a binary system but also responds with hostility when certain bodies are not paradigmatic examples of the binary in which they identify (or are assigned). Amy-Chin understands the leading strand of the intersex rights movement to have de-politicised and taken a turn away from identity politics, instead supporting the medicalisation of intersex bodies. This can be seen in the ISNA's adoption of the new medical nomenclature which now identifies intersex traits as 'disorders of sex development' (Lee *et al.*, 2006). She argues that the endorsement of increasing medicalization is evidenced in the unfavourable journalistic response to Semenya, which largely ignores the notion of intersex identity.

## Medical reform and revision

The ISNA's turn away from identity politics has in part been in response to, and also to further, the increase in interest from medical practitioners to reform practice and approach. In the initial stages of the advocacy movement, medical discourse largely ignored criticism and appeals for change (Dreger and Herndon 2009, p. 205) but since 2004 there have been some improvements in the degree of ethical concern shared by clinicians and the extent to which the views of patients who have been treated for intersex conditions have been listened to by the medical establishment (e.g. Kolon 2011, Lee *et al.* 2006, Warne 2004). The recent 'Consensus Statement on Management of Intersex Disorders' (Lee *et al.* 2006) was the first official revision of the treatment paradigm since psychologist John Money's (Money *et al* 1955) guidelines fifty years earlier. The new guidelines recommend collaboration with intersex advocacy groups as well as dialogue with intersex adults to gain a broader perspective of the aftermath of medical treatment. They also endorse a more psychosocial approach to early genital surgery, but take a frustratingly equivocal stance on whether or not non-consensual surgery should be performed. There is still no explicit recognition (or critique) within the guidelines of the problematic/erroneous medical and societal assumptions of sexual dimorphism.

The revisions in nomenclature proposed by the statement provide an overdue alternative within medical practice to the terms 'pseudo-hermaphrodite' and 'true hermaphrodite', some of the remaining vestiges of the early medical approach; but their replacement, the umbrella term 'disorders of sex development' (DSD), has been profoundly contentious within the intersex advocacy movement. The Organisation Intersex International (OII) published an online blog in response to the new terminology entitled 'Sorry we're not disordered'. On behalf of the organisation, Italiano and Hinkle (2008) argue that the move from intersex to DSD

erroneously pathologized and stigmatized intersex people in order to try to preserve the heterosexist male/female hierarchies that justify the oppression of many classes of people, not just those who are intersexed.

Since the proposed revisions, the socio-political significance of diagnostic terminology has been examined in detail by scholars in the field (Clune-Taylor 2010, Davidson 2009, Feder 2009, Holmes 2011). Whilst much of the literature has argued against the move because of the way in which it semiotically positions intersex within the biomedical paradigm, some academics have supported the change. Feder (2009, p. 225) deplores the use of intersex as an identity category as she feels that it does not 'permit appreciation of the genuine health challenges faced by many individuals with intersex conditions'. The disorder tag, she claims, is a way to lessen the 'extraordinariness' of intersex and to position it as a 'disorder like many others', rather than something which is chiefly an issue of identity, gender or genitalia and worthy of particular revulsion or fascination. Whilst Feder is right to address the stigma of the intersex label, in doing so she neglects the identities of some intersex people who do not see their identities or experiences as 'health challenges', but as a valid option for self-definition (e.g. Holmes 1995).

LaGrace Volcano (in Creighton *et al*. 2009, p. 259), visual artist and intersex activist, notes the difficulties for intersex people in finding an identity 'when understandings of intersex hinge on medical classifications through which atypically sexed individuals may be disempowered'. In agreement with LaGrace Volcano, the disorder classification has been characterised as passivising by many intersex activists, allies and scholars of intersex who believe that the term further necessitates the 'requirement for the unexpected body to be rectified' (Holmes 2011, p. 395). In the recent collection of essays, *Critical Intersex* (2009, p. 1), editor Holmes reasons that 'we [...] are not yet done with 'intersex'. [...] It is too soon to accept the language of *disorder* wholesale and [...], in fact, a critical value remains in the use, deployment, recognition and interrogation of 'intersex'. The very limited number of legal scholars in the field (Beh and Diamond 2005, 2006, 2008; Greenberg 1999, 2012; Haas 2004; Hermer 2002) have also observed existing medical discourse hindering approaches to legal recognition and protection for intersex people (Creighton *et al*. 2009, p. 259), especially when 'legislatures rarely interfere with medical protocols'.

## Split in the movement

The ISNA's initial focus was on supporting intersex people deal with 'shame, stigma, grief and rage' (Chase, 1998b, p. 197) and deconstructing the sex/gender binary, thereby developing as a political advocacy group for founders and members who harboured suspicion (and often a great deal of anger) towards the medical establishment. In its formative years, the ISNA aligned itself with, and was heavily influenced by, direct-action philosophy and other sexual identity activism, as illustrated in the discussion of collaborative protest above. Chase (1998b, p. 195), the founder of the ISNA, once argued that

> the gay rights movement had gathered momentum only when it could effectively deny that homosexuality was sick and inferior and assert to the contrary that 'gay is good'. As impossible as it then seemed, I pledged similarly to affirm that 'intersex is good', that the body I was born with was not diseased, only different.

After a total reversal of Chase's initial claims, the ISNA's support offered to the medical 'disordering' approach to intersex led to a split in the intersex activist movement and left many of the ISNA members feeling alienated by their organisation. Activist approaches and academic scholarship now falls broadly into three (overlapping) groups: i) identity politics, explorations of gender variance, and alliance with other political identity groups (e.g. LGBT), ii) a social model and queer interventionist approach, influenced by critical disability theory and/or post-structuralist thought and queer theory and iii) strategic endorsement of the medical model (endorsed by the ISNA and now Accord Alliance). The former two, which constitute a considerable portion of published work and political online correspondence between intersex people and activists, have established the crucial underlying debates for the position of intersex identity in the current study and therefore require further detail.

## Uniting with LGBT campaigns

Chase (1998b, p. 199) illustrates the 'radical and queer orientation' (Spurgas 2009, p. 99) of the early intersex movement when reflecting on the founding stages of the ISNA:

> I was less willing to think of intersexuality as a pathology or disability, more interested in challenging its medicalization entirely and more interested still in politicizing a pan-intersexual identity across the divisions of particular etiologies in order to destabilize more effectively the heteronormative assumptions underlying the violence directed at our bodies.

In the early 1990s, a period when other LGBT activists were gaining recognition and visibility (Preves 2004), the intersex movement coalesced with other marginalised identity groups 'to strive together for a world more accepting of multiple and diversely sexed, gendered, and desiring bodies and identities' (Spurgas 2009). Butler (2006, p. xxvii) underlined the importance of the parallels between transgender issues and intersex studies to the political context of the 1990s when she acknowledged in her revised preface to *Gender Trouble*, a decade after its first publication, that 'if I were to rewrite this book under present circumstances, I would include a discussion of transgender and intersexuality'.

As mentioned previously, transgender activism at this time was disputing the pathologisation of trans-identities so there were very specific commonalities between the intersex movement and the trans-liberation movement due to the way in which both groups were pathologised by the clinic, and therefore classified as treatable or curable. The relationship between the two groups has been chronicled and appraised with various different outcomes (Chase 1998b, Dreger and Herndon 2009, Greenberg 2012; Spurgas 2009). Some intersex support groups have shared concern about the conflation of trans and intersex issues. For example, the UK-based Androgen Insensitivity Syndrome Support Group (AISSG) warned that the association may imply that 'intersexed people, of necessity, have gender identity issues' (AISSG 2012). Some policy documents (e.g. European Network of Legal Experts in the non-discrimination field 2012) have amalgamated both groups in order to address the broad issue of gender/sex-based discrimination and some theoretical discussion on gender politics has addressed the issues as analogues in terms of social exclusion (Monro, 2005). Although the trans-liberation and intersex advocacy movements may have found some effective unity in fighting for greater

autonomy and against bionormativity, it is important that their differing experiences and goals are not overlooked.

Intersex activists and scholars of intersex have often identified the similarities between their own struggle against medicalisation and the historical (de-)pathologisation of homosexuality (Fausto-Sterling 1993a, Feder 2009, Holmes 1995). Feder (2009, p. 226) acknowledges the parallels in the treatment of the two groups but warns that, much like the association with trans-liberation, comparisons may risk 'obscuring those concerns unique to the treatment of intersex conditions and the consequences for affected individuals'. Contrary to most other scholarship, Feder (2009, p. 229) also claims that 'where homosexuality was 'an invention', intersex conditions resist comparable characterizations of history'. This account seems insufficient when there is so much research which demonstrates the historical contingency of intersex as a concept (Dreger 1998; Dreger and Herndon 2009, Foucault 1980a, Fausto-Sterling 2000, Reis 2009).

In line with her endorsement of the new disorder-tag, Feder suggests that diseases which have been similarly stigmatised but retain a medical urgency would act as more useful analogues to intersex than homosexuality. She suggests that the historical treatment of tuberculosis would be an especially good point of comparison because of the particular social meanings that were taken from its diagnosis. Feder (2009, p. 229-230) claims that despite the late-nineteenth-century discovery that tuberculosis was caused by infectious bacteria, those diagnosed still received a moral, character-based judgement. In cases of intersex, much like tuberculosis, Feder claims that medical involvement should be entirely separate from the social implications. Many other scholars contend, however, that intersex is rarely a medical problem at all (Holmes 1995, 2002, 2009; Morland 2001).

Within debates regarding the motivation for the regulation, treatment and discrimination against intersex people, scholars have also noted a juncture with the pathologisation of homosexuality (Chase 1998b, Holmes 1995, Fausto-Sterling 1993a, Hird and Germon 2001). Holmes (1995), for example, argues that 'societally sanctioned homophobia is partly to blame for the invasive, violent and damaging treatment of intersexuality'. She believes that this is partially due to the prerequisite of two oppositional and recognisable sexes to endorse and naturalise heterosexuality, which may be otherwise confounded. Conversely, it has been argued (see Monro 2005) that sexism and systematic patriarchy predicate the institution of heterosexuality, depending on, and reinforced by, the normalisation of sexual dimorphism and opposite-sex couples. Medical treatment upon intersex people is also undergone with the implicit assumption that heterosexuality is the normal, natural and correct orientation; that vaginas which could not accommodate a penis are dysfunctional and penises which are too small to penetrate a vagina should not be identified as penises, but instead as clitorises (Kessler 1990). The perspective that homophobic beliefs has implemented, or at least fortified, the medical and social approaches to intersex clearly enhances the benefits of uniting the two liberation movements.

## Abject bodies

Allegiances have also been made with the disabled people's movement due to the convergences in the way that the institutional power of medicine has governed both groups' freedom to look, behave and move within their social environment. Holmes (2009, p. 5-6)

comments that 'intersex studies draws as much from the impulses, theoretical frameworks and critical lenses of disability as from the development of queer theory/studies and gender studies informed by feminist theory'.

Literature on the abjectification of bodies (Butler 1993; Grosz 1990, 1994; Kristeva 1982; Shildrick and Price 1998; Shildrick 2005; Weiss 1999, 2003; Wendell 1996) is especially pertinent to the current study and helps to frame the medicalization of intersex within wider social and medical discourses of restrictive bodily norms or biopower (Foucault 1998 [1976]). Weiss's contribution to the field is significant to the treatment of intersex because of the way in which it elucidates the processes behind the relationship between those who fit particular norms and those who do not. Weiss (1999, p. 92) explains that

> abjection is necessary to create the boundaries that will individuate the self, but to recognize the need to create these boundaries is also to recognize the fragility of the self that is so constituted, and so not only the abject, but the very process of abjection must also be buried, repressed, denied.

Weiss explores these processes to illustrate how abjectification is not simply a process of control and 'othering' but also a means to validate those who are not seen to be abject, or as Weiss (1999, p. 96) describes it, 'attempts to repudiate our own abjection'. Grosz (1990, p. 90) makes similar claims, identifying the 'precarious grasp of the subject on its own identity' whose security depends on the abjectification of another. This is essential to understanding the wider social implications of intersex as a medical concept.

The literature on abject bodies also ties into discussions of stigma (Goffman 1990 [1963], Parsons 1975, Preves 2003, Wendell 1996) and an emerging and necessary theme within intersex studies which focuses on the feelings of disgust and shame suffered by intersex people (Feder 2011, Kessler 1998, Preves 2003). Goffman's (1990 [1963]) rich contribution to the social significance of stigma provides important insights regarding the treatment and experiences of those who are disabled or otherwise abjectified. However, in the intervening period, disability studies (as well as theories of abjectification and embodiment) have come a long way. Wendell (1996, p. 57) concisely describes some of the problems with Goffman's approach to stigma, chiefly that he is uncritical of the norms and stereotypes that justify disabled people's treatment, instead 'adopt[ing] a patronizing tone in speaking of people who do not meet them, and to belittle and underestimate their efforts to live by different 'norms'' (Wendell 1996, p. 57). Wendell also points out that Goffman felt it was unproblematic to amalgamate all sources of stigma 'which causes him to overgeneralize' and 'prevents him from seeing some crucial aspects of the stigmas of illness and disability' (1996, p. 57). Similarly, Jenkins (2004, p. 73) notes that the range of stigmas addressed by Goffman 'don't have much in common'.

Goffman's theoretical discussion still plays an important role in current literature on stigma. Whilst an examination of the role of stigma is crucial when looking at the feelings of shame and disgust felt by intersex people and the important role that others play in constituting our identities, Goffman's conclusions require some revision. Wendell (1996, p. 60) rightly argues that Goffman's aspiration for stigmatized people is 'the possibility that their differences may someday be ignored or at least considered unimportant relative to their other characteristics' rather than intending for stigmatized people to be wholly revalued or respected. 'Difference',

Wendell concludes 'remains a curse' (1996, p. 60). Preves (2003) addresses issues of stigmatization and the possibilities of alternative identity formation outside of dimorphic gender roles in her important monograph, *Intersex and Identity: The Contested Self*. In this work, Preves provides a sensitive and comprehensive empirical study using data from life history interviews with adults based in North America who were treated for intersex conditions as children. She contends that medical intervention contributes to, or even *creates*, the stigma experienced by intersex people, arguing emphatically against the current clinical approach. Following from Preves, the current study intends to provide a political perspective of stigma with a salient inclusion of institutional and social power to further discussion around issues of disgust and shame for intersex people.

## A Social Model of Intersex

Analyses of disability as socially constructed have been advanced by disability activists and scholars for the last forty years (Wendell 1996). This conceptualisation now holds the 'most resonance and support in the British disabled people's movement' (Thomas 1999, p. 13) and marked a fundamental turn for disability theory, critically 'recasting disability as a form of social oppression' (Thomas 1999, p. 15). Now more widely known as the social model of disability, advocates argue that 'it is not the individual's impairment which causes disability, or which *is* the disability[...]. Rather, disability is the outcome of social arrangements which work to restrict the activities of people with impairments by placing social barriers in their way'. The fundamentally political dimension of the social model re-shaped the goals for the disability movement, emphasising the validity (rather than the inferiority) of difference and assigning *society* the imperative for correction, rather than the disabled bodies themselves. Liz Crow (1996 p. 206) describes its political and personal transformatory significance:

> It has played a central role in promoting disabled people's individual self worth, collective identity and political organisation. I don't think it is an exaggeration to say the social model has saved lives.

This approach to physical difference parallels some of the attitudes represented by the early intersex rights movement, which also collectivised what had previously been a very disparate group, and 'profoundly moved' (Chase 1998b, p. 197) those involved at the beginning of the movement, some of whom, just as Crow notes for the disability movement, were also suicidal before finding a political and social outlet which acknowledged that an intersex status itself was not shameful or wrong (Chase 1998b, p. 195). In the social model, a dualistic distinction is usually made between the underlying *impairment* and the *disability*, whereby the impairment is understood to be an 'objective, transhistorical and transculutral entity which biomedicine accurately represents' (Tremain 2002, p. 34), and disability is the social response to – or construction of – the particular impairment. Recent post-modernist disability theory has challenged this dualism in the same way that sex (the natural) and gender (the social) has also been contested.

Tremain's (2000, 2002) work has been central to this debate and has particular significance to this study due to its explicit analogue between disability/impairment and gender/sex and the noted import for the relationship between intersex and disability studies. Tremain (2002, p. 34-35) argues that

> both 'natural sex' and 'natural impairment' have circulated in discursive and concrete practices as non-historical (biological) matter of the body, which is moulded by time and class, is culturally shaped or *on which* culture is imprinted.

Much like the advocates of the social construction of sex, Tremain contends that our notions of impairment are created by our understanding of disability. This is not to say that impairments, or sex, are so much of a social construction that physical pain, 'disfigurement', fatigue (or genitalia, chromosomes, etc), for example, do not *exist* – but that they are also 'discursive objects' (Tremain 2002, p. 34) which have come to be understood and politicised in certain ways which are socially, culturally and historically situated. Whilst Shakespeare (2006) justly argues for the importance of recognising the existence of real, physical barriers (or impairments), he strongly supports the value of Tremain's effort to deconstruct the disability/impairment dichotomy. He notes that

> while theoretically or politically it may appear simple to distinguish impairment from disability, qualitative research has found it very difficult to operationalise the social model because it is hard to separate impairment from disability in the everyday lives of disabled people.

Again resembling the approach taken by social constructionists of sex, Shakespeare debates the usefulness of distinguishing between the components of the dichotomy when they are both laden with social meaning. This also has some resonance with my own qualitative approach as the experiences of participants in this study may also not distinguish between what is social, embodied, sexed and gendered.

Tremain attests to the genealogical convergence between the medical discipline of intersex and disabled bodies, noting the 'simultaneous emergence of natural impairment and natural sex' (Tremain 2002, p. 34). In contrast to the present study, Tremain strongly opposes the disability or intersex movements utilizing identity politics as a form of autonomy, liberation or ethical redemption. She (2002, p. 45) maintains that those effected should 'not continue to animate the regulatory fictions of '(inter)sex/impairment' and 'people with impairments/(inter)sex'' because

> in so far as the identity of that subject (people with impairments) is a naturalized construct of the relations of power which the model was designed to subvert, the subversive potential of claims which are grounded in it will actually be limited (Tremain, 2002, p. 44).

Whilst my own research attempts to take a more open approach to the potential personal and political worth of resistant identification, I strongly agree with Tremain's recommendation for junctions between disability and intersex to be further explored. She rightly notes that disability studies, in particular, would benefit from engaging with some of the issues raised by intersex studies to allow 'potentially enriching lines of interdisciplinary inquiry [to] be fostered' (2000, p. 297).

## Debating intersex identities

The preceding overview illustrates the highly-contested status currently occupied by the politics of intersex identity. In their recent analysis of the progress of the intersex rights movement, Dreger and Herdon (2009, p. 199) justifiably identify intersex identity as one of the

key issues in intersex studies in which there remains 'theoretical and political irresolution'. Certain scholars (Feder 2009; Morland 2009, 2012; Tremain 2002; Wendell 1996) strongly advise against intersex identity as a strategy for recognition and better ethical treatment, whilst others have made it a fundamental part of their approach (Holmes 1994, 1995, 2002; Preves 2003; Volcano in Creighton 2009). As illustrated earlier, the recent emergence of the DSD label has had some influence on the (im)possibility of intersex identity, and urged some groups (such as the ISNA) to take a more resolute position against it, instead favouring a patient-centred medical model.

This study seeks to explore some of these issues of identity further, listening and contributing to the theoretical debates and differing perspectives around the political validity, usefulness and potential dangers of identity, but also looking carefully at how thoughts, feelings and experiences of identity manifest in the lives of people with intersex traits. A large proportion of literature on intersex does not include the views of intersex people in its analysis; prohibiting them from speaking on their own terms or sharing their experiences and objectives. Some of the most important work on intersex has centralised intersex voices (Kessler 1998; Karkazis 2008; Preves, 2003) and provided new and exciting insight as a result, but the amount of scholarship in intersex studies currently taking this approach is meagre. As a consequence, Dreger and Herdon (2009, p. 218) advise that future academic work needs to 'listen carefully to intersex people in the same way they have listened to other marginalized groups' and start 'to write about intersex people on their own terms'. This study also seeks to rectify the geographical imbalance in current research as there have not yet been any empirical studies based on the lives and experiences of intersex people in the UK.

Roen (in Creighton *et al*., 2009, p. 254) notes that

> it has been in the interests of the medical establishment to make sure that intersex is perceived by the general public as a highly rare condition, which requires information not available or accessible to the average person.

We may see the social 'blackout' described by Roen as in some way part of the regulation and normalisation of intersex bodies, whereby their abjectification is amplified due to the way in which they are not seen, spoken of or known about. Holmes (1995), too, observes the reluctance/refusal of health journals to publish papers which report on the negative effects of surgery for people with atypical sex traits or the way in which intersex can be adopted as a political or personal identity beyond the diagnostic label. Therefore, more literature in the academic and public domain is urgently required to emphasise the importance of a broader awareness and inclusion of intersex bodies and/or identities with the interests of those diagnosed at the core. Roen (2009, p. 259) argues that the only way for substantial change to take place is through 'communication and collaboration across our differences in perspective and discipline'. Beyond this, as scholars in this area we need to ensure that intersex people are incorporated into our research and the personal narratives of intersex and atypical sex are considered alongside theoretical, ethical and political discussion of the effects of institutional powers.

# 4

## Methods
## Researching the Social Consequences of Intersex Diagnoses

This research seeks to explore how intersex, as an embodied experience and as a process of identification (Jenkins, 2014), is understood and constructed discursively by people who have been diagnosed with an intersex trait or sex development condition. Providing people with an intersex diagnosis an opportunity to represent themselves and to share their stories and ideas are therefore central objectives of this research.

Ethical considerations played a fundamental role in the research design and approach in order to avoid replicating the way in which many intersex people have, and continue to be, the subjects of medical investigation and scientific studies which are sometimes unwanted or viewed as non-consensual. I therefore incorporate a feminist ethics of care into my research design, aiming for a transparent and respectful approach to understanding the experiences of intersex people which incorporates their histories, needs and desires.

To achieve these aims, my research has taken a two-tiered qualitative multimethod approach known as the 'Diary-Interview method' (Zimmerman and Wieder, 1977). Participants were initially invited to write in diaries about their experiences over a period of two months, then the same cohort were invited to in-depth one-to-one interviews to build on the themes observed in the diaries and discuss their experiences in person. This chapter outlines the feminist theoretical and epistemological approaches which have overseen the research design, and provides a detailed description of the methods and analysis used in the study, as well as relevant ethical concerns.

## Feminist approaches

The central tenets of the feminist framework informing this thesis are outlined in the following four methodological principles: the first is a focus on gender/sex inequalities, oppression and bodily subjugation, and a commitment to challenging this; the second is to give a voice to everyday experiences, particularly of the marginalized; the third is for critical reflexivity to be integrated within the research process; and the fourth is to aim for a more equitable and compassionate relationship between the researched and the researcher. These four principles will be integral to the considerations discussed in this chapter.

A commitment to social change and social justice for intersex people underpins this thesis. In part, this is characterised by an attempt to better understand and illustrate the experiences of intersex people, but also in the overtly political aim of acknowledging and challenging the gender/sex oppression experienced by people with intersex diagnoses. Whilst I am aware of the potential limitations of this thesis in making any immediate or substantial changes to individuals' lives, I work with an understanding that improvement is urgently needed, and incorporate this into my conversations with participants as well as in my own reflections.

As a researcher, I felt a responsibility to ensure that empathetic and reciprocal relationships were established with the participants, especially when taking account of the historically disempowering attitudes held towards intersex people as 'objects' of study. As I will discuss, the methodological approaches employed in this research were selected, in part, to assist with the diffusion of power granted to the researcher in this relationship. It is not fair to assume that the researcher's perspective is, in all instances, more valuable than the researched. The stories of intersex people are central to this study. Following feminist criticisms of scientific knowledge production (Harding, 1986; 1991), I question the precedence of researcher over the community being researched. The stories shared by participants are therefore one of the starting points of this project; following Stanley and Wise (1983, p. 167), who argue that 'the best way to find out about people's lives is for people to give their own analytical accounts of their experiences'.

However, I also acknowledge my central role in managing this process. Feminist epistemology starts with the self (Griffiths, 1995), and my research was undertaken with the knowledge that my presence in the study would have an influence on participants and that I come from a particular political standpoint with a commitment to social change. It was therefore my responsibility to '[consider] what influence [I] maybe be having in [my] own and other people's learning' (McNiff and Whitehead, 2011, p. 34). These matters were carefully considered throughout the research process by ensuring the study was undertaken as reflexively as possible. I used a research diary for weekly reflections and personal development during the study. McNiff and Whitehead (*ibid.*, p. 10) advocate a process of 'observe- reflect - act - evaluate - modify - move in new directions' to aim for a research process which acknowledges and amends its deficiencies. Using this approach, I also encouraged participants to reflect on their involvement and the extent to which the collaboration was effectual and comfortable, allowing some methodological choices to be re-negotiated throughout. In the interviews, participants discussed their experiences of completing the diaries. They shared difficulties they had with memory, disclosure, and writing, as well as the benefits of reflection and the thought processes required.

## Insiders and outsiders

Whilst it has been my intention to limit the power disparity between researcher and researched, it was not possible (or desirable) for our differing roles to be displaced entirely, especially as I am required to demonstrate sole authorship of the thesis. Working with a marginalised group or community of which I am not a member led to particular privileges and power implications which are important to recognise. Feminist researchers are at risk of a 'delusion of alliance' (Stacey, 1991) when working with marginalised groups, especially women. Whilst some of my participants were the same gender, race and a similar age to me, which may have helped with a mutual identification and rapport, I was still there to discuss and learn about experiences which were not my own. Much literature on feminist approaches to social sciences incorrectly assumes that the research is being conducted woman-to-woman (Stacey, 1991, p. 25). My participants were mixed gender but, due to their intersex variations, they still often shared experiences of gender/sex oppression and bodily norms which were distinct from my own. Thus, like other feminist researchers, there were points of connection, including gender in some cases, but also very significant departures, creating a relationship of 'partial identification' (Mies, 1991) in which I was both an insider and an outsider (Hellawell 2006; Hayfield and Huxley, 2015).

As I will discuss later, some of the central themes raised by women participating in the research were not discussed by the men. With an awareness of the potential for gender difference to affect my relationship with the men in this study and the perception of distance this may create, I followed their lead regarding the boundaries of what was comfortable to discuss. Categorisations of gender and sex are, of course, heterogeneous and the differences within these groups are just as important as the similarities. Particular attention was paid to observing the varied experiences of intersex people. Ramazanoğlu and Holland (2002, p. 111) argue that

> those who are socially located in the same category can feel differently about similarities and differences. People have differing experiences of what it feels like to be socially included or excluded, successful or subordinated, vocal or silenced.

Just as with all social categorisations, it is unlikely for there to be an 'intersex consensus', even among those who self-identify as such, and it has not been my intention to find one. However, by consolidating a number of viewpoints, I hoped to explore patterns, diversity and anomalies within the group as well as exploring each personal account in depth.

As Weiss (1994, p. 137) points out, 'there are so many different interviewer attributes to which a respondent can react that the interviewer will surely be an insider in some ways and an outsider in others'. Whilst I entered this process knowing that I was an 'outsider' with regards to intersex status, I discovered many important overlaps between my own experiences of childhood and adolescence and my participants' stories. This led me to empathise in ways I had not expected, and negotiating a desire to speak about my own experiences with participants was at times challenging. Whilst empathy is important, the research was not about me.

Ramazanoğlu and Holland (2002, p. 109) caution that 'feminist researchers are exposed as particular, socially constituted, knowing selves with the power to constitute their own 'others' as subordinate'. As many scholars have shown (e.g. Hill Collins 1990; Wilkinson and Kitzinger 1996), academics from a tradition of Western white feminism have often produced women unlike themselves as 'others', 'add[ing] to the tradition of speaking about others and for 'others''' (Letherby 2003, p. 134). Griffin (1996, p. 100) questions the ability for researchers to step outside of this role. She notes, '[r]esearchers are always speaking for others. This is not something to be denied or avoided: it is a (potential) power and a responsibility'. Whilst the researcher's own voice and perceptions may be unavoidably prominent in empirical scholarship, care still needs to be given to highlight and observe hidden power relations rather than overlook them. In my role researching a community of which I am not a member, I aimed to avoid diminishing the personal perceptions of those participating, hoping to accurately depict the experiences they shared and 'hear' them as clearly as I could. This is a precarious and subtle distinction which I have been attentive to throughout the writing process and in correspondence with respondents.

In order to develop a relationship in which my 'speaking for' is done responsibly and sensitively, I have sought to be transparent with participants about the research process, and my aims and interests in the topic. I have also been careful to seek clarity and expansion following assertions made by participants which I have not fully understood or followed. This is exemplary of the need to consider the relational dynamics during interviews and other communication throughout the research process. Ramazanoğlu and Holland (2002, p. 116) note that

interpretation is a key process in the exercise of power. It marks a
critical point of decision about the possibility or impossibility of
connecting ideas, experience and realities, but also marks points of
divergence, as feminists draw on different epistemological assumptions
in making or refusing connections.

For this reason, my research endeavoured to recognise that the process of authorship and knowledge production is political, and decisions I made during these processes were therefore taken reflexively and empathetically. To reflect the range of different subjectivities in the research and ensure that participants were able to contribute to the production of knowledge in a way that allowed them to express their beliefs and experiences comfortably, I took a qualitative triangulated approach known as the 'Diary-Interview method' (Zimmerman and Wieder, 1977).

## Diary-Interview method

This method utilises an initial stage of solicited diaries to form a basis for in-depth interviews. My own interpretation of the diary method is different to Zimmerman and Wieder's (1977, p. 481) original suggestion: 'an annotated chronological record' or 'observational log'. Whilst I allowed participants to adopt their own approach to the diary, I encouraged them to reflect on their experiences and their stories so far, which often led to detailed and intimate accounts of their lives, as I discuss later in the chapter. With the anticipation that some respondents would engage with some methods more than others (Meth, 2003, p. 200), I hoped multiple approaches would allow participants to focus on the outlet which they found most appropriate or comfortable for knowledge production. The multimethods approach can also enhance the 'credibility and dependability' (Barbour, 2006, p. 237) of research findings by developing data in different formats, '[stressing] the iterative rather than the linear nature of research' (Barbour 2006, p. 235). Likewise, Zimmerman and Wieder (1977, p. 493) describe the diary-interview method as 'a continuous process of challenging and refining the investigator's conceptions'. I hoped using this malleable and reflexive format would contribute to my attempts to portray participants' experiences accurately in the research.

In their study of violent men, Meth and McClymont (2009, p. 917) discuss the way in which research participants showed a 'transformation of disclosure' when moving from one method to another, whereby participants' narratives developed over time through the different modes of inquiry. Participants reflected on feeling comfortable sharing sensitive information in some contexts, but not in others. Meth and McClymont suggest that this transformation of disclosure illustrates the intrinsic value of repeat research and the varying benefits (and limitations) of each method, with each offering a particular space for knowledge production to take place. Working with perceptions of identity or multiple-identities and the potentially emotive issue of violence, Meth and McClymont (2009, p. 917) outlined the way in which multiple methods were more able to accurately illustrate or 'access [...] complex and changing identities'. Much like the subject of study in Meth and McClymont's (2009) research, intersex participants in my study explored emotive issues relating to selfhood, identity and discrimination which could be challenging to express, especially with someone who is unknown to you. As I illustrate later in the chapter, the diaries created a 'bridge' in which participants often disclosed sensitive material, and I was then able to approach these aspects of their experience with a greater level of understanding in the interviews.

# Sampling and recruitment

In March 2013, during the very early stages of my research and before I had started to recruit participants, I met Jay Hayes-Light, Director of the UK Intersex Association (UKIA), at a conference in Manchester on Intersex, Theology and the Bible. I approached Jay to ask about his work and he very kindly offered his assistance with my research. The following day I contacted Jay by email to ask if it would be possible to meet with him, discuss his work further, and also talk about my research design and potentially receive some feedback. After conversing over email, I sent Jay the study's recruitment notice, ethics form and information sheet (see appendices A, D and B) to look over, and we met in his office in Chester in April. We spent a couple of hours together, in which Jay generously shared his personal experiences of intersex – he showed me a photograph of a younger version of himself, where he was 'attempting to grow a beard'. Jay explained that tufts of hair grew on only one side of his face; 'it looks like I've just shaved one side of my face and not the other' – and he also reflected on his work with UKIA. We got on well and Jay was relaxed and generous with his knowledge and experiences, and seemed keen to offer his time and provide materials to assist with my study.

An hour into our meeting, a television production team arrived to film Jay for a pilot documentary film on intersex that they were in the process of making. I agreed to help them with their project by continuing my conversation with Jay on camera. However, the producer of the film had a clear idea of the conversations he wanted Jay and I to have, and repeatedly requested that Jay ask me about my own experiences of researching intersex and my plans for the future. The instructions given by the team and their presence in the room transformed the dynamic entirely. As a result, Jay and I did not get the opportunity to discuss my research in a productive way, so these conversations took place through follow-up emails in the days following our meeting. Whilst Jay's response to my plans was mostly that of reassurance and agreement, rather than critique, I trust that he would have been honest with me if he felt there were any issues with the way I intended to approach the topic. The helpful points and opinions he shared in our emails were used as guidance in the decisions I have made since and will be discussed, as applicable, later in the chapter.

For this study, nine participants were recruited, seven of whom have received an intersex-related or sex-development diagnosis and/or identify as intersex, and two who are parents of people with an intersex-related diagnosis. The age of participants ranged from 22 to 54, although one intersex individual discussed in the research was Beth's daughter, Imogen, who is only six months old. All participants presented as men or women (rather than non-binary or other gender variants): seven of the nine participants were women, and two were men. All participants had the appearance of being ethnically white, but they were not asked to disclose their ethnicity or racial identity. In her US-based study, approximately 30 percent of Davis's (2015) intersex respondents were of a racial/ethnic minority status. She notes, however, that 'their experiences of intersexuality did not substantially differ from those of the white research participants' (*ibid*, p. 13). Whilst a greater ethnic diversity amongst the participants would have been preferable, the intersex community is known to be an especially 'white space' (Pagonis, 2016) consisting 'largely of individuals privileged by race and class' (Davis, 2015, p. 161). Whilst both Davis (2015) and Pagonis (2016) discuss the need to actively work towards increasing the diversity of the global intersex community, unfortunately its current state within the UK is not dissimilar to my sample, so this study may therefore be fairly representational of these racial demographics.

Class and educational backgrounds of participants seemed to be more diverse. Participants worked in a range of occupations with various income levels. Whilst not all of the participants' careers would require a degree qualification, many of them discussed attending university education. Participants who discussed their sexual orientation explicitly (three of the seven with intersex traits) were all non-heterosexual. The descriptions they gave of their orientations were not easily categorisable, however, due to change over time, complications relating to their diagnosis, and shame around their identities and bodies. Whilst the other participants *did* discuss sexual interest and desire, they did not confirm or describe their orientation. As intersex-related diagnoses are considered 'contested' and 'dubious' (Davis, 2015), and due to the widespread distrust of the medical institution amongst the intersex community (Karkazis, 2008), I did not use medical diagnosis as the only gauge of intersex status. This decision was most relevant to Ian's status, as he had received various different responses from doctors regarding his intersex traits, and is therefore still not entirely sure how to medically or personally identify.

Participants were recruited through a range of online sources: internet forums for intersex people, support group emailing lists and Facebook groups designed for discussion of intersex issues. Permission was sought from the webmasters of the forums and administrators of the mailing lists and Facebook groups to submit a recruitment notice requesting participants for a study about intersex experiences. Initially, recruitment materials asked for respondents to 1) identify as intersex (or similar) or have received an intersex-related diagnosis, 2) reside in the UK, 3) be prepared to provide written or drawn submissions exploring their intersex experiences, 4) be willing to meet with a researcher for an informal interview to discuss intersex experiences, and 5) potentially adopt a casual advisory role at intervals throughout the research process, to ensure fair and appropriate discussion of intersex people. Due to time constraints and concerns about asking for too much involvement from the participants, I later withdrew the fifth request.

## Accessing the community

I encountered significant difficulties in recruiting participants from the intersex community. In Davis's (2015) US study of intersex people, their parents, and medical professionals, she notes that she 'had no trouble recruiting participants', which she believes is because 'word got around that I was a researcher who had an intersex trait' (*ibid.*, p. 11). Davis travelled all over the United States to interview 65 people, including 36 adults with intersex traits. Working in the US, Davis had access to a much larger population than this study, but her shared experiences with participants may have also led respondents to feel they could trust her research agenda would incorporate their interests, and that she was someone who would have a greater level of understanding of their experiences. Qualitative researchers have often argued that those with an 'insider' insight to the topics of study hold a privileged research position when conducting their research (Perry *et al*., 2004), and it seems likely that Davis's disclosure and involvement in the community was advantageous to the recruitment process, given that the intersex community are such a hard-to-reach population who may be cautious of forming trusting relationships with researchers.

Whilst I had originally intended to recruit up to twenty participants, there have been significant advantages to the small size of the study. This research does not attempt to present large-scale, wholly generalizable findings; rather, the long interviews and rich, detailed diaries have provided

a large amount of in-depth data based on personal accounts. Following valuable sociological and anthropological studies which have centred on a small number participants (e.g. Cornwell, 1984; Frank, 2000; Whyte, 1955), the size of this study has allowed for very detailed narratives which create a more rounded sense of the individuals involved in the research, like a series of case studies rather than a more general overview. This amount of depth would not have been possible with a larger sample size due to the time and word constraints of a PhD thesis.

I posted the recruitment notice on two internet forums which specifically address intersex issues: GendersInX and Bodies Like Ours[1]. These are online discussion forums with some sections dedicated to addressing concerns related to particular intersex conditions, other sections for the broader overlaps between these conditions (e.g. sections labelled 'Social issues: How we deal with our surroundings despite our condition/diagnosis', 'Medical issues: Medications, medical concerns', 'Free talk: Chat about our condition'), as well as spaces to talk about topics which may not be related to an intersex status (e.g. 'Faith', 'Relationships', 'Hobbies'). The recruitment notices were acknowledged by some of the forum users, but only two people responded with interest in participating in the study, both of whom were from outside of the UK. The online discussion forums had been active during my MA research ten years ago but it appeared that many users had since migrated and now use other platforms (e.g. Facebook groups) for communication. With a growing awareness that recruitment might be difficult, I agreed for the two respondents to participate in the study, despite not living locally. Both of these participants later withdrew their involvement.

I also posted my recruitment notice in Facebook groups for UK-based discussions of intersex: OII UK & Ireland, Friends and Allies, a closed group[2] with 131 members; Intersex UK, a closed group with 130 members; and Intersex Allies, a secret group with 624 members, and contacted the administrators of condition-specific support groups based in the UK to ask if my recruitment notice could be sent out to their members. The following support groups were contacted: Living with CAH, Androgen Insensitivity Support Group (AISSG UK), Klinefelter's Syndrome Association (KSA UK), Turner Syndrome Support Society (TSSS), and Adrenal Hyperplasia Network (AHN UK). I also asked for assistance from Intersex UK, who responded to say that they did not have the time to help with the research, but wished me luck with the study. Not all of the administrators of the support groups responded to my email so, in some cases, I am unsure whether the notice was sent out. In all other instances, administrators initially responded with interest about the project and asked for further details, including my approach to intersex, the questions I intended to ask participants, my theoretical framework, methodological approach to the thesis, and my future intentions regarding publishing and career progression. Some of the administrators asked for additions or amendments to be made to the recruitment notice and the participant documents. In some cases we spoke on the phone at length before reaching an agreement.

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[1] Bodies Like Ours is no longer online.
[2] Facebook 'groups' are forums available for users to join and discuss particular issues, and can be easily created by all Facebook users. 'Closed' and 'secret' Facebook groups give their members some levels of privacy and/or allow users to place limitations on who can join. The presence and membership of closed groups can be seen by the public (but not the conversations in the group); whilst secret groups are only visible to members of the group and new members will therefore only be permitted to join by invitation.

Whilst the issue of gate-keeping (Whyte, 1955; Burgess, 1982) had not originally been given much consideration in the research design of this study, my access to the majority of participants in this study was negotiated through people who managed the support group mailing lists. After some detailed discussion about my background and my understanding of the topic, the recruitment notice was usually passed on to members of the support group mailing lists, but in some cases this was performed selectively. For example, one of my contacts for a support group informed me that she had chosen particular members that she thought may be of interest, and contacted them individually on my behalf. It was understandable that the administrators of these mailing lists felt a responsibility to their members and a duty to limit my access, as I was someone who was unknown to them and could therefore pose a risk. However, the criteria by which this contact understood a member of her group to be of potential interest to me was unclear, and this process had definite implications for the scope of who would be involved in the research.

Miller and Bell (2012) consider the relationship between access and ethics, reflecting on the power of the gate-keeper to 'sanction access to less powerful individuals and groups such as Bangladeshi women for example' (*ibid*., p. 56). Thus, they note that, in the hands of a gate-keeper, researchers may feel some concern 'with the ways in which judgements are made about who might be 'suitable' interviewees'. Whilst I recognise that potentially vulnerable members of support groups may need to be considered when calls for research participants are shared, I was unsure whether my own understanding of suitability and vulnerability would be the same as those making the decisions, and also felt that it was important that individuals who may be known to have had especially difficult experiences should not be excluded for that reason, given that these members may have a desire to share their stories. Whilst issues of bias can still arise in self-selection sampling, I hoped that an open recruitment notice would also lead to more active and interested participation in the study from those who volunteered.

Careful consideration was paid to the use of language in the recruitment of participants and throughout the research. Whilst a new term, 'disorders of sex development' (DSD), was recently proposed to replace 'intersex' and other umbrella categorisations of sex variance in medical discourse (Houk *et al*., 2006), many in the community have spoken out against the change in nomenclature (e.g. Davis, 2011, 2014, 2015; Italiano and Hinkle, 2008). One recent study of patients with a CAH diagnosis (Lin-Su *et al*., 2015) found that 71% of respondents disliked or strongly disliked the term DSD, 83.6% did not identify with the term, and 76% felt that the term has had a negative effect on the CAH community. The term 'intersex' is used in this study because, unlike 'DSD', it does not necessarily bear explicit connotations of medical jurisdiction (Davis, 2011).

Some of the diagnoses included in this study are not universally associated with intersex or DSD by patients. For example, on the TSSS website, Turner syndrome is described as a 'chromosomal abnormality' (Turner Syndrome Support Society, 2015) and in some cases categorised as a 'growth condition' (Child Growth Foundation, 2016). When recruiting from support groups for specific conditions, the name of the condition was used in the recruitment material rather than an umbrella term. In interviews, I mirrored the language the participants used to describe themselves in their diaries, but also asked about their thoughts on other nomenclature, especially 'intersex' and 'DSD'. As this research seeks to explore the experiences of those with sex development or sex anatomy which is deemed atypical, participants' classification as, or identification with, intersex or DSD is of interest but is not fundamental to the study. However, all

of the diagnoses included in this research are defined as intersex or disorders of sex development within medical discourse (e.g. Lee *et al.*, 2006).

As my original intention had been to involve up to twenty participants, and I had only recruited seven participants, I started to re-think routes and modes of access to people with sex variations and looked for other convenient points of access. This difficulty was predicted and discussed by some of my participants and other support group members who responded to the notices I posted online. One member of a Facebook group commented that very few intersex people are open about their status, and may therefore be reluctant to discuss their experiences, especially with someone unfamiliar. Three months after my initial contact with the support groups, I asked them to send out a follow-up 'reminder' email to members. I also created a webpage to advertise the recruitment notice (see appendix A) in the hope that this would provide a more permanent location for the information to be viewed and shared. I emailed the notice to the University mailing list for volunteers, which was sent out to approximately 7,000 members of staff and 25,000 students at the University of Sheffield. I shared the notice on other social media platforms, including Twitter. I also contacted ten therapists in the UK who were listed on Pink Therapy[3] as specialising in intersex clients to ask if they could put the recruitment notice in their practice, or pass it on to anyone they thought may be interested. Only one therapist replied to confirm she would offer assistance.

These subsequent attempts to recruit were unsuccessful; all participants recruited for the study had seen my notice in emails from the support groups or in the Facebook groups. Despite this route of access, the participants' experiences and degree of interaction with the support groups were diverse. Whilst some participants were strong advocates of the support groups, others were very critical of the groups they had engaged with, and some had only had minimal (and very recent) involvement as online spectators rather than any active communication or attendance of meetings. The final two participants were recruited near the end of this period. Beth, a new parent to a baby with a diagnosis of congenital adrenal hyperplasia (CAH), had seen the recruitment notice through a support group, and asked if I would allow her to participate from a parent's perspective. The other participant, Nicole, was involved in managing one of the support groups who I had contacted to ask for help with recruitment. We agreed to meet for an interview about her experiences with the support group, but our conversation focused instead on her relationship with her daughter, who has a diagnosis of Turner syndrome. As I had not initially intended for our interview to centre on Nicole's own experiences as a mother of a child with Turner syndrome, she is the only participant who was not asked to complete a diary for the study.

The inclusion of Beth and Nicole's experiences has benefited the study; their accounts of intersex diagnoses and consequent social and medical encounters are important and have enriched my analysis. However, listening to their experiences cannot be treated as equivalent to speaking to intersex people themselves. Nicole's portrayal of her daughter's values, opinions and responses are not necessarily reliable or accurate representations of how these issues have been understood and felt by her daughter. Nevertheless, Nicole's own version of these accounts are still valuable; she is likely to have played a significant role in her daughter's life, and she has memories of her daughter's early years and formative medical encounters which would not otherwise be

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[3] Pink Therapy is the 'UK's largest independent therapy organisation working with gender and sexual diverse clients' and provides a large online database of therapists and their specialisms.

recounted. Parents *also* experience their child's intersex diagnoses, albeit from a different angle. I therefore treat Nicole and Beth's accounts of their children's lives as distinct from speaking to the children themselves, whilst also bearing in mind that all accounts given by participants are constructions devised for the purpose of the study and may be similarly unreliable, misremembered, or in some other sense not wholly 'accurate'.

## Ethical considerations

After initial interest was registered by participants through email communication, I explained the intentions behind the research and the amount of time required from their participation. As well as these informal discussions via email, I sent participants an information sheet (see appendix B) approved by the University Research Ethics Committee which explained the purpose and design of the study and gave a full description of their role, including details of how long their participation would be required. Once respondents confirmed their participation, I gave them the option of receiving a journal by post, or writing their diary submission(s) in a document file on their computer. They were asked to write or draw in their diaries (or on their computer) over a period of two months in their chosen format whenever they felt the urge (see appendix C).

Ethical consent was also sought at this stage. I informed respondents that their participation was entirely voluntary and that they were free to withdraw from the study at any time. Confidentiality was emphasised in our email communication and at our one-to-one interviews. I reassured participants that their privacy would not be violated and that they were in control of the amount of information shared. Personal names and any other information which would make participants identifiable were not used in the write-up, unless individuals involved requested otherwise. To maintain confidentiality, I have used pseudonyms for all participants, as well as for other people identified by participants in their diaries and interviews. As the intersex community is relatively small, and some participants had heightened concerns about anonymity, particular care has been given to altering some of the identifying details given in their accounts, such as occupations and geographical locations. This was also given special attention in the case of the two participants who spoke in detail about their children with intersex-related diagnoses. As the children had not chosen to participate in the study, strict anonymity and care regarding the information disclosed on their behalf seemed especially crucial.

This study has required a range of difficult ethical considerations and decisions. My approach to these questions has not only been focused on participants' encounters with the research, but also on personal care and my own conduct and responsibilities, viewing ethical decisions as 'the moral deliberation, choice and accountability on the part of researchers throughout the research process' (Edwards and Mauthner, 2012, p. 14). As well as seeking approval from the University Research Ethics Committee, I adhered to the Economic and Social Research Council (ESRC) Framework for Research Ethics. However, as Edwards and Mauthner (2012) observe, processes of ethical consideration are continuous throughout the research and the writing processes, and cannot be easily condensed into a simple set of guidelines or principles. My approach here is guided by Edwards and Mauthner's (*ibid.*) adapted feminist ethics of care, in which an emphasis is placed on the researcher's responsibility to others and themselves, centring care in the ethical decisions that are made, and fostering 'nurturant relationships' (Porter, 1999) with participants and others involved in the research process, which are built around empathy (Edwards and Mauthner, 2012, p. 20).

Ethical considerations are also 'complex situationally informed debates' (*ibid.*, p. 22) which cannot be resolved entirely in the planning stages of a study and may need to be dealt with spontaneously. For example, new ethical considerations arose in one of my final interviews when I met Beth, the mother to a baby with a diagnosis of CAH. I agreed to meet Beth at her home, which I had also done on one occasion with another participant, in both cases because the participants felt it would be the most convenient and comfortable setting for them to meet me. Beth's partner, Chris, was also at home during parts of our interview, taking care of their baby, Imogen, whilst Beth and I spoke. During most of our time together, Beth and I were alone – Chris took Imogen out for a walk and later on he went upstairs to give her a bath. However, at other points Chris was keen to offer hospitality – drinks, food – and update Beth on his interactions with Imogen, and this sometimes challenged the privacy of our conversations. On one occasion, Chris intervened whilst Beth was describing his grandmother's level of understanding of Imogen's diagnosis. Chris disagreed with Beth's comment, arguing 'I don't think she understands!' Beth responded to Chris by light-heartedly calling, 'Chris! Butt out, this is *my* interview!' We all laughed about this together, but directly after her retaliation, Beth revised her statement by noting 'yeah, she may not understand and may not *want* to understand' (Interview with Beth, 2014).

I did not know how Chris felt about the research or his partner's involvement in it. As far as I was aware, Beth had written her diary independently and privately, and in her writing she discussed conversations which had taken place between her and Chris, as well as her own personal reflections. In other interviews I conducted for this study, I felt a certain amount of freedom to address most of the diary content with the participants but while Chris was listening to my conversations with Beth I felt I needed to be more cautious to protect her confidentiality. Also, unlike other interviews, some of Beth's account was not only heard by me, but also by her partner, and her comments could have been adapted for his benefit. Despite these concerns, I am aware Beth selected this location for the interview and this may have been because she wanted her partner (and baby) to be nearby.

Due to the personal nature of the research, I was aware that participants may have had difficult or traumatic experiences relating to the content of the diaries and the interviews. Whilst the diaries were not specifically designed to give emotional support to the participants, some of them mentioned that participating in the research had been helpful. Beth talked about this in our interview:

> Beth: I know you sent your sort of instructions and said if you want to write something you can write it, if you don't, don't. And I chose to do it in the way that I did it in the journal and I found it *hugely* therapeutic, writing it. But that was sort of an aside, I suppose, it wasn't what I *thought* I'd get out of it. If that makes sense.
>
> Charlotte: So it was a pleasant surprise?
>
> Beth: Yeah, it was really cathartic. (Interview with Beth, 2014)

One of the intersex participants, Pandora, commented on a similar experience: 'when I was doing the diary it was very… certainly very cathartic just to write everything down, just a chronology of it all and it was really emotional, definitely a positive step to sort of reflect back on it' (Interview

with Pandora, 2014). Whilst I recognise that the talking and writing processes in the study had the potential to be useful to participants, I was careful to present myself as a researcher who was there to listen and learn, rather than someone who was there to offer advice. The 'giver of advice' is still an easy role to fall into without realizing. Letherby (*ibid*.) argues that

> although as researchers we may feel that we want to 'help' our respondents, it is important to acknowledge that such feelings may reflect our own needs – the need to feel better about the research and our involvement in it, or the need to feel useful – rather than those of respondents.

Whilst the aims and intentions of the meetings were made clear to participants and the information sheet informed participants that I would assist with locating an appropriate counsellor if it was needed, I still felt worried that participants might feel like the research had opened old wounds, or extracted traumatic experiences, without delivering a therapeutic process, leaving them feeling abandoned and unsupported. Like most researchers, I was a 'transient figure in their lives' (Weiss, 1994, p. 135), and this needed to be acknowledged with caution.

I was very clear with participants about the purpose of the research, the themes I expected to cover, and largely followed their lead on the direction of our conversation. Special care was taken when participants seemed to find the topics we discussed to be challenging and I tried to handle disclosures with tact. Nevertheless, after some interviews in which participants were clearly upset about the experiences they shared, I was left wondering if I had handled their accounts with the sensitivity and support that they required and if I had always responded 'correctly' and appropriately. In my train journeys home from the interviews, I often took notes on these reflections in my research diary, but after some of the more emotional interviews I needed a break from the topic for a little while and my reflections would be noted down the day after.

During the fieldwork, I took a largely transparent approach to sharing information about myself with participants. In the recruitment process of the research, I did not address whether or not I had an intersex variation, but upon meeting participants I always asked if they had any questions for me before we started the interview. Many were curious to know why I was interested in intersex, or how the research had come about. I interpreted this question as an attempt to determine if I had a personal connection with the topic, so at this point I clarified that I did not have an intersex trait, and provided participants with other reasons for my interest. Whilst I have noted that an 'insider' status may have offered advantages in the recruitment process, some researchers have argued that an 'outsider' perspective can also carry benefits (Bridges, 2001). However, with an awareness that my motives may appear less trustworthy as an outsider to the community (Perry *et al.*, 2004), I discussed previous research I had conducted on intersex as well as my longstanding interest in the area. Discussing my thoughts and knowledge felt beneficial and important in building a trusting relationship with participants; some aspects of commonality (i.e. in insider research) do not necessarily insure that the researcher will understand, agree or share experiences with a participant.

I paid careful consideration to participants' understanding and expectations of the broader outcomes of my research. As noted, some gate-keepers at the recruitment stage requested details of my potential contributions. Some participants also asked for information on outcomes,

and others implied that they had made their own conclusions about ways in which the research would contribute to the field or society more broadly. Whilst I did not want to undermine their involvement in the research or the value of my work, I also aimed to be transparent with participants about the limitations of the thesis and the extent to which I am able to contribute to immediate or radical social change.

Many participants hoped the research would contribute to improving, or changing, the current situation in some way. Beth commented that 'there is still *so* much that needs to be done on this subject, both in terms of the medicine and the whole social aspect so I just thought, if I can play *any* part in terms of helping to drive that forward, the only way things move on is when people do something about it, isn't it?' (Interview with Beth, 2014). Sophie said that she chose to participate because she would like to improve current medical treatment and social acceptance and combat the stigmatisation of intersex conditions. She noted that 'for me, this is my own little way of helping things improve without having to go out there and be open. So I feel if I can help people by doing this kind of thing a bit then it's my own way of doing something about it I guess' (Interview with Sophie, 2013). Natalie felt that intersex is '*completely* misunderstood' and said that many lack knowledge or awareness about intersex variations. She argued, therefore, that 'the more literature that is out there about it the better' (Interview with Natalie, 2014).

## Solicited diaries

The diary stage of the research provided an adaptable format for participants to explore their perceptions and experiences. Participants were asked to disclose whatever they understood to be relevant to their intersex identity and experiences, and encouraged to use a written or drawn format of their preference – whether prose, poetry, illustrations, diagrams or another form of expression (see appendix C). Most participants wrote prose, but some wrote lists, stuck in photographs of themselves and of family, and inserted annotated print-outs from medical documentation. One intersex participant, Ian, also sent digital copies of all of his medical records and correspondence. The diary submissions ranged in length; from shorter, typed pieces (starting from 800 words) filling two sides of A4 paper, to longer handwritten pieces (up to 10,000 words) which filled the journal I provided. Zimmerman and Wieder (1977, p. 488) note, similarly, that there was 'considerable variation in the depth and detail reported' in their diaries. This underlines the importance of conducting interviews after the diary submissions.

Participants were encouraged to write in a way which suited their needs. Ian chose to send his diary to me in five instalments over the period of two months; other participants also wrote in instalments but waited until the last submission before returning their writing. Some participants created an ordered 'collection of observations' (Weiss, 1994, p. 45) by dividing their diary content by theme (e.g. 'psychological aspect', 'surgery'). Diachronic reports (Weiss, 1994, p. 42) were written by some participants, in which the diaries told the histories, developments and discoveries which took place over the life course up until their present situation; Siân's diary opens 'Where to start? I guess I should start where it all began'. The formats and structures of the diaries themselves provided insight into participants' understanding of their experiences.

Solicited diaries are often utilized by and associated with feminist research (Meth, 2003, p.195) because of the way in which they 'can promote participation and engagement by respondents in the research process'. Whilst they are written on request, with a purpose and an intended reader (i.e. the researcher), my influence was minimised due to my absence during the writing process.

The participants therefore had greater control over the content discussed than in an interview, and were able to select the themes covered and the degree of disclosure. Meth and McClymont (2009, p.915) point to the 'more open approach, as the writer has the time, space and privacy to consider what it is they wish to share'. Participants were able to slowly reflect on their situation at their own pace and re-visit the diary over a period of weeks. Some of the participants dated each entry, and wrote frequently of a long period, sometimes just a few lines at a time. In our conversation about research methods, Jay Hayes-Light commented on how much he liked my use of journals, and appreciated that participants would have the freedom and choice to 'write down thoughts and/ or draw whenever' (Email communication, 2013).

The temporal freedom this method grants participants was especially evident in its use by one intersex participant, Natalie, who chronicled her anticipation ahead of medical appointments, then reported back in detail immediately following the events. For example, she writes,

> Aug 2nd
> On way to my first proper appointment about my diagnosis since diagnosed in 2002 whilst studying in Newcastle. Feeling so anxious and resentful at the same time for what I believe are failures on the NHS's part. Seriously hoping today will be the start of finally getting answers to the questions I have spent 11 years thinking of.
>
> [Photo of a digital form listing the participant's personal details in which Natalie has been identified as 'Mr' in the 'title' section. Participant has written on the photo in pen. 'Not a good start ☹']
>
> Looking back at yesterdays [sic] trip to London to see Dr Muller. I am dissappointed [sic] that the sense of relief I was desperate for is still with me.
>
> I know this mainly comes down to admin error such as Dr M not actually being informed of my attendance so therefore me being assigned to a doctor who knew nothing of me or my condition. I had prepared so much my the day and my opportunity was a five minute slot upon passing Dr M in corridor to ask why I didn't get to see him.
>
> Just have to wait til next time. (Natalie's diary, 2014)

Diaries helped participants to negotiate problems with recall, which can occur in interviews, and at times provided me an insight into their immediate emotional responses to events they wanted to address. As illustrated in the extract above, Natalie often felt anticipation prior to her medical appointments, and she was able to portray this in her diary in a way which gave a present and direct response to these challenges, rather than waiting three months until her interview to discuss it with me personally. Beth wrote her diary five months after the birth of Imogen, and met me for her interview two months later. Whilst her experiences of her daughter's initial CAH diagnosis were relatively recent, she commented in the interview that there were many occurrences that she had remembered 'only when I was writing the journal' (Interview with Beth, 2014).

The greater level of control that participants are able to exercise over diary content has led some researchers to question the validity of the method. Meth (2003, p.202) notes 'the obvious

selectivity the respondents maintain in the process of completing diaries' may cause issues regarding the 'truthfulness' of diary entries. She proclaims that 'as in any research tool, what is omitted and overlooked is often as interesting as what is recorded and discussed'. Further, Elliott (1997) mentions the likelihood of retrospective censorship in the diary entries more than in other methods. However, there is no evidence to suggest that selectivity in itself must necessarily lead to falsification or withheld information. Conversely, it may mean that knowledge will be shared that the researcher may not have considered or enquired about in other, more researcher-led, methods such as structured interviewing. In an attempt to build a trusting and empathetic relationship, I felt it was important to grant respondents the agency to choose what kind of information they were comfortable disclosing. I did not want 'to 'do' rapport' or play the role of 'listener' 'in order to encourage disclosure which might later be regretted' (Duncombe and Jessop, 2012, p. 112). Due to the personal subject matter, it was important that the participants felt a sense of control and accurately portrayed by their output. Where appropriate, discussions of omitted or censored material and requests for elaboration were possible and, in some cases, necessary in the follow-up interviews. However, my caution here meant that some topics were not covered in the detail that may have been otherwise preferable and I did not discuss the same themes with all participants. For example, all of the women in the study, but none of the men, discussed experiences of infertility in their diaries and interviews. As this was not a topic I had initially identified as a key interest for this study, I had not listed fertility and parenthood in my interview guide and did not pursue the issue with interviewees. The two men in the study were the second and third interviewees I met, so clear themes had not yet started to emerge when we spoke.

Rather than '*including* others' lives and thoughts in research', this study seeks to '*[start] from* their lives to ask research questions' (Harding, 1991, p. 269, emphasis in original). While superficially this may look something like Glaser and Strauss's well-known 'grounded theory' (1967) approach, there is no formal method or protocol. This is more interpretive and focused on each individual separately. By structuring my themes and points of focus around each participant's needs and emphases, I hoped to 'start [my] thought from the perspective of lives at the margins' (*ibid*.) and ground my thesis in their personal experiences rather than my own expectations. Many of the central themes which have formed a basis for my analysis chapters were not targeted as key areas of interest in my original research plans and were therefore not explicitly posed to participants in their interviews, but rather raised by the participants themselves. Therefore, I believe the thesis gives an insight into issues which are of particular concern for the participants involved, rather than for the researcher alone. Miller and Bell (2012, p. 54) explain that 'as feminist researchers we identify knowledge production as being grounded in individual and collective experiences', which means that 'the course of a project may only be guessed at initially'.

Despite taking this standpoint, I recognise the themes raised by participants may not be the only issues of significance to them; 'we have to listen in stereo, receiving both the dominant and muted channels clearly and tuning into them carefully to understand the relationship between them' (Anderson and Jack, 1991). Respecting the participants' selectivity whilst taking an interest in what is overlooked, hidden or evaded is a difficult balance. As Anderson (1991, p. 13) reflects, her 'fear of forcing or manipulating individuals into discussing topics they did not want to talk about sometimes prevented me from giving women the space and the permission to explore some of the deeper, more conflicted parts of their stories'. This underscores the importance of constructing shared expectations between participant and researcher (which a diary can assist with), and

reflecting on the researcher's position as someone capable of granting 'permission', and how and when this should be managed.

The absence of the researcher during the diary process provides the benefit of helping to obscure the researcher's ability to grant permission and authorisation. Meth (2003, p. 198) commends the diary as a 'discontinuous process' which 'reflects more accurately the diverse range of thoughts and feelings that make up human consciousness'. The flow during interviews, for instance, may not always offer the opportunity for interviewees to introduce material they would like to share, and which may not be immediately relevant to the question at hand. In an interview, an expectant audience (me) awaits a response which the participant may feel needs to make immediate sense. Contrary to concerns of omission, Meth (2003, p. 203) observed that during her research two participants confided that their diary entries included personal stories which they had not divulged at any point prior to the solicited diary. Meth notes that the type of 'traumatic and personal' experiences shared in the diaries were not discussed in subsequent interviews, suggesting that perhaps the self-determined knowledge production solicited by the diary method is a more reliable format for participants sharing complex or upsetting material. Similarly, in my research, some participants told me that there was no one in their lives who they were able to talk to about these issues, so the diary was their first encounter with sharing their feelings with another person. The diaries therefore provided a useful bridge to what could have been quite an emotionally provocative first meeting for participants.

Instead of returning her diary like other respondents, Beth, one of the parents participating in the study, sent me a photocopy of the hand-written diary. Beth put the diary in a box she and her partner had created for their daughter, Imogen, along with her hospital band and other bits and pieces for her to see when she was older. Beth commented that the diary was 'a really positive thing that came out of [the research] for me' (Interview with Beth, 2014). She explains further,

> there was a lot that went on at that time and y'know, it's part of who she's [Imogen]... that's the start of her journey, isn't it? And y'know, it's going to be really nice and hopefully, I mean there's probably stuff in there that would be quite hard for her to read, but it would be really nice for her to understand... and I think if I hadn't written it down, memories change, y'know, your memory of how things were sort of – over the years – will change, and fade, and so hopefully that's quite a nice way of capturing all the details.

Whilst this was not anticipated, it has been rewarding to see that the diary is expected to have some value and legacy for Beth and her daughter, and not just for my research.

## Interviews

In-depth research interviews took place between October 2013 and October 2014, and were scheduled within two months of the participants' submission of their diaries. Interviews ranged between 90 and 145 minutes in length. The average interview was 128 minutes. The interviews were designed to be informal 'conversations with a purpose' (Burgess, 1984, p. 102) which drew on the data produced in the diaries. Meth and McClymont (2009, p. 915) state that due to working with participants who were 'severely marginalised and who are thus angry, upset and emotional

in the research context' they found that the 'contributions can be contradictory and mixing methods enhances qualitative triangulation and furthers the credibility of data'. With the awareness that my own data could be similarly complex, the triangulated and tiered process gave me the opportunity to enquire further about particular material of interest and revise my understanding of the diary content.

All qualitative material was approached with the belief that language is constructive and that discourses 'constitute systems of knowledge and belief' (Fairclough, 1995, p. 6). For this reason, the interviews were approached as 'the construction or reconstruction of knowledge more than the excavation of it' (Mason 2011, p. 63). That is to say, the analysis considered 'the way versions of the world, of society, events and inner psychological worlds are produced in discourse' (Potter, 1997, p. 146), emphasising the discursive embodiment of participants' identities rather than attempting to access or represent intersex itself as a material subjectivity. The interviews (and subsequent analysis) focused on participants' perceptions and interpretations of the issues being discussed.

The interviews were one-to-one, in-person and largely unstructured, and took place in the area participants were living, in a range of different towns across the UK. I asked participants for suggestions for the interview location in the hope that we could find a space in which they were comfortable. On two occasions the interviews took place in participants' homes, whilst other interviews were in public places such as coffee shops and pubs, and some were in booked meeting rooms which I arranged with the participants' permission. As previously noted, location made a difference to our meetings. Natalie and I met in a meeting room at a leisure centre because of its convenient location for both of us and the affordable room prices. The room was small and very dark, with no windows, and situated behind a swimming pool so the sound of children's voices drifted into our meeting. The only furniture in the space was a single table and two hard plastic chairs facing opposite each other. In my research diary I called it 'the police interview room', and joked with Natalie when she arrived about the atmosphere. Despite my concern that the room would not contribute to my attempts to make Natalie feel relaxed and comfortable, laughing about the situation with the participant helped to transform the sobriety that our surroundings cultivated.

I had selected very broad points of discussion for the interviews, focusing on participants' notions of intersex, and their experiences of the social and medical responses to intersex as both a form of classification and of embodiment. I was also interested in their understanding of gender identity and whether they felt intersex traits bore any relation to their experiences of gender, their notions of normalcy and difference, and how their sense of identity more broadly relates to their diagnosis. The content of the interviews was partially determined by the material in the participant's diary. I had initially hoped that the full collection of diaries would be used to form themes of interest for interview topics and discussion starting points in the guide, however recruitment was much slower than I had expected so participants' diary submissions and interviews were undertaken in succession.

Using the participants' diaries, I created a personalised 'interview guide' (Bryman, 2004, p. 113) of broad issues for each participant rather than a list of questions. It was intended that by avoiding a predetermined list of questions the participant would have a greater level of control over the direction of the discussion, and the flow of the interview would be more conversational and reflect

the interests of the participant, rather than solely my own. I used the guide as a prompt during the interviews to check that certain issues had been covered. The key issues were often brought up by me or the participant within the flow of the conversation (e.g. in response to a comment or as a request for further clarification), rather than as a scripted question, especially in later interviews when I was more familiar with the content of the guide. Despite putting the guide to fairly minimal use in some interviews, it was an essential part of the planning and design of my research, and helped me to refine the purpose of the study and reflect on ways to approach participants. I also consulted the guide towards the end of the interviews to ensure that there were no remaining themes left unaddressed.

Participants were at different stages in their lives and at different stages within the medical process, and had experienced various emotional responses to their intersex status. The participants' diaries gave me a good indication of this and allowed me to respond accordingly, with caution where necessary. As previously noted, I aimed for participants to take some control over the direction of our conversation, and what was in/excluded. This intention was made clear to the participants and, whilst there was no way to ensure they would feel *able* to object, they were encouraged to identify any aspect of the research which presented an issue to them. When discussing this approach with Jay Hayes-Light, he commented that 'the way in which you describe the process to potential interviewees is excellent as it stresses that at all times, the other person is in-control of events' (Email communication, 2013). Jay noted the importance of this approach, because

> [m]any intersex people have memories which echo the occasions when
> they were not in control of events, be they physical examinations, [or]
> rather probing, often patronising interviews and instructions (rather
> than suggestions) as to what course one's life should take.

Unstructured interviews were an important way of developing rapport, listening to the participants' own concerns and reflecting on my own role in the interview process. Despite having 'a basic interview plan in mind', in an unstructured interview the researcher has 'a *minimum of control* over how the respondent should answer the question' (Hesse-Biber, 2007, p. 115). In this format, there was more space and opportunity for participants to introduce their own ideas and experiences, and for both of us to behave and respond to each other with a degree of spontaneity.

I started all interviews by asking participants why they got involved in the research. Their response to this question usually led on to other spontaneous questions, including discussions of the diaries, particular frustrations they felt with medical approaches, or social understandings and awareness of intersex. I used this initial question as a way of opening out our conversation, and to give participants the opportunity to shape the direction of our interview early on and underline issues they felt to be of importance. Hesse-Biber (*ibid*.) regards the initial question as a significant moment 'to open up a space for [the participant] to speak about what she feels is important, to convey her own feelings'. Whilst the majority of the interviews lasted over two hours, in most of our meetings I asked participants very few questions. For the most part, participants spoke at length whilst I listened to their stories with occasional words and nonverbal gestures of encouragement. In their interviews, all participants explicitly referred back to accounts they had shared in their diaries.  At times, references to diary content were used to add credibility or confirmation to their spoken claims, and participants also added nuance or clarity to accounts in the diaries that they had since thought differently about. Diaries were also used as a shared

history that we could both call upon in the interviews. Sometimes we would laugh together, or share frustrations about a story we both recalled.

I approached the interviews with a level of informality. Whilst some participants were very focused on their experiences of intersex, others spoke on a number of other themes. Allowing the conversation to drift at times felt like an important way of building a relationship with participants; thus, I did not attempt to reassert focus or order when we moved off topic, and often engaged in lively discussions about various other topics, from ghosts and clairvoyance, to drinking cultures at university. This could also serve as an important 'pause' for participants from conversations which could be emotionally taxing. The interview process was undertaken with continuous ethical reflection, as previously noted. Hesse-Biber (*ibid.*, p. 130) argues that '[r]eflexivity goes to the heart of the in-depth interview; it is a process whereby the researcher is sensitive to the important "situational" dynamics that exist between the researcher and the researched that can affect the creation of knowledge'. The year-long duration of the interview and diary process also gave me plenty of time to re-evaluate my interview practice between each of the nine meetings, and reflect on how to approach certain aspects differently.

With the participants' permission, all interviews were digitally recorded and transcribed verbatim. I completed transcriptions immediately after the meetings so that I was able to remember body language, facial expressions and the tone used by participants and myself. I took care to represent speech patterns, false starts, personal grammar, pronunciations, pauses and emphasis in the transcriptions. Italicised text in the quoted interview extracts throughout the thesis always represent spoken emphases (rather than emphasis for analytical purposes). Like DeVault (2004, p. 242), I hoped to 'preserv[e] some of the "messiness" of everyday talk' in my transcriptions and convey participants' unique articulations as accurately as possible.

## Analysis

Over the course of the year-long data collection period, I started to tentatively analyse the materials whilst still recruiting, communicating with participants, and conducting and transcribing further interviews. I looked for questions produced by the data, recurring ideas or themes, and particular issues that I felt developed my understanding of the experiences or stories shared by participants, and these initial insights gave me a framework to approach later data collection. In light of Anderson and Jack's (1999, p. 19) advice on how we can 'learn to listen', following the data collection my first step was to 'immerse' myself in the interviews. This required listening to the recordings on multiple occasions, and re-reading the transcripts and diaries individually. Once I had become more familiar with the contents of the interviews and diaries, I started a thematic 'breaking down' of the data (Mauthner and Doucet, 1998, p. 135). The familiarity created through the practice of immersion helped to generate indexing categories from the data.

I categorised the diary entries and the interview transcripts into a coding scheme; first coding the large volume of data produced by the diaries, and examining the patterns that started to emerge. This contributed towards developing the themes used to code the interviews. I reproduced the diaries in a digital format by typing their content into a computer document, and then referred to both the digital and material copies of all data. This was an iterative process, in which I returned

repeatedly to the data throughout the coding, analysis and writing-up periods to re-read interviews, diaries, and particular sections or themes.

Most of the initial coding was performed on paper copies of the transcripts and diaries, where I collected notes and patterns in the margins using coloured highlighters and post-it notes to coordinate themes. Hard copies of the handwritten diaries were significantly different to their digital form; they included a range of visual data, including photographs, capitalisation of text, underlining, and drawings. These visual elements were coded and included in my initial notes before I moved onto the digital versions. Digital copies aided coding and analysis in that they were easily searchable and themes could be collated in one document. Using the digital copies of the data, extracts that fit into the broad coding themes were cut from their documents and transferred into themed 'excerpt files' (Weiss, 1994, p. 156). I used these files to create a more manageable collection of data on a particular theme, to allow for further sorting of the material and (sub-) coding. These files were made up of material from the whole data set, and provided a consistent, uniform format for diary and interview extracts to be observed simultaneously. All extracts selected were labelled with the data medium (i.e. interview/diary) and participant pseudonym. The different types of data were cross-referenced with each other in order to reflect on consistency across media, as well as thematic concordance.

For the most part, the broader themes I identified and used to build the excerpt files became the outline for my analysis chapters, and the sub-themes were used to divide the chapters into sections. When planning each analysis chapter, I read through my themes in the related excerpt file and then returned again to the transcripts to check the context and – in the diaries – the visual presentation of quotes. This was to ensure that all relevant data had been observed, whilst also testing my themes against the data. As Mason (2011) notes, my involvement in the data generation, data selection and the interpretation processes is not neutral. I am implicated in the cataloguing and coding systems employed, and the analysis conducted has been to some extent guided by the kinds of phenomena I have found interesting or useful.

The coding process enabled me to 'locate larger meanings related to the research problem' (Hesse-Biber, 2010, p. 94) and the subsequent content analysis provided a way of 'making inferences by objectively and systematically identifying specified characteristics of messages' (Holsti, 1969, p. 14). Whilst Holsti's claim to objectivity is not entirely practicable or necessarily desirable (see above), content analysis helped to ensure transparency in the approach, to assist in making 'personal biases intrude as little as possible in the process' (Bryman and Bell, 2007, p. 303). The content analysis was conducted with an emphasis upon the discursive manifestations of identity and intersex experience. The process of interpretation was understood as a 'political, as well as intellectual process' (Ramazanoğlu and Holland, 2002). In the analysis and writing-up process, I therefore maintained ethical attentions to care in the use of participants' stories and strived to retain the context and meaning of participants' contributions.

The data analysis and the writing of chapters were both undertaken as reflexive processes, with particular caution paid to my own ability to re-construct the stories shared by participants by translating their accounts into 'academic knowledge'. However, Hayfield and Huxley (2015) note the problems with simply *relaying* and potentially validating respondents' stories, and point to the importance of challenging or criticising accounts where appropriate. I aimed to provide an adequate number of extracts from the data which were sufficient in length in order to provide a

context for these stories, allowing readers 'to evaluate the inferences drawn from them and the interpretations made of them' (Brewer, 2000, p. 133). Participants often presented multiple, sometimes contradictory, accounts in interviews, or across the two different methods of data collection. Similarly, the patterns and themes observed in the data analysis were not constant or uniform in all cases; exceptional or anomalous narratives were also considered to be significant and were therefore incorporated into my analysis. It was important for the analysis to reflect these contradictions and complexities, rather than to obscure them.

This study's feminist theoretical grounding provided a framework throughout the research process, prior to and throughout the analysis and the writing of chapters. This theoretical underpinning informed both the research design and approach to the fieldwork. Whilst theoretical insight has also been central to building the arguments made in this thesis, in the analysis of data it was applied with discretion, in order to highlight, explore and develop the everyday realities of the participants involved in this study, and to avoid detracting from these experiences. The rich data collected from the participants' stories in this study formed the basis of these discussions, and theoretical developments were used to illustrate, contextualise and expand these points evocatively. I made detailed notes on theoretical insights, references, analysis and stray ideas throughout the study, including during and directly following interviews. The research diary was used to note down some of these ideas, but other notebooks, post-its and computer documents were also used where convenient. Notes were also used to link the analysis to the theoretical literature in the early stages of reading and coding the transcripts and diaries, and new – sometimes unanticipated – theoretical ideas and strands were pursued and developed throughout the research process, including during the writing stages. Theoretical consideration and analysis were continuous processes, which occurred throughout the study.

## Conclusion

This chapter describes the importance of placing the stories told by participants at the centre of the thesis, my aims to depict their accounts fairly, and to work with them in a way which is transparent and respectful of their needs and experiences. By grounding the research in the experiences of participants, and inviting them to guide the direction of the themes explored, this study provides an insight into the areas that participants themselves consider to be of importance. I show how feminist theoretical and epistemological approaches guide my approach, helping me to negotiate a focus on participants' stories which also acknowledges my own pivotal role, agenda and 'outsider' standpoint in the research.

The use of a two-tiered qualitative multimethod approach, known as the Diary-Interview method, has been key to this chapter. This method was adaptable for participants' needs; some were more comfortable either writing or speaking about their experiences. This was evident in the diverse range and length of diary submissions, and the different ways participants approached and later spoke about the task. Due to the evocative subject matter, some participants shared content in their diaries that they had not discussed with anyone before. The diaries contributed a formative stage to the fieldwork, which provided me with important foresight and background details ahead of the interviews. This method fits into my iterative and reflexive understanding of the research process, and provides space for the depiction of complex, changing and sometimes contradictory views and identities. Using two approaches to data collection therefore also helps to enhance credibility and accuracy in the analysis of the data set.

Whilst I show that there were some challenges in recruiting participants for this study, I argue that the small size of the project has also been advantageous. Rich, intimate and detailed accounts were given by participants in the diaries and the interviews, and these were relayed and explored in depth in the analysis and writing of chapters. Ethical guidelines provided by the university and ESRC were incorporated into the design and followed throughout the study, but the ethical dimensions of this research were complex and messy, and required careful monitoring and situational reflection beyond these guidelines. Edward and Mauthner's (2012) adapted feminist ethics of care provide a useful framework for thinking about responsibility, empathy and care in my approach to the participants and, at times, myself.

It has been important to reflect on the experiences of some participants, who found the research personally helpful; many commented on the diaries performing this function, and the relief they felt to speak to someone about issues which they had not previously shared. Whilst the research is not specifically intended to serve this role, the significant impact that writing and speaking on these themes had on some participants may indicate the current deficiency in support available, and the social boundaries set by the stigmatisation of intersex traits, which can prohibit assistance from being sought and experiences from being shared. This demonstrates the value and importance of conducting research of this kind.

# 5

## Loneliness
## Negotiating Social Relationships and Learning to 'Fit'

*I am twenty-five years old, and, although I am still young, I am beyond any doubt approaching the hour of my death.*

*I have suffered much, and I have suffered alone! Alone! Forsaken by everyone! My place was not marked out in this world that shunned me, that had cursed me. Not a living creature was to share in this immense sorrow that seized me when I left my childhood, at that age when everything is beautiful, because everything is young and bright with the future.*

*That age did not exist for me. As soon as I reached that age, I instinctively drew apart from the world, as if I had already come to understand that I was to live in it as a stranger.*

*– Herculine Barbin (1980 [1872], p. 3)*

According to Mills (1959, p. 14), the relationship between 'personal troubles' and 'the public issues of social structure' should be central to all sociological scholarship. The fraught, complex and heterogeneous interconnection between the individual and society, as well as an exploration into how these two concepts are constituted (and to what extent they are separable) is fundamental to much of our thinking on loneliness, its causes and its significance. Whilst much social theory does not appear to be concerned with issues of loneliness, this chapter will explore how loneliness sits beneath the surface of a range of work on social relationships, bonds and ties, as well as the ontological and epistemological value and security of 'the individual'. Most fundamentally, this is illustrated by the common belief – which weaves throughout many, if not all, of the texts discussed in this chapter – that our potential, pleasure, worth, and even coherence, as individuals is recognised only in and through our meaningful relationships with others.

## Loneliness and intersex

Sociological excursions into loneliness, (in)dependency, social needs and bonding lay the infrastructure for my own considerations in the field.  Reflections on the emotional and social struggles of intersex people require an understanding of the fundamental and interdependent relationships between the constitution of the personal, social and structural facets of our lives. Following Durkheim, this includes a recognition of how social structures can influence, or determine, individual behaviours and choices; that personal actions can never be performed or interpreted outside of a social context and, following Marx (1970), that the actions of those with state and institutional power have crucial, but perhaps unnoticed, affects upon others. Thus there is nothing 'natural' or 'inevitable' about these processes or structures. Whether or not loneliness is the driving force behind all human behaviour, as Mijuskovic (2012) argues, it is clearly a crucial part of all lives (Peplau and Perlman, 1981), in different ways and to varying degrees. When social bonds are seen as fundamental to physical and mental health, and a high

quality and 'successful' life, those who are outcast are disavowed even more severely. Their sense of being, without approval, recognition and engagement from others, may cease to 'make sense'. Loneliness, then, may not only be a form of social deprivation/exclusion or emotional disturbance, but also an indication that intersex people are devalued.

Accordingly, this discussion of loneliness reaches beyond social isolation, in that it considers social, structural and institutional factors which *produce*, or make more probable, loneliness and the various personal and social struggles which may be a *consequence* of loneliness. Echoing Brown and Harris (1978, p. 270) on depression; 'social milieu and the broader social structure are critical because they influence the way in which she *thinks* about the world and thus the extent of […] hopelessness; they determine what is valued, as well as what is lost and how often; and what resources she has to face the loss'. Brown and Harris's empirical work played a significant role in encouraging an understanding that various kinds of struggles and difficulties we may experience in life can play a significant role in the occurrence of depression; life events and social environment – rather than biology – can play a key role in the onset of depression, despair and loneliness.

Since many of the participants in this study underwent medical consultation, diagnosis and – in some cases – treatment, during childhood and adolescence, theoretical dialogue addressing the emergence of self (Mead, 1934) and early bonds (Bowlby, 1951) raises relevant considerations for intersex issues. Children's initial conceptions of themselves, which may also persist into adulthood, are shaped by early representations of their bodies, identities and futures. The presumed centrality of medical responses to intersex, as well as the pivotal role parents take in making decisions about their children's wellbeing, are therefore likely to have fundamental consequences. Bowlby's (1951, p. 84) observations on the importance of social support for parents in order to protect the needs of children also encourages some reflections on the potential for intersex issues to affect *others* within close social networks; perhaps causing wider familial struggles and parental isolation, which could in turn lead to further problems for children.

Social needs theorists, such as Peplau and Perlman (1982), ask us to consider how personal feelings of inadequacy and low self-worth may contribute to the experience of loneliness. They perceive loneliness to be a feeling which responds to social bonds which are, for whatever reason, insufficient. Crucially, despite having many friends, family and other social connections, loneliness may still persist if these relationships are not fulfilling the needs of the individual. This may be especially pertinent to intersex individuals who feel unable to speak to others about their sex/condition. 'Random sociability' (Hortulanus, et al, 2006, p. 17), social needs theorists suggest, can in fact aggravate feelings of loneliness rather than alleviate them. The social value placed upon bonds with others, especially pressures to form what is considered to be 'meaningful' on 'intimate' relationships – and the knowledge that one is perceived to be failing at this – may also contribute to further isolation or feelings of inadequacy.

Lynch (1979), Elias (2001) and Rosedale (2007, 2009) are among the many scholars who have pointed to the complex relationship between health, social and personal needs. The connections between these aspects of people's lives underline the imperative for medical practice to consider its influence upon social and personal, as well as physical, wellbeing. Loneliness can derive from severe marginalisation and extraordinary situations and, in this sense, it affects those whose lives may be exceptional in some way; but loneliness is also mundane and

commonplace. Very few, perhaps none, of us have evaded loneliness entirely. Despite this, as previous loneliness literature confirms, loneliness is an experience which is hard to pin down and frustrates definition. The following discussion is not intended to refine the concept further, but rather to pursue critically the theorisation of loneliness and its various manifestations, and consider how these ideas can be applied in the context of an intersex status.

## Shame and loneliness

After spending the Christmas break with her family, Pandora told her parents that she needed to return to university to study. Instead, she travelled to the hospital to undergo her vagina surgery alone. In her diary, Pandora's memory of this time is distinctly solitary; only magnified by the illusory visions she experienced of a well-populated hospital ward. Pandora spoke of the confusion she experienced after she had woken up from the surgery and started a programme of opioid analgesic drugs: 'I didn't hallucinate as such, but each time I closed my eyes I microdeamt that I was surrounded by people, only to open my eyes to an empty room' (Pandora's diary, 2014). Without informing any of her friends or family, at 19 years old Pandora underwent a surgical procedure to extend her vagina cavity. She chose to undergo a technique similar to vaginal dilation, the Vecchietti procedure, which is a one-step medical intervention in which the vagina 'dimple' undergoes continuous pressure for 7-10 days in order to enlarge the cavity. Pandora was in hospital under supervision for the duration of the procedure, undergoing a tightening of the medical apparatus each day, which caused a 'huge amount of pain' and meant that she was unable to stand independently during the course of treatment. Once the apparatus was removed, she was still unable to walk for two days and lost ten pounds in weight over the duration of her stay.

Not only did Pandora find her diagnosis of complete androgen insensitivity syndrome (CAIS) and her 'non-conforming' body to be shameful, she was also deeply embarrassed by the thought of undergoing surgery. The shame she experienced was so acute that it felt crucial to her that the surgery be kept entirely confidential. She needed to withstand the operation on her own, in secret. Thus, the wider social stigmatisation of her body and condition led to Pandora orchestrating her own isolation during this time. In line with a cognitivist view of loneliness (e.g. Peplau and Perlman, 1982), the isolation Pandora describes at this time does not appear to be a result of an absence or lack of friendships or familial bonds. Instead, there is a perceived disjuncture between what is desired from social interaction and what is presently achieved. Due to circumstances in which Pandora was ashamed and stigmatised by her body, diagnosis and treatment, she felt restricted in her ability to share her struggles or look to others for support, company and companionship. Thus, the social bonds she had at this time were not providing the support she needed, and she felt unable to pursue other means.

Due to her sense of shame, Pandora also spoke of suicidal intentions once the medical procedure had been undertaken. She explains,

> the idea of the surgery was so shameful that I couldn't live with it. So I would have the surgery and take my life after. I prepared, planned and obsessed. It was an awful term at uni, knowing I was going to die made everything so futile, I was reclusive and couldn't sleep. My work suffered as did my friendships. (Pandora's diary, 2014)

In anticipation of her surgery, Pandora reflected on an increasing detachment from society. Whilst much of the seclusion she speaks of she describes as self-imposed, the shame and associated feelings of purposelessness and futility Pandora experienced seem to reflect wider social understandings of the importance of 'naturalness', bodily integrity and binary sex. These feelings of loneliness and the suicidal intentions Pandora describes are not simply individual expressions, but – as Durkheim (1951 [1897]) argued – responses to structural constraints. Underlining the ideological and political import of recognising the powerful role of social structures and constraining social factors beyond the capacity of the individual, Durkheim (1951 [1897], p. 43) argued that many of our actions are 'are outside rather than within us, and are effective only if we venture into their sphere of activity'. Pandora's perceived failure to be the person she felt she needed to be (and, on some level, was *told* she needed to be) led to her feelings of deficiency and a self-imposed social isolation. Her life was not worth living because she feared it was a life, and a body, which did not concur with conceptualisations of social worth.

Pandora's views on normality, recognition and 'fitting' within social environments were central to her paradigm of 'worth'. In Pandora's interview, we discussed what it meant to be 'normal', and – given her own feelings of abnormality – we considered to what extent normalcy was a desirable or achievable goal. She articulated the tensions she felt between her own contentment towards difference, whilst concurrently struggling to find acceptance and belonging,

> It's like, what is normal? And normal's just a silly idea but… but for me, yeah, I don't – *can't* give myself that forgiveness really. Uh, it's not that I don't want to be – I *don't* want to be normal, that's not what it is – it's not that I want to be the *same* as everyone, like I can – I *want* to be different, but not feeling in that – in that, almost it feels like such a crucial way. Or, it has done – of that… 'humans are male or female', and if I don't, that is *the crucial difference*. And that's the one where… that's the one – if we're going to fit in, the one thing that we need to be 'normal' in that sense. And I think that *is* just, just the *one* thing where – the classification that seems like the important one. It's not that I want to be the same, I just want to be the same in *that way*. Um, and yeah, *categorisable*, I s'pose, in that way. For *myself* as much as for anyone else, just, um, so that I wasn't as – I wasn't this anomaly. (Interview with Pandora, 2014)

Whilst she acknowledges the beneficial or tolerable aspects of some kinds of difference, Pandora underlines divergence from the sex binary as a problem; something 'crucial' which casts her as an 'anomaly'. Pandora's understanding of binary sex categorisation as a fundamental element of humanity, and thus of recognition and belonging, has been learnt from her experiences of shame, secrecy and renunciation. Pandora's realisation that 'normal's just a silly idea' demonstrates her awareness of the regulating and ideological function of normalcy, but it does not provide any consolation to her, when social and institutional responses continue to frame intersex bodies as 'a "problem" in need of fixing, as a psychological emergency in need of medical intervention, [and] a "disease" in need of a cure' (Hester, 2006, p. 48). This construction of the abnormal, incongruous body, and the assumed coherence between normality and the sex binary, contribute to the ostracism of Pandora and other people with atypical sex traits.

# Self-worth and loneliness

Some participants expressed a very acute sense of social unacceptance and rejection. This meant that not only did they feel they lacked sufficient support, it was also especially challenging to seek new friendships or reach out for assistance. Ian reflected on how the bullying he experienced during childhood may have impacted his current ambivalence towards forming new social bonds,

> I think because of all the ridicule as a child, I reacted with withdrawing and isolating myself. I think isolating myself, it led to some um... difficulties, I think developmental problems and um... I think the lack of friendships, relationships growing up, that led to... um difficulty in social interactions, um then the um experiences of people that were there, the ridicule and the rejection of me. And um... and you get to the frame of mind that, you know, people won't accept me, so I tend to isolate myself. Um but I guess it's about trying to change my core beliefs about myself, that there are people out there who will be kind and positive. But yeah, I have a hard time with that, trying to engage with people, yeah.
> (Interview with Ian, 2013)

Ian acknowledges that his negative experiences with some individuals have led to a sceptical and cautious approach to forming new relationships. His self-imposed isolation acts as a security barrier, protecting himself from further social harm; which, in this case, unfortunately comes at the cost of loneliness. He battles with the perceived inevitability of social rejection whilst attempting to re-learn the valuable and enjoyable potential of friendship. However, in Ian's reflections on more recent attempts to form new relationships he continues to feel condemned to social rejection. For example, in his interview Ian relayed a story about an occasion when two work colleagues had invited him to attend a baseball game. Ian notes that another colleague, who had previously harassed him and told others at work that he was transsexual (which is not true), had also been expected to attend. However, this colleague cancelled and said he had another appointment. Ian notes that 'my perception was that, y'know, he didn't want to be out with someone like me' (Interview with Ian, 2013). Ian interpreted the harassment, false rumours and avoidance that he experienced in this instance as symptoms of a universal 'human *fear* and disgust and hatred' (Interview with Ian, 2013), which he believes is inflicted widely against transsexual and intersex people.

Whilst Ian frequently reminded himself in his interview that there are 'some people [who] may be more understanding and supportive' (Interview with Ian, 2013), his depiction of the aversion shown towards transsexual and intersex people as 'human', universal and instinctive, offers some justification or, at least, accommodation to this hostile behaviour. Ian also implies that he is in part to blame for the negativity directed towards him. In the extract above, he refers to his 'developmental problems', 'frame of mind', tendency to 'withdraw and isolate myself' and the 'core beliefs about [himself]' as contributing to, and perhaps even creating, the loneliness he experiences. Elsewhere, he excuses the physical and verbal assaults he has received by commenting that he 'allow[s] people to walk all over me too much, I need to stand up for myself more', and remarks that 'I have to kind of get out there and be more open and uh less shameful' (Interview with Ian, 2013). By placing responsibility on himself, Ian feeds into a cycle of low self-worth, loneliness and remorse, from which he has struggled to break away throughout the whole of his adult-life. As I will explore later, a lack of community in which to share or exchange

stories and experiences also prevents Ian from observing the commonality of these experiences amongst other intersex people who, similarly, are not to blame for their ostracism.

Like Ian, Pandora felt uncertainty about the value of her social contribution. In her diary, Pandora detailed how feelings of inferiority led to her experiences of alienation within social interactions. She explained that,

> when the feeling of difference descends it's like a pane of glass has appeared between me and them, and although I'm a few feet away I feel so many miles away. And it's all because I don't deserve to be a valued member of a group. Outsider in terms of identity, so outsider socially. (Pandora's diary, 2014)

The feeling of 'difference', which will be discussed in more detail later in the chapter, is described by Pandora as generating a sense of shame, inferiority and loneliness. Pandora's example illustrates how the intensity of loneliness can persevere despite social connections or the presence of others. As observed above, Pandora's experience of isolation is independent of the quantity of social ties she has formed, or whether she is in company or alone. This is a feeling which is rooted in her own self-worth and her conceptualisations of the social value of difference. She explored the feeling further, noting:

> In groups, I often find myself as the bystander, there but not contributing, watching people laugh together but not laughing with them. For in my mind I am ranked below them, the whole, worthy, beautiful people. Nothing I can say is ever of worth, as it comes from this incomplete lesser. (Pandora's diary, 2014)

Peplau and Perlman (1982) suggested that the experience of loneliness was heightened when combined with a related belief of personal inadequacy. In Pandora's account, her feelings of social inadequacy and inferiority prohibit her from contributing to social interaction in the way that she feels she should. Pandora understands the role of 'bystander' as a witness, rather than a participant, of social interaction. Her awareness of not adequately performing; feeling like *she*, in particular, is not laughing when others are, and that her input is considered to be less valuable, must also be a burden for Pandora. In the extract prior to this, she makes an explicit connection between her intersex status; her 'identity' as an 'outsider', and her social circumstances; 'outsider socially'. As she also noted above, the belief that she is not 'categorisable' and therefore an 'anomaly' situates her as excluded from accepted sex categorisation. Thus, for Pandora, to have a body which confounds classification and recognition, is also to be socially omitted at an everyday, interactive level.

In *Social Origins of Depression: A Study of Psychiatric Disorder in Women* (1978), Brown and Harris observe the role that self-worth can play in the management of challenging or traumatic life events. They note that an 'ongoing self-esteem is crucial in determining whether generalised hopelessness develops – that is, response to loss and disappointment is mediated by a sense of one's ability to control the world and thus repair damage' (p. 235). Both Pandora and Ian explore their ongoing struggles with low self-esteem, which may make their attempts to deal with an intersex diagnosis more challenging. Of course, low self-esteem may also be exacerbated by the diagnosis and subsequent medical/social responses. In Pandora's case, she describes many of her personal struggles with body image and social value as directly responding to her diagnosis.

As well as acknowledging the role that self-esteem may play in coping with personal/social challenges, Brown and Harris (1978) place an emphasis on the sense of control that an individual feels they possess over their own life. They argue that 'if self-esteem and feelings of mastery are low *before* a major loss and disappointment, a woman is less likely to be able to imagine herself emerging from her privation' (p. 235, emphasis in the original). Thus, Brown and Harris make a connection between the sense that one has an ability to 'control the world', experience 'feelings of mastery' and a sense of self-worth, arguing that these three aspects contribute towards a more resilient response to difficulties; averting hopelessness, depression and privation.

Whilst absolute 'mastery' and 'control' may not be viable (or desirable) for any of us; agency, power and self-jurisdiction are of particular significance for intersex issues. Social scholarship in this field has often observed the potential for medical interventions in infancy or childhood to make patients feel disempowered later in life. Preves (2008 p. 9), for example, notes the widespread experiences of 'powerlessness and violation' across her research sample of thirty-seven intersex adults based in the United States of America and Canada. Many participants in her study 'viewed their medical exams and treatments as instances of sexual abuse' (p. 72). The connection between a sense of control and an ability to manage difficult life events highlights the challenges involved in responding to an event whereby, in the case of intersex interventions in childhood, the actor is given very little agency over their bodies or treatments. People who are intersex, treated before a consenting age and feeling a retrospective sense of powerlessness, may, as a consequence, experience heightened vulnerability and an increased likelihood of hopelessness and depression. Thus, despite the framing of surgery in infancy as a means to prevent isolation and stigma later in life (Money 1986, 1991, 1994; Money and Ehrhardt, 1972), according to Brown and Harris's findings and the experiences shared by participants, surgery may make these negative impacts more probable.

## Finding others

Both parents of diagnosed children who were involved in this study discussed a desire to ensure that their daughters would grow up knowing other people with the same diagnosis. They believed that this was a way of helping to ensure their children would have the support they needed as they became older, reducing potential feelings of isolation amongst their peers. This fear of isolation was evident throughout the interviews with these parents, and was also discussed by intersex adults in the study, especially when emphasising the importance of support groups and other forms of social solidarity. Nicole, whose 27-year-old daughter was diagnosed with Turner syndrome a few days after birth, emphasised the parental duty she felt to ensure her daughter was socially included. In her interview, she reflected on the attention she has since given to activism and campaigning about Turner syndrome. She underlined the motivations behind her involvement: 'I'm still just a *mum*. A mum that… wants a better quality of life for her daughter, and her not to feel isolated and um, to feel any less a person because she's been given this diagnosis' (Interview with Nicole, 2014).

For Nicole, the diagnosis of Turner syndrome brought with it apprehensions of seclusion, feelings of inferiority and challenges to personhood. These were concerns which Nicole held when her daughter was only days old, before she was able to express her own fears or struggles. Thus, Nicole's fears of future isolation were attached to her daughter's medical diagnosis and foreshadowed her social existence. To prevent these potential difficulties, Nicole has worked

hard to build a support network of people with similar experiences to her daughter, and understands the role of the support group to be fundamental in combating social isolation for people with a diagnosis of Turner syndrome. This is made especially clear in her positioning of those who are diagnosed and living without the companionship provided by a support group. She explained, 'I feel the people that I *really* worry about are the people that have never met anybody, that have led these very isolated lives, that have not had the wonderful opportunities that [support group] members get, of being together' (Interview with Nicole, 2014). Nicole characterised the kind of support gained from interacting with others with the same or similar diagnosis as different from the support which may be provided by other social bonds:

> It makes me sounds as if I'm daft but, there's a kind of magic that these girls get from each other. I said, you can't take thirty so-called '*normal*' girls and put them in a room and them all be friendly, because they'd just scratch each other's eyes out and be bitchy. Because that's normal behaviour. But it doesn't happen with Turner's. They're all nice to each other! And they all help each other, and they're all supportive of each other. And you still get the odd niggle but on the whole they are incredibly nice, really nice - silly nice [...] because the girls just *love* being together. And when you talk to the girls and you say, 'what is it about you, why do you love being together?' – they say 'we can be ourselves, we don't need to...' because I think they spend their entire life trying to fit in. And lots of [...] parents [of children with Turner syndrome] say that the girls are like round holes in square pegs. So they rattle about but they don't *fit*. And only when they come to [the support group] conference do they fit. But that has its problems. Because some of them, it's so important that they don't want to leave... (Interview with Nicole, 2014)

Nicole recognises the support group environment as one which allows the members to behave in a way which is not permitted in everyday social contexts. This is beneficial largely because she perceives those with a diagnosis of Turner syndrome as feeling excluded from conventional social settings, or made to feel they cannot 'be themselves'. While she understands the social opportunity provided by the support group to be beneficial, she also notes that it can present a challenging reminder to its members of how unsettled and laboured their everyday experiences can be. For some, this contrast may exacerbate feelings of loneliness.

In her diary, Natalie also underlines the significance of a shared diagnosis in her desire to create new social bonds. In one entry, she writes:

> Passed my Driving Test Today
> Although I have independence
> I now have freedom.
> Dont have to stay secluded
> May even be able to start meeting the CAIS from online Support group.
> Yet to meet another like me. (Natalie's diary, 2014)

Natalie's depiction of an individual with the same diagnosis as 'another like me', and the act of meeting these others as a departure from seclusion – one of the advantages of 'freedom' – illustrates the fundamental connection she makes between her own isolation and her lack of access to others with a CAIS diagnosis. In her interview she conveyed her belief that people with

a CAIS diagnosis were subject to similar experiences, and noted that a realisation of this had led to some reprieve from her isolation, helping her to feel more comfortable about her situation:

> you know that, is it the seven stages of grieving or something? It's kind of like that, it's like well this person's got androgen insensitivity syndrome so they – they've gotta go through this, then they've gotta go through this, then this, then this, then this then oh… But like I said, when I realised everybody sort of goes through similar things and it's like the seven stages of grieving or what have you, it gives you – you kind of think, 'Well actually then, it obviously must be a bit more frickin' normal than what it is'. (Interview with Natalie, 2014)

Natalie's reference to Kübler-Ross's (1969) five-stage model of grieving illustrates how a model of CAIS which predicts specific stages, patterns and order can provide reassurance, especially to Natalie and others who have found themselves in a situation which was entirely unexpected, and which disrupted the coherence and familiarity of their life narrative until that point. As I will explore further in Chapter Eight, on narratives of time and sex, sexuality and relationships, a sense of chronological predictability had been ruined for Natalie.

Like Natalie, Pandora characterises a shared diagnosis as a source of social connection, and meeting others as a significant way of alleviating a sense of loneliness. She discusses her experiences and expectations of an AIS support group,

> Um, so I joined last year and felt… one of the reasons was I wanted to meet other women like me, almost to - to see that there are, like, other people like me out there 'cause you feel like lonely, like, 'I'm the only one like this, why did this happen to me?' but there are other people. And I kind of, I s'pose, wanted to see that they could be happy with it, that I wanted to see people who are more accepting, that it's possible to get to that stage at some point. (Interview with Pandora, 2014)

For Pandora and Natalie, whose struggles with their diagnoses and medical treatment were ongoing, the thought of meeting others with a shared diagnosis gave them hope about their own situations; anticipating the discovery that their experiences were not singular, and hoping to see proof that comfort and acceptance may be obtainable. Pandora characterises acceptance as an available 'stage' within the chronology of diagnosis. Like Natalie, she seeks to recover predictability and uniformity from a situation which has often been isolating and turbulent. Preves (2008, p. 133) observes that support groups can provide 'meaning and structure for individuals who have lived with feelings of anxiety, uncertainty, and ambiguity. They encourage people to overcome feelings of powerlessness and provide role models'.

Steve describes himself as suited to the position of 'role model'; unlike Natalie and Pandora, due to his parents' refusal to permit medical intervention during his childhood, he considers himself to be 'less damage[d]' and feels more 'comfortable' than many other intersex people (Interview with Steve, 2013). In his interview, Steve described a perceived responsibility to assist others who were experiencing challenges due to their intersex status:

> I try to take part in online groups because the advantage of online is there might be someone in the middle of nowhere who might be experiencing something on their own, who's reaching out, possibly for the first time, their only contact may ever be someone on that website,

but it feels like a community – some connection. And I try to be part of
the supportive element of that, being in the community.

Steve describes a desire to participate in a mutual network of support and solidarity which roots from his own sense of being part of the 'community'. Much like Beth and Nicole's prediction of their daughters' loneliness, Steve's example of the intersex individual who is entirely spatially and socially isolated demonstrates the foreseeable, or anticipated, nature of intersex struggles and marginalisation.

## Support networks

Beth, the mother of six-month-old Imogen who received a diagnosis of congenital adrenal hyperplasia (CAH), regularly visits a support group website and has attended a conference organised by the group, hoping to find other parents of children with CAH. In her diary, Beth relays an encounter she had with a woman with a CAH diagnosis at one of the conferences. According to Beth, the woman, Sam, spoke publicly at the conference about 'some of the things […] I worry about for Imogen', such as 'issues with sex/relationships, not feeling happy and settled with life' (Beth's diary, 2014). Beth notes that she 'felt drawn to [Sam]' and arranged to meet her after the conference in order 'to build a network for Imogen'. When they later met, Sam was initially 'keen to be there for Imogen, so she could help support her growing up with the sensitive issues', but she has since withdrawn from the agreement in order to 'focus on herself and her wellbeing'. Beth notes that she was 'really upset by this', commenting that Sam's withdrawal 'made me realise how lonely Imogen might feel not knowing others with CAH' (Beth's diary, 2014). Sam's need to retreat from the mentor relationship which Beth was soliciting illustrates how the personal and social struggles faced by some intersex people are not transcended in adulthood. Beth made the important discovery that regardless of age, difficulties and vulnerabilities can persist.

In her interview, Beth told me that she had been regularly speaking online to another mother of an infant with a CAH diagnosis and hoped that fostering this relationship would lay the foundations for greater support for Imogen later in life; 'hopefully our daughters can be friends and support for each other', Beth explained (Beth's diary, 2014). She described to me,

> I think it'd be really nice for Imogen and *her* daughter, 'cause they are
> gonna go through *exactly* the same things, y'know, they might have
> different takes on it but y'know… but medically they are exactly the
> same. Y'know, they've got the same condition, they've both y'know… the
> Prader scale? In terms of um, how they rate the genital changes, if you
> like, they were the same. So she's just had some surgery. They've both
> had to take the same medicine. Y'know, so they're gonna have a lot…
> hopefully they can talk to each other about it. Because it's a small world,
> CAH, and I think the more people that she knows will hopefully be a
> good thing. (Interview with Beth, 2014)

Beth's ascription of CAH as 'a small world' illustrates the way in which a social boundary is placed around the diagnosis; it is not only recognised as a medical label by Beth, but – similar to Steve's account - also as a community. The shared traits within this community, however, *are* described by Beth as bound by medical characterisations and treatments (e.g. measurements on the Prader scale, diagnostic category, prescribed medication).

In her research on women who have survived breast cancer, Rosedale's (2009) observations illustrate why Beth may presume that there is a fundamental link between the sharing of medical experiences with others and the escape from, or suspension of, loneliness. Rosedale notes that her participants became especially conscious of 'feeling lonely when they realized that others were not aware of an ongoing aspect of their breast cancer experience'. Examples of these isolating experiences, as detailed by Rosedale, could be the fear felt before an upcoming mammogram or the significance placed on the anniversary of their cancer diagnosis. Women in the study felt that 'people failed to recognize and comprehend what it was like to survive acute treatment and the long-term aftermath of breast cancer, which led them to become conscious of their loneliness. For some, the experience was intense'. This bears a significant resemblance to Nicole's description of the dejection some members felt following support group meetings. She notes, 'they go away and [...] some of them struggle... some of them struggle' because 'it's tough out there' and 'being different [...] in this country, it is *not* celebrated' (Interview with Nicole, 2014). As Nicole underlines, the difference between spending time with others who have shared similar experiences, and being in company with individuals who do not, is not only a matter of common ground, but also one of potential discrimination, ostracism and hostility, which can have tragic consequences for wellbeing.

When Siân was ten years old, her parents explained to her that, due to Turner syndrome, she 'wouldn't be able to have children naturally' (Siân's diary, 2014). In our interview, she said that she had felt 'shocked' and 'lost' to discover this, but that she had not discussed the topic with her parents since then. I asked if there were other people she could talk to:

> I talk to my friends with Turner's about it, yeah. But that's it really. I don't really talk to anyone who hasn't got Turner's about it, because I don't think – I think it's one of those things that you can't really, truly understand until you're in that position. And it's – it's a very, I guess we're in quite a *unique* position in knowing from such a young *age* as well. (Interview with Siân, 2014)

Siân's inclination to discuss her infertility exclusively with others who can 'really, truly understand' has meant that spending time with other people with a diagnosis of Turner syndrome has been central to her ability to share and explore her feelings on a topic which has been very difficult for her to manage. Siân's representation of her position as 'unique' and beyond the scope of understanding for those who have not shared the experience makes it difficult for her to communicate outside of very narrow range of social settings, an issue which will be explored later in the chapter.

## Feeling left out

Concordant with Nicole's depiction of the discomfort many women with Turner syndrome experience, Rosedale (2009) observes that participants in her study sometimes felt isolated by the effort which was required to enable them to 'fit' within everyday social environments. Adapting their behaviour, withholding information and conducting themselves in ways to make others comfortable were all responses which contributed to their feelings of loneliness. She notes that 'they were afraid to fully reveal themselves to others'. However, she also remarks that support groups did not always provide a solution to this struggle, because 'women described the tendency to withhold aspects of their experience', even when in conversation with other people who had been diagnosed and may have dealt with similar experiences. She adds,

'when faced with other survivors, they could silence or chasten themselves for thoughts they characterized as selfish or for an insufficiency of "fighting spirit"'. Thus, particular narratives – such as those which demonstrate 'fighting spirit' – become dominant within some social spaces, such as support networks; discouraging members with differing experiences or feelings from sharing their perspectives.

The participants in the current study who have made regular use of support groups felt broadly favourable about the potential for the networks to alleviate feelings of loneliness. However, in agreement with Rosedale's observations, there were also some reports of feeling ostracised due to a lack of 'fit' within support group narratives. Natalie felt that her experience, as someone who was diagnosed at 21 years old and has not received any surgical interventions, was not incorporated into most online discussions of CAIS. She explained,

> You look at all the advice websites, there's – there's um… websites that give advice for parents of children who've got the condition, all the advice is aimed at people who've had treatment – the surgery done. But there's no advice for those who still haven't had the surgery. And therefore, then I – I get frustrated when doctors turn around when I – they say to you 'well there is a special support group', it's useless. Because it doesn't support somebody who's still got the cond – the uh problem. They – they support people who've, y'know on the after-side of the procedure, not who's still going through it all, y'know so it's… I don't – I don't bother with support groups. (Interview with Natalie, 2014)

Due to the specifics of her situation, Natalie notes that speaking in a Facebook support group was 'like standing in a crowded room *screaming* and nobody's looking at you. It's like for chrissake, y'know I've got something I wanna ask' (Interview with Natalie, 2014). In these instances, Natalie felt that her attempts to seek advice and reassurance were undermined, and the exclusion of her experiences – especially within networks specifically designed for support – only added to her feelings of isolation and difference, leading her to eventually abandon the groups altogether.

Similarly, after years of searching for medical assistance without receiving any definite diagnosis, 44-year-old Ian spoke about a similar loneliness he felt, due to a lack of peer support or medical label:

> I still feel kind of um… alone, in that – one, is that I never really got my tests confirmed, and two, that I never really proved to doctors that my symptoms exist. So I still feel quite alone. Um I don't really have any support. Well I have *online*, but it's more generic kind of thing but it's… I don't really have any um, anyone I can confide in.

Ian expresses his experience of loneliness or 'aloneness' and the inadequate level of support he has received as directly linked to an absence of a confirmed medical diagnosis or medical affirmation of his experiences/bodily differences. Due to the presumed ascendency of the medical institution and its monopoly over defining bodies, the lack of a confirmed diagnosis has meant that Ian has not received the (conditional) epistemological legitimacy which is largely imputed to medical diagnoses (see Parsons, 1975).

Due to his inability to find any definite response from medical authorities, there has been no opportunity for Ian to participate in the construction of a collective identity (whether based on

health/diagnosis or sex). Hester (2006, p. 47) notes that intersex people 'begin their lives in liminality'. However, for Ian, who continues to recognise his own body as unable to 'fit' within the convention of binary sex (despite a lack of medical certification), liminality has persisted over time. The uncertainty and confusion he has dealt with has, like Natalie, made it especially difficult for him to find others with shared experiences or feel secure in his own status.

Brown and Harris (1978, p. 271) underline the significance of a 'confiding relationship' in their research on women with depression. This was underlined in their definition of 'intimacy' in the study, which was based upon the extent that a relationship provided a confiding function. They (1978, p. 176) note that the intimacy provided by a confidant gave significant protection from depression. Weiss (1969, p. 38) argues, similarly, that strong social ties are ones which give permission to social actors to 'express their feelings freely and without self-consciousness'. He explains that 'for a relationship to provide intimacy there must be trust, effective understanding and ready access'. These types of social bonds, according to Weiss, are most often found in romantic partnerships. Whilst Weiss's centring of romantic relationships could be questioned, this common perception nevertheless poses difficulties for many of my intersex participants who, as I will explore in Chapter Eight, have not found it easy to form these types of relationships. Further, in Chapters Six and Seven on passing, I will consider how total disclosure and honesty comes with greater risks for intersex people than it may for others, thus complicating the desirability of a confiding relationship.

## Feeling different

The self-perception of difference, abnormality and exceptionality was wide-spread across the intersex participants. The significance of this difference was often instilled by medical practitioners and parents from the earliest stages of diagnosis (and in some cases, such as Ian's experience, prior to/without diagnosis). Participants noted that the rarity of their conditions was underscored, often to the extent that they believed that there was no one else who shared their diagnosis. As Paula, for example, said:

> Paula: ...My parents weren't ever given the name [of the diagnosis]. They were literally told we'd never find someone else in the country with the same condition as I had, y'know. And –
>
> Charlotte: So they really thought you were a total one-off?
>
> Paula: Yeah, absolutely. Absolutely. Um, y'know. And my mum's always felt really guilty about it, coming from her side somehow. Um, so I don't know, I don't know, it's one of those things you kind of think back and go 'God, they should've handled it so much differently'.

Paula's parents, like many others in the study, were reported to frame their child's difference in a positive light; as a characteristic which denotes 'specialness', rather than a problem. Paula notes that her mother 'always told me that I was special, I had no ovaries, couldn't have babies, wouldn't have periods, y'know it's – it was kind of the same spiel every time' (Interview with Paula, 2014). Siân describes something similar:

> I s'pose, when I was at primary school it was sort of – I saw it as something that was different, but it was... the way I – sort of my parents sort of got me to sort of understand it was that they told me that it was

something that was a bit special? - rather than sort of different being a *bad* thing. (Interview with Siân, 2014)

Not all participants believed that the root of this sense of 'difference' was found in their diagnostic or sex category. Instead, some participants underlined the connection between their feelings of difference and the imposition of secrecy. Steve wrote in his diary, 'I learned that i was different, that i had to live in a way that NO ONE was to know' (Steve's diary, 2014). Here, Steve's ascription of difference is one he describes as *learned* from external influences. Similarly, Paula reflected that 'it was drummed into us at a *really* early age, that we'd never find anyone with it, keep it quiet, it's quite shameful so keep shut up basically' (Interview with Paula, 2014). Paula ascribes the secrecy and singularity of intersex to a sense of shame. Like Steve describes in his diary, these were not entirely her *own* feelings of shame, singularity or secrecy, but ones which she describes as being instructed and learned.

While Steve and Paula's assertions suggest a relationship between secrecy and difference, the nature of this relationship is unclear. A relationship of causality, for example, could flow in either direction (or both); a sense of difference leading to a presumed need for secrecy, or the enforcement of secrecy constructing a feeling of difference. In his interview, Steve emphasised the connection further: 'I *was* different, I *knew* I was different. I feared people knowing I was different. I feared the repercussions of people knowing I was different' (Interview with Steve, 2013). Here Steve treats his difference as definitive and self-established, rather than necessarily imposed by others, as in the extract taken from his diary. The knowledge of his difference has led to his concern about the visibility of the difference and the anticipation of hostile reactions if detected, perhaps further reproducing these feelings of singularity.

Drawing attention to the singularity, uniqueness or rarity of particular identities or bodily categories can alter the way that we think about them. As Davis (1995, p. 2) comments, despite common representation, 'disability is not a minor issue that relates to a relatively small number of unfortunate people; it is part of a historically constructed discourse, an ideology of thinking about the body under certain historical circumstances'. Individualising and minimising the effects of these disabling processes moves the emphasis away from the structures, which, as Davis argues, 'intimately involve[s] everyone who has a body and lives in the world of the senses'. As Davis further notes, in this individualisation 'people with disabilities are portrayed as "noble," "heroic," and "special"', in an 'attempt to redress the disability by attributing higher powers to it' (*ibid*., p. 106). This 'privileging' of the 'inherent powers' of marginalised bodies or identities can also contribute to a further separation and singularisation of these people and therefore increase their risk of loneliness and/or isolation. A separation, or ontological rift, is created between those that 'are', and those that 'are not'. The depiction of Paula's condition as entirely unique could - no matter how 'special' she is also described to be - forbid the possibility of finding a community or exchanging experiences with others, and therefore imposes isolation from the many others who share her diagnosis. An emphasis on her particularity and/or bravery may also prevent us from looking at the medical and social structures which may be indicted in her struggles.

The emergence of intersex political activism, through which those affected introduced a structural critique of medical interventions, occurred in recent years due to the support networks which had been formed around intersex identities. These communities were, and

continue to be, dedicated to peer support to deal with the 'shame, stigma, grief, and rage as well as with practical issues' (Chase, 1998, p. 197). Beyond these interpersonal relations of support, some groups also advocate a 'longer-term and more fundamental goal [...] to change the way intersex infants are treated' (*ibid.*, p. 197-198) and 'intersex bodies are managed' (*ibid.*, p. 198). It was, in part, the ability to meet others, create communities and find overlaps in experience which led to these personal and structural critiques of the ideological, social and medical responses to intersex bodies. Activist and scholar, Laurent (previously known as Cheryl Chase), describes the formation of the movement as a conversion from intersex people's 'pain to personal empowerment', and, in her own case, the development of 'a newly politicized and critically aware form of self-understanding' (*ibid.*, p. 195). Whilst the intentions of medical practitioners cannot be assumed when they advise patients/parents about the singularity of their condition (and motives are perhaps not relevant here), it is apparent that isolation can be one of the consequences. Critiques emerging from support groups may, and indeed *hope* to, pose a threat to the ascendency and epistemological power of medical authorities. Despite the 'considerable number of former patients [who] have recently come forward to speak out against procedures they consider harmful', intersex activists are often dismissed by the medical institution as 'representative of only an unhappy minority' (Preves, 2008, p. 11).

## Conclusion

The breadth of experiences shared by participants has begun to reveal the complexity, diversity and tensions which come under the single emotional descriptor of 'loneliness'. The loneliness described by participants was grounded in a range of different causes relating to an intersex status, as well as a range of different symptoms, outcomes and ramifications. It is not an easily calculable or predictable experience, although certain social repercussions of an intersex diagnosis, such as secrecy, stigma, and the presumption of difference, were recurring in participants' accounts of loneliness. Mills's (1959) claims about the fundamental connection between the struggles encountered in our personal lives and the social structures which shape these experiences is especially pertinent to these explorations into loneliness. In the spirit of Mills, this chapter considers how the very personal and private experience of loneliness can be interpreted as a public, structural and social concern.

Nicole and Beth's stories of parenting illustrate how, when diagnosis occurs in infancy, social exclusion is anticipated from the earliest possible moment. As intersex participants indicated, medical authorities' claims that their diagnoses are especially rare – and that meeting others with similar experiences is infeasible – obstructs the possibility of finding an intersex community (if this is desired). However, feelings of social exclusion and loneliness were discussed by many participants as distinct from issues of relationships and social bonds. The exclusion described by participants can be interpreted at an ontological level, whereby hegemonic narratives of acceptable bodies, identities, binary sex and reproduction produced a social environment in which participants felt that they did not 'fit' and where they were not permitted to 'be'. This ontological loneliness was experienced by intersex participants as a repudiation of their status, bodies and futures, which – for some participants – placed limitations on different ways of 'being'; leading to an imperative pushing towards surgical and hormonal interventions, binary identification and secrecy regarding their intersex status and medical history. Some participants underscored the importance of support networks in finding acceptance, shared experiences, and respite from isolation. In some instances, these support

networks were not just places of sociality, but of ontological security; a place to 'be' who you feel you are, and to find others who share that state of being.

A self-imposed isolation was described by some participants, in which friendships and romantic/sexual relationships were avoided, due, in part, to the perception that their bodies and identities were shameful, inadequate and undeserving. At times, this led participants to believe they were responsible for their own suffering, despite their experiences of unwarranted abuse, discrimination and intimidation. Attempts to resist hegemonic constraints of identities, bodies and behaviour deemed to be 'normal' and 'acceptable' were perilous, due to the risk of further marginalisation if they were recognised as someone outside of these limitations. The dominance of medical and social 'knowledge' regarding binary sex very often leaves those diagnosed as intersex without the confidence required to resist their categorisation, prognosis and treatment plan. The sense that there is no opportunity for negotiation or resistance (especially in the case of diagnosis during infancy) has meant that many intersex people have felt a sense of powerlessness; an absence of jurisdiction over the direction of their own lives. The primacy of medical categorisation is so persuasive that one participant, without a definite diagnosis, felt uncertain about his body and sex status, and felt excluded from the intersex community.

The research process itself was situated by some participants as an opportunity for disclosing unspoken experiences and feelings which had been concealed during previous social interactions. For some, this was a resistance to the silence imposed with respect to intersex and an opportunity to grant someone else access to this very private knowledge for the first time. This is illustrated by Pandora when, towards the end of our time together, she reflected on her approach to the interview:

> I felt really excited, I dunno, it was like… someone who, to meet someone, a) I was just like interested in someone who was interested in this condition as well, so that was cool in itself - and that was viewing it in quite clearly a *positive* way, in a sense, not running away from it. Um, and just instantly – to meet someone and they'll know, yeah they know – that this is *what* I am and *who* I am. (Interview with Pandora, 2014)

As Pandora explained, the encounter was of great significance to her, providing a rare opportunity to acknowledge 'who' and 'what' she is in the company of someone sympathetic to her situation and intersex status. Whilst the research is not designed specifically to provide emotional support to participants, many of them alluded to the therapeutic effects of taking part. The heavy significance they placed on their involvement and the opportunity to speak freely in the research is perhaps indicative of the inadequate social support currently available. Nevertheless, any research outcomes which are personally beneficial to participants are gladly received. As Preves (2008, p. 133) notes, 'when one's secret or shameful identity is validated, the need to engage in consistent self-monitoring may slip away'. Pandora emphasises my approach as one which regards intersex in a 'positive way'. If participating in this research has given Pandora confirmation that it is possible to communicate with others on this topic without receiving an adverse reaction, then, as Preves argues, there may be potential for her to reconsider her own self-assessments and seek further opportunities to speak to others about her experiences.

As previously noted, the stigma of bearing an intersex status, and the ontological loneliness which may ensue, leads many intersex people to keep their statuses hidden. As I will explore in the following chapter on passing, this secrecy often demands that individuals present themselves in ways which are deemed to be more 'fitting', according to the symbolic system of binary sex. However, as the preceding discussion illustrates, the struggle to contain this information and to assimilate accordingly, can itself cause ontological loneliness and social isolation. The foundational relationship between loneliness, community, understanding and likeness leads us onto the notion of recognition and value. Loneliness of an ontological kind can, despite numerous social relationships, make those who are present feel unnoticed. The next chapter will continue these excursions into loneliness, to consider the complex and often paradoxical processes involved in being recognised, unseen and hidden when intersex.

# 6

## Intersex Passing I
## Interaction and Ethical Dilemmas

In November 1958, Harold Garfinkel first encountered Agnes, a nineteen-year-old woman who, despite being registered as male at birth[1], relayed to doctors her experience of spontaneous physical 'feminisation' during puberty. Over the following nine months, Agnes attended the Gender Identity Clinic at the University of California, Los Angeles, for weekly conversations with Dr. Robert J. Stoller, a psychiatrist and psychoanalyst with expertise in transgender issues, Dr. Alexander Rose, a psychologist, and Garfinkel, a social interactionist theorist with an interest in ethnomethodological approaches to identity.

In 'Passing and the Managed achievement of Sex Status in an "Intersexed" Person' (2006 [1967]), written seven years after the study on Agnes was completed, Garfinkel provides the only detailed investigation into the relationship between intersex and processes of 'passing'. In his paper, he explains that Agnes was born 'a boy with normal-appearing male genitals' (*ibid*, p. 61) and, up until she was seventeen years old, she was recognised by others to be unequivocally male. He notes that 'secondary feminine sex characteristics' started to develop during puberty, which Agnes kept hidden until two years prior to meeting Garfinkel.

The chapter provides some valuable contributions to discussions of gender and passing, especially concerning the emotional and psychological well-being of Agnes and the inescapable presence of biographical narratives which Agnes felt the need to conceal from those who were unaware of her pre-passing history (p. 65). Garfinkel reflects on why it is believed to be necessary to rationalise and consolidate our own pasts, as well as the pasts of others. Further, he explores the regulative function of interpersonal and structural relationships, whereby behaviours and identities are controlled and restricted by social expectations (p. 58). Thus, he underlines the *compulsory* requirement for Agnes to pass (p. 70) and provides empirical attestation to the threat of 'status degradation, psychological trauma, and loss of material advantages' (p. 59) should passing be unsuccessful.

Garfinkel's is an important commentary on the everyday nature of passing; acts which are 'easily overlooked' and 'difficult to grasp because of their routinized character', 'embedded in a background of relevances that are simply 'there' taken for granted' (p. 60). As well as the routinized process of passing, Garfinkel also notes its constancy. As others have observed (e.g. Sedgwick, 2008, p. 68), he argues that 'it would be less accurate to say of [Agnes] that she has passed than that she was continually engaged in the work of passing' (p. 70); 'the active mode is needed: she is passing' (p. 82). Although passing may get easier in some, or all, contexts, Garfinkel affirms that for some people there is never a point when it will cease to be a concern at all. Hence, he notes that the act of passing raises questions of whether there is a 'true' or 'real' self (p. 59) and considers the significance placed by Agnes on 'natural', 'all along' and 'forever'

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[1] I use the language of registration to underline the discursive and constructive practise of 'sexing' infants. However, in Stryker and Whittle's (2006, p. 58) terms, Agnes was born a 'typical biological male'.

bodies/identities, which she imbues with moral meaning. Through passing, Agnes appeals to 'an elevation of herself as a worth-while person' (p. 68). Garfinkel critiques the moral indictment of certain bodies and challenges ideas of gender authenticity in the paper, reflecting on the ways in which society covertly creates gender signification and regulation in ways which appear 'natural' and 'normal' (p. 88).

However, Garfinkel also placed a questionable emphasis upon measuring Agnes's ability to 'pass', especially in his assessment of her physical presentation and gender identity, which is ruthlessly analytical; rendering her as 'appropriately feminine', 'convincingly female' (*ibid,* p.60), and describing the way she 'dressed in a tight sweater which marked off her thin shoulders, ample breasts, and narrow waist' (*ibid,* p. 60) - despite feet and hands 'somewhat larger than usual for a woman' (*ibid,* p. 60). These normative and conventional gestures towards 'acceptable' levels of femininity perhaps tell us more about Garfinkel's uncritical notions of femininity and physical attractiveness, and his understanding of gender appropriate behaviours, than about Agnes herself. This is an example of Garfinkel's broader tendency to treat Agnes in a way which would not be considered ethical today. In other instances, this includes persisting with repetitive, insensitive questioning after it is clear Agnes is uncomfortable with the topic at hand (p. 67) and alluding to the sexual provocations he allegedly made towards Agnes as a form of 'test' during their interviews (p. 68). In contrast to his astute position on the constructions of gender and its potential constraints, Garfinkel also takes a surprisingly prescriptive stance on 'feminine' disposition, at times ascribing simplistic gendered signification to behaviours, actions and appearances exhibited by Agnes (p. 69) which could be recognised, instead, as far more complex and indeterminate.

In an appendix written eight years after his study of Agnes, Garfinkel quotes a passage from Stoller's monograph, *Sex and Gender: On the Development of Masculinity and Femininity* (1968), which was completed one year prior to the publication of the paper. In the passage, Stoller describes how one year earlier, Agnes 'revealed that she had never had a biological defect that had feminized her but that she had been taking oestrogens since age 12' (Stoller in Garfinkel, 2006, p. 90). The oestrogens had, in fact, been stolen from her mother, who had been prescribed the medication following a pan-hysterectomy; indicating that Agnes did not actually have the 'most rare disorder: testicular feminization syndrome' (*ibid,* p. 90). Agnes was actually a transgender woman. So, while, prior to this, Garfinkel had believed his study was unravelling the hidden dimensions of intersex experiences and the struggle to pass as a woman, Agnes was constructing an identity of intersex for Garfinkel's benefit, in order to conceal a trans history she wanted to remain undiscovered. Assigned male at birth, Agnes was *passing* as intersex pragmatically; in order to *pass*, conclusively, as a woman. Agnes believed that if she told the truth about her sex she would be denied genital surgery by medical practitioners. To Agnes's satisfaction, Garfinkel's study did lead to her receiving genital transformation surgery. Garfinkel does not comment at any length on Agnes's deception, but Stryker and Whittle (2006, p. 58) report that specialists in the field of gender identity management have since 'considered the case a prime example of how transsexual patients manipulate their doctor to get what they want'. Conversely, they also note that some transgender people have interpreted the story of Agnes as 'a savvy young woman who accurately mapped the relations of power within which she negotiated and actualized her sense of self' (p. 58).

Considering that Garfinkel's paper was, until now, the only in-depth scholarly discussion of intersex and passing, the revelation that the subject of his study had no personal experiences of

intersex may provide insight into the possibilities/difficulties of 'knowing', the complexities of passing and identity, and the ambiguities involved in the qualitative research process itself.

## An epistemology of passing

In one sense, we could all be said to be 'passing' along various axes of identification every time we step outside. Without deliberation, I pass daily as white, as a woman, and as able-bodied. These are all identities which I 'perform' (Butler, 1990), and which are subsequently sanctioned by others in my social environment. These processes of identification and performance are routine in my life. The concept of passing, however, is largely used to signify an ontological move from one state to another; I can only be said to 'pass' as a woman if my gender is, or was once, in question, and I am only passing as white when my race has previously been contested. Thus, passing is often an evaluation of 'successful' transition, based upon the social scripts attached to gender, race and other identity markers which have become loosely standardised within particular cultures.

The notion of passing is laden with ontological and epistemological values and assumptions. What is the difference between the woman that I 'just am' and the woman that someone else 'passes' as? Does the difference between these two states of womanhood place a greater value upon one and a lesser value on the other? Is this value one of 'reliability', 'truth' and 'authenticity', or is it also one of character judgement? What is it about me, my appearance, my behaviour, my history, that means that I can be recognised as 'just being' a woman when someone else would not? To what extent is the judgement of identification made by others controlled by the individuals who are judged, or is it always beyond us? Might there be any features in my life, my body, or history, which could cast doubt upon my ability to just 'be' a woman, which others or perhaps even I, do not (yet) have access to? What are the mechanisms used to decipher between one state of being and another – are visual cues necessarily paramount, or are there other, perhaps verbal, conceptual, or embodied, ways of 'knowing'?

The 'observable realities' which constitute our environment, Jenkins (2002, p. 70) argues, are used as 'ways of knowing'. His approach, one of everyday realism, acknowledges that the 'reality' available to us is only ever one which is *observable* (i.e. for Jenkins, what is apprehended by humans), which is distinct from the reality which always remains 'there' regardless of my interaction with it and regardless of my existence. Our *observable* reality, what we know of the world, therefore, 'depends on our techniques of knowing' (Jenkins, 2002, p. 93) – in other words – our epistemological approach. Whilst my own epistemology, following Jenkins, may require that I recognise the limitations of observability in my pursuit of knowledge; it does not follow that the 'observable' reality and the 'always there' reality are necessarily of a different worth or value, as is frequently inferred from acts of passing. Furthermore, in my attempt to address the notion of passing, the 'observable' qualifier removes the possibility of a definitive 'truth'; instead there are multiple observable realities, all of which are fallible.

The notion of passing in common use, however, has a different relationship to reality. These two layers of reality (observable/always there), when located within the paradigm of passing, can be understood to reflect the difference between what is *really* 'real' and what gives the impression of the real (i.e. what is observably real). As I will explore in this chapter, locating one status/mode of identification (usually the identity or body which is prior to the passing) in the domain of the really 'real' marks it as authentic and fixed; and the 'natural', original and

objective self (as Agnes described). This is in contrast to the other state of being (usually the passing identity), which is deemed to be voluntary and orchestrated. It is due to this understanding, which renders the pre/non-passing identity as transparent, or as what I simply 'am', that it would be recognised as illogical for me to 'pass' as a woman or as white. I am not in question. Garfinkel proposes that whilst in discussion with Agnes, he too was engaged in acts of passing with regards to his professional capacity. To illustrate, he describes the 'many occasions in the exchanges between Agnes and me when it was necessary for me to side-step her requests for information in order to avoid any display of incompetence and so as to maintain the relationship with Agnes' (2006, p. 80). However, Garfinkel's freedom and authority are not already in question, and the costs of an unsuccessful 'pass', in this case, are minimal. Notably, this political dimension of passing, which provides an important distinction here, is established in Garfinkel's own definition when he employs the language of 'rights' and gravity. He characterises acts of passing as **'**the work of achieving and making secure [the] *rights* [of the passing person] to live in the elected status while providing for the possibility of detection and *ruin* carried out within […] socially structured conditions' (*ibid*, p. 60, my own emphasis).

In *Stigma* (1963), Goffman observes what he believes to be a crucial division between an individual's 'virtual social identity' – how individuals are perceived in public social interaction; what is assumed and anticipated of 'the character we impute to the individual' (Goffman, 1963, p. 12) – and their 'actual social identity', the private reality and 'the category and attributes he [sic] could in fact be proved to possess' (*ibid,* p. 12). When a discrediting 'discrepancy between virtual and actual social identity' (*ibid,* p. 12-13) occurs; a risk especially acute in the process of passing, Goffman believes that an individual will be subject to stigma: a 'spoiling' of their social identity, which has the potential to lead to social isolation and unacceptance (*ibid*, p. 31).

These judgements are regulated by a form of rationalism; the 'parameters of what makes sense' (Jenkins, 2002, p. 95) according to the structures and conventions of knowledge which precede us. Thus, Jenkins notes, to 'make sense, in the first place [truth and knowledge claims] have to broadly fit into existing legitimate frameworks' (*ibid,* p. 95). This is pivotal in the assessments made by others to assemble our virtual social identities. In accessing the stories of intersex participants, this chapter, therefore, seeks to explore the ways in which they make sense of their own identities and public receptions, and construct a sense of reality through engaging with this research, whilst recognising that all experiences, bodies and identities are products of our observable realities, and none to a greater or lesser degree than others. Following Goffman, I explore how virtual social identities are put into conflict with actual social identities and question the dependability of the 'always there' reality, reflecting on the variations of epistemological precedence that this requires.

Within the paradigm of passing, questions of identity and legitimacy are approached with ambivalence. On one hand, the concept places an epistemological judgement (i.e. one of 'knowing best', prioritising a particular epistemological standpoint) on those who are performing or 'failing' to perform the pass. On the other, the possibility of passing conveys the malleability of identity/corporeality, permitting notions of gender, race and dis/ability (and so on) which are often understood to be static, to be instead read as flexible or, at the very least, ambiguous or misleading. This contradiction, and the uncertainty of identity classifications which is invoked by the concept of passing, led Schlossberg (2001, p. 3), amongst others, to suggest that 'there may be something "queer" about the phenomenon of passing itself'.

Whilst passing translates as a very 'real' imposition for some, with threats of physical violence and social rejection if unsuccessful or forgone, its premise in popular use is often founded upon a very dubious assumption of authenticity. Depending on one's epistemological standpoint (i.e. what is believed to be a 'knowable' or recognisable body) and the type of identity in question, the passing body may equate to a masquerade or a masking of the truth (which is especially prevalent in discourses of racial passing); or a legitimate morphological transformation which attempts to harmonise social perception with personal identity (which, whilst still contested, is a more prevalent understanding of transgender passing). The reasons for passing, too, are multifarious, including: to be recognised by the status one feels is accurate, for protection, to assimilate, to feel happy and comfortable, and to hide. Passing may be desirable, but difficult/impossible to achieve; it may be carefully rehearsed and practised; it may happen by accident; and it may be necessary or enforced, regardless of inclination. Successful passing, an act of recognition, is tied to what is socially legible, familiar and coherent according to a set of norms, rather than what is personally comfortable for the passer (although these may often coincide). As Robinson (1994, p. 718) observes, it is 'the spectator who manufactures the symptoms of a successful pass'.

The often arbitrary nature of sex assignment implemented by medical professionals after intersex births (see Kessler, 1990; Karkazis, 2008) provides a clear illustration of why discourses of origin and nature should not be decisive in determining a 'true' or 'real' identity/embodied state. As Butler (2004, p. 7) also points out, 'intersex activists work to rectify the erroneous assumption that every body has an inborn "truth" of sex that medical professionals can discern and bring to light on their own'. Thus, the pursuit for truth or credibility when approaching bodies and identities has an arguably harmful history. Ginsberg (1996, p. 4) argues optimistically that through the epistemological complexity of transition and recognition we can 'disclose the truth that identities are not singularly true or false but multiple and contingent' (p. 4) and highlights the potential for the discourse of passing to 'challenge the essentialism that is often the foundation of identity politics'. However, the notion of passing and the importance of the debates encompassed within it transcend scholarly significance alone. As Schlossberg (2001, p. 11) notes, 'who we are and who we appear to be remain matters not merely of academic interest but also of survival'.

## The imaginary of passing

The approach to passing in this and the following chapter will therefore be one which is concerned with, what I call, the *imaginary* (Gatens, 1996) of passing, with a focus on the burden and potential salvation of (il)legitimation and (un)recognisability, rather than on the authority/authenticity of one status or another. Thus, in these chapters (and in contrast to Garfinkel), the 'failure' or capability to pass is not taken as epistemologically/ontologically conclusive, and the attribution of 'passing' itself will also not be a judgement of (in)authenticity. The acceptance of intersex participants' modes of self-identification is fundamental to this thesis. Gatens (1996, p. viii) replaces an attention on 'physiological, anatomical, or biological understandings of the human body' with, what she calls, 'imaginary bodies'. Using the notion of the imaginary, Gatens emphasises 'those images, symbols, metaphors and representations which help construct various forms of subjectivity' (*ibid*, p. viii). It is through this process that 'we make sense of social bodies and which determine, in part, their value, their status and what will be deemed their appropriate treatment' (*ibid*, p. viii). These standards of treatment and boundaries, named by Shildrick (2001, p. 1) as 'uncontainable and ultimately unknowable',

profess to be the natural, undisputed and unmarked rules which are suitable to equip our ontological relationships. Thinking with Gatens's use of the imaginary in my approach to passing, I will address the processes through which intersex bodies are produced and politically located in the process of passing, whilst disengaging from attributions of truth or realness.

Emphasising the *imaginary* element of passing is not, however, an attempt to defuse the 'real' experiences or consequences of passing. With reference to racial passing, Wald (2000, p. 70) comments on the 'failure of race to impose stable definitions of identity, or to manifest itself in a reliable, permanent and/or visible manner'. Despite this, she argues that 'we cannot lose sight of the power of race to define'. Similarly, with respect to gender, Butler (1990, p. 136) elucidates the performative composition of the gendered body, which she argues 'suggests that it has no ontological status apart from the various acts which constitute its reality'. Hence, whilst passing may demonstrate the complexity and vulnerability of racial categorisation, as well as categories of sex, gender and dis/ability, these classifications still retain important personal and social significance which is not necessarily surmountable.

In the next two chapters, the identity/morphological categories of race, dis/ability, gender, sex and sexuality (amongst others) are not understood to be equivalent or interchangeable. However, due to intersex scholarship's minimal contributions to passing thus far, and the vast and illuminative discussions of passing within studies of disability, queer and transgender identities/bodies, the contributions from these fields will be especially instrumental to my own ideas on passing. Academic scholarship and other literature from writers on race (e.g. Larson, 1929; Ellison, 1952; Griffin, 1962; Williams, 1991) also continues to be foundational to many conversations about passing. However, the perceived immobility of race identification[2] raises different epistemological and ontological questions; therefore the writing on this theme is less applicable to questions of sex. Transgender, disability, intersex and, historically, homosexual acts of passing share an essential relationship to medical practice, whereby these identities/bodies can both depend upon and controvert medical interventions. They also tend not to be shared across family members (as with race), and thus lack an immediate or 'inherent' community (Samuels, 2003, p. 243). These connections are, however, made tentatively and somewhat critically. As Samuels (2003, p. 243) argues, analogy is a vexed issue 'which cannot be extracted from the tangled history of the use and misuse of such identity analogies in past liberation movements'.

## Intersex passing

For intersex people, the desire to 'pass' can be a move away from the pathologised, unrecognised identity/morphological status of 'intersex' and towards a binary, permissible sex (i.e. male or female), and thus gender (i.e. man or woman). The act of passing can also be tied to other battles for embodied recognition; for example, passing as intersex, passing as sexed, passing as sexually desirable or sexually competent, passing as healthy, passing as normal, and passing as human. These different, often dualised, states are hierarchically positioned at a social and ontological level. In his exploration of disability and passing, Siebers (2004, p. 5) argues that

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[2] For example, see the media response to Rachel Dolezal, who – despite being born to white parents – now identifies as black. This has been widely recognised as Dolezal 'pretending' to be black (http://www.telegraph.co.uk/news/general-election-2015/politics-blog/11700056/Why-black-women-feel-so-betrayed-by-Rachel-Dolezal.html).

social hierarchies are secured through the desire to pass. He notes that 'individuals want to rise above their present social station and that the station to which they aspire belongs to a dominant social group'. Through the act/desire to pass, Siebers believes that the dominant social position is authorised as 'simultaneously normative and desirable'.

Siebers's claims would not necessarily hold true in all cases of passing. For example, transgender women may well be deprived of many of the privileges they were previously entitled to when recognised as men. However, the 'success' of a passing trans woman may require a certain conformity with hegemonic understandings of femininity, which may not have been expected of their unquestioned male status. This is because our ability to pass is not measured by equal criterion, and because we are not 'tested' with the same degree of vigilance in all cases. The extent to which those who do not 'need' to pass are permitted to transgress their allotted social scripts by far exceeds the freedom of those whose identities are in question. This is not just an issue of identity security and acknowledgement, but also of personal safety due to the threat of violence against 'illegitimate' or intelligible bodies and identities, as many have previously discussed with regards to transgender and racial passing (e.g. Schlossberg, 2001; Butler, 2004). Robinson (1994, p. 736), too, reminds us of the 'cost in-group recognition is purchased'. To this extent, Siebers is right to point out the way in which passing re-constitutes dominant social positions as desirable and necessary (i.e. quite a narrow/specific definition of 'woman' may need to be demonstrated in order to 'pass' in public spaces), but not to assume that the goal, passing identity is necessarily one which is 'higher' in social status than the former state.

However, if – for example – a trans woman is moving across the binary from one status (i.e. assigned male at birth) to another (i.e. woman), then the status of *man* and *woman* may not be the only identities which would have been observed or noted by others, but also – in some cases – that of a '*non-passing' trans woman*. Fundamentally, there may be absolutely no difference in the gender identity of the trans woman when she was passing and when she was not; her personality, her ideas and tastes, her clothes, her behaviour and her social relationships may have all been identical but others around her may still make a judgement which assumes a fundamental difference. The degree to which an ontological judgement and an assessment of value is present in this distinction is made clear by the threats posed by trying, but 'failing', to pass. Thus, if we take the 'trying but failing to pass' status as a position of its own, Siebers may be right to identify the passing status as one which is always placed higher in the hierarchy. However, the passing identity may not, in all circumstances, be preferable to the 'passer', as I will explore later in the chapter.

## Invisible bodies

Due to the variability of intersex morphology, which is *internally* manifest in some bodies (e.g. testes/ovaries, chromosomes) and *externally* in others (e.g. 'ambiguous' genitalia, secondary sexual characteristics), there is not a particular 'intersex aesthetic'. Thus, the public and social detectability of intersex is variable amongst those diagnosed. For many with intersex traits, 'passing' is an embodied process of obscuring physical characteristics which may disclose their intersex status, whilst for others the act of passing is more concentrated upon a cognitive or behavioural enactment of the 'appropriate' gender and life history. Hence, issues of passing are not only relevant to intersex bodies which present an external, physical indication of their diagnosis.  Similarly, in her discussion of invisible impairments, Lingsom (2008, p. 2) observes

how the potential to pass instils an individual with 'dilemmas of concealment and disclosure', which can be themselves be considered 'impairment effects'. Goffman (p. 57, 1963), too, emphasises the burden of 'managing information' for those 'whose differentness is not immediately apparent' (*ibid,* p. 57); that is, the 'discreditable'. Goffman observes the following predicament of concealment and exposure: 'To display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when, and where' (*ibid,* p. 57). These dilemmas present new issues due to the possibility, or perceived duty, of disrupting the act of passing by disclosing sex difference (whether internal or external). For many, the concern with disclosure will also be at tension with the endurance and frustration of 'containing' (Bion 1962, 1963) issues of bodily and/or identity dissonance.

For some participants, distinctions between external/visible intersex characteristics and internal/invisible characteristics played an important role in the extent they felt capable of passing as non-intersex (i.e. with a binary gender presentation). More visible intersex traits were discussed by participants as contributing to greater social marginalisation and stigmatisation. This was an issue which provided some relief for participants who felt that their intersex characteristics were invisible in their social environments. One participant, 22-year-old Pandora, was told about her diagnosis of complete androgen insensitivity syndrome (CAIS) at the age of eleven, when her Mum announced during a car journey that she had no womb. When discussing her feelings about her body and the way she felt others interpreted her, she explained that,

> I tell myself that in some ways I'm lucky in that, whilst I *do* feel there is this ambiguity in some ways, like bodily, generally, I am female. Um, and now rationally, I still worry that people can see just from the way that I look that I'm intersex, I s'pose I know rationally that's not the case. But it hasn't actually made me, from the exterior, look any different. So I can easily get away with it – whereas I think there are conditions where it is more obvious. Particularly sort of, the term that's banded around, 'ambiguous genitalia', and things like that. Um, it's probably more difficult. (Interview with Pandora, 2014)

Even though Pandora is reassured to be visibly recognised as a woman by others, she still experiences anxiety around passing successfully, and her body is subject to a process of self-monitoring and suspicion. Furthermore, her judgment regarding her ability to successfully pass, whereby she 'can easily get away with it', illustrates the ontological precedence she gives to her status as intersex, suggesting that any expression of a sex/gender identity other than intersex is fraudulent. As Samuels (2003, p. 239) notes, the ability to pass 'provides both a certain level of privilege and a profound sense of misrecognition and internal dissonance' for those with invisible/hidden impairments. Viewed in this light, Pandora demonstrates a struggle against the feeling that she is misrepresenting herself by achieving recognition as a woman. This is something that troubles her at various points during social interactions and relationships, as I will return to later in the chapter.

Like Pandora, 54-year-old Steve, who was diagnosed with partial androgen insensitivity syndrome (PAIS), also interpreted his ability to pass within the gender binary as valuable in forming relationships and preventing the risk of social stigma. He explained that,

> the benefit for me is by the time I got to school I was easily able to be definable
> as male and it was not an issue visually. I have other friends with androgen

insensitivity syndrome who have had problems because they either looked - in a way – different, or that they had very visible problems that got their attention. (Interview with Steve, 2013)

Steve describes his ability to pass as a man as a 'benefit' and Pandora refers to her 'luck' in receiving recognition as a woman. In accordance with Samuels's thoughts on disability, both participants reflect on the invisibility of their sex difference as a privilege which offers practical advantages of security and social integration. Due to its perceived privileges, 'invisible' forms of intersex are positioned by both participants as distinctly different to a more visible form of intersex. For Pandora, this is exemplified by the diagnosis of 'ambiguous genitalia'; a diagnosis which Steve has, in fact, received. Thus, Steve has a different understanding of perceptibility, referring to other cases of 'very visible' forms of AIS (in comparison to his own) and, more broadly, to those who 'look [...] different'. The somewhat vague, subjective and divergent notions of other, more visible states of intersex which are introduced by both participants represent the symbolic threat/Other of the imaginary intersex experience which is deemed to be 'difficult'.

This 'difficult' status of the visibly intersex (i.e. those who are understood to have external/viewable markers of intersex) is interpreted by Steve and Pandora as personally detrimental and unenviable. However, Steve's attempt to avoid being understood as different - which stems from the act of passing - is fraught with tension. He notes that,

> with regards to intersex conditions, life is more comfortable if you're less visually identifiable as different, and that's what I've learnt. And I may be colluding with the whole discrimination by hiding. (Interview with Steve, 2013)

Despite Steve's preference to go unnoticed, he feels uncomfortable about his ability to 'hide' his intersex status. Samuels (2003, p. 240) comments on the common perception that non-visibly disabled people prefer to pass. She notes, but does not endorse, the belief that 'passing is a sign and product of assimilationist longings'. For example, Swain and Cameron (1999, p. 76) argue that the passing of non-visibly disabled people as non-disabled 'minimis[es] the significance of their impairments within their own personal and social lives'. They suggest that if 'disabled people pursue normalization too much, they risk denying limitations and pain for the comfort of others and may edge into the self-betrayal associated with 'passing'' (*ibid,* p. 76). Steve illustrates that this interpretation of his ability to pass, or 'hide' (as he puts it), is one which concerns him. However, he reflects upon this as a conflict of in-group solidarity/collusion, rather than an issue of personal dissonance, as Swain and Cameron imply.

In Wendell's work (1996, p. 76) exploring her personal experiences of passing as non-disabled, she argues that whilst she benefits from the advantages of being treated as non-disabled in public environments, she is more concerned with how passing could restrict her ability to maintain a position within the disabled community, with all the political struggles and fights for justice that this entails. These issues can be categorised into two kinds: Swain and Cameron emphasise internal/personal discord and the potential for feelings of self-betrayal (*a duty to the self*), whereas Steve and Wendell focus upon a responsibility to others within the 'pre-passing' group, which may be compromised by an ability/attempt to be read as part of the passing group (*a duty to others*). In the latter, the attempt to pass may be read as an attempt to 'transcend' the pre-passing status, which places a negative value upon the 'transcended'

identity. The importance of visibility is stressed in theories of identity in Western culture (Schlossberg, 2001, p. 1) and often invoked in liberation politics, where it is understood that knowledge, awareness and the open/public presence of those who are marginalised will lead to their better treatment and greater recognition[3]. This is a problematic assumption for a number of reasons, not least because of the responsibility it places on the marginalised to 'elevate' their social position (a duty to both self and other), rather than placing it on those who are complicit in, or instrumental to, the ostracism. The necessary political and practical benefits and adversity of being '*unseen*' will also be explored later in the chapter.

## Visible bodies

In concurrence with Pandora and Steve's observations of the privileges and benefits granted by less detectible intersex traits, other participants reflected on the difficulties they faced due to the public perceptions of their physical difference and their inability to pass. One participant, 44-year-old Ian, who after a persistent search for medical support, has now received a diagnosis of hypogonadism and a provisional diagnosis of chimerism, spoke at length about his discomfort around his 'feminine shape and gait' (Ian's diary, 2013). He believes his physical femininity is very visible to others and the cause of his low self-esteem as well as the frequent discriminatory behaviour directed towards him. Ian referred to ambiguous genitalia as an example of an intersex characteristic which he believes would be *less* prohibitive in daily life. He commented,

> to me, that's kind of hidden away, because if you um – some people's conditions aren't visibly, *outwardly* visible um – […] um so they have an easier – I wouldn't say 'easier time', but they have a less […] – y'know I don't think by looking at them that you'd see anything *wrong.* (Interview with Ian, 2013)

Ian, Pandora and Steve demonstrate a diversity in their understanding of the kinds of intersex traits which would be more or less troubling, and the degree to which certain characteristics can be understood to be 'visible'. For Ian, his own body has been the non-passing 'difficult' state of the kind that Steve and Pandora have been thankful to avoid. The visibility of his own difference has caused him great anxiety and self-inflicted isolation which he has only recently begun to address. In his journal, he relayed one incident where he was approached by a man in a nightclub in a threatening manner. He explained that 'the man had picked up on my differences and had reacted with hatred towards me and that is why he approached me' (Ian's diary, 2013). Ian appealed to staff at the venue to help him with the situation. This felt like a significant injury to Ian's confidence because this was the first time he had been invited out to socialise 'in many years'. He describes the effect that incidents like these have had on his self-esteem,

> This is something that I have experienced in the past and has been part of the reason why I isolate myself because of the fear of how people will react to me. This is why I've developed low self-esteem and lack of self

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[3] For example, the 'One Minute's Noise' or 'Shout Against Hate' which has replaced a minute of silence at some 'International Day Against Homophobia, Transphobia and Biphobia' events, 'revealing the hidden (or until then silent) power of collective passion for change' (2013, dayagainsthomophobia.org); and the tradition of gay pride parades, which often focuses on the public spectacle of LGBTQ identities (e.g. Brighton & Hove's 2015 Pride LGBT Community Parade was marketed as 'out and proud celebrations and visibility' and 'the spectacle of the year' (2015, brightonparade.org)).

worth because of how people have treated me based on my appearance. The ridicule and ignorance I've had to endure since my childhood. (Ian's diary, 2013)

Ian's inability to be recognised by others as 'male enough' imposes a threat of physical danger or violence. More broadly, his difficulty in passing has been a hugely disruptive influence upon his life, leading to feelings of shame, loneliness and misrecognition. He describes this, however, in similar terms to Pandora; both feel that their visible embodiment does not accurately express their 'true' selves. He notes on a number of occasions that that he doubts 'anyone will ever accept me as I am' (Ian's diary, 2013). In contradistinction, Pandora interprets her identity as a woman as fraudulent; whereas Ian views his sex/gender ambiguity as disguising his 'correct' (male) state of being. In both cases, there is a fundamental mismatch between what is visible and invisible, and in Goffman's terms, their virtual and actual social identities.

Schlossberg (2001, p. 1) has underlined the Western cultural primacy of 'the logic of visibility', which she argues structures our 'theories and practices of identity and subject formation'. For Schlossberg, this is especially pertinent to acts of passing, which she believes are produced with a 'trust that our ability to see and read carries with it a certain degree of epistemological certainty' (*ibid,* p. 1). Robinson (1994, p. 716), like Schlossberg, is doubtful of the reliability of the 'visible as an epistemological guarantee'. Whilst Schlossberg and Robinson are right to locate a presumed epistemological certainty in the process of recognition, this chapter will proceed by arguing that this recognition is not only formed through visual practice, but also through 'unseeing', as well as other performances and discourses; our histories and our projected futures, the stories that we tell, and the relationships formed around this. The narratives that are told to others during social interactions are fundamental to processes of bond formation and play a pivotal role in constructing and supporting passing identities. Ian, Steve and Pandora's struggles for recognition are intricately bound to the production of these narratives, not just upon their visual presentation, as I will explore later in the chapter.

## Passing imperceptibly

Other participants shared Pandora's anxiety around the visibility or perceptibility of their intersex status. Twenty-four-year-old Sophie was given a diagnosis of Swyer Syndrome when she was fifteen years old. In her interview, she described the apprehensions she felt before attending her first support group meeting for people with a diagnosis of Swyer Syndome or AIS,

> I'd been like, 'everyone's going to be really tall,' because you read online that it makes you taller because it's something to do with your bones and the hormones – I don't, I don't really understand, but so I was like, 'everyone's going to be really tall, everyone's going to have thin lips' because I'd got this in my head, because I was like, 'you're a man, you have thin lips,' I don't know. And then I was like, 'everyone's going to look really ugly and manly and it's going to be *gross*,' and then I walked in and I was like, 'oh no, actually it's just a room of girls' – there are fat people, there are thin people, there are not... there are short people, there are tall people. And just to see that everyone is, you know, it could be a hundred women – or fifty or whatever, who walked in off the street, so you just don't know. It's just to meet people, everyone says the same thing... to meet people and just to see they're women, just *normal*

women and like it's just important to do, I think. (Interview with Sophie, 2013)

Prior to the meeting, Sophie anticipated that she would feel 'an almost intuitive faculty of recognition' (Robinson, 1994, p. 715); expecting specific visual codes which – despite 'duping' the 'unwise' (Goffman, 1963) – are recognised as indicative of a shared stigma by the 'in-group clairvoyant' (Robinson, 1994, p.716). Robinson describes this exchange between the 'knowing', and locates the ability to 'tell' as a 'discursive encounter between two epistemological paradigms' (p.724). Sophie felt relief to encounter other people with the same, or similar, diagnoses who she felt passed as 'normal women'; this was also a reassurance of her own normalcy.

After observing their successful passing, Sophie was reassured of her own ability to pass as a 'normal woman', and less convinced that her own morphology – thin lips, tall stature – was necessarily 'gross', abject or exceptionally masculine (especially in a way which may disclose her intersex traits to the unwise). Witnessing others successfully managing the perceptibility of their 'secret' helped Sophie to believe that her secret, too, was undetectable. She was safe from the harms that disclosure/exposure may bring. As Robinson (1994, p. 723) indicates, the value of (not) being able to 'tell' spectatorially is prioritised over the ontological act of 'knowing'. Hence, she argues, 'identity politics is indeed a skill of reading and not merely a feeble reproduction of dominant ideologies' (*ibid*).

## The masquerade

There is a clear discord between the visibility and invisibility of intersex traits in terms of both social and personal perception. Above, I have considered the ways in which the ability to pass as binary sexed/gendered (or as 'normal') is understood be beneficial, and how an inability to pass can lead to physical threat, as well as other social and psychological harms. To interrogate these distinctions of in/visibility further, it is necessary to consider the anxieties and other difficulties contained in an 'invisible' intersex status which grants the ability to pass as non-intersex.

Due to the epistemological and ontological transference which takes place in the act of passing, participants often analysed the authenticity, truthfulness and potential deception of their different states of embodiment and identity. We saw this previously in Pandora and Ian's discomfort around how they are publicly perceived. Whilst receiving legitimacy and recognition in a passing identity may offer certain benefits; passing, with its implications of concealment, can also play a destructive role in the route to seeking a harmonious status after a potentially turbulent medical history. Pandora's discovery of her AIS diagnosis in childhood led her to ask fundamental questions about her own identity. In her journal, she described the diagnosis thus:

> The death of me, because who I was before the truth was in fact just imaginary, so now I had the task of building again a person, an identity, to fill this body. I now hated this body, it had been a fake the whole time, it had failed me in being what it was meant to be, it was the thing that now contained my condition. (Pandora's diary, 2014)

Despite growing up as a girl who, until this point, had no doubts or confusion about her gender/sex identity or the gendered adequacy or her body, Pandora received the medical

interpretation of her morphology (i.e. an intersex diagnosis) as decisive. Her female sex, which she had once understood to be 'the truth', was now 'imaginary' and 'fake'. The medical institution carries such a weight of epistemological credibility that Pandora's own knowledge and experiences of her own body and identity were crushed; it was 'the death of [her]'. All of the participants who were given their diagnoses later in life experienced a similar severance in the stability of their identity. For example, Natalie, who was diagnosed with CAIS at 21 years old, refers to the diagnosis as the moment she 'started [...] questioning, 'Christ, what *am* I?'' (Interview with Natalie, 2014), which then led her to seek counselling and start a course of anti-depressants.

Pandora's interpretation of her 'fake' body as having 'failed' her in 'being what it was meant to be' also invokes a rhetoric of passing. Whilst she had felt her identity as a girl/woman was marked out by her visible body, her sense of self and her behaviour, Pandora's diagnosis of CAIS, including the absence of a womb, revealed that there was a different, 'invisible' status beneath, of which she had been unaware. The body which she 'now hated' was interpreted as a location of deceit; her body had been passing and even Pandora, herself, was unknowing. Ahmed (2004, p. 104) illuminates the relationship between concealment, exposure and shame. She notes that 'the desire to take cover and to be covered presupposes the failure of cover; in shame, one desires cover precisely because one has already been exposed to others'. Hence, once Pandora had been shamed by her 'exposure' as intersex, her womanhood was translated as a cover or masquerade. Now she could only ever 'pass' as a woman, she could never simply 'be'.

Pandora describes the hormone treatments she received during adolescence as an attempt to 'continue masquerading as a woman' (Pandora's diary, 2014) and discusses the difficulties she experienced as a result of attending a girls' school, where she 'definitely felt like a *fraud*, especially more so at a *girls'* school, surrounded all by girls and trying to sort of masquerade as, as one of them really' (Interview with Pandora, 2014). In knowing about her condition, Pandora felt that her legitimacy in a space intended exclusively for girls was in question. This meant that it was necessary to assimilate in a convincing way, so as not to draw attention to her invisible condition/sex. As suggested earlier in the chapter, the rules of assimilation for those who feel the need to 'prove' their legibility are potentially much more stringent than for those whose identities are experienced as transparent. Steve, for example, notes the active effort which he devotes to averting shame and securing a passing identity; 'I have worked hard at being male, and had to hide anything that suggested that I wasn't' (Interview with Steve, 2013).

Without informing any of her friends or family, Pandora underwent a surgical procedure to create a vagina at 19 years old. The decision to go ahead with surgery was a very difficult process, and only made easier because of the reassurance she gave herself that suicide was also available to her once the operation had been accomplished. She describes the creation of her vagina as a necessary apparatus of passing (Goffman, 1963, p. 85) as well as survival; the absence of a vaginal cavity was a sign which – pre-operation – could have exposed her as an 'inauthentic' female. Pandora explains that 'I felt a lot of shame about it, that y'know, in order to be *normal* – or *masquerade* as normal I s'pose, I need to have this done' (Interview with Pandora, 2014). Thus, the medical ascendency which first cast doubt upon her legitimacy to be female also granted her the most important insignia of her passing as a woman. Crucially here, I would like to underline how the surgical and pharmaceutical treatments assigned to people

with an intersex diagnosis can be understood as fundamental to the process of visibly passing; these treatments are themselves an apparatus of passing. This will be returned to later in the chapter and in the chapter which follows.

In her journal, Pandora outlines the different surgical options which were available to her. One procedure, which she dismissed, was a process whereby a vagina would be constructed using tissue from part of her bowel. She explains her reasons for rejecting this option;

> [the] idea of having a vagina made of bowel was horrid, so fake and something I couldn't live with. What if my partner, if there ever were any, could feel that it was wrong and different. I could lie to them in that way, make out like they were fucking a real vagina rather than a piece of bowel; who'd want to do that? (Pandora's diary, 2014)

Pandora justifies her constructive surgery as a desire to partake in penetrative intercourse. However, her concern that using the bowel to construct her vagina may unmask the 'truth' of her intersex status indicates that a key factor in her selection process was the potential for a convincing pass and to bypass the threat of 'discrediting' (Goffman, 1963). The use of her bowel to build a vagina was not a sensible option for Pandora because she is committed to giving the impression of 'realness', which she implies is in some sense more honourable. For Pandora, a piece of bowel is fundamentally different to a vagina, in such a way that the operation would not restore a sense of normalcy; instead she felt she would preserve the 'stain' of intersex, undergoing a 'transformation of self from someone with a particular blemish into someone with a record of having corrected a particular blemish' (Goffman, 1963, p. 19-20). As Schlossberg (2001, p. 6) notes, during a convincing performance of a passing identity, 'the seams must not show'. Of course, some intersex bodies are marked with the very literal seams of their surgical encounters.

## Involuntary passing

Whilst Pandora was an adult when she chose to undergo vaginal surgery, many people with intersex diagnoses receive medical corrective interventions in infancy before they are of a consenting age. Agency and autonomy is always under negotiation[4] so although Pandora's choice may have been heavily influenced by the regulative social demands of normalcy, in cases of surgery during infancy the medical contribution to passing is more explicitly an *imposition* than a service. Their bodies, deemed to be unintelligible, are made forcibly comprehensible according to the medical paradigm of sexual dimorphism. As Butler (2004, p.53) describes, 'the ideality of gender morphology is quite literally incised in the flesh' in intersex surgery, by the 'knife of the norm'. This underlines the importance of problematizing assumptions of agency and control in processes of passing. Not all passing is achieved with the awareness, consent or intention of the passer. When Pandora was around 6 months old, eleven years before her mother made the disclosure to her in the car, Pandora's parents 'noticed two inguinal [groin area] lumps' (Pandora's diary, 2014) on her body, leading to a diagnosis of CAIS. Following her parents' discovery of the lumps and the medical diagnosis, Pandora 'had surgery to remove what were my gonads'. She explains that,

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[4] Butler (2004, p. 7), for example, notes that 'choosing one's own body invariably means navigating among norms that are laid out in advance and prior to one's choice or are being articulated in concert by other minority agencies'. Our choices and methods of choosing are always restricted.

> growing up, I knew about the scare from the surgery but was merely
> told by my parents that I'd had a huirnea [hernia] as a baby. I never
> questioned this at all. All they said was that I would have to take tablets
> so that I could go through puberty, and as a child I just accepted this link
> between childhood surgery and puberty. I didn't know what this was a
> cover up of the bigger picture. (Pandora's diary, 2014)

Medical staff removed Pandora's reproductive glands before she was of an age to consent to surgery. This meant that puberty was later pharmaceutically induced using doses of oestrogen which were increased gradually throughout her teenage years. Pandora begrudges the decision not to disclose her diagnosis or the nature of her surgery to her until she was older. This is a common issue for people with AIS (Preves, 2008, p. 66), as I will discuss later in the chapter.

The testes of individuals with CAIS are often removed by clinicians, who claim that this is due to their increased probability of becoming cancerous (Preves, 2008, p. 76). This justification has been problematised by some intersex scholars and advocates (e.g. Davis, 2015; Deans *et al*, 2012), who argue that the probability of malignancy is relatively low and that a heightened chance of cancer in other instances (e.g. hereditary breast cancer) is not usually legitimation for non-consensual surgical intervention. Instead, it is believed that the removal of the testes is an example of 'normalisation' surgery, much like the cosmetic procedures carried out upon 'ambiguous genitalia', where in both cases bodies are altered to fit accepted morphological norms within the sex binary. The presence of anatomy which is medically characterised as male (i.e. testes), even when physically imperceptible without an internal examination, potentially endangers the prospect of medical staff, parents, and the patient themselves recognising the body in question as female. Thus, this surgical protocol is both a literal and figurative elimination of a 'stigma symbol', which Goffman (1963, p. 59) identifies as a sign which threatens to '[draw] attention to a debasing identity discrepancy, breaking up what would otherwise be a coherent overall picture, with a consequent reduction in our valuation of the individual'. These stigma symbols are also potential interruptions to a successful pass, therefore the medical institution recognises the elimination of these symbols (e.g. the removal of Pandora's testes) as an important apparatus of passing for people with intersex traits. Notably, the imperceptibly of the stigma symbol in this example illustrates how the act of passing can also be enacted or sanctioned at the level of the symbolic/imaginary.

## Conclusion

In this first of two sections on passing, I start by using Garfinkel's (1967) study of Agnes to frame my own considerations of what it means to 'pass'. By suggesting that passing can be understood as an 'imaginary' (Gatens, 1996) act, I critically engage with static or rigid understandings of authenticity, naturalness and the ability to 'know'. I argue that the authenticity of some identities and bodies, but not others, is expected to be proven and consistently demonstrated.

Extending discussions from the previous chapter on stigmatisation and secrecy, this chapter explores the range of ways in which participants engage with the threat or fear of visibility and perceptibility. This fear translates as a personal responsibility to keep identifying stigma symbols hidden. I observe some of the participants' concerns about the legitimacy of their virtual social identities, and their belief that passing could be understood a form of 'masquerade' and, thus, betrayal. This is connected to the knowledge that parts of themselves

are being hidden, or perceived to be misrepresented in some sense. Finally, I suggest that passing may be imposed upon others without their permission. The early corrective surgery paradigm is perhaps the most obvious example of this, whereby binary sex is surgically performed, sometimes without the subject ever being made aware. The following chapter further explores the quest to 'know' sex, and I consider how an understanding of 'epistemic vulnerability' (Gilson, 2014) may present a different way of thinking about passing, and about consistent or stable sex (and gender) identities.

# 7

## Passing II
## The (Un)certainties of Sex

This second section on passing will develop the arguments presented in the previous chapter by further examining the possibility of 'knowing' sex. I start with a critical exploration into the relationship between truth, authenticity and a notion of naturalness, then introduce Gilson's (2014) concept of 'epistemic vulnerability' to reflect on different ways of thinking about knowledge and certainty. I turn to the medical sex categorisation process of Imogen, and consider how the belief that parents require certainty in their child's binary sex may frame the clinical approach to sex ascertainment. I explore how epistemic certainty is experienced by intersex adults and, returning to themes from the previous chapter, I examine its connections to participants' concerns of fraudulence and deceit. This is considered alongside the management strategies deployed to ensure an intersex status remains confidential and passing is secure, as well as some of the complexities of thinking about the 'closet', a place which can be safe and comfortable, but also restrictive and – much like passing – complex in its relationship to authenticity.

## Embodied truths

This chapter starts with a focus on the pursuit of 'knowing' sex and how specific epistemological approaches to the body are invoked by the notion of passing. Garfinkel (2006 [1967]) observed a social preoccupation with the rectitude of genital attribution/construction. He argues that to be acknowledged as a 'valid' female, it is necessary to possess 'a vagina that *should have been there all along*, i.e., the legitimate possession' (*ibid,* p. 64, author's own emphasis), or 'the vagina the person is entitled to'. This is a position that was even ascribed to by Agnes, his research participant, the transgender woman seeking genital surgery, who I discussed in the previous chapter. Garfinkel notes that whilst the 'natural'/born-with vagina is understood to be the preferred course of possession, surgeons can also provide acceptable versions 'if they repair a natural error, i.e. if they serve as nature's agents to provide "what nature meant to be there"' (*ibid,* p. 64). This understanding of nature; attributing intentionality to the processes involved in developmental biology and taking for granted the possibility of a 'wrong' or 'right' course of development is, of course, a problematic position.

According to this belief, regardless of whether one has a visible and 'functional' vagina (or penis/other genitalia) which was present since birth or constructed later by a surgeon, there is an ontological distinction – carrying connotations of authenticity and value – which is made between anatomy which is natural and/or 'meant to be', and anatomy which is deemed to be in some way 'counterfeit'. These distinctions are especially commonplace in debates on transgender bodies. Whilst academic, feminist and wider social understandings of transgender identities and medical care have changed since Garfinkel's article in 1967, there continues to

be a strong emphasis in trans[1] narratives and advocacy literature upon inherent gender characteristics and a preferential disposition towards a 'trapped in the wrong body' biography, where genital surgery is framed as correcting an error or producing the anatomy which should have always been there (see Lovelock, 2015). These narratives can reproduce notions of gender essentialism and support the presumed need for biographical consistency (i.e. regardless of sex/morphology, a 'true' gender is known from the earliest possible age and this gender is fixed and constant). These representations of trans experiences are frequently depicted in the national press and legitimated by wider society (see the recent case of Caitlyn Jenner, for example[2]). These narratives of essentialism and gender stability and dependability are, of course, also ubiquitous in cisgender[3] representations of identity.

Similarly, the early medical protocols for intersex followed a model in which the 'true' sex of a patient was sought to be uncovered by medical practitioners, who believed the intersex body masked the natural and authentic identity of their patient. This framework establishes the medical practitioner in the role of 'the *doubly inscribed*: both discoverer and determiner' (Hird and Germon, 2001, p. 166). Garfinkel's description of surgeons as 'nature's agents' committed to discovering, revealing and (re-)building the truth of the intersex body underscores the rhetorical positioning which continues to be assumed in later surgical encounters.

Clinical approaches to intersex have since adapted to advances in medical science, mobilizing a greater understanding of the complexities of sex, thus medical classifications of sex now rely on a number of different biological indicators. Hird and Germon (2001, p. 167) characterize the modern regulation of intersex by a further 'epistemological shift from the notion of a 'true' sex that determined one's sex destiny, to that of *best* sex'. The label of 'best sex' in this context acknowledges the attempt to find a morphological compromise between the aesthetics of the genitalia, the results of chromosomal, hormonal and gonadal testing, and the prospect of fertility. However, as Hird and Germon (*ibid,* p. 168) and others (e.g. Karkazis, 2008; Bing and Bergvall, 1998) note, despite this transition in the conceptualisation of sex, medical specialists in conversation with parents continue to frame infant genital surgery as a process of detection and the pursuit of an 'authentic' or 'natural' state, rather than a case of volition or functionality. In doing so, they protect the primacy of the '*one sex* per body model' (Hird and Germon, 2001, p. 166) as well as their own ascendency in dealing with intersex patients. This is an act of reassurance (both to the parents and to themselves): an appeal to the certainty of 'knowing'. Feder (2014, p. 43) raises questions about the objectives of normalisation surgeries for intersex infants, asking – when we consider how medical practitioners stress the surgery's utility in diminishing *parental* stress – 'for whose relief is [the surgery] performed'. In making the aim of medical interventions the relief and comfort of parents' suffering, Feder adds 'the child *is not seen*' (p. 107).

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[1] I use 'trans' as an umbrella term to connote people who identify as transgender, transsexual, or somewhere within the transgender spectrum. However, these narratives are especially common in narratives of binary transitions.

[2] For example, see an article in *Hollywood Life* (Benozilio, 2015), entitled 'Bruce Jenner: Tired of Being Trapped in a Man's Body'.

[3] Cisgender is a term used to describe people whose gender matches the gender they were assigned at birth.

# (Un)certainties

The impression of certainty and truth constructed through medical practice forecloses the possibility of 'epistemic vulnerability' (Gilson, 2014). Our epistemic vulnerability, Gilson (2014, p. 93) argues,

> is what makes learning, and thus a reduction of ignorance, possible. Undoing ignorance involves cultivating the attitude of one who is epistemically vulnerable rather than that of a masterful, invulnerable knower who has nothing to learn from others or for whom other are merely vehicles for the transmission of information.

A rejection of the mutability of what we know, and how we know it, permits the medical institution to serve as 'nature's agents' and proclaim to parents the sex of their newly-born infants. This unequivocal certainty of sex is not only damaging in the context of intersex births, but could also be considered restrictive for all babies, whose genitalia is announced, often during the pregnancy, as a marker of gender signification[4]. Gilson (2014, p. 103) considers the relationship between epistemic certainty and disciplinary control. She notes that 'epistemic certainty – or the pretence of it – makes disciplinary control possible, and disciplinary control is effected through epistemic certainty'. Medical practitioners believe it is necessary for sex to be assigned 'immediately, decisively, and irreversibly' (Kessler, 1990, p. 8) in order to give the impression 'that something that was there all along has been found'. Thus, jurisdiction is enacted over intersex patients (and their parents) through the medical semblance of epistemic certainty[5]. This scientific advocacy of certainty and intentionality contributes to a narrative of destiny, presenting a life which is planned and foreseeable beyond doubt. Further thoughts on these themes will be developed in Chapter Nine on fertility and reproduction, which explores how the anticipated futures of people with atypical sex are implicated in the process of diagnosis and medical treatment strategies.

Recognising the value of epistemic vulnerability is especially pertinent to the institutional context of the classification, pathologisation and surgical 'repair' of intersex, but it is also consequential in intersex patients' personal quests for 'self-discovery' throughout the life course. Epistemic vulnerability is, according to Gilson (2014, p. 96), an 'openness to changes in the self [...] and the formation of the self', 'rejecting the closure of the self', 'open to the revision of the self and the conceptions of the self – past, present, future'. The mutability of bodies and identities; our epistemic vulnerability, is manifest in the viability of passing. Through the very 'process and the discourse of passing [we] interrogate the ontology of identity categories and their construction' (Ginsberg, 1996, p. 4). The pasts, presents and futures of intersex bodies have been moulded and continue to be mouldable: these bodies which have been altered without consent, bodies whose identities have been prescribed, bodies which develop in unexpected ways, bodies whose histories are not told to their owners. Passing is an acknowledgement of biographical discontinuity, the vulnerabilities of 'knowing', and the pluralities in corporeal meaning. For many intersex individuals, passing also provides the

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[4] Butler (1993, p. 232), for example, argues that ascribing the label 'girl' initiates a process in which an enactment of 'girling' is compelled. She argues that this 'girling' must be recognisable by normative standards 'in order to qualify and remain a viable subject'. Thus, femininity is 'indissociable from relations of discipline, regulation, punishment'. A similar argument could be made for processes of 'boying'.

[5] There is a significant body of literature on clinical uncertainty which I do not have space to explore in this study (e.g. Davis, 1960; Timmermans and Angell, 2001).

potential to retrieve agency in their pursuit for bodies and identities they find comfortable and intelligible.

## Categorising Imogen

I have considered how, in some cases, a conviction of the 'truth' of medical sex assignment results in physical and psychological harms for intersex infants, as well as adults. I argue that an appreciation of our epistemic vulnerability impedes the possibility of a definite, identifiable and static sexual classification, and encourages individuals to form independent ideas of self. To develop these considerations alongside notions of passing, I now look to the example of Imogen and her parents, Chris and Beth. I start by addressing how medical specialists have conceived of a range of strategies to help to frame their interventions as corrections and repairs, rather than processes of construction, disguise or passing (as it is perceived by some participants). The recent changes in nomenclature from 'intersex' to 'disorders of sex development' (Lee *et al*, 2006) illustrates the importance placed on viewing atypical sex as pathological and requiring correction. Similarly, in Preves' reflections on the surgical procedures performed upon the gonads of intersex patients, she (2008, p. 76) adds that

> it is standard for doctors and family members to refer generically to the organs removed during this surgery as "gonads" or "precancerous ovaries" to downplay the discordance between a female sex assignment and testicular anatomy.

In this practise of strategic naming, the medical staff participate in a further act of concealment and passing, whilst exposing their investment in asserting a coherent gender/sex identity for the patient. Not only must the stigma symbol be removed; its potential to be discrediting must also be disguised.

At the time of our interview, Beth, the mother of Imogen (who was born seven months earlier with a diagnosis of congenital adrenal hyperplasia (CAH)), was in the process of making a decision with her partner, Chris, about whether to agree to an operation on Imogen's genitals during her infancy. Beth clarified her position,

> I guess where I am on it is, and this is just… I think Chris broadly shares the same view, is I've always thought – rightly or wrongly – there's probably so many different… it's a real personal thing, is I want Imogen to have a vagina, vaguely functional. It won't ever be… perfect. Um, and for that, it transpires, because of her particular set of circumstances, it's probably better to do that when she's younger. (Interview with Beth, 2014)

Whilst some of our conversation, including the extract above, suggested that Beth was likely to seek surgical assistance for Imogen, she reflected on the resolution as 'quite honestly, *the* most horrendous decision I've ever had to make'. Beth repeatedly advised that there was 'no wrong or right answer' to the dilemma of surgery, which is broadly reflective of the dissensus amongst intersex advocates and the medical community, and indicates her own unease with either option. Although Beth believes that Imogen's genitalia will never be 'perfect', the absence of a vagina is understood by Beth to be a stigma symbol which could potentially discredit Imogen's status as a girl, and in the future (especially according to heteronormative

developmental milestones), as a woman. This resonates with Pandora's reflections about her own decision to request vaginal surgery.

The medical pursuit to sexually categorise Imogen was complex and confusing for her parents. At Imogen's birth, Beth recalled in her diary that upon seeing their baby for the first time, Chris was encouraged by medical staff to announce her sex. She noted that at this stage 'he said little boy' (Beth's diary, 2014). Very soon after this initial proclamation, Chris and Beth became aware that there was some uncertainty in 'sexing' Imogen. Beth described the course of events,

> I can remember Imogen crying straight away so I was so relieved. She was then taken into the corner where a doctor checked her over. I could tell there was something wrong as they were talking longer than I'd expect and there were a few doctors gathering round. The next thing I remember there was a more senior male doctor telling me that they couldn't determine the sex of the baby and that they would need to take baby to special care for monitoring and tests. In the meantime we shouldn't name baby or register birth. This was obviously not at all what you expect to hear and I remember feeling utterly stunned and shocked, but whilst Chris was crying I just had to believe everything was going to be ok. (Beth's diary, 2014)

The instructions to suspend the 'gendering' and naming of Imogen, and to delay registering her birth, were received with some anguish by her parents, in part due to the initial lack of psychological and social support or guidance given to them by medical staff. Beth notes that 'Chris and I sort of got there by ourselves […] rather than being guided' (Interview with Beth, 2014). Beth recounts her experience of the testing which led to the medical ascertainment of her child's sex, a process which lasted two to three days after Imogen's birth,

> I think it was the next day that we met a dr from the endocrine team – Dr Jeffries I think and a nurse we'd get to know called Jess. This Dr was not going to be Imogen's dr, it would be Dr Hayfield but he was not around that day.
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> I can't remember most of what we talked about, but a couple of things I do remember. Firstly they told us that they had had one test result back which was the chromosomes to determine whether she was XX, XY, YY and she was XX – female. They at this point were careful not to confirm she was a girl as there were other tests to do. One of the next tests was going on inside and whether or not you could see female parts, male parts, both or neither.
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> Imogen went off for her ultrasound and then the next day we met Dr Hayfield, Yvette the psychologist who gave us the results of the scan. They confirmed that they could see a uterus and a vagina and although they couldn't see the ovaries he was confident they were there as the hormone they release was there in her blood tests. After what felt like an absolute lifetime, I felt I had to then ask the question does this mean we have a little girl. And we did our baby was a little girl. I cried a lot with happiness and also relief that we now knew. (Beth's diary, 2014)

By reporting the results of chromosomal testing and gonadal investigation, Beth appears to recognise that there is no single determinant of sex and there could be a variety of possible procedures involved in the process of medically 'sexing' Imogen. After undertaking the

assessment, the doctors felt able to provide Beth and Chris with a definitive answer as to the sex of their child. On a number of occasions in our conversation, Beth reported to me that she was satisfied with the certainty of Imogen's female sex. She was especially clear on this issue in the discussions we had about other types of intersex conditions and the ambiguity, and hence *uncertainty*, that Beth felt other parents/patients may experience. She reflected, 'like what if she – what if they don't know? What if she's both? What if she's neither? What if – y'know, what if, what if, what if. But yeah, but they knew. She was a little girl' (Interview with Beth, 2014).

Whilst Imogen *does* have a uterus and most likely has ovaries, as well as XX chromosomes, her genitals were medically classified as 'ambiguous' and placed at 'a three or a four' on the Prader Scale[6] for the assessment of people diagnosed with CAH. The genitalia of someone graded as one on the scale are described as exhibiting 'mild clitoral enlargement' (Meyer Bahlburg, 2012, p. 207), and at the other end of the scale, at level five, the genitalia are understood to show 'extreme male-like masculinisation with a penile urethra' (*ibid*, p. 207). Whilst the reliability and purpose of quantifying anatomy in this way may be considered suspect, the Prader scale dictates that Imogen's genitalia are halfway between *medical categorisations* of male and female. Beth confirms that she 'can see why Chris thought she was a little boy' at the time of birth, but she believes that

> now, the *hormones* – 'cause of the hormones that they've been replacing, just by itself it's changed so much. It looks *completely* different and I think I'm not just being – maybe I am just saying it 'cause I'm her mum, but I think it looks a lot more female than male. (Interview with Beth, 2014)

In acknowledging the possibility that her maternal relationship with Imogen may have affected the validity of her judgement, Beth suggests that she perceives there to be a value in genitalia which is deemed to be adequately female, or binary, in appearance. Viewing these changes in her daughter's genitalia may also reassure Beth of the validity of the clinician's sex assignment, and of Imogen's future as a comfortable, self-defining woman.

Ascribing Imogen's body one distinct 'measure' of sex is not an entirely easy process. In addition to the classification of genital ambiguity, Imogen's vaginal passage has no orifice at surface level and is not a 'typical' size. It is therefore considered 'non-functioning' (e.g. for future sexual penetration or menstrual discharge). Without the hormonal supplements Imogen is currently given, Beth acknowledges that she 'will grow loads of *hair*… she probably would get a *deep* voice, y'know – it's that – it is masculinisation' (Interview with Beth, 2014). Without the supplements, Imogen could also potentially become more muscular, grow facial hair and undergo a rapid growth in height. Furthermore, what is understood to be 'typical' pubertal development for girls would not occur (e.g. no breast development and no menstruation). Without future medical treatment, it is also very likely that Imogen's fertility would be affected due to the absence of ovulation.

So-called 'natural' tendencies towards 'masculinisation', or the absences of 'feminisation', could be interpreted as a challenge to Imogen's female assignment. However, as sex is a contested

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[6] The Prader Scale, named after Dr. Andre Prader, is a five-stage system for grading/measuring the degree of 'virilisation' or 'masculinisation' of intersex genitalia. Meyer Bahlburg (p. 207, 2012) notes that 'if normal females and males were added to the Prader scale, they would be classified as 0 and 6, respectively'.

mode of classification, its regulation and capacity to be measured pose major ethical and epistemological quandaries. My argument here should certainly not be taken as an attempt to counterclaim Imogen as male. Imogen's gender identity is just as credible as any other infant, intersex or otherwise; so her validity as a girl should not be in question. Nevertheless, it is important to note the medical discernment involved in the selection of characteristics which are deemed significant in the sexual categorisation of Imogen (those which, in this case, provide *greater certainty* of 'female-ness', i.e. gonadal status and chromosomes) and the medical disavowal of the significance of other sex traits (those which, in this case, may produce some *uncertainties*/discrepancies of sex, i.e. genital formation, hormonal status, potential secondary sexual characteristics, 'natural' reproductive capacity).

Despite the complexity of Imogen's physiology (according to dimorphic standards), medical staff still felt capable of relaying epistemic certainty to her parents in the ascertainment of her sex. Imogen's medical recognition (or 'passing') as female involves a rejection of any traits (or 'stigma symbols') which may compromise that singular identity/sex. As I suggested in the closing of the previous chapter, with regards to the removal of Pandora's testes, the elimination of these symbols help to construct a more coherent or unified idea of self. Siebers (2004, p. 3) notes, 'passing is possible not only because people have sufficient genius to disguise their identity but also because society has a general tendency to repress the embodiment of difference'. Nevertheless, this bodily difference should not negate or contradict Imogen's gender identity as recognised by her parents or, later on, herself. As I note in Chapter Six, the burden to 'prove' one's sex is not expected of most bodies, and our assigned sex classifications are widely accepted despite any thorough procedures to confirm them.

The fundamental relationship between epistemic vulnerability and the notion of passing, as well as parents' common desire for their intersex child to pass as 'legitimately' binary-sexed, may lead to an assumption that the family of intersex infants would be invested in acknowledging epistemic vulnerability in order to protect the futures and autonomy of their children. However, a lack of certainty in sex or an appreciation of the flexibility and complexity of an infant's sex are deemed by medical institutions as a threat to familial bonding. In her study of the views and approaches taken to intersex by medical professionals, Kessler (1990, p. 9) notes that it is understood that 'a clear gender assignment and correctly formed genitals will determine the kind of interactions parents will have with the child'. One geneticist in her study argued that when parents 'change a diaper and see genitalia that don't mean much in terms of gender assignment, I think it prolongs the negative response to the baby' (p. 9). Medical intervention (and, thus, a binary identity/morphology) is therefore recognised as a fundamental contribution to helping the intersex patient receive a loving and affectionate upbringing. However, there is no research which indicates this causal relationship is necessarily true or universal, and many participants in this study reported familial relationships which were damaged due to decisions made about medical treatment on their behalf, especially when it had been kept hidden from them.

## Feeling like a fraud

These chapters have suggested that in some cases, processes of passing may not be 'free-willed' or chosen, but outwardly enforced. Now I also want to consider the consequences of passing in this context, and ask: who are the beneficiaries of intersex bodies passing as binary, whether self-elected or imposed? How is epistemic certainty invested in these sex classifications, and

how is it experienced by intersex people and their parents? I have demonstrated how the epistemic certainty which is performed through the medical ascertainment of sex is not upheld by all intersex patients during their development into adulthood. Some participants spoke of the distrust they felt towards the binary identities/sex they had been medically assigned in infancy and the anxiety they felt about being exposed as 'truly' intersex. Steve notes that he 'did feel constrained to a degree and in my teens felt increasingly isolated and feared being found out' (Steve's diary, 2013). Pandora, too, expressed a discomfort around the dis/honesty of her identity, when she explained that her female status felt like a masquerade. She says,

> there is a feeling that I'm lying to people, the worry that you're going to get found out kind of, sort of a bit of an *imposter* in a way. And um, so that's always something that's sort of been on my mind really, yeah, just being – being discovered as a liar kind of thing, which isn't a nice feeling really. (Interview with Pandora, 2014)

Whilst a discourse of truth and conviction – the imperative to unequivocally '*know* the *real sex* of the body' – is recognised within medical practice as reassuring and constructive, the same notions operate as sources of anxiety and suspicion for those diagnosed. Ian notes similarly, that 'I think I've always felt like that. I feel like I'm deceiving somebody, like um… because I've always felt like no one would accept me with the problems I have' (Interview with Ian, 2013). The act of concealment, which some intersex individuals feel is necessary in order to mitigate potential stigmatisation, can also lead to feelings of dishonesty and deception. Presenting a 'normal' self (Goffman, 1963) – that is, one which is not stigmatised – can be a heavy emotional and psychological investment and burden.

## Keeping the secret

These chapters have illustrated the personal and social ramifications of concealment and the distress of feeling that one's gender/sex identity is in some sense fraudulent. Thus secrecy, privacy and the processes of managing and sharing knowledge are crucial issues for many people who are intersex and engaged, in the broadest sense, in a process of 'passing'. Participants spoke at length about how it felt to discover new information about their body (in some cases after diagnoses and treatment had previously been withheld from them); the realisation that – in some instances – knowledge regarding their medical treatment is *still* unavailable to them and probably always will be; and, also presented reflections on the tribulations involved in deciding whether or not to tell others about their intersex status. Keeping intersex a secret felt burdensome for many participants, and was understood to create feelings of distance and a sense of alienation in otherwise enjoyable relationships. Some participants questioned the allocation of 'secrecy'; disputing why some information would be considered to be 'withheld' or deceptive when undisclosed, whilst other information is recognised as private or insignificant (there is usually no expectation to disclose to a partner a diagnosis of eczema or a short-term childhood illness like influenza, for example). There are specific conditions or stipulations which dictate what kinds of knowledge are significant, who has the right to keep knowledge classified (i.e. who counts as a 'subject' entitled to privacy), and the particular social, psychological and legal consequences of disclosing, not disclosing, or disclosing 'too late'. Keeping an intersex status undisclosed or concealed is one of the most important factors in passing as binary gendered/sexed.

In her journal, Natalie noted that she had only disclosed her intersex status to me, a small number of people she had spoken to through online AIS support groups and two close friends. She wrote, 'here I am, Not Told my father, Not told my sisters, Not told my limited amount of friends. The only people who know are strangers who understand the condition. I can tell strangers but not my own flesh and blood' (Natalie's diary, 2014). Natalie's diagnosis was made when she was twenty-one years old so her family were not informed by medical staff, and she anticipates that most people would be too unaware of intersex/AIS to respond respectfully or fully understand her condition/status. If they were to find out, she suggests that 'some people just might say, 'Well you're a freak aren't you'' (Interview with Natalie, 2014). On the occasion she decided to tell her two closest friends, Natalie was hurt to find they responded by laughing. She explained, 'they thought it was funny so I thought 'fine then, I won't tell anybody'' (*ibid*). She notes that she has since become more private,

> I was like – I said to them, 'Well I'm glad you find it funny but it is actually-' I over-exaggerated, I said it could actually be life-threatening. Y'know, and they were like, 'Oh, we didn't realise'. Well, perhaps you should've *realised* before you started bloody laughing! But we won't talk of it again now. So whenever they hear me on the phone making an appointment, or they see a hospital letter, they're like, 'Is everything ok?' and it's like, 'No, you laughed! You don't need to know anything now'. (Interview with Natalie, 2014)

Feeling disappointed by her friends' responses, Natalie reflected on the way in which their relationships have since changed. She notes, for example, 'I don't trust them anymore' (*ibid*). Natalie's retort to their laughter was to embellish the health-impact of CAIS and tell her friends that the condition could, in fact, be fatal. Whilst many people with intersex traits are resistant to the pathologisation of their bodies, Natalie found that in this context re-centring the discussion onto her health, rather than her non-typical physiology, was a way to provoke a more sober response from her friends. For that moment, she endeavoured to pass as severely unwell, inhabiting a 'sick role' (Parsons, 1975) whereby it was anticipated that words which had otherwise been understood to be comical by her friends (i.e. gonads, sex) would lose their humour and Natalie would receive the more compassionate reaction that she desired.

Ian had a similarly upsetting experience when he was 17 years old and he undressed in company for his first (and only) sexual encounter. He told me that,

> I'd met this girl and uh I was trying to – I don't know whether you'd call it denial, but I was just trying to um just live my life and try with the problems I have, but then um… um yeah we got y'know intimate and then she told people um about certain physical characteristics about my body, my lack of experience, and um – so people were laughing, saying stuff, and um – so it kind of just re-confirmed how I felt that no one would accept me with the problems I have. So it kind of made me more um… um withdrawn, and less open to engaging with people. Um so yeah I'm very uh… um awkward, I'm not really *open* with people, it's very difficult for me to kind of allow people in. (Interview with Ian, 2013)

Ian, like Natalie, understood the negative social response to his disclosure/exposure as a caution. He explained that 'as soon as she picked up on my differences, I was rejected. As she informed her friends about me, I became just a joke to people living on my street' (Ian's diary, 2013). From then on, he was more careful to protect himself from potential humiliation or

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rejection by ensuring that people in his social environment were unaware of his intersex status. As a result, he notes he 'never really had any more friends or girlfriends' (Ian's diary, 2013).

Other participants, who were diagnosed during infancy or early childhood, were given specific orders to ensure that their intersex statuses was kept hidden. Steve notes that, 'I've always been brought up with a 'don't tell everybody'', although he also recognised independently during childhood that 'in order not to be bullied, you just didn't tell anyone about this' (Interview with Steve, 2013). Other than the medical practitioners, it was only his parents who were aware of his condition until he reached adulthood. He notes that his parents made sure that even his sister was not to find out. Paula, too, explained that she was told to 'keep it quiet, it's quite shameful so keep shut up basically, keep shtum, so that's how I've always been like' (Interview with Paula, 2014). For both Steve and Paula, information management was prescribed and rehearsed from an early age. As Paula notes in the extract above, the rule against disclosure was also very much tied to the experience of shame for her and many other participants. Sedgwick (2008) explores the notion of 'closeting' and concealment, underlining the connections between knowledge and sex. In conversation with Sedgwick, Siebers (2004, p. 2) notes that closeting 'involves things not merely concealed but difficult to disclose – the inability to disclose is, in fact, one of the constitutive markers of oppression'. The intricate connections between knowing, oppressing, and – as Sedgwick, following Foucault, acknowledges – *surveilling* each other, illustrate the tensions involved in disclosure and exposure.

Pandora underlined the strong imperative she felt to ensure that her intersex status was undisclosed. She has chosen not to tell any of her previous or current sexual/romantic partners due to the risk that they would respond negatively. She explained that,

> for me it's just filled with fear, it's just filled with the idea of... that conversation is just, to me, it just spells rejection still. Just that idea that, of them finding out, just means that that's the end of whatever relationship I'm in, basically. (Interview with Pandora, 2014)

The perception that no one would choose to be or stay in a relationship with Pandora if they discovered that she was intersex meant that the process of passing as a woman/female *without* an intersex status/history was crucial. The social cost of her status becoming exposed was a great ongoing threat to Pandora. When discussing her experience of adolescence, she notes that,

> One of my major fears was that people would find out my horrid secret, find out who I really was. I made a pact with myself that I would kill myself if anyone ever found out about the AIS. I couldn't live with anyone knowing. The intensity of this fear of discovery meant that I was paranoid that people could tell just by looking that I was this fake. (Pandora's diary, 2014)

Pandora's wish to not live with the social costs of being exposed as intersex illustrates the degree of disavowal she anticipated from others, as well as the considerable aversion and shame she felt towards her own body and state of being at that time; in her own words, she experienced 'suffocating feelings' of 'self-hatred' (Pandora's diary, 2014). As Siebers suggests, her inability to speak of her sex/condition is indicative of the social position she believes it is given.

The act of passing, and the feeling of dishonesty and concealment which is integral for some passing individuals, can be detrimental to a sense of personal security and coherence. However, many participants also spoke about its personal and social advantages: to varying degrees, it granted them protection and made them feel 'normal'. Goffman (1963) argues that the management strategies involved in these processes are *expected* to be deployed by stigmatised people. He notes, 'the line inspired by normals, then, *obliges* the stigmatized individual to *protect* normals in various ways' (Goffman, 1963, p. 145, my own emphasis). This may suggest that some of the concealment which is achieved by those who are diagnosed as intersex is performed on behalf of those in their social environment, rather than simply for their own benefit. It is the stigmatised person, notes Goffman, who is expected to 'help [normals] and the social situation by conscious efforts to reduce tension' (*ibid*, p. 141). This is enacted, in part, through the duty of the stigmatised to remove all traces of the stigma which may make others uncomfortable. Goffman argues that 'the stigmatized individual is advised to accept himself [sic] as a normal person because of what others can gain in this way, and hence likely he himself, during face-to-face interaction' (*ibid*, p. 145).

Thus, for an intersex person to accept their morphological differences as pathological – and to then inhabit a binary identity, status and body – may be a reassurance for those of us who are deeply implicated and invested in the notion of sexual dimorphism. This, in Goffman's terms, *protects* others from, amongst other things, the need to re-evaluate their understanding of sex and their own position in the binary. It may be, in fact, this act of protecting *others* which then allows intersex people themselves to feel protected – an exchange of mutual benefits.

Epistemic certainty and successful, sustained passing is tied to the interests of the medical institution. Medical specialists, who have in some cases been performing normalisation surgeries for decades, may not want to feel compelled to morally indict themselves. Despite longstanding pressure, there has been only one instance of a public apology made by a physician to a former patient (see Guterman, 2012). Recalling a distinction made in the previous chapter regarding the direction of the duty to pass (i.e. to the *self* or to *others*), the burden of concealment and feelings of deceit articulated by some intersex participants emphasise an asymmetry in benefits. Passing, in this sense, may be enacted for the relief and comfort of those occupying one's social environment, much like the medical interventions which Feder (2014) argued were for the contentment of parents and their relationship with their child. Thus, their passing is in some instances an act of hospitality, endured to accommodate the interests of others. This hospitality, in turn, provides reassurance and social security for the passing individual.

## Coming out of the closet

Disclosure, whilst often understood as desirable, has – as described above – also led to some unpleasant experiences for participants, which have prompted higher levels of privacy and social isolation. It is not surprising, then, that other participants shared a heightened anxiety of disclosure/exposure, and made the decision to keep their intersex status hidden at all costs. However, privacy is not always understood to be 'controllable' and the possibility of visible identifiers of intersex are therefore seen as especially intimidating or risky. Reflecting further on the complexities of disclosure, Goffman (1963, p. 108) notes the expectations of knowledge exchange placed upon various kinds of social relationships. He argues that 'every relationship obliges the related persons to exchange an appropriate amount of intimate facts about self, as

evidence of trust and mutual commitment. Close relationships that the [stigmatised] individual had before became compromised, automatically deficient in shared information'. For some participants, however, the potential deficiency or compromise in trust incurred as a result of keeping their intersex status undisclosed was preferable to the consequences of exposure. In either instance, the closet is certainly a 'shaping presence' (Sedgwick, 2008, p. 68). Pandora notes that 'to be physically intimate with someone who's not fully… like, who's not female in *all* aspects, I worry that that would *freak* people out, that especially… I think especially men, that if they were to find out, that they'd think to themselves, 'my God, I've been having sex with a man''. Despite not having had a sexual partner, Paula, who is 35 years old and has a diagnosis of partial androgen insensitivity syndrome (PAIS), spoke about the discretion she felt was necessary to employ in sexual relationships. She notes,

> I've got a really good friend who, y'know, who's had boyfriends in the past and she *tells* them and it's *fine*, and then they break up and then it gets messy and then it gets spread around. And you're like [exhales loudly] just don't tell anybody. It sounds awful, because you shouldn't have to hide who you are. But sometimes it's just better to keep your mouth shut and to keep everything… that sounds *really* cynical and really awful, but d'you know what I mean? Sometimes it's just better to kind of protect yourself rather than… [sighs loudly again] say what you're gonna say.

Whilst Paula and Pandora, along with other participants, fear their intersex status could be publicly perceptible or otherwise learned by others, they still affirm the belief that to 'know' the diagnosis/sex is to 'know' them better personally. This understanding has been critiqued in 'coming out' narratives in LGBTQ biographies. Butler (1991, p. 15), for example, argues that,

> in the act which would disclose the true and full content of that "I," a certain radical *concealment* is thereby produced. For it is always finally unclear what is meant by invoking the lesbian-signifier, since its signification is always to some degree out of one's control, but also because its specificity can only be demarcated by exclusions that return to disrupt its coherence. […] If I claim to be a lesbian, I "come out" only to produce a new and different "closet". The "you" to whom I come out now has access to a different region of opacity.

To some extent, this narrowing or restricting of 'I' could be said to be symptomatic of all forms of identification and labelling, not only those which are produced or proclaimed by the process of coming out. However, Butler's concerns regarding the extent to which we have control over the signifiers which are deemed 'true' is especially pertinent to intersex, a status which is determined by the medical institution rather than the individual or community.

Pandora, for example, described her intersex diagnosis on a number of occasions as a 'trap' from which she felt unable to escape. She reported that 'there was no way out. It felt quite trapping, 'cause I couldn't change it. And there wasn't really anything that I could do about it' (Interview with Pandora, 2014). The epistemic certainty which Pandora believed was intrinsic to her intersex categorisation meant that, despite her discomfort, she interpreted her medical label as infallible and obstinate. This feeling only abated when she first encountered a doctor who gave her a range of surgical options to transform her vagina. She describes that 'very quickly she gave me a lot more options so um, it didn't feel quite so trapping' (Interview with Pandora, 2014). As

discussed previously, Pandora understood vaginal surgery (using the Vecchietti procedure[7]) as an essential component of passing successfully as a woman. Feeling like, and passing as, a woman – an identity which had been unambiguous to Pandora prior to discovering her diagnosis – was liberating for her. The intersex status, on the other hand, felt oppressive and confining. Thus, in this sense, the identity/sex which Pandora holds to be 'true' (i.e. intersex) is not one which she understands to necessarily emancipate her in the fashion that acts of 'coming out' can often convey. Siebers (2004, p. 8), for example, notes the connection made between 'coming out', rejecting oppression and, ultimately, finding happiness.

This is not straightforward for Pandora, however, as she shows a great deal of ambivalence about disclosure. For instance, she was relieved and reassured after disclosing her diagnosis to two close friends after her surgery (describing their accepting response in her diary as 'life-saving'), and looks forward to a time when she will feel confident in trusting a romantic/sexual partner with information about her intersex status. She believes that this

> would be quite therapeutic in a sense, just like a final like, 'Well, it's *okay* to be like this!' Y'know, nobody has such a problem that *you* do, even, *even* someone who sort of – you're in an intimate relationship with […] it would *have* benefits definitely, of… just to help *me* accept it.
> (Interview with Pandora, 2014)

Pandora's repeated emphasis on how disclosure may impact on (and has, in fact, impacted on) her *own* sense of self, rather than improve a partner/friend's understanding of her identity, may illustrate the cause of her ambivalence. Disclosure (or 'coming out') is understood to be a route to escape shame and isolation for Pandora as well as a way to alleviate a sense of deception, but she is resistant to the notion of intersex as a *defining* characteristic; a revelation which could mean that she will be seen as different in the eyes of others – and, thus, perhaps endanger her ability to pass. As Sedgwick (2008, p. 70) observes, those who are closeted are 'bayonetted through and through, from both sides [self and other], by the vectors of a disclosure at once compulsory and forbidden'. Pandora is pulled in two directions.

## Avoidance and camouflage

Prospects of 'coming out', disclosing or sharing information were complex and treated with ambivalence by all participants. I have explored how Pandora, for example, was 'trapped' by the perceived certainty of her (inter)sex, not just the act of concealment. Other participants, such as Natalie and Ian, who had attempted to entrust others with new information, found themselves pushed into a position of heightened privacy and seclusion due to the unsupportive responses they received from their confidants. I will now consider how some participants sought to avoid situations which they believed could threaten to 'expose' them and compromise their ability to pass successfully as non-intersex, and reflect on how this process of avoidance has impacted their everyday lives. The following sections extend and reflect upon Feder's (2014, p. 107) claim, drawn upon earlier in the chapter, that the treated intersex child is one which is '*not seen*'.

When discussing issues of disclosure, Steve informed me that he manages information regarding his intersex status very carefully in order to ensure that only individuals who he is

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[7] As described in Chapter Five, similar to vaginal dilation, this is a one-step procedure whereby the vagina 'dimple' undergoes continuous pressure for 7-10 days in order to lengthen the cavity. Patients are in hospital under supervision for the duration of the procedure.

certain would provide a supportive response are aware of his sex. Like Ian, he notes that this has led to some social isolation; 'I think I have *engineered* that and therefore have been far more of an individual, a loner, far more quiet, and more circumspect perhaps' (Interview with Steve, 2013). Steve's vigilant approach to trust and privacy has meant that the only occasions in which he has been drunk are when he has been in the company of the two close friends he lived with at university and continues to meet with once or twice a year; a friendship group he refers to as 'the tripod'. He explained to me that,

> Steve: I have *never* been drunk except when I've been with the tripod. Outside of those two people who know me and I know them, that is the *only* place I've ever been *safe* enough to… *cross* the boundaries of alcohol.
>
> Charlotte: Ok. Does that feel linked to the condition or is that - ?
>
> Steve: [Interrupting] *Absolutely*. Yeah. As a student, I left school, went to university, and for everyone else there was a big explosion. For me there was actually… an explosion, but I was still as reserved as possible about alcohol, and about *casual* relationships. Because I didn't want to have to explain myself, or pick up the pieces of… of someone knowing who will then tell somebody else and then the information disseminating. (Interview with Steve, 2013)

In our interview, Steve discussed his approach to his body and identity as becoming increasingly confident and relaxed with age, despite many of the defence mechanisms he had developed in his teenage years remaining in place. This includes his abstention from alcohol due to a feeling that he was not 'safe' enough to be drunk in the company of others. He observes that 'my ten, eleven, twelve-year-old privacy model still works with me at 53' (*ibid*).

Siân, who is 28 years old and was diagnosed with Turner Syndrome three days after her birth, describes a similar attitude to alcohol. She wrote in her diary that her aversion to alcohol made her feel alienated at university, explaining that 'not knowing what might happen in a situation where people around me were inebriated made me anxious. As this is a large part of life for most students I felt particularly outcast amongst my peers because of this' (Siân's diary, 2014). For both participants, drinking alcohol was seen as a risk which may lead to a loss of control over their conditions and the related information management.

Steve's family were members of the Presbyterian Church, which he believes may have had a bearing on his parents' and his own attitude to intersex. He notes that

> Steve: I think part of the experience that I know of people with my condition is that they will either excuse themselves from religion, if for *fear* of being judged, or they would *hide* beneath it, uh, in a sort of asexual context and be *lauded* for being not someone who's out drinking or making people pregnant. The *virtue* is that it's a smokescreen, and I think that's one of the things that religion has – it offers a smokescreen… providing I - it's like a 'don't ask, don't tell'. You can be gay, you can more or less have sex with anyone – you can be gay, but you mustn't be *gay*!
>
> Charlotte: Just don't *act* like it? Yeah! [Both laugh]

Steve: It *is* bizarre. (Interview with Steve, 2013)

Steve believes that some intersex individuals gravitate towards communities which foster an understanding that sexual intercourse should not be assumed to be desirable and/or commendable. For instance, in the same interview he asserts that,

> I suspect there's a fair number of people with an intersex condition within these asexual communities and also in communities where sexuality is frowned upon like in particular religious groups. Because you can *hide* behind it, you are not abnormal if you don't have sex with your girlfriend if you're an Evangelical Christian.

Steve illustrates the pragmatic relationship some intersex people may form with the communities they join, wherein he argues that these communities provide a place where suspicion is not raised regarding the typicality of their bodies, identities or behaviour, and prying questions will not be asked. Describing the function of these communities as a 'smokescreen', or an affiliation to 'hide behind', Steve highlights the requirement often placed upon those who are attempting to pass to justify or explain behaviour deemed to be peculiar or deviant, such as sexual inactivity. Furthermore, he alludes to the appeal of finding others whose behaviour or views are complementary to their own, in order to maintain a level of secrecy, comfort and normalcy, to blend in and remain *unseen*, securing the success of their pass.

## Building a narrative of normalcy

Developmental and sexual norms also threaten to draw attention to the atypical experiences of those who are intersex: to make their bodies more 'visible'. This can be dealt with by further hiding or concealment through the construction of biographies which meet particular social demands. Natalie notes that as a teenager, prior to her diagnosis of CAIS, she was aware that some of her female peers were discussing their experiences of menstrual periods; something which has never occurred for Natalie. She described her response to this in our interview,

> I used to even *lie* in some conversations, 'cause um the girls... when I was in school, obviously the girls started their periods around the same time. And of course I couldn't say I hadn't because I didn't want to be branded a freak so I used to actually keep a box of tampons in my school bag and purposefully show 'em off, y'know like opening my bag and like 'Oh God, they've fallen out, oops'. And that could be embarrassing, couldn't it! And I didn't need them! (Interview with Natalie, 2014)

Natalie used the tampons as a prop to convince others of her normalcy. At this stage, she was not intentionally obscuring her intersex status, although she later came to recognise the absence of menstrual periods as one of the first indicators that her body was not 'typical' for a female. During adolescence, her desire to be seen as someone who menstruates was to ensure her experiences approximated those recognised as female in her environment. She confirms, 'if they knew that I wasn't having them they'd consider me a freak and I'd get bullied more than what I already was' (Interview with Natalie, 2014). The box of tampons Natalie kept in her school bag to prove to others that she, too, was a menstruator, became a 'prestige symbol' (Goffman, 1963, p. 59), despite, as Natalie acknowledges, menstrual sanitary products often being understood as a badge of shame for many teenage girls. Natalie demonstrates how suggestions of sexual digression (i.e. an absence of, or very 'delayed', menstrual periods) can

cause feelings of insecurity and introduce social threats of hostility and rejection, even in isolation from an intersex diagnosis.

Participants who have experienced little or no sexual activity with a partner often emphasised this absence as a mark of shame, as I will explore in more detail in Chapter Eight, which discusses issues of sex, sexuality and relationships for people with intersex traits. The understanding of virginity and masturbation as 'rites of passage' felt stigmatising for these participants, so in some cases - like Natalie with her tampons - participants constructed narratives which provided the 'credibility' they felt was needed in order to pass as binary sexed/gendered and, by extension, sexually active. In his diary, Steve notes that,

> at 15 i was aware that other boys spoke of 'wanking' and when i learned about it, i became aware that it was generated by sperm production, which i did not do! I began to get angry that i was not 'normal' and fearful that the abnomality [sic] would be exposed. (Steve's diary, 2013)

As Steve illustrates, the desire to prove to others (and to himself) that the body is developing and responding 'normally' correlates with the fear of exposure. The 'wrong' body becomes a source of potential betrayal, whereby the imperative to prove one's normalcy produces feelings of self-doubt and vulnerability. Paula, too, describes the narrative of normalcy that she constructed in order to protect the confidentiality of her intersex status. She describes feeling 'too embarrassed to admit the truth' about her virginity (Paula's diary, 2014). Acknowledging the social recognition tied to sexual activity, she prepared a fictional anecdote to tell to friends and family to ensure that her biography was interpreted as suitably 'typical'.

Proving sexual competence, both to others and to one's self, was discussed by many participants as a crucial aspect of feeling, and passing as, 'normal'; a theme which will be expanded further in later chapters. Sexual activity, especially at the age in which first encounters are most anticipated, and pubertal changes (such as beginning menstrual periods and/or starting to masturbate), are both represented as 'rite of passage' events which are fundamental to demonstrating conformity with a normative 'developmental' path into adulthood (with all the heterocentric and ableist presumptions this often entails[8]). This 'failure' to meet the expected temporal and corporeal norms has the disciplinary function of positioning the intersex body as one which is 'wrong' and requiring secrecy, and/or correction, and draws attention to a biography which does not satisfy the required 'coherent narrative or stable history, a mappable trajectory' (Schlossberg, 2001, p. 4). The temporal framing of these events will be further explored in Chapter Eight.

## Hiding

I have shown how the ritual of concealment, whereby an effort is made to guarantee that potentially 'discrediting information' (Goffman, 1963) is kept secure and private, can alter the social behaviours and decisions made by those with intersex traits. Concealment was evident in participants' attempts to construct narratives of normalcy in order to disguise the ways in which their experiences did not conform to social expectations. The notion of 'hiding' was also invoked by participants on many occasions during the interviews for this study. In contrast to

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[8] See, for example, Kafer (2013) who explores the story of Ashley X, a disabled girl who has been 'frozen in time' by the medical interventions made to prohibit pubertal changes in her body.

the prior discussion, this was also a form of corporeal concealment, as well as one of behaviour. Building on the acts of social avoidance and hiding discussed above, the following analysis will explore the desire to hide one's body specifically.

Steve and Pandora, who despite describing themselves in the previous chapter as not very 'visibly' intersex, reported the desire to 'hide' their bodies to ensure that their intersex traits went unseen. For Pandora, this act of hiding was most apparent in her eating disorder. She feared that 'somehow my fatness was the big give away, and that if I could be thinner, people wouldn't know [about her condition]', also reflecting on 'a desire to fade away out of vision so that people could never find out' (Pandora's diary, 2014). Pandora first began losing weight in response to the hormone replacement therapy (HRT) she was prescribed shortly after her Mum informed her of her diagnosis at 11 years old. She notes that the initial weight loss 'was seen as a positive thing', but after reaching 'a healthy weight' she then 'kept going and going' (*ibid*). In our interview, she explained her experience of anorexia as an apparatus of hiding her intersex status,

> It's sort of – when I started to obsess more about *weight* sort of, that was a bit of a smokescreen in a way. That was a comfortable place to hide, because I *could* do something about it, that was in my control. So that was a place that I could go to. 'Cause I used to just think about the condition *all* the time and just found it really painful because there was no way out [...] whereas if I could hide in my mind, sort of keep my thoughts on *food* and weight and things like that, that's a place where you *are* in control so um you *can* do something about it. And, so yeah, that sort of was a bit of a smokescreen and *did* make me feel like I disappeared slightly, so it made me feel more comfortable in… yeah, I just felt that people didn't notice me at all, so *couldn't* notice my condition. (Interview with Pandora, 2014)

Pandora outlines the number of ways in which her eating disorder provided a 'cover' for her intersex status. Cognitively, anorexia diverted her attention away from intersex, it gave her an alternative focus; suppressing and obscuring her fixation on AIS. So long as there was a new 'problem' to be consumed by, the intersex issue felt less present for Pandora. Goffman (1963, p. 117) briefly discusses the capacity for the signs of a particular stigma to be presented instead as the signs of another attribute, 'one that is less significantly a stigma'. He suggests, for example, that someone with an intellectual disability may attempt to pass as someone with mental health problems, or someone with a hearing impairment may intentionally give the impression of being 'a daydreamer, an absent-minded person, an indifferent, easily-bored person'. Whilst his examples may not correspond with today's measures of stigmatisation (i.e. mental health problems would not necessarily be less stigmatising than an intellectual disability), Pandora's description of the exchange or deflection which occurred from intersex to anorexia conforms to the diversion strategy Goffman describes.

However, contrary to Goffman's suggestion that one diagnosis may be exchanged for another, the medical imputation of Pandora's eating disorder (i.e. anorexia) was not revealed to, or recognised by, others. At a social level, she describes her intention to present herself as minimally visible and hardly noticeable, rather than, necessarily, someone with a different condition. She underlines the physical dimension of shrinking in size, feeling less 'visible', less 'noticeable' and, essentially, 'disappearing'. Pandora explained, 'by losing a lot of weight, by

becoming really thin, [I hoped] that it would *hide* it [the AIS], [...] that's been I s'pose quite a big, a big upshot of knowing about the condition really' (Interview with Pandora, 2014). In her diary she expands on the desire to be thinner, exposing the significance of size in her aspiration to conceal her intersex status and ensure she was read as appropriately feminine. She clarified, 'maybe if I looked more like the other girls, then I'd feel more like them, maybe even become more like them' (Pandora's diary, 2014). This process of diversion, and of hiding, was thus also an attempt to pass as a woman and assimilate to those who 'passed' so readily; those she felt she needed to resemble. Not only this, but she was also influenced by a desire to 'feel' and 'become' them; a desire to leave behind the intersex status which she felt threatened to jeopardise the legitimation of her womanhood.

After the discovery of her intersex diagnosis, Pandora's body was an ongoing source of anxiety. As well as trying to reduce its size, she also attempted to conceal it in other ways. She notes,

> I became very, very conscious of my body and *yeah*, it did change the way I dressed so I sort of *hid* in a lot in clothes for a lot of years, just sort of just wearing incredibly baggy clothes just to kind of cover up myself so that people couldn't see my *form* and, from that, *know*... that it was *bizarre* or different. (Interview with Pandora, 2014)

As discussed in the previous chapter, the reassurance one might anticipate from Pandora's belief that her condition is not visible to others has, in fact, failed to grant her amelioration from social anxiety about her physical difference. Thus, a process of physical containment is unavoidable for Pandora, who feels vulnerable and exposed even when she trusts that her observable/virtual social identity matches the identity she seeks to proffer. This illustrates how the burden and apprehension of passing 'sufficiently' can be rooted in an anxiety at an ontological or conceptual – rather than observable/aesthetic – level. The ambiguity surrounding Pandora's medical sex assignment supersedes the conviction she feels in the alignment between her virtual social identity and her proffered identity[9]. The anxiety to 'prove' oneself is still experienced corporeally, compelling Pandora to comply with the imaginary of passing.

Steve spoke about the discomfort he felt about nudity. The importance of keeping his naked body hidden was endorsed by his parents and school. Steve explains,

> for *me*, it was about um hiding my genitals I suppose. And, for the school context, I didn't do showers, didn't swim, so I did everything I could to avoid being in a situation where one had to undress. And the school had a note saying that I was not to be examined, uh, or to have intervention without the involvement of the family... so... 'though to my recollection no one else was examined for anything in particular, um, but it was a *fear*, it was a family fear that became part of our family story really. But um I had to *learn* to not be seen. (Interview with Steve, 2013)

The secrecy involved in obscuring Steve's intersex status, and potentially the affiliated shame, are bi-/multilateral; a communal experience, 'a family fear' and a stigma by association, or what Goffman (1963, p. 44) refers to as a 'courtesy stigma'. Goffman (1963, p. 43) believes that a relationship wherein a stigmatised individual has confided in the other ('the wise') can lead to a

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[9] I use my own term, 'proffered identity', rather than Goffman's (1963) 'actual identity' because Pandora does not express certitude in her identity as female and/or intersex. Whereas, 'actual identity' suggests a single, definite sense of self.

broader social reception where 'both individuals [are treated] in some respects as one'. The wise, he claims, are 'obliged to share some of the discredit of the stigmatized person to whom they are related' (p. 43). Thus, another thread is added to the imposition of secrecy: it is not only the intersex individual who may be protected when others are unaware of their intersex status, but also those who are close to them, who may worry they will be similarly indicted. In the case of intersex, this may be especially pertinent in sexual relationships where, for example, Pandora raised concerns over heterosexual male partners whose sexuality, she believes, may be questioned if people were to find out that Pandora is intersex.

The problems which are understood to arise from socially associating with those with intersex traits can, in some cases, create further pressure for intersex individuals to pass as binary sexed/gendered. This pressure, which may come from the 'wise' or from the intersex individuals themselves, derives from the threat of the possibility that the 'wise' will be affected, resulting in a relationship which is damaged or altered in some way, or to the wise feeling similarly socially isolated. Goffman (1963, p. 43) argues that 'the tendency for a stigma to spread from the stigmatized individual to his close connexions provides a reason why such relations tend either to be avoided or to be terminated, where existing'. Of course, this termination may be especially injurious at a time when social support would be beneficial. This is another reminder that the needs of an intersex person are not necessarily prioritised above the needs of others in the negotiation of privacy, comfort, and happiness.

## Being hidden

Much like passing, hiding was not only discussed by participants as a deliberate, autonomous act, but also as an imposition. Some participants felt they had *been* hidden. Ian recounts an experience where he became aware of his mum's fear of potential social stigmatisation, and the concealment which followed as a result. At around 23 years old, when Ian had been 'unemployed for a number of years, living a very isolated life and severely depressed' (Ian's diary, 2013), he explains that he

> finally broke down and told my parents how I feel, but their reaction was not what I expected. Instead of the help and support I needed, my father didn't care and offered no help or support. My mother seemed to deny that the problems even existed, and her family seemed to support her, even though they were aware of my problems.

Receiving no assistance from his parents, Ian decided to seek help from a local doctor. However, he notes that,

> my mother was extremely anxious about me talking about my problems to someone in the community. Her reaction was to make an appointment with my doctor before I got there. I believe she told the doctor it was all in my head, as the doctor didn't take my concerns too seriously. Looking back now, I realise that my mother's biggest concern was the shame of people finding out about my problems. The thought of people gossiping was more important to her than her son getting help. This was when I thought about taking my own life. I was completely isolated, no one would help, it was one of the lowest and desperate points of my life. My suicide attempt was unsuccessful, as the bottle of pills I took just made me sick. No one found out about what happened.

> This was when I decided to leave to seek help on my own. (Ian's diary, 2013)

Ian left his parents' house in the UK and travelled to America, where he sought to find medical support during the eleven years that he lived there. In the extract, Ian describes how his condition was hidden, not only from the doctor, but also vicariously hidden from himself, and from others who Ian's mother may have believed would be at risk of discovering the details of Ian's situation if any formal diagnosis was made. Ian's mother's decision to place a veil over Ian's suffering and, thus, prioritise her own needs over those of her adult son, resembles the imbalance Feder (2014, p. 107) underlines, in which parental anxieties are relieved by surgical interventions at infancy but the intersex child, whose feelings, ideas and futures are as yet unknown, '*is not seen*'. Ian's story reveals the potential for those whose sex is stigmatised to be hidden and unseen beyond childhood. Ian was urged to protect his mother from the tensions that disclosure may bring to both of their lives, the 'courtesy stigma'. As Ian had actively sought conversations about his condition, in this instance it was only his mother who felt that further concealment would be beneficial. She therefore solicited this act of deference, and of disappearing on Ian's behalf.

## Controlling the closet

In his discussion of closeting, Siebers (2004, p. 2) reflects on the imposition of secrecy and concealment upon disabled people. He notes,

> The closet often holds secrets that either cannot be told or are being kept by those who do not want to know the truth about the closeted person. Some people keep secrets; other people are secrets. Some people hide in the closet, but others are locked in the closet.

Siebers's reflections on the imposition of secrecy and closeting echo many of the experiences described by intersex persons in this study, at times 'locked' in the closet and secreted away. However, Sieber's presumption of a pre-passing 'truth' does not reflect the epistemological complexities of sex, and the ambivalence participants felt about notions of corporeal/identity authenticity and 'realness'. Rather than placing honesty and authenticity in direct opposition to passing, a position of epistemic vulnerability underscores the impossibility of ever permanently 'knowing'. The possibility of passing troubles our ability to hold a stable position on credibility, reliability and validity when it comes to identity and the signification of bodies. As Schlossberg (2001, p. 2) notes, 'the passing subject's ability to transcend or abandon his or her "authentic" identity calls into question the very notion of authenticity itself'. Passing, Schlossberg adds, 'calls[s] attention to the performative and contingent nature of all seemingly "natural" or "obvious" identities' (p. 2).

Siebers's perspective, which assumes a pre-passing identity is in some sense more honest, not only fuels feelings of dissonance, guilt, and fraudulence – as we can see in the experiences described by Pandora and Steve – but also supports notions of 'selling out' (Walker, 2001, p. 8), whereby a personal responsibility to others in the pre-passing category is understood to be unfulfilled (again, the assumed obligation to others). Siebers (2004, p. 19) extends this by arguing that passing as non-disabled when one is, in fact, disabled, 'support[s] the continued oppression of the group to which they belong'. Swain and Cameron (1999, p. 76), too, regard the process of coming out as a disavowal of 'self-disgust' and a challenge towards the notion that

disability is 'something to be denied or hidden' when, in fact, it is an 'imposed oppressive social category to be challenged and broken down'. For them, the act of disclosure demonstrates a 'political commitment'; a rejection of the medical model of disability. Siebers (2004, p. 8), too, argues that whilst people with disabilities have a lack of power, their identities bear 'theoretical power' because they 'reflect perspectives capable of illuminating the ideological blueprints used to construct reality'.

In accordance with Siebers's observations, passing – especially as a medical imposition in infancy/childhood – can operate as a form of subjection and discipline upon those who are intersex, whereby the unrecognizability of their bodies permits them to be 'unseen'. Passing is a requirement which is not only exercised by the medical institution, but also enacted and reinforced in wider society. There was an ongoing, at times critical, threat of unwanted discovery for intersex participants, due to the belief that 'knowing' or being able to 'tell' was out of their control. Frustrated attempts to regain control; for example in Steve and Siân's abstention from alcohol and Pandora's eating disorder, illustrate the lack of agency and authority participants felt they had over their own identities and bodies. In their attempts to pass, some participants *did* feel the self-disgust, denial and the desire to be hidden that Siebers describes. Passing, however, can also be an attempt to *reclaim* control. Pandora's self-perception of womanhood is not ontologically inferior to the medical institution's pronouncement of intersex. Passing, as a 'form of passive resistance' (Schlossberg, 2001, p. 3), not only protects Pandora from the social isolation of stigma, but also allows her further options of identity requisition, to present as whatever she finds most comfortable, albeit within the confines of social recognisability.

Acknowledging the impermanence of our social histories, presents and futures has the potential to be comforting and protecting for intersex subjects, as well as for other social actors who are also labelled and socially produced from the earliest possible age. Conversely, for some the stability of these roles is reassuring and fortifying. We are all a 'work in progress', but as Schlossberg (2001, p. 4) notes, 'the risk and pleasure of narrative […] seems intimately connected to the risk and pleasure of passing'. Recognising epistemic vulnerability may pose a challenge to the social risks usually imbued in 'inconsistent' narratives or 'unsuccessful' passing. Gilson (2014, p. 93) argues that it is 'the pursuit of invulnerability [which] is integral to oppressive social relations because it operates as a form of epistemic reductionism and ethical closure'. Hence, a challenge to these oppressive social relations poses questions to all of our states of being, actively compelling us to reconsider 'knowledges' we often accept as given. Likewise, of passing, Schlossberg (2001, p. 3-4) notes its solicitation for us to 'reconsider our interpretive strategies' and force our 'most cherished fantasies of identity to self-deconstruct'. Thus, critiquing the validity of sex categories makes the security of our own bodies and identities uncertain. It is our epistemic vulnerability, a disavowal of the dependability of what is 'true' or 'real' that Gilson believes to be a fundamental resource for an 'ethical response and political resistance to oppression' (*ibid*), in contrast to the commitment to 'truth', advocated by Siebers.

## Ways of seeing

The fundamental tensions between epistemic certainty and vulnerability are, in part, produced by the erroneous supposition that the observable and visible is an 'epistemological guarantee' (Robinson, 1994, p. 716). Specifically, the act of seeing (both literally and figuratively) is often

recognised as one of *knowing* rather than one of *interpreting*. Seeing is ideological and powerful, and the processes involved in being *unseen, hidden, visible* and *transparent* are contingent, political and intimately tied to the possibility of recognition and intelligibility. Thus, it is possible, as Garfinkel argues, to be 'seen but unnoticed' (2006 [1967], p. 59). To notice, acknowledge, and recognise, in this sense, can be a form of governing: defining 'which lives are livable, and which are not' (Butler, 2004, p. 4). A positive re-evaluation of vulnerability could remind us that we are all 'susceptible to being affected and affecting in relations to others' (Gilson, 2014, p. 96) and ask us to reconsider our understanding of passing.

This chapter reflects on the reliability of 'knowing' and suggests that discourses of authenticity and certainty many not always be supportive or helpful approaches for those with atypical sex traits. This is considered alongside participants' experiences of secrecy and 'closeting' (Sedgwick, 2008), in which I explore how these responses can be closely tied to feelings of shame. For some, various management strategies have been deployed in order to ensure confidential information will not be revealed without their approval, and stories, biographical accounts and purposefully placed props have been used to help build their profiles as individuals with 'typical' sex statuses. 'Coming out', therefore, can be perceived as a form of resistance to shame and to secrecy, and is understood as commendable and beneficial by many participants, despite all participants with atypical sex traits feeling that it would not currently be safe or comfortable to do so in all areas of their public lives. The act of 'coming out', however, also has the potential to place precedence upon the newly disclosed state/identity, which – much like passing – affirms a particular 'truth', and potentially obscures the complexities of sex experienced by intersex people.

The following chapter further considers the social and personal negotiations involved in participants' public and intimate relationships. With an emphasis, in particular, on romantic and sexual partnerships, the chapter considers how expected biographical narratives impose normative frameworks onto the lives of people with intersex traits, which may not always be available or desirable.

# 8

## Sex, Relationships and Time
## Questioning Typical Narratives of Sexual Interaction and Partnership

## Introduction

The logics of normative time lay out particular pathways for all of us which, regardless of our intentions, probably few of us follow faultlessly. Nevertheless, this linear structure of life events, social progress and personal development, from birth through to death, advocates and naturalises some routes, whilst discouraging and castigating others. These 'normative narratives of time' (Halberstam, 2005, p. 152) are social, cultural, and medical models in which particular 'schedules' are anticipated and promoted (Kafer 2013, p. 39). This is not only a concern or a vision of own futures, but also the futures we deem to be our responsibility. Expectant parents, for example, often discuss images and expectations of their unborn child: how they will look, their clothes, their behaviour, and the futures they may encounter in adulthood.

For many, an intersex diagnosis is a considerable surprise and an obstruction to these anticipations; whether to parents of a new-born child, to teenagers whose pubertal development is not as expected, or to unaware adults whose diagnosis may generate a re-interpretation of their histories and planned futures. Janoff-Bulman (1992) speaks of an 'assumptive world', a personal framework of all that is assumed to be true and predictable about our lives and environment (see also C. M. Parkes, 1988). 'Our assumptions', argues Janoff-Bulman (1992, p. 4) 'are guides for our day-to-day thoughts and behaviours'. The violation of the assumptive world can be experienced as traumatic; as a loss of what was assumed to be known and reliable. In their study of depression, Brown and Harris (1978, p. 236) note that the 'more a woman has committed herself to a given identity or cluster of identities […] the greater the severity of a crises that deprives her of an essential part of it'. In response to this trauma, Janoff-Bulman observes that coping strategies need to be developed, as well as an eventual 'relearning' of expectations.

Futurity[1] is routinely conceived in reproductive terms, and the figure of the Child is fundamental to our visions of the future (Edelman, 2004). Reproductive futurity (or repro-futurity) is a 'political orientation' which relies upon 'the sacrifice of adult needs, the desexualisation of children, and the disavowal of the negating potential of queerness itself' (Freeman, 2007, p. 166). The hopes and desires of society are placed upon 'those not yet born or grown up' (*ibid.*, p. 166). Therefore, if reproductive potential is uncertain, or the future of the child/foetus is unknown or compromised, an investment in a coherent, linear and secure future is understood to be threatened. For intersex infants, we often see a situation in which concerns about the child's future are 'solved' with urgency, regardless of the potential costs to the child's sexual prospects or autonomy in adulthood. Feder (2014, p. 143) notes that 'parents want

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[1] Alison Kafer (2003, p.28) defines futurity as 'an investment in an attention to the future or futures'.

solutions in the present and they don't project into the future. You can engage in all the arguments you want, but in the end, you have the choice of an apparently easy fix versus no fix and an uncertain future'. The medical management of intersex offers some assurance when the assumptive world is in dispute. As Kafer (2013, p. 36) argues, 'the very notion of "prognosis" sets up the future as known and knowable'. On these terms, bodies which are deemed to be medically unstable or uncertain are understood as problems.

Normative narratives of time prescribe particular 'paradigmatic markers of life experience' (Halberstam, 2005, p. 2), such as marriage, reproduction, and full-time work. Not only are these markers expected to be achieved in the life course, they are also expected to occur at the 'right' time (i.e. not too early and not too late). 'Chrononormativity' is defined by Freeman (2010, p. 3) as the way in which we are 'bound into social meaningful embodiment through temporal regulation'. The social and physiological impact of an intersex diagnosis can disturb the normative scheduling (and occurrence) of pubertal and other physiological development or transitions (e.g. menopause), sexual relations, reproduction, and romantic partnerships. Regardless of how the individual feels personally about this disruption, the social stakes and judgement of non-conformity may cause challenges and anguish.

As I have explored in previous chapters, concerns about potential exposure or information leaks have led some of my research participants to keep details of their diagnoses contained and their bodies concealed. This preoccupation with 'consequences' has meant that the future is viewed with apprehension for many intersex adults and adolescents, and forming close bonds or seeking sexual/intimate relations feels like a risk. However, the future also represents a 'different' time, which has not yet arrived, about which some are optimistic for an improvement to their present circumstances; this provides a sense of hope and defiance against a present in which their situation is less than ideal. The future is something which is being waited for.

For parents, the future can be a troubling vision of the anticipated 'consequences' of their intersex child's diagnosis. These consequences may be used as a justification for surgery and other medical interventions, just as they may be an explanation for *abstaining* from medical action. However, as Feder (2014) points out, the child's future is often absent from conversations about an intersex infant's wellbeing, especially in cases where, in their decision regarding surgery, parents may be required to recognise their child's potential desire for sexual pleasure. Time plays an important role here; the 'medical emergency' paradigm (Preves, 2003, p. 151) demands an efficient surgical response in which the child's future *is* acknowledged, and surgery is understood to increase the probability of the patient experiencing a happy and healthy adulthood (e.g. Meyer-Bahlburg, 2008), and the parents, too, of feeling secure in the identity of their child. However, narratives of reproductive futurism, which construct the image of the innocent, non-sexual and dependent child, may obscure the parents' commitment to some of the child's future needs and agency in making this decision, especially those relating to sexual pleasure and desire.

Our assumptions about future prospects reveal what it is we consider to be a 'desirable present', and disability, for example, 'cannot be a desirable location' in a society in which 'cures' are understood to be paramount to happiness (Kafer, 2013, p. 43). Kafer further argues (p. 46) that it is necessary to imagine 'crip futures' to stop disabled people from being 'written out of the future, rendered as the sign of the future no one wants'. Halberstam (2005, p. 1) considers the possibility that a resistant queerness can be found through temporality; in particular, 'strange

temporalities, imaginative life schedules, and eccentric economic practices'. He also argues (p. 2) that 'queer subcultures produce alternative temporalities by allowing their participants to believe that their futures can be imagined according to logics that lie outside' of normative narratives; outside of 'reproductive and familial time' (p. 10).

This chapter explores how medical accounts of intersex construct the sexual and romantic futures and destinies of those living with an intersex status, how presumptions about desirable futures can carve out our present, and how normative narratives of time locate some (a)sexual and (a)romantic lives as successful and others as failing. I also reflect on the ways in which these paradigms can be resisted or challenged by those with an intersex status, and what a 'crip' or 'queer' future may look like for intersex people when they are permitted to 'imagine [themselves] and others otherwise' (Butler, 2004, p. 29).

## The child

Nicole was first told that her daughter, Emma, had received a diagnosis of Turner Syndrome the day after she was born. Nicole and her partner were unfamiliar with the condition so they were taken to a consultant's office, where they were given a list of possible symptoms/traits:

> They said she would never be taller than 5 foot. I went, 'So?' um… and then they said she might have some ear, nose and throat problems and I went 'Ok.' They said she might have a *heart* problem, and I said, 'Could you operate on that?' and she said 'Yeah' so I went 'Right, ok'.
>
> 'She might have kidney problems', 'Uh-huh,' um… and then, […] I said 'Can she go to a normal school?' They said 'Yes!' So you know that bit where it kicks - what're they going to tell me that's *that* bad? 'Cause it's not *that* bad, so that was my… in my head I'm going, 'This is ok, I can cope with this, I can cope with this'. Um and then they said 'She will never have breasts' and that's… when I kind of… *sat up*. Bearing in mind that I'm 24 hours after birth, hormones are everywhere, y'know. And I'm going 'No breasts', so all of a sudden I'm sort of twigging… […]
>
> 'She won't have any periods,' so then the penny is dropping, because she doesn't have any ovaries. And then she can't have any children. So by then I'm like 'Aaahhh! Oh my god!' Um, *then* they told me there's only ever been one other baby born… in this hospital. So there'd only ever been *one* baby born, well, in *that* hospital. And I went 'Oh my god, is she some sort of freak?' (Interview with Nicole, 2014)

In Nicole's recollection of the events that happened 27 years earlier, the issues potentially affecting Emma's heart, kidneys, ears, nose, throat and height are interpreted as surmountable or negligible, whilst she portrays her reaction to discovering issues relating to Emma's breasts, periods and fertility as deeply troubled. Despite being only one day old, life events which were part of the future which had been imagined for Emma by her parents; events such as breast-development and menstruation, which are considered to be fundamental to her identity as an adult woman (see Prendergast, 1995), were already being investigated and mourned. From the earliest point in Emma's life, her future was envisioned as uncertain and unconventional.

Later in her interview, Nicole referred to Emma's own distress about the late development of her breasts. She recalls, 'I can always remember about saying how I *felt* for Emma, because we are *all* busty in my family. Like, all really, really busty. And all she wanted was boobs, y'know. They *came*, but they took a long, long time. And I said, y'know, that's really distressing'. Whilst the expectation of secondary sexual characteristics (e.g. breasts), menstruation, and reproductive capacity may not necessarily be articulated or dwelled upon by parents of new-borns, these traits are assumed to be part of the future of most babies born with the label of 'girl'. In Emma's case, these developmental events, which act as traditional markers of 'adult/womanhood', were contemplated and anticipated from infancy. Nicole recalls, '...cotton wool – in her bra. We need to put cotton wool in her bra, I thought [on] day one' (Interview with Nicole, 2014). Similarly, in the previous chapter on passing, I noted how Beth argued for the importance of Imogen bearing a 'vaguely functional' vagina (Interview with Beth, 2014) 'that was some way towards 'normal'' (Beth's diary, 2014). These physiological characteristics (i.e. vagina, breasts), whilst not of immediate functional importance or developmental relevance to infants (see Creighton, 2004), take on symbolic importance for the envisioned potential of the children.

Gittins (1998, p. 174) observes how 'physiological maturity has in recent times often been seen as marking the boundary between childhood and adulthood, intimating that there is a radical difference that changes a person irretrievably, and that this change is rooted in, defined by, sexual maturity'. In tension with popular figurations of children as asexual and belonging outside of sexual discourses, both Nicole and Beth narrate their worries about their children's prospects as fertile and sexually-active adults. The fear expressed by the parents of a future of no breasts and no vagina locates Emma and Imogen's unexpected bodies as inadequate. In Beth's case, this led to the desire to revoke the difference and construct a vagina. Kafer points to the various medical treatments prescribed to disabled people 'on the grounds that such acts will lead to better futures for the disabled person' (2013, p. 29). Within these discourses, Kafer argues, 'disability cannot appear as anything other than a failure'. In a similar way, non-typical intersex bodies are understood to require improvement in order to be successfully equipped for a 'good' adulthood.

The future can loom heavily over intersex infants with early diagnoses. Doctors and parents often work hard to retrieve a sense of normalcy and predictability in children's lives, whether through surgery or other means. However, this, as Edelman remarks, can follow 'a logic of repetition', whereby a quest for a fixed identity is located in a loyalty to the 'future of the social order' (2004, p. 25). Our assumptive worlds are products of this social order, and challenges to these structures may appear to be socially threatening or unsettling. Ahmed (2006, p. 91) notes that bodies, too, 'take the shape of norms that are repeated over time and with force', whereby the body is formed 'from a congealed history of past approaches'. These bodies are anticipated and reproduced through medical and social means, with the hope of creating futures which are reliable, familiar and successful.

Kafer observes that, due to their often uncertain role in a reproductive- and productive-centred life course, 'disabled people [...] are figured as threats to futurity' (2013, p. 31). Similarly, Beth's reflection on the dilemma of surgery reveals the way in which an uncertain future can feel perilous:

...historically *most* baby girls have been operated on around about the age of one. And there just simply aren't that many people in Imogen's situation who've been left alone, so if we left Imogen alone... when she reached however old – like whether they did it before – y'know so she could have periods out of her vagina or whether she wanted to have sex. Whatever age, there wouldn't necessarily be... she'd be a test case. Or not *literally* a test case, I'm sure there are – but they just haven't got that wealth of... see, I don't want Imogen to be a test case. (Interview with Beth, 2014)

Beth explains how her desire for predictability or 'knowability' demands perpetuation of previous medical treatment. Her concern that Imogen would be a 'test case' if 'left [...] alone' also reveals Beth's sense of moral responsibility, to replicate the patterns of medical treatment in order to provide a recognisable and safe future for Imogen. Winnubst comments on our 'unwitting obedience to the future', which she believes 'render[s] [us] docile, most often at a whole unconscious bodily level', observing further that 'we do not interrogate [...] [the] power [that temporality holds] over our lives and the norms that we unconsciously enact' (2010, p.138). The developmental schedules Beth and Nicole anticipated for their children revolve around a particular vision of the future that is taken for granted as axiomatic. The apprehension caused by this temporal framework is elucidated in Beth's diary, where she reflects:

I almost focus on all the worst aspects and worry this is what will happen to Imogen – I think she'll grow too fast as a child, she'll not be able to control her weight easily, she'll have really bad acne, she'll hit puberty early, she won't be able to have children, she won't find happiness in a relationship, she'll not be happy living as a girl, she'll have facial hair, her surgery won't be successful, she won't cope with having a lifelong condition, so I have to remind myself not to worry and to take each day at a time and as long as we are doing the best we possibly can for her, which includes ensuring she has access to the right specialist endocrine team then Imogen will be ok. (Beth's diary, 2014)

In contrast to the concerns she raises here regarding the timetable of Imogen's development, later in the interview Beth makes a clear attempt to critique the restrictions created by normative narratives of time, and consider the value of a more flexible approach. She explains, 'I am a great believer in "life is what you make of it". So Imogen's life might be a little different to what I imagined, but hopefully there will also be lots of positives we could never have imagined too' (Interview with Beth, 2014). Here, Beth demonstrates her awareness of the various different life trajectories available to Imogen, and notes that a deviation from the direction she had assumed for her daughter does not need to be treated as a failure. In fact, Beth argues that there is a possibility that a different future could be a good/better one, and uncertainty does not need to be threatening.

On other occasions in the interview Beth explores this perspective with specific examples. She discusses the 'important part' played by Yvette, the psychologist assigned to Beth and her partner, Chris, who has encouraged them 'to stop and think about things'. Beth describes how Yvette has introduced the experiences of other intersex clients when discussing different options available to Imogen. For example, Beth notes that she may

[throw] nuggets in about – anecdotes about different patients... y'know, clearly she doesn't tell us names or anything but, y'know, or 'I've got a

woman that…' I can't remember the exact – but it was along the lines of, she was thinking about… because she was obviously older and sexually active and must have had a vagina but had um… a large clitoris. And was thinking about wanting to do something about that to change that and then had a conversation with her boyfriend who was like, 'No! Why would you want to do that? I love it!' – y'know, and really getting us to think about things differently. And I almost felt that she was trying to sort of encourage us *not* to do something. Whereas actually, I'm not sure she is, but I think she was just trying to get us to think about *different* things. (Interview with Beth, 2014)

Yvette's account of the experiences of an intersex adult reveals one of the many alternative visions of the future which are available to Beth and Chris. Beth had shown concern over Imogen's ability to 'find happiness in a relationship', and Yvette's story illustrates that, in contrast to the advice emerging from the surgical model, a happy relationship is not necessarily dependent upon cosmetic clitoral reduction. A body perceived to be 'different' can still be one which is loved and desired.

Beth also discusses an encounter which encouraged her and Chris to reconsider the impact that their current behaviour towards Imogen may have upon her future. On one occasion, where Chris's mum was bathing Imogen, she invited Chris's grandmother upstairs to join them. Beth notes that Chris's mum and dad 'know *everything*' about Imogen's status/diagnosis, but his grandmother 'know[s]… roughly' and 'may not understand and may not *want* to understand'. Beth recalled that she felt the invitation was 'completely normal behaviour' and she was 'absolutely fine' with them bathing Imogen together. However, Chris's mum 'had this lightbulb moment and suddenly thought 'Oh my god, she [Chris's grandmother] can't see her [Imogen]!' And like literally whipped [Imogen] away' (Interview with Beth, 2014). Beth recalls that despite '[picking] up on it' at the time, this took place prior to the useful conversations Beth and Chris later had with Yvette about 'openness'. She recalls that 'all [her] lightbulbs hadn't started clicking on at that stage'. However, she notes that later on she had a realisation that

> *that* kind of behaviour, if Imogen ever became aware of that kind of thing… that is *never* ok. She's going to think that there's something *wrong* with her, that she can't like… she's going to think there's something wrong with her when she takes her clothes off. And that's going to have *serious* issues for like sexual relationships and stuff, isn't it? Um, so that's sort of when we just made the decision that this is ridiculous and… we, I think it's about saying it with confidence, isn't it? Yeah, my daughter's got CAH and yeah, that's fine. (Interview with Beth, 2014)

The different roles played by the vision of an impending future are illustrated here. Beth indicates the importance of behaving in a way which does not stigmatise Imogen; concluding that she and Chris need to show a confident and accepting approach to their daughter's body and diagnosis in order to foster Imogen's own development and future self-image. Her circumspection around future outcomes includes a concern that when Imogen is older, she may also construct her own (potentially damaging) interpretation of her family's behaviour if they concealed her body and her intersex status. Beth did not show the same anxieties regarding the decision to operate on Imogen's genitalia, and the potential here to stigmatise Imogen. Rather, Beth's apprehensions regarding surgical intervention were focused on the medical precedent,

and the potential risk in choosing an approach outside of medical conventions. This may indicate a difference in approach taken to dilemmas which are posed as social, and those which are posed as medical. Beth sees an opportunity for her to take some control over the former (i.e. ensuring the family are open and accepting of Imogen's body and diagnosis), but the latter is recognised as an avenue which she is unable to determine (i.e. by following medical protocol and assuming its necessity without challenging its potential to stigmatise Imogen or impede sexual relationships).

## Sexual (im)possibility

Beth's apprehensions regarding Imogen's sexual future are materialised in the experiences of many of the intersex adults in this study. The majority of the intersex people I spoke to were not, and never have been, sexually active. This was not always perceived to be a problem, however; some participants expressed feeling comfortable and happy without sex (and, often, romantic relationships) playing a role in their lives. Paula, for example, notes that from an early age she accepted that sex was not going to be a part of her future. Paula, now 35 years old, received information about her diagnosis of AIS incrementally throughout her childhood and adolescence. At eight-years-old she underwent 'exploratory surgery' whilst under a general anaesthetic, at eleven-years-old she had her ovaries removed, and at fourteen-years-old she was told that she needed vaginal construction surgery 'to create [an] opening & to lengthen the "blind pouch"[2] I was born with' (Paula's diary, 2014). Paula reflects on attending sex and relationships education classes in secondary school, and recalls that by this age she had decided that she did not expect to become sexually active:

> It was more about sex and feelings and emotions and how to handle it and I was kind of like... 'I don't think this is gonna be me'. You know, sitting there and going, 'I don't think this is *ever* gonna be me at all'. And *even* now I'm like, I can't ever see me having sex. It's not a problem, I'm alright with it. (Interview with Paula, 2014)

Paula and I discussed her current attitude towards sex in more detail at various points in the interview. In these discussions, Paula's feelings about sex were consistently tied to her dismissal of marriage and children:

> It's not me. It's not going to happen to me, you know. And even in my twenties, even at University, I was like, 'Never gonna get married, never gonna have kids'. And *even* now, and someone asked me this the other day, they were like, 'Are you married?' and I'm like, 'Oh God, don't be silly, are you mental?' [Laughter]. And I'm like, I just *can't* see it happening for me. You know, I'm like, I want my sister to get pregnant, I want my sister to have babies, I want my sister to get married. I want to be bridesmaid! Love it! Do *not* want it for myself at all. Never, ever thought, 'I need to be married. I need to do this. I need to have a house'. (Interview with Paula, 2014)

The links Paula constructs between sexual activity, reproduction, marriage and house ownership evoke a schedule bound by normative narratives of time, particularly, 'straight time' (Freeman, 2007). This package of events is a familiar, linear development 'shaped by linked

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[2] A 'blind-ending vaginal pouch' is a medical term used to refer to a vaginal canal which is shorter than typical, and does not connect to a cervix.

discourses of heteronormativity, capitalism, [and] modernity' (Boellstorff, 2007, p. 228). By placing her inability to have – or indifference towards – sex within this framework, Paula illustrates how one deviation from straight time may have a knock-on effect, or become subsumed within a larger structure of temporal mapping. This understanding of a deviation from straight time as an occurrence built within a larger temporal map may lead isolated instances, such as Imogen's absent vagina, to be seen as indicative of further departures from normative expectations. Beth's extended list of concerns about Imogen's future (see above) may attest to this. For instance, Beth is not only concerned about Imogen's ability to menstruate and participate in sexual activity, but also her ability to conceive, have a 'happy relationship' and live contentedly 'as a girl'.

Despite later becoming sexually involved with others during his time at University, Steve recalls experiencing a realisation similar to Paula's when he was at secondary school:

> Steve: In my teenage years, all the males in my school were interested in sexual activity [laughter]. I soon realised that I didn't have the equipment for the activity that people were obsessing about. And therefore I simply believed sexual activity wasn't something that was going to be part of my lifestyle.
>
> Charlotte:  Mm. Was that something you felt okay with at that point?
>
> Steve: [Long pause followed by a sigh] I'm not sure. I think I probably was angry. I was angry, at the difference. There was a degree of *anger* and a degree of *loss*. There was definitely a sense of loss; I knew there were things that I couldn't do because of a physical attribute. (Interview with Steve, 2013)

Steve frames the recognition that sex was not possible for him as one of 'loss', in which he yearns experiences he had assumed would definitely take place. In their discussion of assumptive worlds, Harris and Brown (1978, p. 234) note the potential for 'a great loss' to occur if 'ideas about the future [...] can no longer be believed'. Here, the *expectation* of sexual experiences, and perhaps the expectation of particular morphology (e.g. a vagina for Beth, and breasts for Nicole), leave a noted absence when missing. Kafer comments on the capacity for 'people who [have] never "possessed" what they allegedly "lost"' to experience the 'presumption of loss'; in the context of disability she believes that a 'compulsory able-bodiedness/able-mindedness' informs the feelings of nostalgia and loss for 'what can now never be' (2013, p. 43). Similarly, a compulsory notion and expectation of 'straight time' may impose a logic in which sexual intercourse involving an 'adequate' penis and an 'adequate' vagina is necessary for a happy, fulfilling and successful life. Without it, these feelings of loss, even on behalf of those who have not yet articulated sexual desire or orientation, may be inevitable.

Other participants spoke of feelings of ambivalence regarding their inability to participate in sexual activity. Natalie explored these feelings in our interview,

> Natalie: Because I've not had any treatment, it actually means that I physically can't have *sex*. Right? *So* I don't even bother with the dating side of things because you think, I always think, perhaps I think too much into it. I'm thinking, 'Right, what if I do kiss him? What if he does wanna have sex?' - I can't do it! And it's not because oh, I'm emotionally

not ready, it's because I physically can't have sex and you don't know what other people are gonna think of it, so I'd just rather put a line underneath it and say 'Right, we won't bother with the whole thing anyway'. I mean, the doctors have actually *offered* me treatment for it. And I'm like, 'No'.

Charlotte: What, for being able to have sex?

Natalie: Yeah. They've offered me dilation treatment, they've offered me a vaginoplasty.

Charlotte: Yeah. So what did you… you don't like the idea of that?

Natalie: That means I'd have to share a bed with somebody and I don't do sharing [laughter]. As I say, I s'pose that if I – I dunno, if I were, if I *did* have the ability to have sex, it's like 'Oh God, I can't really say no now, can I?' (Interview with Natalie, 2014)

Prior to our interview, Natalie had written in her diary about her recent experience at a hospital appointment. Despite the intense discomfort she felt about receiving a genital examination, she commented that the results had been 'very reassuring'. She writes, 'in fact, it proved to be beneficial as [the health practitioner] told me my situation wasn't as bad as I thought it would be and that sex is actually possible for me without the need for surgery. I really dont [sic] know why I am so happy about this. Need to have a word with myself' (Natalie's diary, 2014). Here, Natalie's self-censorship seems to illustrate feelings of ambivalence and a sense of discomfort in her own responses to the possibility of sex, suggesting that her attitude towards sex may be, at times, more conflicted than previously stated.

## Avoiding sex

Several research participants discussed their attempts to avoid sexual encounters. In some instances, this aversion was described as reluctant (due to a perceived inability to have sex), and in other instances participants were fearful or indifferent about sex, concerned about showing a partner their body, worried that it would raise unwelcome questions about fertility, or, due to previous negative experiences of sexual or medical encounters, they took steps to avoid situations in which sexual/intimate activity might occur. Shuttleworth (2012) theorises the connection between sexuality and disability, and notes that the relationship between these two issues has been largely lacking from the literatures in sexuality studies and disability studies, especially – and of particular interest to this chapter – 'in terms of disabled people's sexual access'. He identifies concerns around limited sexual access as:

> the effect that socio-political processes and structures and symbolic meanings have on disabled people's sense of desirability, sexual expression and well-being, sexual experiences, and embodied sexual feelings, as well as the resistance they often deploy against sexual restrictions. (2012, p. 55)

Whilst some of the issues affecting the fourteen men with cerebral palsy in Shuttleworth's study are specific to their circumstances and diagnoses, many of the wider issues of sexual access bear similarities to the experiences of participants in this study. In particular, their references to the cultural imposition of an asexual status, the negative prejudices towards their sexuality, sexual

rejection, body insecurities and the restrictive social norms and expectations of personhood and desirability (p. 61). In talking about this as an issue of *access*, Shuttleworth acknowledges that their sexual lives become politicised (p. 61). Thus, it is important for this chapter to consider how *social barriers*, not just physical ones, prevent intersex people from having sexual partnerships.

On a number of occasions in her diary and interview, Paula referred to Rob, a man who had previously been a close friend. For many years Paula, now 35 years old, felt a romantic attraction to Rob but did not pursue this further. She identifies him as her 'biggest regret', noting that she 'still hold[s] on to my 20ish year old feelings for him, no–one since had ever compared to him' (Paula's diary, 2014). Paula has not had sexual intercourse with anyone, but in her diary she refers to Rob as one of the two people who 'came close to relieving me of my 'V' plates [virginity]'. The first person, a 'very lovely rugby player I was seeing whilst at university' agreed to wait until Paula said she was ready for sexual activity. However, after three months Paula felt 'it was something I couldn't put off for much longer' so she ended the relationship by explaining that she was too busy and 'didn't have the time for him'. She notes that this has been a recurring pattern in her relationships; she has 'always backed off when it looks like things might get physical' (Paula's diary, 2014).

On one occasion with Rob, Paula recalls that 'just before we got physical' she purposefully instigated an argument and told him to leave. What followed was 'the worst argument of my life' (Paula's diary, 2014). Despite her previous opposition to the 'straight time' narrative, Paula indicates that Rob was 'someone I could see spending the rest of my life with'. At other moments, too, Paula demonstrates an aspiration towards paradigmatic markers of a reproductive future. For example, in her diary she discusses a visit to her clinical psychologist. She recounts their conversation, in which she told her psychologist about her 'want of normality including the frustration about my longstanding virginity' (Paula's diary, 2014). She also recalls a visit to a nurse practitioner two years ago, where she was advised on dilation and given 'a set of hollow pink dilators & a tube of lubricant'. She notes that 'even in my thirties I was embarrassed at the thought of dilation but knew it was essential to prepare my body for sex'. At some points in her interview (see earlier), Paula emphasises that sex and relationships were not elements she expected – and, perhaps, desired – in her future. However, the content of her diary suggests some level of internal conflict. This conflict is apparent again, when she notes that now, two years later, she 'no longer need[s] to dilate' and is 'ready' for sex, but she has 'other insecurities about my body that prevent me from seeking someone to love' (Paula's diary, 2014).

Steve and Pandora both spoke about how their belief that sexual activity was unavailable, or not possible for them, led to their withdrawal from friendships and potential relationships during adolescence and young adulthood. Steve recalls that he '*withdrew* from the common obsession [of sex] because it would have met some form of revulsion' (Interview with Steve, 2013). He notes that this need to 'disengage' led to some feelings of resentment and frustration. He describes distancing himself from potential sexual encounters during this time; 'I had at least one – possibly two – females in my class who expressed an interest in *me*, and I knew that for my needs, kissing and fondling and the other things people get up to, I didn't feel able to engage in that or to be able to commence that journey' (Interview with Steve, 2013). Pandora, too, notes that prior to her vaginal surgery at 20 years old, she 'completely hated [it] when I felt attracted to any men' because she felt unable to 'act on my feelings physically, and emotionally really'

(Pandora's diary, 2014). As a result, she notes that attraction was experienced as 'pretty painful' and 'a constant reminder of my inadequacies'.

Sophie, who has since had sexual partners and is currently in a long-term relationship, recalls that she avoided sexual activity during adolescence. She remembers that she 'didn't really want to [have sex]' because she was 'a late developer' (Interview with Sophie, 2013). Sophie believes that her inclination to avoid sex derived from insecurities about the timing and in/adequacy of her bodily development. She explains, 'obviously I didn't have boobs and things and just not very sexually aware, I think I was like 18 and again it was that big thing of, but I'm a man! They're going to know, […] it's just that *fear* again, that just came into it' (Interview with Sophie, 2013). Freeman (p.161, 2007) remarks on the:

> comfort, power, [and] even physical legibility [we achieve] to the extent [that] we internalize the given cultural tempos and time lines. […] Correspondingly, when we are away from our cultural context, we often experience our social failures as a sign that we are immature or prematurely aged, that we are too late to the party, or worse, too early.

Sophie's anxieties about the size of her breasts, and the 'manliness' she worries would be revealed by her 'slow' development, illustrate her attention to temporal achievements. Much like Paula, Pandora and Steve, Sophie recalls withdrawing from potential sexual encounters during adolescence and young adulthood. For Sophie, the 'delayed' but, nevertheless, eventual breast development provided her the possibility of, or confidence for, sexual encounters. Pandora's vaginal surgery also granted her the possibility of sex. Paula and Natalie, however, repeatedly allude to the temporal dissonance of their status as 'virgins', which – unlike Steve, Pandora and Sophie, who became sexually active – preserves their sense of being 'out of time'.

On numerous occasions, Natalie brands herself in her diary as 'a 32 year old single VIRGIN' (her own emphasis). In her diary, Paula, too, refers to her sexual inexperience with a demonstrative abashment, noting 'yes, you read correctly, I'm a virgin, at 35 years old'. Like Natalie, Paula alludes to the shame she feels regarding her sexual inexperience at various points in her diary. For example, when recollecting the experience of returning home after finishing university education, she notes that:

> at 22 it was just presumed that like most other 22 year olds, that I'd had sex. I was too embarrassed to admit the truth so I lied. When asked I had a story ready, I had lost it to a guy from my halls of residence, I was adamant no-one who had ever heard the story would ever find out the truth. (Paula's diary, 2014)

Elsewhere, Paula explains that she 'recently "came out" with regards to my AIS to my closest 3 friends, aside from my virginity, they know everything'. Here, the link Paula makes between her diagnosis and her virginity reveals the close relationship she perceives her intersex status to have to her sexual inexperience, as though virginity could be recognised as a 'symptom' of her experience of AIS. However, in her act of disclosure she also differentiates her AIS diagnosis from her virginity. The omission of virginity from her 'coming out' story, and the lie Paula constructs about her sexual encounter at university, point to the heightened sense of shame Paula feels about her sexual history. Pandora, too, listed the anticipation of 'constant made up stories of sexual experiences' as one of the reasons she felt vaginal surgery was necessary. Paula's prepared story and her vows to secrecy indicate the perceived importance of: firstly,

being evidently sexually active from sometime in early adulthood, and secondly, having an account of 'the first time' to share with others. Constructing these important temporal markers of 'straight time' allow Paula to depict a performance of normative heterosexuality for her friends, or others who may enquire.

Virginity is also figured as a foundation for sexual self-knowledge. In her diary, Natalie remarks that, due to her sexual and relationship inexperience, it is difficult for her 'to know what my sexuality is' (Natalie's diary, 2014). On a related note, Pandora frames surgery and its provision for sex as 'a step towards being more womanly in a way'. Kaler (2006, p. 51), who spoke to women about their experiences of chronic vulvar pain, observed that participants who were unable 'to perform this one hallowed heterosexual activity [...] invoke[d] images of gender failures, of women who were not really women'. As many intersex people may *already* feel that the authenticity of their gender, sex and sexualities are in question, this perception may be especially challenging.

## Sex work

The role of the medical institution in conceptualising – and, sometimes, enabling – the sexual activity of intersex people is understood to be significant by many, regardless of their stance on medical involvement, or whether they have received any interventions. As we have seen, sexual potential is an issue which is discussed within a medical context, often from the earliest possible stage of diagnosis and the life course. In addition to the cosmetic procedures surgically enacted on the genitalia of some intersex patients, surgery, hormone treatment and other physical therapies (e.g. dilation) can be performed to make penetrative intercourse more feasible. Decisions regarding interventions within traditional medical protocol are often made with an anticipated model of 'straight time'. Intersex scholars have demonstrated how the guidance on interventions 'privilege[s] male genitalia and heterosexual relationships' (Morland, 2009, p. 191). Holmes (1995) argues that the cultural imposition of genital surgery upon infants is a 'heterosexist requirement that humans live as either male or female', in part driven by 'societally sanctioned homophobia'. This belief was recently reinforced by a medical professional in Davis's (2015) study, who argued that 'homophobia [in the medical community] is always under this' (p.83). The gender allocation for an intersex infant is recommended based, in part, on 'fertility potential' (Committee on Genetics, 2000). Vaginal-penile intercourse – especially within the context of heterosexual marriage – is often understood to be one of the goals of surgical models (Reis, 2009), and is also used as 'proof positive of a successful surgical outcome' (Morland, 2009, p.191).  Holmes (1995), like many other intersex scholars and activists, note that the costs of this surgery can be 'paid in terms of physical function and sensation, in terms of self-image and self-esteem'.

As I will explore in more detail, there is little indication that healthcare professionals attempt to challenge the compulsory 'straight time' presumption of the inevitability of a heterosexual child (Stockton, 2009), the heteronormative paradigm of 'real' sex (Jackson and Scott, 2001), the age at which sexual potential must be realised, or the notion that the desire to participate in any kind of sexual activity is given and 'natural' (Loe, 1999). Cacchioni (2007, p. 299) notes that it is 'increasingly taken for granted that 'successful heterosexuality' is contingent upon having a 'normal' and 'healthy' sex life', and she develops the concept 'sex work' to describe the efforts that women, in part as a result of this belief, 'devote to managing theirs and their partner's sexual desires and activities' (p. 307). She identifies three distinct types of sex work, one of

which, 'Discipline Work', describes a form of sex work which is 'aimed at changing one's mental and physical response to standard heterosexual practices' (p. 307). I will consider the role of Discipline Work in participants' discussions of monitoring their bodies' potential for sex and 'preparing' their bodies for sexual activity. In Cacchioni's research on women 'experiencing a range of sexual problems' (p. 302), she observes that participants viewed Discipline Work as the method 'most likely to be advocated by sex 'experts'' (p. 307). Participants in this study also spoke about the medical assistance they received in the manipulation of their bodies in preparation for sex, or the implementation of 'body work'.

Many participants spoke about their experiences of vaginal dilation. Dilators are plastic or metal instruments which come in a range of sizes, designed to widen and/or lengthen the vaginal cavity to allow for sexual penetration. Vaginal dilation has, in some cases, been undertaken by healthcare professionals or parents and performed upon infants or children until a 'suitable size', or until they are old enough to carry out the dilation themselves. This can be prescribed as an alternative to vaginal surgery, or as a form of post-operative 'after-care', in which dilators are used daily to preserve the cavity constructed through surgery. The distress that this can cause is increasingly recognised in social and psychological scholarship. Tosh (2013), for example, reports how parents and – once older – children have compared the experience to rape and sexual abuse. As Kessler (2000, p. 59) asks, 'what meaning does the intervention have for inserter and insertee? Does the body part lose all its sexualized connotations or is it experienced by the [child] as a violation by [their] parents—indeed, as sexual abuse?' Children, teenagers and adults with intersex diagnoses are also sometimes advised to perform self-dilation. However, even consensual, self-administered, adult use of the dilators can be painful and experienced as embarrassing or shameful (Boyle, Smith and Liao, 2005).

In her diary, Pandora characterises vaginal dilation as 'that thing which filled me with dread' (Pandora's diary, 2014). The doctor who first introduced Pandora to the Vecchietti procedure (the vagina surgery Pandora eventually selected) advised Pandora to initially try vaginal dilation, 'to avoid any unnecessary surgery' (Pandora's diary, 2014). Pandora recalls that she was given a set of dilators to take home, but she 'hated using them' and 'became very distressed every time' she attempted to perform the dilation procedure. She explains:

> I felt worried that someone would come in my room and be horrified by what I was doing. I felt a certain paranoia that somehow people could see me doing this, and again felt shame, embarrassment and disgust, hatred for my condition for reducing me to what I saw at the time as depravity. (Pandora's diary, 2014)

Pandora also remembers finding it difficult to manage the vaginal dilation around her university work, and worrying that someone might find the dilators in her bedroom. She notes that using the dilators often led her to self-harm by cutting herself because 'it always brought to the forefront of my mind my feelings towards the AIS' (Pandora's diary, 2014). Natalie, who was recently introduced to vaginal dilation by a clinical nurse, described the experience in a similar way in her diary. She notes that 'it felt degrading', adding that 'the fact I was tense showed OMG' (Natalie's diary, 2014). Pandora continued the vaginal dilation treatment for nearly 18 months, during which time she was required to undergo several genital examinations to check on the progress of the dilation. She notes that this, too, was very distressing and would often lead to suicidal feelings. She recalls that, because she 'was so ashamed of my genitals, this felt like a

horrid ordeal' (Pandora's diary, 2014). After 18 months of treatment, Pandora reports that there were 'very little results', which meant that the Vecchietti procedure was still necessary in order to make vaginal-penile intercourse possible.

Unfortunately, the surgery also 'wasn't a done deal' (Pandora's diary, 2014); Pandora was told to 'use the dilators twice daily to prevent 'it' [her vaginal cavity] from simply shrinking back to how it was before'. Once more, Pandora felt ashamed of her actions and concerned that she would be caught; she responded to these feelings with further self-harm. Pandora describes her initial experiences of sexual activity (post-surgery) as 'incredibly painful'. She recalls that 'it took a long time – as in lots of times, before sex was anything but agony throughout the whole thing'. She notes that her current experiences of sex are 'still pretty painful at first but after a while that eases' (Pandora's diary, 2014).

Pandora describes herself in her diary as bisexual, and notes that she has 'had relationships with both men and women since my surgery, [...] although I feel more attracted to women' (Pandora's diary, 2014). I asked Pandora whether there was any discussion of her sexual orientation or preferences when she consulted with medical practitioners about surgical interventions. Pandora explains that:

> ...it was like, 'We need to get it so that you can get a penis in there' [laughter]. Basically! Um. Yeah, so they never really talked about that or the fact that y'know, you could still be in a relationship and not have that. Like, with *anyone*, whoever you wanted to kind of... y'know. It's not quite so cut-and-dry as 'Yeah, in order to have someone you need to whatever', so yeah. I s'pose they, yeah, they were quite *simplistic* about it I s'pose. It's – it's, yeah, 'It's this *physical* change you need to make and that's what we're going to sort of focus on'. (Interview with Pandora, 2014)

In her study involving healthcare professionals with specialisms in intersex conditions, Davis (2015, p. 95) pointed to the way in which intersex patients were often 'urge[d] [...] to pursue heterosexual relationships' by the medical staff. She notes that only 32 per cent of the thirty-seven intersex people she interviewed identified as 'straight' or 'heterosexual' (p. 93), but nevertheless heterosexual partnering was framed in medical correspondence as 'the only route to "normalcy"' (p. 93).  Pandora's experience seems to corroborate Davis's observations. In addition to the presumption that she was heterosexual, she also notes the over-emphasis on supporting 'physical change', rather than offering psychological or social support. Pandora recalls that at eighteen years old, she believed that a 'functioning' vagina was the only way romantic relationships would be available to her. She elaborates, 'it [vaginal surgery] would allow relationships essentially. Which is what I *did* want, I didn't like – it upset me, the idea that sort of... I was always going to be alone and I didn't want that' (Interview with Pandora, 2014). As noted above, Pandora has since decided that relationships and (a)sexual activity can be enjoyed in a range of forms.

By undertaking this Discipline Work, responsibility is placed upon Pandora in particular. As Frith (2015, p. 103) argues, 'the 'sexy body' becomes a site which is subject to intense rational control, self-examination, measurement and improvement'. This process largely overlooks the social context in which these constructions of 'successful' and 'necessary' sex lives are created – instead prioritising an 'individualising approach' (Cacchioni and Wolkowitz, 2011, p. 276). As

Cacchioni and Wolkowitz further argue, 'practitioners operate largely within current conventions of healthcare and heterosexuality, rather than promoting a collective challenge to the current state of sexual politics' (*ibid*.). This reflects wider feminist concerns in the sociology of health, in which it is argued that a focus on biomedical/physiological aspects of sex overshadow the socio-political foundations of experiences of sexual discontent (Tiefer 2008, Cacchioni 2007, Cacchioni and Wolkowitz 2011).

Paula was fifteen when she received vaginal construction surgery to create a vaginal opening and lengthen her cavity. In our interview, she recalled that she did not instigate the decision for surgical intervention, so she suspects that:

> ...they [healthcare professionals] did it in preparation for me... kind of being sixteen and, y'know, thinking I was going to have sex and everything at kind of a normal age. Um, but I was *terrified* of it! Oh my God, *no*!
>
> Charlotte: Terrified of sex?
>
> Paula: Oh my God, it just, *yeah*, it just – the thought terrified me, even probably even a little bit now. I'm still a bit like [Paula pulls a 'revolted' face]... it's just *weird*. Y'know. It seems... *completely* normal for everyone else, but for me I'm a bit like, I don't – it just seems odd. Why would you bother? It just looks messy and gross [laughter]. (Interview with Paula, 2014)

Despite her sexual disinterest at this age, Paula concludes that the medical decision to operate on her vagina was guided by normative temporal ideals, or 'straight time' milestones. On reflection, Paula notes that she received quite minimal information on the purpose of the surgery and had very limited involvement in the decision for it to take place. She notes, 'I don't know if I'd have chosen that then, or chosen it later on. I really don't. Y'know, I probably would've still had it done at the same time. But I would've probably *asked* for better after care' (Interview with Paula, 2014). Following the surgery, Paula says that there was no after care offered at all. She recalls attending an appointment with a healthcare professional after the surgery, in which:

> ...they *literally* told me at my appointment after my surgery, and this was while my parents were out of the room, thank God [laughter]... but, now that I have a vagina, I literally have to 'use it or lose it'... *literally*. And I was *fifteen*. And again, that kind of was like, 'Oh my God, what am I going to do? Oh my God!' and y'know, not everyone is going to have sex at sixteen. Some people wait until they're, God forbid, in their forties! God forbid, oh my God! [Laughter] Oh my God! (Interview with Paula, 2014)

The ambiguous request to 'use' her vagina seemed to be soliciting Discipline Work from Paula, without specifying exactly what this would be. Paula explains that receiving this advice changed her attitude towards her own virginity. Until then, she recalls feeling comfortable with her sexual inexperience, and content to seek sexual activity if, or when, she wanted it. However, she notes that the post-surgery consultation 'kind of put a thought into my brain that 'Oh my God, if I don't do it *now*, what if? What if I never do it?'' (Interview with Paula, 2014). At a recent

hospital appointment, Paula met with a gynaecologist for the first time in more than ten years. Paula requested a genital examination because 'I was convinced that because I hadn't used it, I've lost it'. She was relieved to be told that, in fact, she was 'doing pretty good after seventeen years after doing surgery' (Interview with Paula, 2014).

## Work and/as pleasure

Medical professionals in the multi-disciplinary specialist team, who have provided care to Paula for the last two years, have shown surprise that she was not (explicitly) advised to, or instructed how to, perform vaginal dilation following her surgery. She recalls that, at the time,

> ...they didn't ask me to do any kind of dilation, there was *no* talk of *how* I should 'use it or lose it'. There was no talk of whether I should just go out and get laid or - ? D'you know what I mean? There was no – no, there was no indication. It was *so* vague. And there was no aftercare, y'know! (Interview with Paula, 2014)

Since successfully seeking a referral to meet with the multi-disciplinary team, Paula has now started vaginal dilation. This was a process she says she '*knew* [...] was coming'. She notes that two years on, she is now 'at the point now where I don't have to do it every day, or I don't even have to do it weekly or monthly. And that's pretty good' (Interview with Paula, 2014). She recounts that before starting the treatment, a clinical nurse sat down with her and advised her on how the dilators worked; they 'got the little kit out and everything'. Paula describes her interactions with her nurse over the course of the dilation treatment,

> ...she [the clinical nurse] got this dilator out for me, she's like, 'So, you can use these... this is kind of where we start, this is where we want you to end up, and if you get to this point, why not try a vibrator?' and I was like, 'Okay!' [laughter]. And you know, she's like – I went back six months later, she's like 'So, how're you getting on?', and I'm like 'Yeah, I've just skipped these completely and I've got –' and she's like, 'It's more fun, isn't it?' [laughter] and I'm like, 'Yeah! It really is'. [...] Y'know, she's like 'Take a bath! Y'know, get yourself in bed, light a candle' and I'm like, 'This is hilarious!' [laughter]. (Interview with Paula, 2014)

Whilst Paula portrays the vaginal dilation as a task which makes demands of her, and which she is pleased to have seen reduce, she also narrates her use of the dilators and her correspondence with the clinical nurse with a playful retrospection. In contrast to Pandora's account, Paula seems to eroticise the use of the dilators and, to some extent, regard them as their own sexual means-to-an-end. Following her initial consultation about dilation, she recalls that she:

> ...rang up one of the girls I was friends with in the support group, I was like, 'I'm walking round with the dilators in my bag! This feels a bit strange'. She was like, 'Don't worry, don't worry at all. Y'know [laughter]. They'll never see the light of day *again*. Y'know, they'll never go out of the house again. But y'know. It's quite fine!' and she's like, 'Do you not feel a bit risky?' and I'm like, 'Yeeees... [laughter] I'm feeling saucy'. So y'know, off to buy my giant tube of KY, and then kind of, off I went really with it. Um y'know, it's really awkward. And it's – it's *really* uncomfortable but you kind of do what's best. You go, again it's one of

those things you kind of think back and go, 'Why didn't they tell me to do it fifteen years ago?' (Interview with Paula, 2014)

Despite the pleasure she finds in obtaining the dilators, Paula continues to frame dilation as laborious, or within the domain of Discipline Work; this is a treatment she regards as 'really awkward', '*really* uncomfortable' and a testament of her intention to 'do what's best'.

Paula's narration of her enjoyment during the discussion with the nurse and treatment is also important. In previous extracts, Paula represented sexual intercourse as 'weird', 'odd', 'messy and gross', and referred to the insecurities she feels about her body, which continue to prevent her from seeking sexual relationships. However, in her discussion of the dilators she shows a sexual curiosity which may contribute towards defying these otherwise negative feelings. As Cacchioni (2007, p. 306) found in her own research, 'untangling 'authentic' bodily urges and pleasures from social expectations is not easy' and there is not a clear way of deciphering the root of Paula's simultaneous sexual interest and repulsion, and the social pressures or presumptions which may be embroiled in either feeling. The dilators may, for example, encourage her to take pleasure in 'finding her way' back 'in line' (Ahmed, 2006); that is, undertaking work in order to direct her desires in accordance with those of straight time.

Cacchioni and Wolkowitz note that there is potential for sexual therapy body work to, in some cases, 'encourage women to overcome sexual shame, anxiety, and discomfort quite literally by facing their vaginas' (2011, p. 276). Paula spoke of her apprehension prior to visiting the gynaecologist, due to the belief that she may have 'lost' her ability to 'use' her vagina (i.e. 'use it or lose it'). Here, Paula demonstrates relief and satisfaction to be able to recognise her vagina 'as an active organ' (Cacchioni and Wolkowitz, 2011, p. 276) and to develop a sexual relationship with her own anatomy, recognising its potential for experiencing pleasure. Whilst this, a kind of Discipline Work, is characterised by Paula (and other participants) as a form of preparation for sexual partnering, the nurse directs Paula to find a personal, self-sufficient pleasure in the dilation, thus potentially providing an important alternative to the notion that heterosexual romantic sex is the only, or primary, form of sexual pleasure to aspire towards or participate in. In this instance, the nurse helps Paula to challenge normative definitions of sex by privileging, or valuing, masturbatory sexual activity.

## Resistance

Siân demonstrates the pressures and expectations produced by the hegemony of straight time narratives. She describes a sense that, as someone who has never been in a romantic relationship at the age of 28, she is monitored and counselled by others for not fulfilling particular milestones. Siân describes her experience thus:

> What I feel is more of an issue is when I feel like other people *judge* me because of it... Um, I guess it's more of a, y'know, why do people y'know... I think society in general probably has a thing that y'know, sort of seen, that people sort of were expected to be in relationships to be happy, and if they're not in a relationship then there's perhaps something *wrong* or whatever! There's no sort of 'Oh, ok, she might just be happy being by herself' or whatever, sort of thing. So it's – that's what bo-, it's the other people's perceptions of it that's the issue, rather

than it being an issue *for* me personally, I s'pose'. (Interview with Siân, 2014)

Siân's emphasis on the possibility of living a life which is happy and successful without a partner demonstrates her resistance to the demands placed on her by straight time milestones. Her disagreement with the premise that a single life is necessarily a lonely, sad, or unpleasant one, presents a form of refusal. By not taking 'the direction promised as a social good', she opts for a future that Ahmed (2006, p. 21) calls a 'queer life', in which other desires and imagined futurities are prioritised above, or recognised as an adequate alternative to, 'the reproduction of the family line' (Ahmed, 2006, p. 71). As Ahmed (2006, p. 71) observes, 'moments of deviation from the family line [are read] as signs of the failure' of the subject 'to "find its way"'.

My notion of 'queerness' in this chapter is an attempt to set certain practices apart from 'the everydayness of compulsory heterosexuality' (Ahmed, 2014, p. 147), an 'ideal coupling' which 'shapes what it is possible for bodies to do' (p. 145). Therefore, the practices, behaviour and processes I describe as 'queer' here are relational; those which are situated outside of the norm. Following Halperin (1995, p. 62, emphasis in original) '[q]ueer is by definition *whatever* is at odds with the normal, the legitimate, the dominant. *There is nothing in particular to which it necessarily refers*. It is an identity without an essence'. Thus, 'queerness' encapsulates a range of ways of 'being' which are outside of heteronormative structures and 'straight time' hegemony. Esteban Muñoz's (2009, p. 173) characterisation of 'queer failure' as the 'rejection of normative ideas of value' is especially pertinent here. Siân recalls that 'sometimes, at my dad's, if his girlfriend's around, she's always like, "Right! What are we going to do to get you a boyfriend?" or whatever and I'm just like, "Just leave me alone!"' (Interview with Siân, 2014). Whilst Siân's diversion from straight time is interpreted by her family as a problem in need of solving, she claims the diversion as a counter-narrative; one in which she is not lost, struggling or deficient, but organising her life according to her own comfort, enjoyment and principles.

A form of resistance of a different kind was expressed by Sophie, when she found new and different ways of thinking about her body. In a story similar to the situation described by Yvette, Beth's psychologist, Sophie recounts two different encounters with medical practitioners:

> ...because I was so *ashamed* and confused, in denial, it was quite – I just felt like my clitoris was just this big, giant thing, and it's disgusting and it looked like a willy and I was, 'Oh God!' And then I – and the doctor mentioned, she was like, 'Oh, you have a minimally large clitoris, you can do something about it!' and I was only 15. I was like, 'Yeah, I want it gone, it's gross, I'm never gonna have sex, blah, blah, blah, it's horrible'. And then she put me in [touch] with this surgeon and I was really lucky actually! - That the appointment took ages to come through, like years. And then the doctor got like struck off! […] I'd luckily never met him.

> But what happened was it took so long, that by that time I was like, 'I actually…' – I'd again got that acceptance of myself, so actually I don't *need* this, my body's ok, my body's natural and normal and there's nothing wrong with it. But I also got there because one of the gynaecologists I did see, the first one, before she quit, um I mentioned it to her as well, and she said, 'Before you go to see the surgeon, let me just explain something,' and she showed me loads of pictures of different vaginas and went, 'They all look very different to you, don't they?' And

she showed me, you know, you have big clitorises, you have little ones, you know – you have all different types of vaginas! And mine was just somewhere in the middle. And I was like, 'Oh, I'm being a bit silly, aren't I?' She didn't say that, but she was like, 'Actually, there's all sorts of things' – so again, by just educating me, and just having that conversation it stopped me from making probably quite a silly decision. Um, you know, you could lose like loss of sensation and other important things and actually, my body's fine, it's completely normal. And she was like, 'You're on the normal spectrum, you don't need to have surgery,' but it was quite interesting that I *could* have had it. And then I just didn't need it, at all. (Interview with Sophie, 2013)

Sophie's belief, at 15 years old, that she would 'never […] have sex' due to the size of her clitoris fits with a medical understanding of intersex people as 'unfinished' (for example, see Hendricks, 1993, p. 10). Despite later realising that she 'just didn't need it, at all', the first piece of medical advice she received validated her fears and prescribed an interventionist approach in order to 'right' the 'wrong'. Now at 24 years old, and living with a partner of five years, Sophie shows an ease with the size of her clitoris, and a relief not to have jeopardised genital sensation. Sophie describes the 'education' provided by her gynaecologist as the route into her refusal to perceive her clitoris as 'disgusting'.

## Sexual exploration

Some participants spoke in detail about the relationship between their bodies and diagnoses, and their sexual desires, opportunities and orientations. Steve explained that his 'sexuality, sexual expression and relationship history has been considerably affected by my condition [PAIS]' (Steve's diary, 2013) and noted that his 'sexuality's informed by my equipment' (Interview with Steve, 2013). Steve describes the relationship between his sexuality and his anatomy as a process which has developed over time. As previously noted, during adolescence, Steve felt that sexual partnerships were not going to be possible for him. He recalls that the only sexual activity which was acknowledged within his social environment at this time was 'penetrative male/female sex' (Interview with Steve, 2013). Once at university, he 'discovered there was other alternative [LGBTQ] communities' in which 'as a male you can have a boyfriend', 'the lack of penis for penetrating someone else was not considered an issue' and 'there are many women whose benefit for sexual activity doesn't necessarily include penetrative' (Interview with Steve, 2013).

In his diary, Steve describes the moment his 'sexual exploration began'. One night, whilst intoxicated at university, he ''confided' in a female friend [about his PAIS diagnosis]'. He recalls that, following this, she 'used the 'show me yours and I will show you mine' approach' (Steve's diary, 2013). In this encounter, he describes participating in sexual activity which sits outside of normate[3] heterosexual practice (Wilkerson, 2012) and expectations. For example, Steve recalls that, as well as engaging in vaginal-penile intercourse, his sexual partner also 'explored my [vaginal] 'opening' with [her] fingers & tongue' (Steve's diary, 2013). Steve also notes that his sexual partner was in 'confusion [sic] but stimulated by my non production of sperm'. In

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[3] Wilkerson (2012, p. 184) considers transgender and intersex as departures from what she terms 'normate sex'. She argues these bodies/identities are sites where a more critical sense of sexual interdependence might be forged.

another account, he discusses a sexual encounter which occurred three months later; his first sexual partnership with a man. He recalls that the 'much older male [...] allowed me to penetrate his anus and I allowed him to penetrate my opening' (Steve's diary, 2013). Much like the previous encounter, the presence and involvement of Steve's 'vaginal opening' queers his sexual experience – in this instance, he confounds normative expectations of homosexual relations by introducing a vagina to the interaction. He adds, however, that his own 'lack of orgasm' in this encounter 'diverted me from interest in much sexual activity' (Steve's diary, 2013).

At this time, Steve reports that he experienced a 'sort of sexual renaissance' in which he realised he 'could be with people who were happy for *me* to please *them*, without necessarily expecting me to want to penetrate' (Interview with Steve, 2013). In his diary, Steve wrote in some detail about the sexual activities he started to enjoy outside of heterosexual vaginal-penile penetrative sex, including 'the practice of oral stimulation which has satisfied those I have had relationships with'. Steve talks in his interview and diary about how he feels fortunate to have parents who refused to consent to medical interventions on his behalf, and he believes that his life has been easier as a result. In her study on women with sexual pain and discomfort, Cacchioni (2007, p. 310) observes that 'queering normative sexual practices was more often the result of not seeking any 'expert' advice on sexual problems'. As the sample size of my study is relatively small, and nearly all participants have been subject to medical interventions, I cannot make reliable conclusions about the connection between queer sex and medical guidance from Steve's experiences alone. However, Steve does demonstrate confidence and gratification in his approach to sex, which incorporates his intersex anatomy and queer and non-normate sexual practice. This was much less evident in other participants' stories which, regardless of the participants' orientations[4], were largely oriented towards the milestones of straight time.

Muñoz (2009, p. 173) explains that straight time is 'laden with temporal obstacles and challenges that ensure a certain kind of queer failure as axiomatic for the queer subject and collectivity. Within straight time the queer can only fail'. Similar to Siân's situation, this failure can pose an active resistance to straight time; 'the politics of failure are about doing something else, that is, doing something else in relation to a something that is missing in straight time's always already flawed temporal mapping practice' (p. 174). Pandora describes normative notions of bodies and desire which enlist unnecessary and restrictive prescriptions of behaviour. She notes, 'it feels like they assume we all use our bodies in the same way, so it's like, "Well, obviously if you're going to have a vagina then you'll be doing *this* with it", which it's like... obviously not always as simple as that' (Interview with Pandora, 2014). Steve's failure to fulfil the expectations of straight time are evidenced in his inability to ejaculate, difficulty penetrating a vagina using his penis, and in his identity, confounding hetero/cis-normative presumptions, as a man with a vaginal opening. Steve chooses to forego a biomedical 'curative' approach to his body, which could re-construct his anatomy according to the expectations of binary sex. Instead, he does 'something else', by forging sexual experiences which are organised around his own (and others') preferences, anatomy and abilities.

Other participants spoke of their resistance to orthodox models of sexuality, in which they felt their orientations and/or intersex status were insufficiently incorporated. Natalie explains that she does not conceptualise sexuality in terms of discrete categories or easily defined or labelled

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[4] Straight time and heteronormativity still play a central role in constructing the experiences of lesbian, gay, bisexual and queer people (see Richardson, 1996 and Cacchioni, 2007).

orientations. She notes that she has 'never really thought about people's sexuality as if they're gay, straight and stuff' (Interview with Natalie, 2014). However, she adds that when speaking to others, 'to make it easier I refer to myself as either bisexual or lesbian, depending on what mood I'm in'. In her interview, Natalie described her sexuality to me as fluid and free of the constraints of gender; she notes that 'I just think if you like someone you like someone, doesn't matter what sex. Y'know, I've liked male, I like women, I've actually liked transgender people. I like transvestites, you know' (Interview with Natalie, 2014). Similarly, Steve remarks that although he feels 'comfortable kind of in an obvious maleness', he also 'embrace[s] the possibility to not see sexuality – and not [see] the *world* in the form of two different poles' (Interview with Steve, 2013). Pandora also spoke of her desire to see 'less emphasis on the importance of [gender]'. She argues that 'if you're male or female […] or in-between, it doesn't really matter' (Interview with Pandora, 2014).

Intersex scholars (e.g. Holmes 1995, Fausto-Sterling 1993) have drawn attention to the way in which intersex bodies destabilise conventions of sex polarity and, consequently, of heteronormativity, which are both consistently (re)figured in Western, heterosexist culture. Fausto-Sterling (1993, p. 24) reflects on this point:

> But why should we care if a "woman", defined as one who has breasts, a vagina, uterus and ovaries and who menstruates, also has a clitoris large enough to penetrate the vagina of another woman? Why should we care if there are people whose biological equipment enables them to have sex "naturally" with both men and women? The answers seem to lie in a cultural need to maintain clear distinctions between the sexes. Society mandates the control of intersexual bodies because they blur and bridge the great divide.

Holmes (1995) notes that 'only by limiting the possibilities to two distinct sexes can a predominantly homophobic culture posit that heterosexuality is "normal/natural" and not a constructed imperative'. Furthermore, without recognisable sex polarity, as Fausto-Sterling (1993) argues, it would be difficult to identify a clear notion of heterosexuality and homosexuality at all. The images described by Natalie, Steve, and Pandora refute a binary system of sex and sexuality, and open up the possibility for an intersex status (and non-binary identities) to be located alongside others in discourses of desire.

## Conclusion

The assumptive worlds which are constructed by us and for us leave all of us vulnerable to feelings of failure, loss and inadequacy. Edelman (2004) contends that queer people, especially, would benefit from rejecting the future altogether, arguing that the future is only ever visualised in reproductive terms, leaving intersex and other bodies which are interpreted as queer as 'off line'; a deviation from the 'good life' (Ahmed, 2006, p. 21). From the earliest point of their diagnosis, intersex bodies 'raise the spectre of homosexuality' (Fausto-Sterling, 1993, p. 24). These bodies are a challenge to the anticipatory scheduling which is very often made up, not just of 'temporal milestones', but of hopes, dreams and desires.

However, the defeat and disappointment which is expressed by parents, the non-consensual medical management insisted on by doctors, and the presumption made by many that something needs to be 'done' (Roen, 2008), projects an uncertain future, a queer life, and a queer body, as undesirable. Holmes (1997) argues that parents and doctors need to 'give up

ownership of the sexual future of minors'. Whilst building assumptive worlds may be an inevitable part of all of our lives, it is important to recognise that children and, later, adolescents are social actors who, like adults, can create their own ideas, experiences and futures. For some, like Steve, a queer body and a queer life may be a desirable location within that world. This has been all the more achievable with the support of his social surroundings.

Rather than rejecting the future as Edelman suggests, Kafer (2013, p. 34) reflects on the notion of 'crip time' and appeals for us to 'imagine disability and disability futures otherwise, as part of other, alternate temporalities that do not cast disabled people out of time, as the sign of the future of no future'. For Kafer, part of this re-imagining is an effort to embrace asynchrony and temporal difference, some of the defining features of a 'queer' or 'crip' time. The failure to comply with the milestones set by normative narratives of time may invite us to reconsider what constitutes a good, successful, or valuable life. Many participants demonstrated different ways of failing, questioning and resisting the milestones of straight time. None of the participants are, or have been, married, none have children, and many do not want to have children. Most participants were not – and had never been – sexually active with a partner. Steve demonstrated how sexual activities which may be typically deemed as foreplay, or not considered to be 'conventional' sex, could still be just as important and/or pleasurable as vaginal-penile, or anal, intercourse. Paula, too, illustrated the enjoyment which could be found in self-stimulation, and the lack of appeal of intercourse. Siân, like many of the participants, also questioned the overall importance often placed on sexual or romantic relationships and practises.

Weeks reminds us that 'sexuality is not a given, it is a product of negotiation, struggles and human agency'; this is a struggle which is bound up with power; 'between those who have power to define and regulate, and those who resist' (2003, p. 19). Medical and social forces provided barriers to participants' access to the various different expressions of sex and (a)sexuality which could be available to them. Pandora, for example, felt frustrated by the 'simplicity' of the heteronormative medical model of sexual practice; Paula felt her (hetero)sexual potential had been assumed – and surgically imposed – on her behalf as soon as she was approaching legal age, and was also left confused and unsupported afterwards; many of the participants spoke of their feelings of shame, judgement and isolation due to their sexual inexperience or inability. In some of the experiences relayed by participants, these feelings are closely tied to their infertility, which I will explore in greater depth in the following chapter.

Whilst agency was compromised in some of the stories told by participants, they also provided accounts of reclaiming power and a sense of control. In Steve and Sophie's experiences, this was through their own sexual exploration and body acceptance without genital surgery, whereas Paula and Pandora expressed a degree of autonomy in seeking medical assistance and taking steps towards various kinds of sexual activity, Natalie demonstrated an assurance in her desire to forego sex altogether, and Siân spoke about living a happy and enjoyable life without a partner. Paula's nurse, Beth's psychologist, and Sophie's gynaecologist provided examples of institutional power which opposed conventional narratives, and encouraged patients/clients to think about bodies and sexual practice differently. Yvette opened up an alternative future using her story of a woman who took pleasure in her large clitoris, proposing that an intersex body is open to interpretation, and dominant cultural perceptions of sex and of bodies can be transformed, reversed and inverted.

In the following chapter, I will consider participants' discussions and experiences of a key milestone in the straight time narrative: reproduction. Exploring participants' concerns about their reproductive potential, I will consider the desires, decisions and negotiations which have taken place since many of those involved in the project discovered their infertility. I will draw on some of the central themes already identified in the thesis, including the stigmatisation and shame which can be carried by a status of infertility; the social, familial and gendered expectations of fertility, maternity and temporality which place restrictions upon 'successful' lives; the potential impacts of infertility upon relationships and sexual encounters, in some cases preventing commitment or involvement altogether; and issues of loneliness, integrity and disclosure.

# 9

## Reproduction, Fertility and the Future
## The Imagined Life Course and the Pursuit of Alternative Milestones

The focus of this chapter is on intersex women's experiences of reproduction and related discourses. The men participating in this study did not raise any issues regarding fertility or parenthood in their interviews or diaries and I did not attempt to determine their fertility statuses[1], and therefore cannot assume their situations or presuppose their feelings about parenthood. There are many reasons infertility may not have been identified as an issue for men specifically. For example, Greil (1997) indicates that infertility may be experienced in a fundamentally different way by men than by women, and various studies have revealed that infertility may be a more stressful experience for women (e.g. Slade *et al.*, 2007). Scholarly attention to 'pronatalist' discourses have emphasised how motherhood, in particular, is 'constituted as compulsory, normal and natural' (Woollett and Boyle, 2000, p. 309), affirming an ideology which implicitly links a woman's social value to her ability to procreate (Ulrich and Weatherall, 2000). Many scholars have observed that the stigmatising potential of infertility may be experienced as especially severe for women. Greil (1991, p. 53), for example, notes that that the women in his study 'described themselves as having not only imperfect bodies but also spoiled *identities*' (emphasis in the original) and Woollett and Boyle (2000, p. 309) state that infertile women continue to be positioned as 'empty and deficient'.

Whilst there may be specific cultural dialogues which construct experiences of, and attitudes towards, infertility as gendered, it is important that reproduction is not assumed to be central to the lives of all women or insignificant to men. This is reflected in the diverse attitudes of women in this study, and in the infertility literature which has turned towards men's experiences, developing an understanding of the connections made between a stable masculine gender identity and fertility (Mason 1993, Barnes 2014), including doctors' attempts to protect the masculinity of their male patients (Barnes 2014). Annandale and Clark (1996, p. 32) note the danger of sociologists replicating a biomedical approach by positioning the reproductive capacities/struggles of women as exceptional or fundamental. They argue for the need to 'dislodge the opposition between men and women and recognise the ground in between' (*ibid.*, p. 33) whilst 'destabilis[ing] gender as a hierarchical binary opposition' (p. 39). Whilst these aims are especially pertinent in the study of intersex, gender and sex are also often experienced as 'under examination' for people in this research (see Chapters Six and Seven on passing). This scrutiny may create different ways of thinking about the gendered dimensions of infertility.

Despite its prevalence and significance in the lives of many intersex people, sociological literature on the reproductive experiences of people with intersex conditions is scarce. Intersex scholarship, with the exception of medical literature, also tends to put very little emphasis on infertility. When addressed, it is usually raised in critical discussions relating to the

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[1] See Chapter Four on methods for further discussion on this issue.

determinants of medical gender assignment, surgical consultations and treatment. For example, in her interviews with medical professionals, Davis (2015, p. 81) illustrates the prioritisation of reproductive capacity in the process of assigning gender to patients with 'ambiguous genitalia'. One clinician refers to 'the potential to carry a child' as 'the *holy grail'*. Some scholars have also observed that fertility is emphasised in girls' gender assignment, but not in boys' (Karkazis, 2008, p. 4), and drawn attention to the ways in which reproductive organs are gendered by clinicians and (in)fertility is placed within a heterosexual context (*ibid*., p. 112).

All the women with intersex-related conditions interviewed for this research spoke of their inability to conceive. In all cases their diagnoses correlate strongly with involuntary childlessness. In most circumstances, Turner syndrome results in infertility (Karnis 2012, Gonzalez and Witchel 2012), complete androgen insensitivity syndrome (CAIS) results in infertility in almost all cases (Oakes *et al.*, 2008) and most individuals with partial androgen insensitivity syndrome (PAIS) raised as boys will also be infertile (NHS Direct, 2016). A medical report, in which 100 women and girls with Turner syndrome were interviewed, confirmed that infertility was the participants' greatest concern, and noted that 'health issues' associated with the syndrome were considered to be significantly less important (Sutton *et al.*, 2005).

As the literature on *intersex* experiences of infertility is meagre, my analysis will be guided by existing scholarship on *non-intersex[2]* experiences of infertility, with reflections on how intersex experiences can develop and contribute to this literature. In most sociological studies of reproduction, 'infertility' is identified when individuals present themselves for medical treatment (Greil *et al.*, 2010, p. 144). Thus, it has been observed that there has been a 'failure to study those who have not sought treatment' (Greil, 1997, p. 1679). Given that it has been estimated that only around half of those worldwide who are considered infertile actively seek treatment (Greil *et al.*, 2010, p. 151), it seems crucial to consider the experiences and subjectivities of those who do not seek help as well, as for some of whom infertility may not be understood as a problem. Due to the lack of consideration towards this group, and the usual reliance upon a biomedical diagnosis, there is an uncertainty about how to define or recognise their status. As Greil *et al.* (*ibid.,* p. 144) ask, 'how are we to classify a woman who would not see herself as having tried to conceive and who does not consider herself to be infertile?'

Similarly, a biomedical concern with infertility is often understood to arise at the point that an individual seeks fertility interventions. However, for participants in this study, their inability to conceive was registered as a symptom of their intersex diagnosis. This took place within a medical context prior to any of their own concerns about fertility or parenthood; for some participants in infancy, others in childhood, and some in adolescence. All participants discovered their status as 'infertile' before attempting to conceive and, at present, none of the participants have sought any assistance with conception or other routes into parenthood. For Greil *et al.* (*ibid*., p. 141), infertility can be recognised as 'the absence of a desired state'; however, as some of the participants in this study were diagnosed before a 'desire' (or otherwise) for pregnancy or parenthood was possible or acknowledged, this chapter seeks to incorporate experiences which may complicate understandings of infertility as a status which is necessarily linked, or equivalent, to an unfulfilled aspiration towards parenthood. Infertility, when first diagnosed, may not be perceived as a problem and may never be. The timing of the

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[2] It is worth noting that some participants in 'non-intersex' empirical work on infertility may be intersex, but may not have received a diagnosis, or may not have disclosed their intersex status to the researcher.

discovery of their infertility, whether early or later, is central to many of the participants' accounts. Much like the previous chapter, visions of the future and a sense of normative scheduling were strongly embedded within their attitudes towards their status as 'infertile'.

The proliferation of technological advancements in biomedicine over the last forty years has meant that more, and better, treatment options are available to those who are struggling to conceive (Reed, 2012). Responding to the development of new reproductive technologies in the 1970s and 1980s, some feminist scholars celebrated women's increasing control over reproductive options (e.g. Petchesky, 1984), whilst others raised concerns over the potential for these technologies to be used as a method of patriarchal control over reproduction (e.g. Corea, 1985). Some scholars have also argued that the biomedical framing of these options presents an expectation that infertility is a hurdle to overcome (Donchin 1996, Bell 2010). However, Greil *et al.* (2010, p.141) note that, unlike other medical conditions, for individuals diagnosed as infertile there are more obvious possibilities available to pursue outside of a medical 'cure' (e.g. living as child-free, adoption, fostering, or changing partners). These other options are not always represented, or recognised, as appealing or viable, in part due to the cultural emphasis placed upon the supremacy of 'natural' and/or biological parenting. This emphasis can also make experiences of infertility especially distressing (Becker, 1994).

For many people who are intersex, the medical identification of infertility was acquired at the same time as their intersex diagnosis. This chapter explores the significance of this timing, and the extent to which infertility, in particular, can be experienced as a 'biographical disruption' (Bury, 1982) in various intersex life narratives; some where the 'potential for biological reproduction is a basic expectation' (Becker, 1994, p. 394), and others where infertility is known and understood from the earliest possible stage. This chapter also discusses the circumstances in which none of the participants are currently seeking, or have sought, medical assistance with fertility. Reflecting on the tensions involved in feminist aspirations towards reproductive control and autonomy alongside a simultaneous ambivalence towards biomedical power, I will consider how social, relational and material barriers related to an intersex condition may interact with a status of infertility in the biomedical context of diagnosis and treatment.

## Imagined futures as fertile

Like many of the participants discussed in this chapter, Pandora says that 'one of the facts about AIS [androgen insensitivity syndrome] that struck me hardest at first was the fact that I couldn't have children' (Pandora's diary, 2014). She describes her history in which, at 11 years old, an assumed motherhood was forestalled by the discovery of her condition:

> Before finding out that I was intersex, I adored children and always imagined that I would be a mother to a lot of children. I am part of a large family and loved being so, and I wanted to carry that on with my own breed. When I found out, it was almost as if I had lost a child, albeit only an imaginary future one. (Pandora's diary, 2014)

Pandora's reflections illustrate Ulrich and Weatherall's (2000) conceptualisation of infertility as an unanticipated life course disruption. Pandora's description of her upbringing positions parenthood as a normal, natural and inevitable life event, in which infertility acts as a critical disruption (Becker, 2000; Hudson *et al.*, 2015). Becker (1994, p. 384) observed that women in

her research, like Pandora, often described their experience of infertility as being 'like a death'. In the previous chapter on sex and relationships, I explored how a 'presumption of loss' (Kafer, 2013, p. 43) can occur when we experience an absence or nostalgia towards an idea, state or assumed future, despite never actually encountering it. In her diary, Pandora equates the loss of her 'imaginary' child with the loss of her future, writing that 'I also lost my future in some senses, as the path I had hoped to follow was now resolutely closed, and a big empty space remained to be filled, but all I could feel I wanted to fill it with was the thing I couldn't' (Pandora's diary, 2014). For Pandora, parenthood felt like such an irreplaceable part of her future that its omission came with a loss of certainty and ambition: if not this, then what?

Becker (1994, p. 392) considered how, in some participant narratives of infertility, 'the baby is distilled into "the essence of hope," giving meaning and order to life'. She notes that an infertile status, often considered 'the death of the baby', 'removes hope' and 'symbolizes loss of the future' (Becker, 1994, p. 393). As Edelman (2004, p. 13, emphasis in the original) states of repro-futurism, '*no baby*' means '*no future*'. For Pandora, the hope and reliability of the future is tied to her reproductive ambitions. She notes that parenthood was an ambition which she felt was irreplaceable, and infertility, therefore, left an empty and ultimately unfulfilling future. Brothers and Maddux (2003) found that infertile women who perceive an especially strong link between future happiness and motherhood often exhibit higher levels of psychological distress. Pandora's happiness as a child felt closely connected to the large network of familial relationships she grew up with; in adulthood, she makes a fundamental link between family and future happiness.

In her diary, Siân recalls how her parents explained 'the full implications' of her Turner syndrome diagnosis when she was 10 years old:

> As well as the injections it was explained that I would need hormone replacement therapy to induce puberty and that because of TS [Turner syndrome] I wouldn't be able to have children naturally. I suppose in a way because my growth hormone injections had helped with my height so although I was short I wasn't that much noticeably shorter than my shorter peers so hadn't really felt like there was anything different about me up until that point but here was something that made me significantly different that I couldn't ignore. I think the best word to describe how I felt at the time was lost. Aged 10 you have no idea what the future holds and what you want to be when you grow up changes on a daily basis but for me I simply just wanted to be a Mum. All the games I played as a child were around families and family life. (Siân's diary, 2014)

After the discovery that 'natural' conception would not be possible for Siân, she notes that 'at this point my attitude towards TS changed. Instead of it being something I was happy to talk about and didn't mind people know it then became something that I was embarrassed about and didn't really want people knowing' (Siân's diary, 2014). Like Pandora, Siân's experience of discovering her infertile status was a significant disturbance to her hopes and desires for the future. Siân identifies motherhood as singular in this sense, acknowledging that during childhood the future is unknown in many respects, but that parenting was a fixed and stable ideal which was integrated into her everyday life from a very early age. The connections Siân draws between feelings of shame, a reluctance to disclose, and the discovery of her infertility, highlights her added struggle with the presumption that fertility and parenthood are universal

and 'normal'. Siân not only expresses a personal disappointment in her inability to conceive in the way she had expected, but also self-consciousness about how her infertility is perceived by others.

Siân and Pandora employ spatial metaphors to express the disorientation they felt following their discovery. Siân describes feeling 'lost' and Pandora depicts the 'path' she had hoped to follow as 'resolutely closed', leaving an 'empty space [which] remained to be filled'. Earle and Letherby (2007, p. 236) outline the tendency for life narratives to be interpreted as 'a simple unidirectional journey' from birth to death rather than a route filled with 'false starts, changes in direction and hidden obstacles' (Hockey and James, 1993, p. 5). Corresponding with the discussion in the previous chapter, this normative narrative bound by 'straight time' (Freeman, 2007) presumes a simple, direct pathway and contributes to the normalisation of conception, pregnancy and parenthood as fixed events in the life course. Becker (1994, p. 396), too, notes how the infertile women in her research expressed defeat because 'the future could not be foreseen'. By the age of 10 and 11 years old, Siân and Pandora had already developed a clear vision of their reproductive ambitions. Thus, their imagined life courses were disrupted significantly and both participants were required to re-think their biographies and 'self-concept' (Bury, 1982, p. 171). The identity of 'mother' is understood to be no longer attainable, and therefore needs to be relinquished.

Nicole, whose daughter, Emma, has a diagnosis of Turner syndrome, describes infertility as her main concern and remarks on her wish to 'fix' it for Emma. She recalls her initial response to finding out about potential reproductive issues a day after Emma's birth:

> Oh… my… God, devastated. Emma said to me when she was seven, 'Did you cry when they told you I had Turner's?' and I said, 'Oh Emma, I cried myself to sleep for six weeks'. I says, 'I was *devastated'.* She said, 'You know something, Mum, that was a terrible waste of time'. And I said, 'D'you know something, Emma? You're right. But I didn't *know* that at that time, I just *cried*, because I didn't know what else to *do*!' (Interview with Nicole, 2014)

Her initial devastation demonstrates the importance placed on the reproductive potential of her daughter, even when she was in infancy. However, despite identifying Emma's infertility as a continuing difficulty, Nicole's reflection in this extract indicates a change in perspective over time. Here, the degree of devastation is also questioned by Emma, who is characterised by Nicole throughout her interview as fairly impervious to her infertile status. In fact, it is Emma's nonchalance, a response Nicole could not have predicted, which makes her mother's devastation a 'terrible waste of time'. Bury (1982, p. 18) writes on the significance of the 'limits of tolerance' exhibited by social groups and settings. He emphasises the variability in social and material resources available to those who need support, depending on the attitudes of those in their networks. As I will discuss later in the chapter, Nicole's commitment to ensuring her daughter is aware of the various parenting options available, as well as normalising childlessness as an acceptable alternative (i.e. her substantial 'tolerance'), may also contribute to Emma's apparent composure and unconcern. It is important to note that all reports of Emma's experiences, feelings and behaviour are taken from Nicole's accounts (and perspective), and not told directly by Emma herself.

# Knowing the future

Paula describes an occasion in her final year of primary school, in which a nurse visited the classroom to speak to pupils about sex, puberty and intimate relationships. She recalls that the discussion was gender-segregated: 'the boys all went off to play sport, the girls sat in there and had the talk' (Interview with Paula, 2014). She describes the talk the nurse delivered to the girls:

> 'You're gonna get this, you're gonna do that. This is how you're gonna grow,' and I was like, 'I'm not gonna grow, I'm not gonna have babies, I'm not gonna have periods'. And she's like, 'Yes, you are'. And I got into an argument with this woman, at probably like 12 years old. She *called* the principal – like, the head teacher – who called my parents in, and was like 'Paula's got some kind of Peter Pan problem. She doesn't think she'll grow up'. And my parents were like, 'She's right! This is what – y'know – this is the truth!' And um like, they were like, 'Oh right, sorry'. And I *never* had one of those talks ever again. Never. (Interview with Paula, 2014)

Paula recalls that in all subsequent discussions about puberty and sex, she was told to join the boys and 'go and play sports'. Up until she discovered the AIS support group when she was 18 years old, Paula says that she had a very limited understanding of her diagnosis, which she encapsulates in the three core characteristics she has 'always been told by mum & dad':

> that I wouldn't have periods
> that I wouldn't have babies
> that I was special. (Paula's diary, 2014)

Despite coming to learn and understand more about her own body and condition later on, at twelve years old, Paula was already informing healthcare professionals about her status, and, in this case, drawing attention to the limited and prescriptive explanation of girls' development and life course which was provided in schools at the time. Rather than reconsidering or broadening their narrative of development, Paula was excluded, like the boys, as a pupil for whom these classes were not applicable. This marked her out, as she says, as 'special'; she was refused access to the private conversations designed to give preadolescent girls a space to discuss their thoughts and concerns about development and to learn about themselves as well as others. Paula's retrospective account portrays her as a child who had the confidence to oppose what she deemed to be an adult's inaccurate description of her body and future. Paula's defiance disturbs the normative narrative of development the nurse relays to the class of girls, and this is addressed by the nurse with the suggestion of both discipline and correction.

In Karkazis's (2008) study with intersex adults in the US, she tells the story of a mother of a girl with a diagnosis of complete androgen insensitivity syndrome (CAIS), who – despite her daughter not yet attending school – expressed concern about the talks she would later attend about sex and puberty when she, like Paula, was nearing the end of primary (or elementary) school education. The girl's mother decided to

> attend [the school] to find out what information was presented about menstruation and other physical developments that her daughter would never experience, so that she could prepare her child beforehand, but

also so that the teachers could normalise her experience by explaining to the class that some women are infertile. (Karkazis, 2008, p. 192)

This very different approach, if adopted by the school, would allow pupils like Paula to remain in the classroom and hear about bodies and experiences which were familiar (as well as unfamiliar). An education from an early age which integrates a diversity of experiences could be beneficial for other children in the classroom also. It is likely that other girls in Paula's class would have gone on to experience infertility in adulthood, some would be childless by choice, and some may be transgender, gay or queer, and experience different reproductive limitations/options and life decisions.

There have been many attempts to draw attention to the lack of information and discussion on lesbian, gay and bisexual (LGB) sexual health and experiences in schools (e.g. Forrest *et al.* 2004; Martinez and Emmerson 2008, Formby 2011). Formby (2011) notes that the insufficient information provided in schools has led LGB pupils to feel marginalised and invisible in the classroom. Further, she argues that schools 'can therefore serve to regulate sexuality through the existence or promotion of a 'dominant' sexual culture', not only limiting the reach and efficacy of sex education, but also 'undermin[ing] young people's sexual agency' (p. 5). In addition to these existing conversations around LGB exclusion, intersex experiences are also withheld from the classroom. Normalising these experiences can play an important role in helping affected children to feel comfortable in their own bodies and identities, and also increase understanding and awareness in others, helping to normalise sex and reproductive diversity and reduce stigma.

## The timing of discovery

Participants discussed the significance of the timing of their discovery of infertility. This was often positioned in terms of the level of difficulty they encountered in dealing with or accepting their status, and an imagined notion of how an earlier/later discovery would transform the experience. Impressions of 'earliness' and 'lateness' were contingent and diverse. Nicole and Siân both underlined the social and psychological import of receiving a diagnosis at an 'early' age. Nicole commented on the inability for people without a Turner syndrome diagnosis to understand the experience of an early discovery:

If your daughter *was* infertile she wouldn't know until she'd met somebody and married – don't get me wrong, that would be absolutely terrible, but they don't know what it feels like to grow up with that feeling. And I think that trivialises [it], y'know. (Interview with Nicole, 2014)

Nicole presents the discovery of infertility during infancy as both critically different to, and potentially more harmful than, a discovery of infertility in adulthood when attempting to conceive.  Siân, too, comments that

we're in quite a *unique* position in knowing from such a young *age* as well. Whereas, y'know, a lot of people would discover it at sort of our age when they start trying for children, so it's more of a – it's a bit of a different scenario. (Interview with Siân, 2014)

Due to the early discovery, Siân adds that 'I don't really talk to anyone who hasn't got Turner's about it, because I don't think – I think it's one of those things that you can't really, truly

understand until you're in that position'. Both Siân and Nicole make a clear division between the experiences of 'conventional' or expected infertility narratives, and those of women with Turner syndrome.

Siân recalls that, despite her emphatic desire for motherhood, 'it was something that wasn't even on the radar at [the time of the discovery]' because she was 'so young at the time' (Siân's diary, 2014). She notes that this meant that her infertility was 'never really talked about apart from that conversation', and that it was likely her parents would have felt that there were 'a lot of other hurdles we've got to get through before we get to that' (Interview with Siân, 2014). At 27 years old, Siân notes that this is an issue which she still does not discuss with her parents. As I explored in Chapter Five on loneliness, Siân underlines the importance of the peer support she has received from other women in the Turner syndrome support group.

Sophie, who is now 24 years old, identifies infertility as 'one of the biggest things that sticks out' and 'obviously the hardest thing as well' (Interview with Sophie, 2013). However, she believes that it was 'so much easier, so much easier' to become aware of her diagnosis at 15 years old, rather than later on.  She notes that she was 'quite lucky' to have discovered her infertility at this age,

> …because I've always known. Before I ever had the urge to want
> children I've known so it's not a big deal. I mean, maybe when I'm 30,
> like older and really want children, when all my friends are having
> children, it might be worse, I don't know. But it means you can come to
> terms with it a lot easier and you don't get that big surprise later in life.
> (Interview with Sophie, 2013)

Sophie expands on the distinction she makes between the adult, whose life is ordered and planned, and the adolescent, whose future feels more pliable:

> To just suddenly be told at like thirty/forty, like I think I'd find that
> really hard. But because I've always known, it's like you grow as a
> person as a teenager anyway, so it just becomes part of that growth.  Um
> like even if you don't have something like that happen, you still have
> that acceptance of yourself, everyone has that journey of accepting
> themself anyway, so it just incorporates it into that. So I think it's
> almost, if you're a grown adult you feel you're sorted with your own life,
> and then something random happens. (Interview with Sophie, 2013)

Sophie says that receiving her diagnosis in adolescence 'means that I have to tell my boyfriend right at the beginning because he was my friend for years anyway, like… and everyone who knows me knows that kind of thing anyway'. She notes that this has meant that her infertility has never been 'a secret', 'so it's just fine, so he can come into it with his eyes open […] rather than it having to be a big surprise later in life' (Interview with Sophie, 2013). For the many people who encounter issues with fertility for the first time when trying to conceive with a partner, relationships can be put under strain. Hudson *et al.* (2015, p. 7) found that many women in their study on infertility 'suggested to their partners that they should leave them in case they could not have children'. They argue that this is due to the impact that infertility can have upon women's perceived ability to adequately perform the 'dominant gender scripts associate[d] with being a wife or girlfriend'. Sophie has not found her infertility to cause issues

in her relationship; this may, in part, be due to both parties happily entering the relationship with this shared knowledge.

In contrast to Sophie's views, Pandora expresses a frustration that her parents waited until she was 12 years old to disclose her reproductive status. She remarks,

> I'd just – I'd just assumed that that *was* going to be part of my life, so to sort of… that was how I saw my life *to be*, or where it was heading, but then when I found out it was sort of – I almost felt like that was stolen away from me in a way. Like the life that I… sorted of planned, the children that I wanted were sort of taken away from me, whereas if you just grow up knowing, that's not really going to be there for you. Um, I think it would've been easier to… *accept* and form just – form other plans and ideas from being younger. And just not question it quite so much, and just like – if you *always* know that just like from childhood, that 'Oh, I can't have children, that's fine'. 'Cause it's – a bit better having longer to accept it, to not see it as a problem. (Interview with Pandora, 2014)

At 11 years old, Pandora had already created a vision of parenthood, whilst Sophie understands 15 years old as an age which precedes any reproductive ambition. The very different accounts are illustrative of the diverse ways in which individuals can approach reproductive decisions, and the different stages at which these decisions may become relevant or important in the life course (if ever). Perhaps pronatalist discourses are also experienced in different ways and to different extents. Sophie predicts that at a particular age (30 years old), her experiences may change, suggesting that the confines of a straight time narrative are understood to be more or less demanding at different life stages.

## Relationships

In her interview, Siân discusses the struggles she has encountered due to her Turner syndrome diagnosis, and indicates that infertility is 'probably the thing that bothers me most, I s'pose, is the best way to describe it' (Interview with Siân, 2014). She says that she chooses not to disclose her infertility to others:

> I don't know *why*, but I just y'know, it's not something – I guess because it's y'know a private and personal thing – there are lots of people who don't y'know go into details or, y'know, it's not something that is y'know public knowledge for *anyone* who's had fertility issues, *not* just Turner's. I guess it's something that's not generally discussed or whatever. (Interview with Siân, 2014)

Her concerns around disclosure and the potentially stigmatising consequences of an infertile status are two of the main reasons she has not established an intimate relationship. Siân explains,

> Because of all this I have never been able to form or have any kind of physical relationship. I have tried various avenues of trying to meet people but the thought of having to lay bear [sic] my infertility issues and fear of having to adapt to such a big change in how I would live my life should anything develop into something more serious has always meant that nothing has ever come of any attempt I have made. (Siân's diary, 2014)

Siân upholds that her infertility would definitely 'be an issue' in a relationship. She notes that 'there's nothing I can change about it so it's something that will – or would – have to be dealt with', 'it *is* there and it can't be ignored' (Interview with Siân, 2014). Siân's aversion to disclosure and the 'big change' engendered by a relationship lead her to remove herself from the possibility of intimate relations altogether, thereby preventing (or mitigating) the anticipated disruption her infertility could create during her adult life.

Pandora recalls that 'when I found out that I couldn't [conceive 'naturally'] *that* was quite devastating. And it, to *me*, that also felt like… if I can't have *kids* then no one's going to want to *be* with me and so it sort of stamped *aloneness* to me' (Interview with Pandora, 2014). Similarly, Natalie listed her infertility, alongside her inability to have sex and her lack of femininity as the reasons she 'know[s] that I am NOT what anyone would want as a partner' (Natalie's diary, 2014). Pandora's feelings about infertility have changed over time; she describes being 'more at peace' with her status now and notes that she has 'sort of accepted' it; however, she still believes that infertility may 'be an issue one day'. As with her intersex status, she has not yet spoken to any sexual/romantic partners about her infertility, but in her interview she reflected on the possibility of raising the issue with a partner in the future. She says,

> If I ever was to have that conversation with someone […] it's maybe going to be quite difficult, potentially upsetting. But no, I think I can hold my own on that. In terms of… I feel okay about that now, so there's only so much they can… that situation can hurt me. (Interview with Pandora, 2014)

Although Pandora wished that she had been aware of her diagnosis earlier in life, she narrates a significant change in perspective over the ten years since she has been told. From her initial belief that intimate relationships of any kind would not be available to her, to now asserting the confidence and self-assurance to 'hold her own' if, or when, she discloses her status to a partner.

## Other babies

Some of the women in my research commented on the difficulty of witnessing the pregnancies and parenthood of their friends, family members and, in some cases, strangers on the street. Paula wrote in her diary,

> Currently I have 4 friends who are pregnant.
> My housemate has a child.
> Probably 60% of my school friends have at least one child.
> I'm jealous!!
> I want one!!
> Im [sic] too poor & single to adopt!
> The only chance is to marry someone with kids. (Paula's diary, 2014)

Similarly, Siân explained in her diary, 'I never walk past a woman pushing a pram or a parent with a child without imagining myself in that situation and wishing it could be me' (Siân's diary, 2014). Siân commented that she 'think[s] about [the infertility] quite a lot because I'm at the age where my friends are settling down and having children and things like that. I've got one friend, I went out for tea with her last night, and she's thirty-three-weeks pregnant with her first baby and that sort of thing' (Interview with Siân, 2014). Pandora, too, notes that 'for a while it

became very hard to see children and be around them, or to hear or talk about pregnancy. Essentially I was bitterly jealous' (Pandora's diary, 2014). Much like Pandora, Sophie's feelings about her infertility have changed over time. She states that she's 'ok with it' now, 'it's such an insignificant bit of me' and 'I forget about it most of the time'. However, she recalls that 'while you're trying to come to terms with it, it's all you think about. Like, so weird. Like you'll be sitting on the bus thinking, 'Oh, pregnant people, go away. Why can't I have a baby?' all those things. But over time you just forget about it' (Interview with Sophie, 2013). The preoccupation with pregnancy that many of the participants describe causes personal, emotional distress and also interferes with social relationships. Women who are seeking or undergoing infertility treatment have been depicted as 'totally immersed in the process' (Greil *et al.*, 2010, p. 146). Whilst most of the women in this research were too young to seek treatment when they discovered their infertility, they describe a similar immersion, or fixation, on conception at the time of their discovery.

Pandora recalls that her sister's pregnancy, four years after she had discovered her own infertility, was especially difficult to deal with:

> My sister, who is much older than me, and her partner came down to visit. Shortly after their arrival they revealed that she was pregnant. After a brief well done, congrats thing, I ran upstairs to my room and cried. It had just brought home the fact that it will never be me sharing that news, or making my parents as delightfully happy. At the same time I felt so guilty about my envy, as I knew really all I should be feeling was joy for them. (Pandora's diary, 2014)

As Pandora acknowledges, feeling ambivalent in a context in which celebration and unequivocal happiness are expected adds a further dimension to her emotional response: guilt. As some of the (negative) feelings experienced by Pandora are not the ones that 'ought' to be felt at this time, she attempts to manage, or hide, these expressions of 'inappropriate affect' (Hochschild, 1983). By displaying her happiness and concealing her sadness, Pandora recognises her failure to fully attain the emotional response which is expected in the ritual of announcing one's pregnancy; thus attempting to withhold 'feelings that do not fit the conventions designed for them' (Hoschschild, 1983, p. 59). Ahmed (2010) notes the isolating and alienating consequences of experiencing these 'misfitting feelings' (Hoschschild, 1983, p. 73), arguing that 'we become strangers […] in such moments' (Ahmed, 2010, para. 7). Despite the potential for these feelings to be interpreted as 'inappropriate', Pandora's struggle with this scenario is understandable and, perhaps, foreseeable. Nicole, for example, mentions that she has worried about [the event in which Emma's sister becomes pregnant] all her life, from the day Emma was born, I thought 'How am I ever going to handle that?'' (Interview with Nicole, 2014).

Some of the participants mentioned that comments they receive from others, who assume that they will also become a parent, can be similarly confusing. Siân describes, 'when people who don't know necessarily, when they come out with – y'know people at work who've got children at school or whatever and they come out with, 'Ooh, you've got all this to come!' and whatever and you think 'Mm'' (Interview with Siân, 2014). Paula also described an encounter she had with a customer in her workplace, a dental surgery:

> Today was hard, I took an infant out of the dentist's room, the mother
> was having her teeth examined & the baby was screaming, I put my head
> around the door and offered to take her for a little bit.
> She just wanted a hug, I held her & walked around the surgery until
> mum was finished with her examination.
> She & the dentist thanked me & the mum said that I would make a
> wonderful mother someday.
> I felt my face drop, I felt my colleagues all look on in sympathy & I felt
> myself tear up.
> I thanked her & went to the staff room for a little cry.
> I was ok after a couple of minutes but I always feel sad about this.
> (Paula's diary, 2014)

Siân notes that she does not blame those who make these comments 'because I understand that *they* don't know', but 'it's more of a reminder, I guess, rather than anything else' (Interview with Siân, 2014). Siân and Paula demonstrate the potential challenges which can result from 'remembering' the infertile status they both discovered many years earlier. Lambek and Antze (1996, p. xvi) consider how 'memory offers a certain scope for the kind of play or freedom that enables us to creatively refashion ourselves, remembering one thing and not another, changing the stories we tell ourselves (and others) about ourselves'. Forgetting issues we find difficult to think about can be part of a healing process; an approach which may be more readily available to those who encounter their infertility early in life, before reproductive decisions are applicable. Remembering and retrieving this issue, just like discovering it for the first time, can be a disruption in itself, whilst forgetting it may allow for a day-to-day sense of continuity and order.

Encountering pregnant bodies or parents with children also presented an unwanted reminder to some. This was understood as especially difficult in particular settings. For example, when describing her visits to the multi-disciplinary team at the hospital, Paula notes that due to '*really* poor planning' intersex patients were situated in the maternity clinic. She says, 'you're sat there with all these preg-o women and you're like [pulls face], it's just not right! It's crazy!' (Interview with Paula, 2014). Similar circumstances have been described as troubling by women attending gynaecological and antenatal clinics for infertility treatment (Doyal, 1987, p. 183). As Doyal remarks, 'it is hard to imagine anything more certain to cause distress'. Paula also notes that in the last few months, four of her friends have given birth, and two more have babies which are due imminently:

> I've held them all, I've seen them all, it's all like, it's really nice. But while
> they've got the babies in their hand I'm okay,  but it's the whole
> pregnancy thing I'm jealous of. It sounds really strange because y'know,
> who wants to be pregnant? And it's all the silly little things they get to
> do that I'll *never* get to do, like go and have an antenatal class and
> y'know go and have a scan and hear the heartbeat. Things like that,
> y'know, even if I adopt I'll still probably get all the experiences they get
> as a *parent*, but it's all the stuff that I *know's* not gonna be an option for
> me, y'know it's… I can't… (Interview with Paula, 2014)

Paula and I discussed the elimination of pregnancy as an available 'option', regardless of whether or not she would choose to conceive. She underlined, 'it's not a *choice*. I *haven't* had that choice at all'. Pandora framed her circumstances in a similar way, whereby reproduction

was effectively prohibited. She described, 'I saw this beautiful amazing process that I was being denied, and it stung bitterly'. One of the key themes women experienced in Williams's (1997) research on infertility was feeling a 'lack of personal control'. The issue of disempowerment is central to feminist reproductive literature, but scholars tends to focus on the use of, or lack of sufficient access to, reproductive technologies (Parry, 2005). The experience of powerlessness, like Paula and Pandora describe, has led feminists who support women's choice to access reproductive technologies to argue that these technologies provide women with the agency to take control of their reproductive decisions (*ibid*). However, physical and social impediments prevent both participants from having total access to conceptive technology, thus their capacity to 'choose' is still severely limited.

## 'Doing' womanhood

Feminist literature on infertility and miscarriage has provided considerable evidence of the connections between an inability to achieve conception and/or a full-term pregnancy and feelings of personal failure as a woman (Pfeffer 1987; Oakley et al 1990; Earle and Letherby 2007). Pandora reflected on the role her infertility has played in her identity as a woman:

> I don't have a uterus… no periods, no chance of children. In a lot of ancient cultures, the image of a woman is a symbol of fertility, the central part of which is the womb. So the lack of this female organ saddens me hugely and again questions my female mind. I suppose there's a disparity for me between mind and body: my mind is female, my body is not. AIS is not the only example of this, transgender people also must feel this difference also, although there are a lot of differences between this and intersex. (Pandora's diary, 2014)

Pandora battles with ambivalent narratives of gender identity, fertility and womanhood and notes that her conflicted gender identity is a topic she has talked about with her therapist. On one hand, she writes, 'I can't have children, this makes me feel like a failure as a woman, and takes away part of my identity as a woman'; however, she also acknowledges that 'when I look at other women, if they were unable to have children biologically, I wouldn't think of them as any less of a woman' (Pandora's diary, 2014). In her research on infertility, Becker (1994) underlines the way in which an inability to conceive is an 'embodied' disruption, as well one which is social, psychological and biographical. She discusses the 'gendered nature' (p. 394) of embodied knowledge; infertility 'unravelled basic understandings [women] had of themselves' and challenged their 'fundamental bodily knowledge' (p. 394). This embodied disruption and bodily/gendered uncertainty was dominant in all participants' biographies because of their intersex diagnoses, although for some this was a historical struggle rather than a current concern. Pandora muses on this issue further,

> Is being a woman the presence of a uterus? For me, the absence of one truly plagued my mind, maybe because that was the first fact about my AIS that I found out, and maybe too because it's the biggest physical difference between me and a 'normal woman'. But again, when a woman has a hysterectomy, does she become less of a woman, or stop being a woman? No. (Pandora's diary, 2014)

For Pandora, the embodied disruption caused by infertility is tied intimately to her intersex status. The absence of a womb brings substantive physical consequences, but also symbolic and

ideological ones. Pandora also spoke of the importance of providing her parents with a grandchild, and feelings evoked by 'the fact that it will never be me sharing that news, or making my parents as delightfully happy' (Pandora's diary, 2014). These feelings were especially acute when her sister announced her pregnancy because she 'just thought 'Oh, that's never going to be me, it's never going to be me making my parents smile in that way,' um… sort of giving them that happiness, I'm not capable of it' (Interview with Pandora, 2014).

Siân made a similar connection. She notes,

> [Conception and parenthood] is something that society accepts as being so natural that it does make you feel like you have failed in some way and I will always struggle with the fact that I can never give my parents biological grandchildren and that when they are gone I will never be able to look in my children's faces and see my parents in them. In this respect I think I will probably always have some grief for what could have been. (Siân's diary, 2014)

Both Siân and Pandora discuss grandparenthood as something they desire to 'give' to their parents, providing them both happiness and familial legacy. Their 'failure' to fulfil this is not only troubling for them personally; they also feel inadequate as daughters and perceive, or presume, their parents' disappointment in them. Ahmed (2006, p. 85) discusses the heterosexual futures imagined of children by their parents as 'a gift that becomes socially binding' because 'when given, [it] demands a return'. Pandora and Siân experience guilt due to the asymmetry of this 'failed' contract.

## Potential parenthood and fertility treatment

Whilst some participants felt that parenthood was no longer an option, or concluded it was not something they desired, other participants spoke about the parenting options they felt might still be available to them and showed some intention to pursue particular routes in the future. However, most of these participants felt ambivalent about the potential options, gave conflicted accounts in their diaries and interviews and remained uncertain about how they wanted their (non-) reproductive future to look.

Becker and Nachtigall (1992) observed how options presented as alternatives to biological parenthood (such as remaining childless, adoption and fostering) were viewed by parents who were unable to conceive as 'more undesirable' once a biomedical approach to infertility had been instigated. These routes were understood by participants as a 'dual failure: the failure to conceive and the failure to be cured' (*ibid.*, p. 468). As none of the participants in this study experienced a 'failure to conceive', their understanding of alternative options differed from those who have attempted to conceive. Nevertheless, most participants were still constrained by notions of failure and 'naturalness'; parenthood which was not achieved 'naturally' was still perceived as medically and socially deviant (Earle and Letherby, 2007, p. 234) and therefore less desirable.

Earle and Letherby (2003, 2007) observe the 'many interrelated factors' that prevent women from making use of the biomedical possibilities now available, such as societal expectations, social exclusion, and the relationships formed with others, both in medical and familiar/intimate contexts, which can prevent a freedom of movement and autonomy. As I discussed in Chapter Eight on sex and relationships, participants in this study also commented

on significant obstacles to parenthood further to biology; relating to social issues and stigmatisation. Previous chapters have also underlined the stigma which can result from social and medical responses to intersex, and the experiences of loneliness often encountered.

Social constraints such as these, in addition to physiological factors, may create significant barriers to parenthood. Most participants have struggled – and, in many cases, continue to struggle – to 'access' intimate partnerships and/or sexual encounters. Whilst some literature on infertility discusses the social barriers and inequalities which can prevent prospective parents from accessing treatment, this scholarship tends to focus on issues of wealth/class, race and disability (e.g. Stanworth, 1987) and medical, rather than sexual/relationship, access. Discrimination, exclusion and stigmatisation of those with an intersex status affects their location in the social structure and their ability to consider certain parenthood options. Wasserman and Asch (2012), for example, suggest that the stigmatisation of Turner syndrome may impose challenges if diagnosed women wanted to adopt. They note that '[w]omen with TS [Turner syndrome] may be considered poor candidates for adoptive parenthood, based on exaggerated concerns about their health or longevity' (*ibid.*, p. 794).

As noted earlier in the chapter, Paula's financial concerns and relationship status have led her to believe that adoption would not be available to her, and that her only route to parenthood would therefore be to 'marry someone with kids' (Paula's diary, 2014). Whereas Sophie, who is 24 years old, notes that her boyfriend of five years is 'really supportive' about her infertility 'and we plan to adopt' (Sophie's diary, 2013). In her interview, Sophie told me about a report she had heard about someone with the same diagnosis of Swyer syndrome receiving hormones to develop their uterus. She said that this allowed them to conceive and give birth after undergoing in vitro fertilization (IVF). She adds, 'I might [have a baby using IVF], who knows, who knows. But obviously you can adopt, you can do whatever, you can *not* have children, do whatever you want' (Interview with Sophie, 2013). Since Pandora has become increasingly comfortable with her infertility, she notes that she is now 'more open to the possibility of adoption if I was with someone who wanted a child' (Pandora's diary, 2014).

Siân says that she has given some consideration to her reproductive options, but feels 'it's one of those things where you have to sort of – I think you have to get your circumstances right to y'know – sort of put those things in place' (Interview with Siân, 2014). She says that 'I've never sort of felt my circumstances have been right to sort of even begin' and 'you have to sort of be a bit sensible […] and think of it realistically'; however, she does have 'ideas in my head of what I would do'. Siân notes that despite no longer discussing her infertility with her parents, at the time she discovered the diagnosis she received 'reassurance […] that just because I couldn't conceive my own children naturally it didn't mean I couldn't become a Mum later on with assistance' (Siân's diary, 2014).

In her interview, Nicole showed frustration that infertility is 'never *dealt* with' in children because 'nobody ever thinks about fertility as a *children's* problem' (Interview with Nicole, 2014). Through her active involvement in Turner syndrome support groups, she has observed that the medical assistance provided to infertile children (or their parents) is 'no better today than it was' when her daughter, Emma, was born twenty-seven years ago; arguing that reproductive options for those given an infertile status early are in fact '*less* [now], not more'. Consequently, Nicole says that she tells parents in the support group that

the *best* thing you can do is start saving. Because you're not going to get
anything on the NHS. So if you want treatment for your daughter,
private treatment, and none of this 'mothers freezing her eggs'.
(Interview with Nicole, 2014)

Nicole was keen to demonstrate to Emma from an early age that there were other reproductive
options available to her, to 'try and not make her feel that she was *any* less a person'. Nicole says
that she 'always planned to be *honest*. So if [Emma] ever asked me a question, I would have
always told her the truth. I made a decision that I was never going to lie to her. Um, and I was
never going to avoid the hard questions'. Nicole describes a process in which she equipped her
daughter with knowledge about her body, diagnosis and future reproductive options over a
number of years, starting from the earliest possible age. For example, Nicole says that some of
the dolls Emma was given as a child were introduced as '*adopted* dolls'.

When Emma was four years old, Nicole recalls that together they watched the film *Look Who's
Talking* (1989). At one point in the film, Nicole describes a scene in which a sperm is chasing an
egg. She notes, 'I'm watching, thinking, 'she would understand that... she would get that she has
no eggs, and that the sperm can't catch your eggs because you haven't got any''. She then
proceeded to explain this to Emma, adding that, 'so when you grow up, if you want a baby, you're
gonna have to borrow some eggs... for your tummy'. Nicole describes Emma's response as
indifferent.

Nicole narrates another scenario a few months later, where Emma was sharing a bath with her
cousins, Peter and Sam, who were of a similar age. Nicole was absent on this occasion, but her
sister, Alice, had told her later that Emma had addressed her, saying 'Y*ou* must have eggs in your
tummy and Uncle Mike must have had *sperm* because you have Peter and Sam' (Interview with
Nicole, 2014). Nicole notes that Alice 'got a bit choked because she thought something awful...
I'm going to kill Nicole for going out of the country and leaving me with her daughter and this
difficult question'. Emma then asked Alice, 'When I grow up, do you want to give me some of
*your* eggs?' Nicole adds that Alice cried at this question, and agreed to provide Emma some eggs
despite knowing, as Nicole notes, that she would have been too old to donate. The scenarios
described by Nicole show the considerable impact an early diagnosis can have upon the
childhood conditions, discussions and experiences of intersex individuals as they grow up, and
as parents/guardians attempt to respond to these unexpected circumstances.

When Emma was two years old, Nicole recalls that she introduced her to the first baby conceived
by a donor egg in Scotland. She also introduced Emma to parents of adopted children, and others
who had chosen not to have children. Nicole says that she sought these relationships
intentionally:

> I purposely, if there was a programme on about adoption I watched it. If
> there was a programme on about fertility I watched it. [...] I just, I just
> wanted her to... have options. To *know* that there *wasn't* restrictions.
> And... in my heart I *wished*, and I think this goes for all these conditions,
> that there is a more open discussion about infertility in children.
> (Interview with Nicole, 2014)

As noted above, Nicole has struggled with Emma's infertility. She remarks that 'it's still *my* issue,
but I work hard on not making it *her* issue'. We discussed what it was that Nicole finds difficult,
given Emma's fairly comfortable and accepting attitude towards her reproductive options:

There will always be a wee sadness there, there will always be...
d'yknow what was interesting, it was never about being a *grandparent*
for me, it was never like – I never thought, 'I'll never be a granny'. Um, in
the sense of, 'Oh, that'll be awful, I'll never be a granny'. [...] It was never
about 'for me'. Um, but I think that's just because I'm not an – I'm quite
an unselfish person. So... I think that, that's just the way I thought about
it, y'know. I'm now a granny [to Emma's sister's child] and it's the best
thing in the world, *but*... [...] It's just – that she wouldn't have the
moment that I had with her, that I had with her sister, y'know. That
*that*... y'know, she might not have that. But, what I was trying to say is,
you can get it in other ways, y'know. And I, *I* have always imagined uh... I
think she'll *adopt*. (Interview with Nicole, 2014)

Whilst Nicole clarifies that her sadness is not caused by her own deficit, but Emma's, she also
notes that she believes that it is likely Emma will, in fact, become a parent by adopting. The
deficit, then, is the absence of 'the moment', which presumably cannot be experienced through
adoption; perhaps this is a 'moment' which is anticipated to occur between biological parent
(mother) and infant, after their shared process of childbirth. Whilst it is important not to
devalue the significance of this moment for Nicole, especially as she notes that 'you can get it in
other ways' too, her sadness at its absence in Emma's life may indicate the way that she
continues to implicitly privilege 'real', genetic parenting over other kinds.

## Other life paths

Despite Emma's interest in adopting children in the future, Nicole mentioned in her interview
that she has also encouraged her daughter to think about alternative experiences which could
also be available to her. She recalls, 'We tried to say to her, 'y'know, if you want to travel the
world, travel the world. You can't do that with kids very easily. So it's... so do that, do something
different'' (Interview with Nicole, 2014). In contrast to her previous struggles with infertility,
Pandora also spoke about the appeal of exploring different experiences outside of parenthood:

Over a long period I sort of realised that there's more to life than
children [laughter]. And there is... and *now* I kind of *don't mind* not
having kids, like I've seen a couple of friends my age having kids and
like, oh God I wouldn't want that! [Laughter] So, you know, I can try and
see the benefits of it now and that that isn't – that doesn't really upset
me that much anymore, that sort of thing, but, y'know it was something
that for a lot of years, yeah. [...] But I s'pose it's – it's *more* since I went to
uni and more careers have opened and there's a lot to *life* and there's – I
s'pose it, again, 'cause it's, at the time I didn't really have that many
friends around me, so I know now it doesn't mean I have to be *alone*, um
I s'pose that was... But there are people who just don't want them, there
are people who can't have them for all sorts of reasons and that it's not
the be-all-and-end-all, even though I once thought it was, so... it's not
really the issue to me. (Interview with Pandora, 2014)

Pandora's realisation 'that there are other... other possibilities of, like, a life plan' and that 'it
doesn't have to evolve around family' demonstrate the process in which the pressure to live a
life centred on parenthood, whilst persistent, can still be disregarded. Pandora notes that
because she's 'from a large family and my siblings have got kids and things like that', she
'assumed *that* was the way it was done'. Much like Siân and Pandora's concerns about their
failure to 'give' their parents grandchildren (discussed above), Pandora illustrates the

importance placed on discourses of familial legacy. Infertility can threaten the presumption of a 'future that is "in line" with the family line' (Ahmed, 2006, p. 83), in which there is often an implicit understanding of a tradition of parenthood; 'the "hope" of the family tree, otherwise known as the "wish" for reproduction' (Ahmed, 2006, p. 83). This is not only characterised as a wish or a hope, but a natural or instinctual inclination (Downing, 2004), whereby inability, resistance or indifference to reproduction are recognised as problems in need of solving, and complications which discontinue tradition.

Pandora explores how a route outside of parenthood can be taken and enjoyed, not just endured. She explains, 'it doesn't have to be your life plan, there are a lot more options out there, and a lot more options that will be *happy*, that they can lead to sort of contentment in life, and fulfilment' (Interview with Pandora, 2014). Pandora describes a process through which she has re-discovered feelings of hope and optimism about her future, whilst revising the value she places on life options outside of parenthood. She also develops a more critical understanding of parenthood. For example, in her diary Pandora reflects on 'the positives of not being able to be pregnant':

> Pregnancy can ruin women's bodies, cynical though that sounds. As sensitive as I am to my body image maybe it's good that such a process won't come along to change my body. In a trusting relationship I don't have to worry about condoms or the pill or the chance that my life will change radically with an unexpected pregnancy. On a less boy-orientated thought plane, I can continue to live a life of relative freedom without the burden of children, I can have more time for hobbies and careers etc. I have to look at the positives, even though they sound so selfish, or the future can look gloomy. (Pandora's diary, 2014)

Pandora's admissions come with disclaimers, in which she exhibits a fear that her views will be understood as 'selfish' and 'cynical'. Her own disregard of mothering as a goal is still haunted by a concern that others will judge her negatively for her criticisms of parenthood. As Woollett and Boyle (2000, p. 309) contend, in opposition to the image of the 'warm, caring and 'good' mother', we see 'the 'bad' mothers, selfish, childless and career women, and empty and deficient infertile women'. In challenging the desirability of pregnancy and parenthood, Pandora moves from the role of 'deficient infertile woman' to the 'selfish, childless' woman who prioritises other life goals. These cultural dialogues leak into Pandora's reflections, even when she talks about taking a more affirmative approach to alternatives to parenthood.

Williams (2000) adapts Bury's (1982) theory of biographical disruption to incorporate concepts of 'appraisal' and 'revision' and point to the ways in which people 'engage in ongoing cycles of reflexive assessments and amendments in relation to their biographical narrative, and in response to biographical disruptions' (Hudson *et al.*, 2015, p. 3). Pandora describes an appraisal of parenthood as her approach to infertility develops and changes, 're-examining expectations and plans and the activities of decision-making' (*ibid.*, 2015, p. 9). Hudson *et al.* (*ibid.*, p. 9) point out how thinking about 'appraisal' as well as disruption 'draws attention to an active process of biographical work'. Pandora chronicles a process over a number of years in which she manages a cycle of appraisals and re-appraisals of her understanding of reproduction, infertility and gendered embodiment.

In her diary, Pandora wrote further about the period between the discovery of her infertility and her more recent acceptance:

> I dealt with my sadness of being unable to have children by telling people, including myself, that I did not want children at all. I acted slightly disgusted and disinterested in all babies, acting like I just had no grain of maternal feelings. Having told myself for so long that I don't want children, I'm now no longer sure if I do or not. (Pandora's diary, 2014)

Here, in another re-appraisal of parenthood and infertility, Pandora describes an attempt to 'recreate a sense of continuity in life' (Becker, 1994, p. 390). By convincing herself that she had no reproductive ambitions, Pandora believes she found a way of 'dealing' with the challenges and disruption caused by her infertility. Becker (*ibid.*, p. 400) describes how an 'illusion of continuity' can be constructed in personal narratives to enable those experiencing disruption to 'view their lives as having order and consistency in the midst of change'.

Many of the infertile women in Becker's (*ibid.*, p. 396) research used a metaphor of being in 'limbo', like Pandora, who upon discovering her infertility, envisioned a 'big empty space [which] remained to be filled' and her chosen 'path […] resolutely closed'. Becker notes that being in 'limbo' meant their 'understanding [of] disorder and disaffection [was] temporary' and 'they were able to better endure their sense of disruption' (*ibid.*, p. 396). She believes that the limbo metaphor can therefore enable women to reorganise their experiences. Indeed, in the extracts above, Pandora indicates an adjustment in which children have become a 'burden'; thus creating a new narrative in which childlessness is liberating rather than limiting, and a life with no children is described as one with 'openings' rather than 'closures'. Becker (*ibid.*, p. 396) observed how her participants'

> need to envision a future for themselves became the pivot on which all of life turned. Efforts to restore order to life necessitated reworking understandings of self and world, from the meaning on the disruption to the meaning of life itself. Reestablishing a future was a slow and painful process, however.

Pandora's emphasis on inauthenticity in the extract above suggests that her attempt to develop a narrative of continuity by rejecting children altogether was not beneficial. However, her sustained efforts have since led her to place a greater focus on the goals, achievements and future milestones outside of parenthood which she has begun to recognise as valuable and appealing contributions to her own sense of fulfilment and esteem.

## Infertile benefits

Natalie was the only woman in this study to say that infertility has never caused her any distress. In her diary, she commented that she is 'NOT broody around baby's [sic]' and, whilst she is 'appreciative of the hard work that goes into look[ing] after/raising children', she 'struggle[s] to see whats [sic] so special about the whole thing' (Natalie's diary, 2014). Natalie believes that it was her indifferent disposition towards infertility which led her to disregard her absent periods during adolescence:

'Cause I didn't start my periods, I thought I'm just one of the lucky women who doesn't have them! Bingo! You know, I didn't think that... I mean, obviously when I was younger my mother told me to go to the doctors and I wasn't that fussed about it. I just thought 'Oh well, I don't have them'. [...] I just thought – I don't have 'em. Y'know, just leave it at that. I'm not interested in having kids. Can't *stand* kids. Can't... even picture myself being a mother of any kind or anything, and I thought 'Oh well, it doesn't matter', but then you don't think about... well, if you're not having periods that means there *is* something wrong. You don't think that, you're just thinking, 'Hey-hey, I don't have 'em!' So, I thought this was working out perfect for me, you know, 'cause I don't *want* children! So yeah, bonus! And then they're like, 'No, no, no, it doesn't mean that, that everything's all y'know, cushty, you just gotta... be investigated'. (Interview with Natalie, 2014)

In reproductive scholarship, infertility is often identified as a process in which individuals 'define their ability to have children *as a problem*' (Greil *et al.*, 2010, p. 141, my own emphasis). This definition may be used by scholars under the assumption that infertility would only ever be discovered when attempting to conceive; in the extract above Natalie exhibits gratification towards the 'symptoms' and consequences of her inability to conceive without assistance. As Natalie has not engaged in vaginal-penile intercourse, enjoys an exemption from menstrual periods, has no ambitions towards parenthood, and does not feel a sense of 'desperation' (Pfeffer, 1987, p. 82); she is, in many ways, entirely removed from the exemplary 'infertile' woman.

In her interview, Natalie discussed an imagined notion of who she might be without a diagnosis of complete androgen insensitivity syndrome (CAIS). She notes that 'if I *was* without it [CAIS] anyway, I'd probably have had a hysterectomy' because 'I'd like to think that even if I didn't have the CAIS I wouldn't have had children anyway, and I wouldn't have been interested' (Interview with Natalie, 2014). When Natalie discovered her infertility, she did not withstand a 'fundamental re-thinking of [her] biography and self-concept' (Bury, 1982, p. 169) like other participants in my research and the many other studies into women's experiences of infertility preceding my own. Instead, Natalie constructs an ordered and stable narrative in which parenthood is such an undesirable route that, without a diagnosis of CAIS, Natalie still believes (or hopes) she would have followed the same trajectory. Moreover, she says she may have undergone a procedure to recreate her current embodied experiences; an absence of periods and an inability to conceive. However, Natalie comments that she does not know 'what my brain would be thinking like' if she had never received the CAIS diagnosis.

Natalie's imagined future does not contain the same 'fixed bio-social stages' (Earle and Letherby, 2007, p. 237) described by other participants; thus she experiences reproductive concerns in a very different way. However, the disruptions which may occur due to infertility and/or an intersex diagnosis, are not only biographical. Bury (1982, p. 180) observes how 'disruptions in biography are, at one and the same time, disruptions of social relationships', and earlier in the chapter I considered the 'embodied disruptions' (Becker, 1994) experienced by Pandora, in which her gender and the physical certainties of her body felt under question. Natalie has – and continues to – encounter many challenges related to her diagnosis, including issues with disclosure, friendships, sexual relationships and body image, as I have explored in previous chapters. She depicts the impact of her diagnosis as enormous; stating that she

'think[s] somewhere along the line [everything I do and say in life can] always stem back, […] can all be related back to having this condition' (Interview with Natalie, 2014). The complex synthesis between her CAIS diagnosis and her infertility, despite the latter being more warmly received, make them hard to untangle. This confounds the pathological status given to her condition, which in many ways has granted considerable benefits as well as difficulties. As an active agent in the process of constructing and defining her experience, Natalie demonstrates alternative interpretations of 'infertility' outside of medicalisation and unsuccessful aspirations towards parenting.

## Conclusion

The profound isolation, alienation and discomfort described by most women involved in my research, regardless of when they were diagnosed, suggests that the age at which an infertile status is discovered may not necessarily be a reliable indicator of how challenging the experience will be. The everyday nature of their struggle, whereby some participants found sharing the same spaces as children and/or pregnant bodies to be upsetting, suggests that infertility can be experienced as an ongoing disruption, or a cycle of repeated disruptions. This is not only a disruption at the scale of biography, life course and future plans; but also at a micro level, a disruption which interrupts the capacity for some of the women in this study to go about their everyday lives, see friends, go to work, visit family and attend hospital appointments.

Different ways of dealing with this were discussed by participants, including 'forgetting' the issue, as well as ongoing appraisals/revisions of the appeal of parenthood, and the value of other options which might be prohibited (or deterred) by parenting duties. The disparity between 'cultural ideals of how things are supposed to be and how they actually are' (Becker, 1994, p. 401) means that no ones' lives are entirely predictable and stable throughout. Nevertheless, as Becker (*ibid.*, p. 402) remarks, the 'heavy weight of the cultural model of continuity' makes these disruptions difficult to encounter, and as unexpected as they often are, we are usually unequipped in ways of 'dealing' with these issues.

Whilst infertility literature often focuses on the processes of *trying* to become pregnant (Greil *et al.*, 2010), I have explored the experiences of women who have not sought medical treatment and received their diagnosis before attempting to conceive. Like women who encounter their infertility in more 'conventional' circumstances, narratives of 'naturalness' and 'failure' have still stigmatised participants' experiences and affected their disposition towards conceptive technologies and non-biological parenthood. However, some participants made a clear distinction between the experiences of infertile women in 'conventional' circumstances, and the experiences of women with intersex-related conditions who discover their infertile status before conception is an option, regardless of whether it is desired. Their childhood, adolescence and imagined futures are mapped out and, sometimes, re-drawn according to this revelation. Identities and broader conceptions of the future/past self are also constructed around this knowledge.

Social as well as physical impediments to parenthood were present in participants' accounts. An ambivalence towards relationships and sex, as well as heightened anxieties around gender/sex identity and body acceptance, mean that instigating romantic and/or sexual relationships can be daunting and, in some cases, unappealing. Critiques of 'pronatalism' and cultural narratives of reproductive futurism often underscore the compulsory function of conception and

parenthood (e.g. Edelman 2004), however some of the participants' accounts illustrate how competing narratives can, and do, co-exist for some individuals. Infertility is not central to the lives of all women who are unable to conceive 'naturally', although different stages throughout the life course were understood to provoke different levels of social attention and personal anxiety.

The language we use to talk about 'infertility' (including alternative terms, such as 'involuntary childlessness') does not accurately describe the full range of experiences of people whose bodies are unable to conceive without assistance or, in some cases, at all. An 'infertile' status is not understood by all of those affected at all stages of their life course to be pathological or prohibitive. Some participants felt, at times, disempowered or restrained by their infertility, but there were also examples of ways in which participants actively took control of their futures, challenged dominant 'straight time' narratives, searched for alternative directions, and constructed, and re-constructed, visions of futures and goals that suited their own needs.

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## Conclusion
## Developing a Critical Understanding of Sex

*'[D]isruptions in biography are, at one and the same time, disruptions of social relationships.'*
*- Bury, 1982, p. 180*

This research comes at a time when conversations about intersex are mobilising globally. High levels of interest in this area were illustrated by the overwhelming level of attention given to Caster Semenya in the months preceding and the aftermath of her recent win in the 800 metres women's race at the 2016 Olympics. Semenya's eligibility to compete had been in question since her win at the 2009 Berlin World Athletics Championships, following other athletes' concerns about the legitimacy of her female identity, apparently due to her 'masculine' appearance and her impressive performance (Longman, 2016). Semenya was temporarily suspended from competing and subject to sex testing by the International Association of Athletics Federations (IAAF), the sport's governing body. These concerns led the IAAF to produce a new policy in 2011 which placed limitations on permitted levels of naturally-occurring testosterone in women athletes. Women with higher levels of testosterone (referred to medically as hyperandrogenism) would be required to take hormone-suppressing drugs or surgical measures in order to compete. Last year, the Court of Arbitration for Sport suspended the practice of 'hyperandrogenism regulation' (Branch, 2015) and granted the IAAF two years to provide strong scientific evidence connecting high testosterone levels and improved athletic performance. It is not known whether Semenya's testosterone levels were found to be higher than typical, or whether she took any steps to 'amend' this.

Speculations around women's – especially intersex women's – legitimacy to compete in sporting events are not new, and this scrutiny has often been racialized (Kerry, 2011). Various high-profile cases have occurred throughout the twenty-first century, and in 1966 sports officials declared a mandatory genital check of all women competing in international games. Following complaints about the humiliation involved in what was known as the 'nude parade' (Ritchie *et al.*, 2008), genital checks were replaced two years later by a chromosome test, a method which was critiqued by geneticists, endocrinologists, and others in the medical community who argued that sex categories could not be ascertained by chromosome testing alone (Simpson *et al.*, 2000). Testing did not, and still does not, solve this problem. Dividing sporting competitions by two sex categories will never be entirely practicable simply because bodies are not binary. However, these tests, their consequences and the public responses to athletes like Semenya demonstrate the efforts which are made to suggest and prove otherwise.

In this thesis, I contribute formative and original material to the nascent body of sociological literature on intersex experiences in the UK. In particular, this study demonstrates the strong social compulsion or obligation to conform to bodily and identity norms and conceal difference. I show how the potential for stigmatisation and ostracism imposes a requirement to 'pass' as binary sex, binary gender, and as a body which naturally conforms to aesthetic ideals. This feeling of difference and of deviance can lead people with atypical sex characteristics to feel like

they do not 'fit' or 'belong'; a sense that – despite their friendships, relationships and families – they are alone. To pass does not necessarily mean to 'fit' or to 'be'; the idea of passing and its presumptions of authenticity can in fact present a barrier to belonging comfortably. Further, I illustrate how experiences of difference can manifest through social and personal expectations of biographical continuity, and 'normal' and predictable lives, including sexual and reproductive milestones and behaviours, which are not always available or desirable to people with intersex traits.

Intersex studies scholarship and activism have spoken in detail about the ethical dilemmas and harmful consequences of the early corrective surgery paradigm (e.g. Davis 2015, Karkazis 2008, Reis 2009, Roen 2008, Morland 2001, Holmes 2002, Preves 2003). This study extends these concerns and builds on this important work, but also presents new focal points in intersex experiences beyond infancy, centring in particular on loneliness, passing, sexual activity and relationships, and infertility. Taking a two-tiered qualitative multimethod approach, starting with diary accounts and followed by in-depth interviews, this research provides detailed insight into the social and medical experiences of nine participants.

Re-visiting Garfinkel's (2006 [1967]) now infamous study of Agnes, I use the concept of passing to contribute to existing discussions about authenticity, (un)certainty and the medical determination of a 'true' sex. In asking how people with atypical sex characteristics understand the validity of their bodies and identities, my research shows that some participants experience a dualistic understanding of the 'real' and 'fraudulent' self, causing significant anguish. This has important consequences for thinking about the social framing and medical approaches to intersex and the potential harms which result from treating sex as a knowable, strictly biological, and binary categorisation. I demonstrate how negative and unsupportive social responses which often lack an understanding of intersex traits, as well as inadequate medical training and support, have led to further suffering, secrecy and isolation. This shows that greater education about sex differences in schools and in medical training is urgently needed. Whilst intersex continues to be treated as a pathological concern, medical staff are the first point of contact for parents and patients, and can therefore greatly influence responses and attitudes towards the bodies and diagnoses in question. My research shows that both positive and negative experiences with practitioners can have significant lasting consequences, and their collaboration in changing practice and understanding is therefore vital. Honesty and transparency for all concerned may also be helpful here.

In some cases participants' successful engagements with support groups has shown the potential for these networks to be hugely beneficial to people with intersex traits and their parents. These groups can be a venue for acceptance, advice, solidarity and comfort. However, my research also alludes to the limitations of these groups for people whose intersex experiences are in some sense less 'typical'. It is crucial for medical staff to provide parents and patients with knowledge of these networks and groups, but the support groups themselves also need to reflect further on how to create a more actively inclusive environment for a diverse spectrum of experiences, backgrounds and identities.

Participants' conversations about the numerous ways in which they felt powerless and lacked a sense control have been fundamental to this thesis. These points mainly occur in three domains: first within a medical context, where some adults reflected on the clinical approach to atypical

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sex as a breach of their autonomy, in which irreversible surgical and pharmaceutical decisions were made on their behalf in infancy, childhood and adolescence. Participants discussed how these approaches were informed by often erroneous presumptions about their identities, sexual orientations and futures. Some adults with intersex traits were also seeking information about their medical history which was not supplied, or was provided very late and only after a long and difficult process. This led them to feel that their medical and bodily history was shameful, opaque and out of reach. Medical ascendency can also prevent differing views and experiences from being seen, understood or accepted. I argue that bearing an identity or understanding of one's body which is in contrast to the orthodox medical approach can therefore feel impossible.

In the second, a social context, participants spoke of experiences of, as well as the threat of, ostracism and rejection. I show how in some instances, friends or sexual partners had responded to participants' disclosures or bodies in a way which was hurtful. The requirement to keep their intersex status hidden sometimes felt like a significant burden, and a continuous risk. By investing trust in others when disclosing, there was an ongoing danger of exposure which felt like it was outside of participants' control. The third domain, the body – one which is categorised as outside of recognisable and acceptable binary sex categories – can itself feel noncompliant. Participants who were frustrated or distraught at being incapable of sexual activity or conception often felt helpless. This was sometimes aggravated by a perceived lack of knowledge of their own body and diagnosis. In some instances, participants believed that medical staff had not fully equipped them with the information that they or their parents required to live their lives independently and seek treatment, if applicable. This created a sense of medical dependency.

These three domains are not distinct, but instead overlap and connect in various ways. Whilst there is clearly not one easily achievable remedy for these concerns, placing a greater value on the voices of intersex people is likely to provide many benefits and contribute towards the community regaining some control over their own identities, bodies and lives. Medical practitioners, in particular, need to listen more to the experiences and perspectives of those with intersex traits. Healthcare consultations need to be a conversation, in which normative presumptions do not shape the treatment approach for patients, and the vocabulary used to describe anatomy, traits and status is suited to their preferences. This also means that consensual treatment at the discretion of the individual concerned is paramount. My research also shows that some people with intersex traits describe attempts of resistance, self-determination and control. These contestations are important to recognise and observe; participants in this research were not always passive or compliant recipients of hegemonic discourses. As one of the central intentions of this research is to listen to the stories told by participants, I hope this thesis can provide some contribution to helping a diverse range of perspectives to be heard.

However, this small scale study cannot, and does not, attempt to represent all intersex/atypical sex experiences. Whilst it has been important to focus on a UK context in particular, salient cultural differences within and outside of the UK need further discussion. Research is also crucially required into the lives of ethnic minority intersex people, who are often not members of the visible intersex community and therefore regrettably do not feature in this study. There is currently no sociological research which incorporates the views of children with intersex or atypical sex diagnoses and this also needs to be rectified. Whilst there are various studies into

the experiences of parents (e.g. Davis 2015, Karkazis 2008), some participants' narratives in this study referred to their siblings' roles, and this, too, could be a fruitful area for further research. Due to the word limitations of this study, there was not space to discuss broader reproductive issues connected to intersex, including intersex-selective abortions, genetic testing, prenatal screening and foetal treatment. These are important themes which require exploration in a UK context. Finally, existing literature on infertility would benefit from building on the insights of this study to further theoretical and empirical work on reproductive discoveries in childhood and adolescence. Whilst this may be a minority of cases, their absence is currently conspicuous in the literature.

This thesis also has significant reach beyond the field of intersex. I argue that concerns with loneliness are fundamental to a diverse range of canonical social theory texts. Exploring participants' stories, I illustrate how the personal and private experiences of loneliness can be interpreted as public, structural and social concerns. This excursion into loneliness provides new insight into the important connections between social relationships and perceptions of self, and the impact and power of wider society. I develop recent attempts and appeals to consolidate intersex studies with critical disability literature (Tremain, 2000, 2002; Davis, 2013), and illustrate how these two areas of interest can profit from each other. I also situate this study alongside other important feminist research which takes a critical approach to concepts of 'sex'. This is distinct from gender studies and feminist scholarship which continues to overlook this core debate by implicitly promoting dualistic and essentialist understandings of sex. This omission is not only a reductive representation of morphology, but also leads to the silencing and erasure of intersex experiences. My research indicates that people with atypical sex characteristics are often subject to significant sex and gender based discrimination, and it is vital for feminist scholarship to recognise this alongside other forms of sexist violence and oppression.

The importance of feminist scholarship which acknowledges intersex traits and integrates a critical approach to sex extends beyond academia. One of the participants in this study, Sophie, described learning about the social construction of sex at university as a 'light bulb moment' which was 'really enlightening' and 'just made me feel so much better'. Reading texts on this topic, she reflects, allowed her to 'be at peace with [intersex]' (Interview with Sophie, 2013). Whilst intellectual development is important in itself, Sophie's comments are a valuable reminder of the potential for academic work to also impact people's personal lives and understandings of self and the world around them.

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# Appendix A
## Participant Recruitment Notice

**Experiences of Diverse Sex Development in the UK**
**Participants Needed**

Do you have atypical sex development, a chromosome 'abnormality', identify as intersex or have a condition which may sometimes come under, or be associated with, the intersex/DSD umbrella?

I'm a PhD student at the University of Sheffield and I'd like to invite you to participate in my research project. The project explores the experiences of people who have been diagnosed/identify as having atypical sex development, a DSD or intersex condition. I'm interested in how participants understand the relationship between their diagnosis and their everyday experiences, as well as how they perceive their own identities and bodies to correspond or contrast with traditional medical understandings of what is 'normal' for particular sexes or genders. I also hope to explore how participants feel about any medical treatment received and whether/how this treatment can be improved.

If you agree to participate, I will ask you to provide written or drawn submissions (of any length) exploring your identity and your thoughts, feelings and experiences of your diagnosis. Following this, I will ask you to meet with me for an informal interview/conversation to discuss your understanding of your diagnosis/identity and how it relates to your experiences and life history.

In order for you to have maximum possible input, I would like to encourage you to take an active role in considering what you would like to talk about in our discussions. We will also work together to ensure you are represented accurately in the final write-up.

Please contact me at charlotte.jones@sheffield.ac.uk to ask any questions you may have or show interest in participating. I will provide a more detailed information sheet about the research before asking you to commit either way. If you do decide to take part you will be asked to sign a consent form. You will still be free to withdraw at any time and without giving a reason.

Your name and any other personal information which will make you identifiable will not be used in the write-up of the study in order to protect your anonymity, unless you request otherwise. All communication between us will also be kept confidential. The research has been approved by the University of Sheffield Research Ethics Committee and is supervised by Dr. Kate Reed, Department of Sociological Studies, k.reed@sheffield.ac.uk.

Please pass this message on to anyone you think may be interested.

Thanks for your help.

Charlotte

# Appendix B
## Participant Information Sheet

**Research Information Sheet**

You are being invited to participate in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Ask me if there is anything that isn't clear or if you would like more information.

Your involvement will provide data for my thesis which will contribute to my PhD in Sociology at the University of Sheffield. The thesis explores the experiences of people who have been diagnosed as having a range of conditions, including [name of diagnosis]. This may include your thoughts on medical treatment, support groups and your experiences and processes of self-identification in relation to your diagnosis.

In order for you to have maximum possible input, I will encourage you to take an active role in selecting the topics we discuss and comment on how to ensure your comfort during the research. I also aim to ensure accurate representation of the views of all who are involved. You will be welcome to review sections of the thesis which involve you before they are finalised if you would like to do so.

Up to thirty participants will be participating in this study. Once you have confirmed you would like to be involved you will be given a journal to write or draw in as often as you would like to over a period of six weeks. This does not need to be filled; you are welcome to write/draw as much or as little as you like. As an alternative, you can write things down on the computer and then email them to me. I hope this will give you the opportunity to share some of your thoughts and feelings about the medical, social and personal implications of having [name of diagnosis] in your own time, with privacy and in whatever creative format you are most comfortable with. I will ask for you to return the journal (or documents on the computer) before our meeting.

Following the submission of the journal, we will have an informal interview which will last for around 1-2 hours. I hope the format will be more of a relaxed conversation than an interview to ensure that you are able to have some control over the areas we talk about. You may find some of the topics discussed to be of a personal or challenging nature but I intend for all discussion to be undertaken as sensitively and respectfully as possible.

As the interview will not be formally structured, it is likely that new questions will emerge during the discussion so all eventualities can't be entirely anticipated. However, you are free to refuse any questions you would rather not answer or request to move away from a particular topic. It is up to you how much information you share with me during this research. I hope the content of our discussion will be interesting to you and may raise some issues which you will enjoy thinking and talking about.

With your permission, the interview will be audio recorded to ensure your answers are represented accurately when I write up the study. You can request that I turn the recording device off at any time if you would like to ask a question or make a comment which will not be used in the study.

Your name and any other personal information which will make you identifiable will not be used in the write-up of the thesis in order to protect your anonymity, unless you request

otherwise. Data will not be shared outside of the confidential correspondence between you and me and, in some cases, my academic supervisors.

Recordings of the interviews and the material from the notebooks will be kept safely in a locked filing cabinet in University office space. You will be identified by pseudonyms throughout the research so all data will be anonymous. Digital files and USB sticks containing recordings of the interviews will be encrypted. If you do not give your consent to the recordings of the interviews being saved and used in future research I undertake then all files containing your data will be deleted.

Details of counsellors who can help with issues in this area will be provided should you wish to explore any of the themes which will be covered in the research.

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. You will still be free to withdraw at any time and without giving a reason.

The research has been approved by the University of Sheffield Research Ethics Committee and is supervised by Dr. Kate Reed, Department of Sociological Studies, k.reed@sheffield.ac.uk.

Thank you for taking time to read this information sheet.

Charlotte Jones

Department
Of Sociological
Studies.

Charlotte Jones
Postgraduate Researcher

[Participant's name]

[Participant's address]

The University of Sheffield
Department of Sociological Studies
Elmfield, Northumberland Road
Sheffield, S10 2TU

**Email:** charlotte.jones@sheffield.ac.uk

[Date]

Dear [Participant]

Thanks for agreeing to participate in my research. I've enclosed a consent form in this envelope. Please initial next to each section of the form that you agree with and sign at the bottom of the sheet before returning it to me. You can either send a scanned version via email or you can post it to me along with the journal if you prefer.

The journal I've enclosed is for you to use to write down or draw some of your thoughts about intersex/[diagnosis] before we have the informal interview. You can also glue pictures or photos into the journal, or do anything which helps you to express your thoughts or experiences.

As people feel comfortable expressing themselves in a variety of different ways, some choose to draw pictures or use diagrams, cut things out from newspapers or magazines or insert photos and write about them; some people also like to write things by hand or take their journals out with them to spaces where a computer might not be practical. There's no pressure to fill the journal, so please use up as many pages as you wish to.

You're also welcome to send me pieces of writing you've done before if you have written about intersex/[diagnosis] previously and you would like it to be included in the research.

Please return the journal by [date] if possible, and feel free to get in touch if you have any questions in the meantime.

Best wishes,

[Signature]

Charlotte Jones

# Appendix D
# Participant Ethical Consent Form

**Ethical Consent**

Please add your initials next to the statements you agree with.

| | |
|---|---|
| I confirm that I have read and understand the information sheet explaining the above research project and I have had the opportunity to ask questions about the project. | |
| I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. | |
| I give permission to the researcher to audio record an interview with me. | |
| I give permission for my email correspondence with the researcher to be used in the study. | |
| I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the thesis or any articles that result from the research.<br>I understand that my responses will be kept strictly confidential. | |
| I agree for the data collected from me to be used anonymously in relevant future research.<br>(Note: If you do not consent to this, all files containing your data will be deleted after the current research is complete). | |
| I agree to take part in the above research project and will inform the researcher should my contact details change. | |

| | |
|---|---|
| Name of participant | |
| Participant's signature | |
| Date | |
| Name of researcher | |
| Signature | |
| Date | |