

Are You A Boy or A Girl?
Contesting the Uncontested:
Intersex and Genders

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I hereby certify that the work embodied in this thesis is the result of original research and has not been submitted for a higher degree to any other University or Institution.

(Signed) _____

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In this town - something's gotta change
In this town - something's gotta change

I'm looking at the world -
Looking for a scene -
Waiting for a day -
Filling in time like I'm digging
My own grave ...

In this town

Eurythmics (1986)

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ABSTRACT

One question that is perhaps most familiar in contemporary western societies is “is it a boy or a girl?” This question goes uncontested unless a child is born with ambiguous genitalia. The medical responses to these births have recently undergone considerable attention and criticism from within the medical profession, from parents, but most loudly from the individuals themselves. In contemporary discourses these individuals are referred to by and large as intersex. The burgeoning intersex movement has coalesced around a shared lived experience of trauma brought about in no small way by the invasive procedures of medical management in its attempts to diagnose, treat and cure. These procedures leave intersex individuals with feelings of isolation and abuse and that they have been lied to and misinformed. A ‘culture of silence’ has been created whereby not only has the incidence of intersex been vastly underestimated, but also the psychological, social and physical ramifications have been omitted from medical, patient and broader social discourses. While intersex individuals cite their own experiences as evidence of these ramifications, the medical profession has been largely unresponsive. Aside from the demand for more information, counselling and a change in the medical management of intersex, there are broader ramifications of intersex within society, notably a conceptualisation of sex, gender and sexuality. While these aspects are secondary issues for the intersex movement its presence and its significance cannot be understated. This study takes note of the significant issues pertinent to the intersex movement and employs a comparative analysis of the lived experiences of Intersex Australians and Americans. Further, this project investigates the historical and cross-cultural evidence of intersex, the way in which medical discourses dominate twentieth and twenty-first century conceptualisations and how the intersex movement itself was formed in the last decade.

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Hurt that's not supposed to show
And tears that fall when no one knows
When you're trying hard to be your best
Could you be a little less?

Do you know what it feels like for a girl?
Do you know what it feels like in this world?
What it feels like for a girl

What It Feels Like For a Girl
Madonna (2000)

You have the same human rights as everyone else in the world because you are a human being. These rights cannot be taken away from you. Everybody, no matter who they are or where they live, should be treated with dignity.

Article 1. The Universal Declaration of Human Rights

CHAPTER 1: INTRODUCTION

Introduction

1.1 There Is No “I” In Research

1.2 Gendered Language

1.3 Postmodernist Thought

Conclusion

Introduction

“Are you a boy or a girl?” I was asked this question often in primary school. I’m still not one hundred percent sure. When we are born medical professionals pronounce whether we are a boy or a girl. It is argued that it is the *pronouncement* not the *fact* that you are a boy or a girl that determines, not only your sex/gender, but also all your lived experiences and social behaviours, relationships and identities from that day forward. Further, it is this decision, or more to the point the *indecision* that is the epicentre of many individuals life-shattering lived experiences. Lived experiences that include, but are not limited to, psychosocial trauma, physical debilitation, relationship disruption, social ostracism and identity confusion. During this thesis you will meet individuals who have lived some, if not all, of these experiences. Within contemporary western cultures these individuals are conceptualised and referred to as “intersex.”

“Intersex” is a contemporary western conceptualisation of individuals whose bodies do not conform to the traditional notions of what it means to be sexed or gendered. In western cultures this conceptualisation is deeply embedded within a medicalised paradigm, whereby medical professionals have implemented a range of protocols to manage the occurrence of intersex. These protocols are designed to intervene on the individuals’ behalf and can be implemented prenatally, at birth or at any time during an individual’s life. This intersex management has not been uncontested, and in the past fifteen years in particular intersex individuals have coalesced into an intersex movement to challenge this medicalisation and to voice their lived experiences as intersex individuals.

One of the most significant, if not the most vocal, ramifications of this movement is a reconceptualisation of the notion of sex, gender and sexuality in western cultures. It is argued that intersex individuals are the embodiment of contemporary discourses of gender and queer theories. Our birth is more than the beginning of life as a sentient human being. It is the beginning of a process - a gendered process. Gender and queer theorists turn to these individuals, some of whom live on the margins of sex, gender and

sexuality, to guide our (mis)understanding of the influence of gender on the human condition.

Presently I shall endeavour to introduce to the reader some considerations necessary to guide you through this thesis, namely how the researcher sees themselves as part of the research, not necessarily as 'subject,' nor as objective observer. Intersex deconstructions of the conceptualisation of sex, gender and sexuality have considerable influence on institutions within western cultures, not least of which is language. Therefore I draw the reader's attention to issues of language and the considerations deliberately undertaken in the use of gendered language in this thesis. Also I wish to emphasise the influence that postmodernist thought has had on me as researcher and subsequently the research itself. For now I wish to introduce some of the principal arguments you will encounter throughout this thesis.

Contemporary intersex necessitates a catalogue of those forces that guide its trajectory. It does not exist in a vacuum; intersex influences and is influenced by several theoretical spheres. Chapter 2 will map out the gravitational pull of several schools of thought. While the term intersex is modern, the fact that people are born with ambiguous genitals is not a contemporary phenomenon. Throughout western history and across many cultural boundaries the occurrence of ambiguous genitals has found its way into the conceptual maps of humanity. Chapter 3 offers a myriad of examples of how intersex has been conceptualised in historical and anthropological texts. This journey will take you into the twentieth century and the way that contemporary western cultures have medicalised intersex as a condition to treat, cure and prevent (Chapter 4). Rather than suggesting that this is a teleological process culminating in contemporary intersex this conceptualisation of intersex is changing. The past fifteen years have seen growing dissent to the medicalisation of intersex with the coalescence of the intersex movement. In Chapter 5 I will isolate numerous arguments of this movement, for example the fact that the current medical management caused psychosocial trauma in intersex individuals. In Chapter 6 I will allow the reader to hear intersex individuals narratives as articulated in an array of forums, such as newsletters, websites, anthologies and academic texts.

Chapter 7 begins our own journey of exploring the lived experiences of Intersex Australians; it is here I will introduce the methodology employed in this study. The responses given by my participants are catalogued in Chapter 8 while Chapter 9 involves an analysis of these responses in the context of the intersex narratives and literature discussed in previous chapters. Further, I will utilise the work of North American sociologist Sharon Preves (2003) as a comparative analysis; thereby noting intersections between the Australian and North American intersex lived experience. Chapter 10 will draw together some key threads made throughout this thesis, namely the broader ramifications of the lived experiences of intersex individuals on our (re)conceptualisations of sex, gender and sexuality.

1.1 There Is No “I” In Research

Objective research implies that the researcher is removed from the work. I argue that this does not have to be the case. Subjective research is not a new concept, and I do not argue that I am the first researcher to allow myself to be heard within research. Throughout this study I will investigate and ask individuals some very personal questions about their lived experiences, sense of self and relationships. An individual's genitals are central to conceptualisations of intersex, its regulation by the medical profession and individuals' personal stories. It could be argued that one of the most private aspects of ourselves are our genitals. To ask individuals to talk about their genitals and documenting and theorising their responses is not without its problems. Prior to consenting to be part of the study one of my participants - Mel - asked me rather personal questions, and quite rightly so. Who am I to ask these people these questions if I am unprepared to be asked or to ask them of myself?

There are perhaps two reasons I came to write a PhD on intersex. Firstly, I met Michael Noble, a 'reluctant' intersex activist, in 2000 at a queer university student conference; we became friends through shared interests in postmodernism, queer activism and Buddhism. Michael's strength and courage in revealing a personal history to the conference piqued my interest; here was someone I would like to meet. Michael inspired me to learn more

about intersex issues. Secondly, via an interest (and a career) in gender studies. I admit that gender is not necessarily a central issue for intersex individuals, however, I am not the first gender or queer theorist to be intrigued by the potential for (re)conceptualisations of gender. However, it is more than a professional interest, I have always wondered about my own sex, gender and sexuality identities.

I predicate this thesis on the argument that I want intersex individuals to speak for themselves. To enable this I concede that my own motivations, my own voice needs to be distinguishable from those of my study participants. I don't see this self-disclosure as an indulgence, but as a necessity. When pushed I identify as queer - a non-gender specific queer. However, I argue that my identity is merely a label, a name, a signpost to my systems of belief, thoughts, and lived experiences. Further, I've asked study participants to contribute to my understanding of their lives by enquiring about demographic information: age, spirituality, nationality, and occupation. Again is this information sufficient in contributing to my understanding? Would it contribute to your understanding if I answered them also? I guess as traditional aspects of one's identity they have their place: I'm 34, Buddhist, first-generation Australian and casually employed within the Tertiary education system.

Assuming 'non-gender specific' is at best insufficient, and at worse incomprehensible, and if I argue that I come to this thesis from a background in gender studies, perhaps I need to concretise my gender for the reader in more identifiable terms. Therefore, I followed a version of the Bem Sex-Role Inventory (BSRI) (Bem, 1974) that I found on the International Foundation for Androgynous Studies website (www.ifas.org.au). The BSRI determines how 'male' or how 'female' you are. With a score of "-3" I am categorised as "androgynous," that is a "sex role thus represent[ing] the equal endorsement of both masculine and feminine attributes" (1974: 159). I guess 'androgynous' is another label I could use. I could be transgendered. As you will read, 'transgender' has come to be used as an umbrella term for a range of gendered experiences. While writing this thesis I even thought maybe I am intersex. In particular, I thought I might have Klinefelters Syndrome. I compared my lived experiences with those

listed in a study of Klinefelters individuals (Bucar, 1999). But my doctor refused to do the chromosome test. I didn't push the issue.

As I stated above I don't believe this self-disclosure is self-indulgent. Rather I ask myself these questions and flag the answers such that the reader is best able to discern for themselves significant influences that may or may not be embedded within the project. What is striking about these questions is that they have been asked, that I have asked them of myself, that a person's gender is so unstable that one could easily undergo such reconsideration of what appears, on the surface at least, to be an irrefutable fact. As I mentioned above locating one's self within one's research is not new. I see my gender contemplations not only as a significant motivating force in this project but also as a significant part of the research.

Transman Stephen Whittle also places emphasis on the fact that the doer of research ultimately makes a mark on and becomes part of that research

So I become a part of the object of my study by studying it. I politicise, theorise the culture of gender, and in that way, I irreversibly change it. In the politics of gender, sex and the body, the existence of the body is, for us all, a statement of gender from the moment of birth. No matter how hard you try to talk about somebody else, you are always going to be talking about yourself (Whittle, 2002: 61)

Ethnographer James Wafer considers a similar point in regards to one's sexual identity

A gay ethnography would be one in which the identity of the ethnographer as a lesbian or as a gay man is an explicit and integral part of the text (Wafer, 1996: 261)

I propose therefore that I have deliberately installed a 'non-gender specific' sense of self into the text.

A final reflexivity between this thesis and myself as non-objective researcher has emerged that warrants attention. As a researcher there is a certain expectation of 'objectivity.' However, as queer, as a Buddhist and as a human being I cannot ignore the way the lives of these intersex individuals made me feel. I cannot ignore the tears I shed and the pride I felt and I cannot ignore the fact that these lived experiences engendered a rethinking of my own identities, relationships and body. These are all reactions that are not 'objective.' I do not apologise for it, nor do I shy away from letting it influence this work. Without it this thesis would never have been thought of in the first place.

1.2 Language

Right now, much of the sensitive language that was won by the liberation movements in the United States during the sixties and seventies is bearing the brunt of a right-wing backlash against being 'politically correct.' Where I come from, being 'politically correct' means using language that respects other peoples' oppressions and wounds. This chosen language needs to be defended (Feinberg, 1996: ix)

Language matters. More than a project of 'political correctness,' an analysis of language needs to be employed. The English language is inherently flawed when it comes to negotiation around gender diversity. Among other problems is its failure to allow gendered pronouns other than "he," "she," "her," and "his." Rather than being constrained by these limitations, there is evidence that some within queer communities have attempted to replace these terms with others. They use language as a tool, a weapon, wielded at these seemingly impenetrable barriers to expression. They have faith in the capacity of language to be flexible and organic, arguably not dissimilar to feminist discourses that attempt to replace the terms "women" and "woman" with "wimmin" and "womyn."

More common, and arguably the most conservative, attempt to replace gendered pronouns is the amalgamation of recognisable terms "s/he," "she/he," and "her/his."

Another variation on this theme is the alternate use of “he” and “she” when referring to the one person (Valentine and Wilchins, 1997: 216). Arguably the more radical, and hence the least frequently used is invention of new gendered pronouns: “per” (Elan-Cane, cited in Haynes and McKenna, 2001: 221), “ze” (Feinberg, 1996: x), “hir” (Feinberg, 1996: x; Valentine and Wilchins, 1997: 216; O’Keefe, 1999: 115), and “sinhir” (O’Keefe, 1999: 115). To date however, none have gained universal acceptance within queer communities, let alone usage in mainstream discourses. To contribute to the attempt however, I choose none of these. My choice is neither a conservative reliance on already gendered terms nor a radical invention of seemingly foreign words, I employ the terms “them,” “themselves,” “they” or “their.” I concede that at times this was a stumbling block to sentence construction, yet I argue that a minor and infrequent discomfort is worth acknowledging that not all of us wish to be labelled “he,” “she,” “her,” and “his.”

However, one may ask if most intersex individuals do not have an issue with their gender, and fewer still are adopting alternative gendered identities, why then do we need to explore the possibility of gender neutral terminology? Do “he,” “she,” “her” and “his” need to be abandoned in favour of other terms? Indeed most people, to whom I will refer in this work, do identify as one of the two traditionally sanctioned genders: man or woman. Yet there are those who do not. And I’d rather not be the one left to make an arbitrary decision regarding one’s gender, based on my perception of their lived experience. Further, I wish to explore the notion that something as seemingly entrenched in our society as gendered language is flexible and organic and is easily adaptable to less strict gendering.

Another significant dimension to the use of language in this thesis is my choice of a term that accurately yet considerately refers to its subjects. I have deliberately employed the term “intersex.” Although its use historically as a medical term has rendered it problematic, not unlike “homosexual,” it does appear in certain contexts, such as the Intersex Society of North America (ISNA). I prefer it to others because of its simplicity. The literature is not unified in its terminology. Various authors, inside and outside the

intersex movement, will use different terms (sometimes at different times) to refer to, by and large, the same thing, terms such as “people with intersex conditions,” “hermaphrodites,” “intersexuals” or “intersexed.” I have not removed these terms in other authors’ quotes. In Chapter 4 however, I have maintained the phrase “intersex condition” to indicate and remind the reader of the dominance held by the medical profession.

1.3 Postmodernist Thought

I am strongly influenced by postmodern thought. A few years ago some fellow queer activists adopted “po-mo” as a derogatory term and used it against me. In true postmodern style I happily reclaim “po-mo.” Yet, I don’t see postmodernity as an ‘identity’ to take on. Postmodernity is a way of theorising the world that best reflects my own way of thinking. In *Queer Theory Gender Theory* Riki Wilchins (2004) suggests that

Postmodernism has generated a powerful set of tools for dismantling arguments, revealing their hidden assumptions, and diminishing their power so that difference can emerge. That’s great for the struggle for gender rights, because that’s exactly what we want to do (Wilchins, 2004: 97)

The writing of a PhD thesis is meant to make a significant contribution to social knowledge. While I concede that furthering social knowledge is a noble pursuit, my primary goal of this thesis is giving intersex individuals a voice. I argue that this motivation is postmodern. Allowing intersex individuals to speak out destabilises the hitherto dominated medical viewpoint. Thereby, using Wilchins’ phrases I ‘diminish the power’ and allow ‘differences to emerge.’

While I support those who have speculated that we are on the verge of a Kuhnian revolution of gender (Grimm, 1987: 84) I argue a position that is not dissimilar to Steven Seidman’s standpoint on a “postmodern perspective” (Seidman, 1997: 43). That is, postmodernists give up seeking complete human emancipation and prefer

Deconstructing false closure, prying open present and future social possibilities, detecting fluidity and porousness in forms of life where hegemonic discourses posit closure and a frozen, natural social order. The hope of a great transformation is replaced by the more modest aspiration of a relentless defense of choice, democratization, and struggles for social justice (Seidman, 1997: 43-44)

Therefore rather than working toward a rose-coloured future free of injustice towards intersex individuals, I put my energies toward a future within which intersex individuals have access to the opportunities of choice, democracy and struggle.

Adopting postmodern thought and applying it to an intersex discourse is not new (Dreger, 1998: 170). Dreger's view of postmodernism and intersex is included in Chapter 6. However, a brief elaboration is necessary for this discussion. According to Dreger there are five aspects of postmodernism that are relevant to understanding intersex individuals' lived experiences. Firstly, postmodernists value voices previously considered non-authoritative. Secondly, it does not recognise a single 'true' story. Thirdly, there is an acknowledgement that one's body has been 'colonized' by medicine. Fourthly, postmodernism challenges the power in a doctor-patient relationship. Finally, postmodernism emphasises the social rather than the inherent naturalness of people's bodies (Dreger, 1998: 170-172).

While I argue that I have endeavoured to prioritise the voice of intersex individuals I also argue that academic analysis is given. Yet I do this cautiously and with careful consideration of my own subject position, which I have offered up here to allow the reader to determine the influence of "I" within the hearing of intersex voices.

Conclusion

The conceptualisation of intersex can be quite unique. Further, this conceptualisation is dependent upon the context within which we find it: historical, anthropological, medical, political, personal or academic. Yet there is more at stake here than how intersex is seen,

what is at issue is the lived experiences of individuals whose bodies do not conform to the traditional notions of what it means to be sexed or gendered in the societies in which they are born. For some historical and cross-cultural societies, intersex has been socially sanctioned. In others it has been used as a sign of evil. In contemporary western countries intersex is dominated by a medical paradigm. However, paradigms change. Such that in the past fifteen years the emergence of 'different' points of view, namely from intersex individuals themselves, who have hitherto been unheard, have come forth and coalesced into a movement to counter the contemporary conceptualisations of intersex. This movement has not only added their voice to the intersex management but also western conceptualisations of sex, gender and sexuality. This thesis is their story.

CHAPTER 2: SOCIAL THEORIES

Introduction

- 2.1 Contemporary Queer
- 2.2 Queer Theory
- 2.3 Gender Theory
- 2.4 Disability
- 2.5 Female Genital Mutilation
- 2.6 Theories of the Family

Conclusion

Introduction

Before turning our gaze to such stellar phenomena as the intersex movement or the current intersex medical management what is necessitated is a grasp of the gravitational forces being acted upon them by other celestial bodies. Currently several social theory spheres have been catalogued as cutting across the orbital trajectory of the intersex movement and the current intersex medical management. To date no other research has yet to consider all of these social theories and their implication for the intersexed in one opus, therefore I speculate that I boldly go where no one has gone before. What this chapter attempts, therefore, is a unique one-stop star-log of that which has been identified, either by this current project or elsewhere, as having a significant influence on the coalescing of such stellar phenomena as the intersex movement and the current intersex medical management.

However, just as peering through a telescope leaves the stargazer with a restricted gaze, so too my gaze is restricted to the scope of the current project. Subsequently, this mission to boldly go where no one has gone before is by no means exhaustive of the immense and diverse ecological landscapes of the social theory spheres herein discussed. What is attempted is an understanding of how different social theories, such as queer theory, gender theory, feminism, transgender theory, disabilities theory, the female genital mutilation movement and theories of the family, have come to say something about and to both the intersex movement and the current intersex medical management.

2.1 Contemporary Queer

Contemporary queers are defined by their in-definability. As a product of the late twentieth-century post-modern deconstructionist movements queer has become: an umbrella term to include sex, gender and sexuality identities such as (but not limited to) lesbian, bisexual, transgender, and gay; and a non-identity to challenge the stereotypes and heteronormative assumptions surrounding terms such as (but not limited to) lesbian, bisexual, transgender, gay and straight. It has been argued that the predecessor of the

contemporary queer can be located in the medico-legal discourses of the nineteenth century, whereby medical practitioners and legislators established a taxonomic structure through which individuals could be ‘diagnosed’ and ‘criminalised.’ This taxonomy of certain aspects of human behaviour, rather than leading to incarceration within medicalised and criminalised institutions, offered individuals a way to identify. According to French historian Michel Foucault a new species “the homosexual” was created (1990: 43). Over the next century ‘the homosexual’ would undertake many socio-political, geographical and epistemological migrations whereby ‘the homosexual’ may not recognise itself in the contemporary queer. The emergence of the contemporary queer is well documented both in a broader western context (Foucault 1990, Adam 1987) and in the Australian context (Jagose 1996; Reynolds 2002; Willett 2000a; Willett 2000b). Thus what follows is an inexhaustive summary of this documentation. The significance of including the evolution of the contemporary queer is because it has been often noted that the nascent intersex movement has employed similar tactics to that of the contemporary queer (Kessler, 1998; Chase, 1998a; Holmes, 1998).

Much of the language of intersexuals has decidedly been formed by the history of the gay movement (Kessler, 1998: 83-84)

2.1.1 A “new species” Homosexuality in the Late Nineteenth Century

The latter half of the nineteenth and the first few decades of the twentieth centuries are dominated by the works of Karl Ulrichs, Richard von Krafft-Ebing, Magnus Hirschfeld and Havelock Ellis. Aspects of humanity, notably sexual behaviour, were increasingly coming under medical observation and legal regulation. Known as sexology, it was a profession that sought to understand aberrations of human behaviour through a reconceptualisation of sex, gender and sexuality, in particular homosexuality.

Karl Ulrichs, “one of the first self-declared homosexuals” (Califa, 1997: 12), opened the discussion around homosexuality in Germany through the publication in 1864 of *Vindex*, the first of twelve volumes to deal with homosexuality (Adam, 1987: 14; Califa, 1997:

12). Although Ulrichs went on to argue for the legal rights of homosexuals in 1867 to the Congress of German Jurists, Ulrichs was “shouted down” (Adam, 1987: 14). Ulrichs’ contemporary K. M Kertbeny penned an open letter (within which was coined the term homosexual) to also plea for the decriminalisation of homosexuality (Adam, 1987: 14). However, this too ultimately failed.

Regardless, Ulrichs’ work came to have significant influences on the theorisation of homosexuality. Ulrichs argued that homosexuals were “natural” (Hall, 2003: 30), a third sex (Adam, 1987: 15; Califa, 1997: 12) and Ulrichs theorised that homosexuals comprised of the soul of one sex trapped in the body of the other (Adam, 1987: 15; Hall, 2003: 30). As Pat Califa describes it

[Ulrichs] set up a paradigm of sexual deviance in which sexual desire for a member of one’s own sex is paired with a desire to be a sex other than the one that was received at birth (Califa, 1997: 12)

Although Ulrich’s taxonomic manoeuvres contradict contemporary nomenclature it indicates the first attempts to identify and classify diverging behaviours in the human.

It has been argued that much of the negativity surrounding homosexuality and other forms of sexual expressions today can be traced back to the work of Richard von Krafft-Ebing and the publication in 1886 of *Psychopathia Sexualis* (Califa, 1997: 14). This is largely due to the fact that most of the people Krafft-Ebing studied were in the hands of law enforcement or were confined to mental institutions, hence it is not surprising that, as Califa agrees, for “Krafft-Ebing, there is no such thing as benign sexual variation. Everyone who departs from reproductive, monogamous, male-dominant heterosexuality is described as criminally insane” (Califa, 1997: 13). As such, Krafft-Ebing’s work pathologised homosexuality. It was not only seen as a manifestation of illness but also an indication of the degradation of society (Hall, 2003: 32). The subsequent pathologisation of ‘sexual variation,’ and in particular homosexuality, was what Hausman refers to as “sexology’s classic move in modern Western society: the ... medicalisation of sex and

sexual behaviors” (Hausman, 1995: 112). While increasingly unpopular, these thought threads are carried today in contemporary homophobic discourses.

Magnus Hirschfeld, also a self-described homosexual (Califa, 1997: 13) founded the Scientific Humanitarian Committee in 1897 (Califa, 1997: 13; Jagose, 1996: 23). Hirschfeld worked toward depathologising homosexuality (Hausman, 1995: 112) and the overturning of the 1871 penal code that criminalised homosexuality. Hirschfeld extended Ulrichs’ ‘third sex’ theory (Jagose, 1996: 23), and argued a “theory of intermediates” whereby there are not only two sexes but there are also several departures from that norm (Califa, 1997: 13) such as hermaphrodites and homosexuals. Hirschfeld’s compartmentalisation is a sign of subsequent demarcations of different gender and sex behaviours and identities that would be familiar to the contemporary queer.

In Britain Havelock Ellis published *Studies in the Psychology of Sex* (1905-28) and in 1914 founded the British Society of the Study of Sex Psychology with Edward Carpenter. According to Jagose (1996) Ellis’s organisation had affiliations with its German contemporary, publishing its pamphlet of the ‘third sex.’ However, while “Ellis supported the attempts of reformers like Hirschfeld who sought decriminalisation of sodomy and other sexual-minority conduct” (Califa, 1997: 14) the British movement did not have the “legislative focus of the Germans” (Jagose, 1996: 24). Nonetheless, Ellis’s position stood “in stark contrast to the Puritan black-and-white thinking of Krafft-Ebing” (Califa, 1997: 14). However, Hall informs us that they

Still used a model of easily recognizable ‘normal’ and ‘abnormal’ behavior that attempted only to replace vicious homophobia with something like pity for the invert (Hall, 2003: 32-3)

In consideration of the (re)conceptualisation of homosexuality Michel Foucault says “the sodomite had been a temporary aberration; the homosexual was now a species” (Foucault, 1990: 43). The creation of ‘the homosexual’ as a species and its subsequent medicalisation resulted in sexologists constructing an array of “elaborate theories

detailing ‘normal’ and ‘abnormal’ sexualities, their manifestations, genesis, and social consequences” (Hall, 2003: 31). ‘Elaborate theories’ that would become antecedents for the theorisation of homosexuality and sexual deviance for the next hundred years.

2.1.2 The Forgotten Movement: The Early Twentieth Century

According to Adam (1987) the first social movement to advance the civil rights of gay people was in Germany in 1897 (Adam, 1987: 1) with the founding of the Scientific Humanitarian Committee originating with Magnus Hirschfeld (1987: 17). However, “in 1933 the early gay movement came to an abrupt end” (1987: 49). The rise of Nazi Germany and the advent of World War II decimated the movement. However, there existed forty years worth of significant achievements that have largely gone unheralded by latter twentieth and early twenty-first century queers.

The Scientific Humanitarian Committee was involved in a range of campaigns: they worked at petitioning the German Parliament, circulated surveys, and attempted to engage women in their committee. After World War I “gay society experienced an unprecedented flourishing” (Adam, 1987: 23) and Hirschfeld established the Institute for Sex Research in 1919, which became internationally respected (Adam, 1987: 23). By the close of the 1920s the German Parliament “approved a penal reform bill that would at last drop the infamous paragraph from German law” (Adam, 1987: 25).

In France, Adam explains, homosexuality revolved around the lives of “the artists and writers who reflected upon the meanings of their homosexuality” (Adam, 1987: 26). While England had no organised movement, it did possess literature resulting from “a very cautious British Society for the Study of Sex Psychology, a public forum for homosexual issues” (Adam, 1987: 32). In the United States the predominantly medicalised view of homosexuality legitimated the suppression of gay and lesbian voices (Adam, 1987: 39). So as Europe experienced a strong community, public awareness in the United States was limited to negatively portrayed images in the media (Adam, 1987: 39-40). In 1924 the Society for Human Rights was the first formally organised gay

movement in the United States (Adam, 1987: 42). According to Bullough in America the medical establishment was disinterested in sexual issues (1994: 303).

However, the western world was about to change. Both in Europe and North America, sites of a considerable homosexual social scene and potential political reform, would be changed forever, as Adam (1987) says of Germany

The work of the early gay movement was soon to be so thoroughly obliterated that few would remember that it had existed at all (Adam, 1987: 25)

2.1.3 Homophile Movement: The Mid-Twentieth Century

While in Europe the pre-war homosexual movement underwent some recovery after World War II, it is, however, in North America that a significant portion of the post-war discourse was articulated. A discourse that would eventually transport itself across the globe and take the form of the more familiar gay liberation and queer movements of the late twentieth and early twenty-first centuries.

The agenda of post-war North American homophile groups was informed by what has essentially been described as an assimilationist position (Adam, 1987: 64; Jagose, 1996: 26). Initially the Mattachine Society - founded in 1951 in Los Angeles by Henry Hay - “drew on Communist models for inspiration in organizing and effecting social change” (Adam, 1987: 62). They sought to “represent homosexuals as a minority group oppressed by the dominant culture” (Jagose, 1996: 25-26).

Named for the medieval Italian court jester who expressed unpopular truths from behind a mask, Mattachine originated with a comprehensive vision of social and political change for gay people and a willingness to challenge antihomosexual attacks even in the midst of McCarthyism (Adam, 1987: 62)

But by 1953 the founders were replaced by an anticommunist leadership which led to the adoption of a “low-profile, accommodationist stand that defined movement strategies for more than a decade” (Adam, 1987: 63). The Daughters of Bilitis formed in 1955 in reaction to the Mattachine Society’s largely male membership, its masculinist orientation and its focus on issues pertinent only to homosexual men.

Named for Pierre Louys’s poems on a lesbian theme, the Daughters of Bilitis (DOB) was founded by four couples in San Francisco and was the first postwar lesbian organization (Adam, 1987: 64)

The Mattachine Society and the Daughters of Bilitis argued that homosexuals were just like everyone else, except in bed (Adam, 1987: 64) and to effect change they needed to co-operate with experts in the fields of medicine, law and education (Jagose, 1996: 26). Further, they encouraged members to conform to the dominant heteronormative values of the time. In particular the Daughters of Bilitis “recommending that lesbians dress in recognisably feminine ways in order to increase their chances of better paid employment” (Jagose, 1996: 27).

While this conservative assimilationist position seems out of place in a contemporary queer context, McCarthyism and a steadfast medicalisation of homosexuality dominated post-war North America.

The McCarthy terror exacted an immense toll from ordinary lesbians and gay men, with *thousands being thrown out of work and imprisoned in jails and mental hospitals* (emphasis added, Adam, 1987: 60)

Fear of repercussions from being identified as homosexual in the 1950s meant that political organisation was difficult; even seemingly simple tasks, like publicising events or finding a mailing address of the organisation, were fraught with difficulty. Deference to the authority of professionals was problematic, and compromises to enable potential alliances with sympathetic heterosexuals were

often made at the expense of developing a supportive homosexual milieu (emphasis added, Jagose, 1996: 28)

And further

Of course, most homosexuals were able to avoid institutions ... But there was *almost nothing to counter the medical view of homosexuality*, the myth that homosexuality is an illness, that homosexual stories end in early death, that mature homosexuality is an impossibility, and that ‘nobody loves you when you are old and gay’. It was easy to believe the lies; evidence was censored and hidden from us (emphasis added, Young, 1995: 46)

However, in the face of medical and legal crusades against them North American homophile organisations “petitioned governments, and sought statements from political candidates in periods leading up to elections; they published and distributed political newsletters and pamphlets and conducted ‘large scale statistical inquiries into homosexual behavior’” (Jagose, 1996: 29).

2.1.4 Birth of Gay Liberation 1969

The Stonewall riots of 1969 symbolise the iconic, mythic and sentimental birth of the gay liberation movement of the late twentieth century - if not its actual temporal beginning. On Friday 27th June 1969 the Stonewall Inn in New York was raided by police, according to Adam (1987) “bar raids were an American institution” (75). What then was unique about this particular evening?

Judy Garland was buried the day before ... Judy’s persona held a special appeal for homosexuals of the old school, who identified her with a poignant mixture of vulnerability, defiance, yearning, self-pity and pills, and of course with the classic film *The Wizard of Oz*, a perennial gay favorite (Young, 1995: 53)

Whether as a mythic coincidence or posthumously added anecdote, Judy Garland's death can, at best, only partly explain the Stonewall riots that would ensue for three days, and have ramifications for over three decades.

The sixties saw the rise of globe-wide movements of social unrest and disquiet over oppression and obvious inequality in many aspects of western culture. Unhappy with a decade and a half of 'assimilationist' rhetoric, a new homosexual generation joined the fray, as Jagose reports

Among certain sections of the homosexual community in the late 1960s there was a growing dissatisfaction about the quietist position assumed by many groups dedicated to improving conditions for homosexuals. While still seeking legal and social recognition on the same terms as heterosexuals, homophile organisations were committed to securing this gradually, by means of persuasive rather than militant techniques (Jagose, 1996: 30)

Regardless of whether its origin was in the counter-culture wave spreading across the Western world, a reaction to assimilationist rhetoric of a decade and a half from the homophile movement, or Judy Garland's death, gay liberation was well and truly in full blaze by the time the embers of the burnt and razed Stonewall Inn went out.

Annamarie Jagose highlights five main differences between the homophile movement and the nascent gay liberation, they 1) "articulated notions of self determination," 2) "were militant in their expression of political disquiet," 3) "challenged the status quo," 4) "refused to pander to heterosexual anxieties and scandalised society with their difference," and 5) "gay liberation was constructed around the notion of a distinctly gay identity" (1996: 31). Gay liberation articulated a position that went further than campaigning for a minority group; it wanted to free up notions of sexuality for everyone.

For gay liberation there was no 'normal' or 'perverse' sexuality, only a world of sexual possibilities ... Once everyone was free to express her or his latent

sexualities, boundaries between the homosexual and the heterosexual should fade into irrelevance and false partitions in the flow of desire give way to personal fulfilment (Adam, 1987: 78)

Within a year of the Stonewall riots gay liberationists had protested psychiatric, medical, and behaviour modification conferences in San Francisco, Los Angeles, and Chicago “where sessions on the ‘treatment’ and ‘correction’ of homosexuality were disrupted with cries of ‘barbarism,’ ‘medieval torture,’ and ‘disgusting’ and with demands for equal time” (Adam, 1987: 81). This and other in-your-face tactics led to the removal of homosexuality from the American Psychiatric Association’s official diagnostic manual in 1973-74 (Adam, 1987: 81). According to Adam (1987) by 1971 there appeared gay liberation groups “in every major city campus in the United States, Canada, Australia, and Western Europe” (82).

2.1.5 Lesbianism, Bisexuality, Transgenderism and Queer: 1970-1990s

While gay liberation did not originate only with gay men, the 1970s and 1980s would see the rise of discourses that would articulate positions that were not being addressed by a largely male-based movement. Lesbians were battling to have their voices heard in both gay liberation and the feminist movement throughout the late sixties and early seventies, and by the end of the 1970s and the beginning of the 1980s bisexuals and transgendered people would begin to speak up in their own voices.

According to popular Western lexicon: feminist equals lesbian. However, in the nascent feminist movement there was not only a distinct articulation of feminism without reference to lesbianism, but also an active anti-lesbian rhetoric marked by Betty Friedan’s phrase “lavender menace” (Jagose, 1996: 45). The Daughters of Bilitis slowly began shifting their attention to more radical positions, brought on in no small way by the increase of gay men’s ignorance of women-specific issues. While men sought to work toward issues of entrapment by police and sodomy law reform, they ignored such basic issues as equal opportunity employment and violence against women. As Adam (1987)

states “in a movement that was supposed to forward their cause, lesbians grew angry at having to devote time and energy to ‘reminding’ men of their existence” (92).

The emerging discourse of bisexuality did not just articulate a position of silence and ignorance of bisexuals and their issues, although this was a significant part of their movement. Within the bisexual movement came a critique of the prevailing theory of a mutually exclusive binary system of heterosexuality and homosexuality, and offering in its stead a denaturalised and pluralised way of conceptualising sex, gender and sexuality.

In the 1991 anthology *Bi Any Other Name* Hutchins and Kaahumanu suggest that when bisexuality is studied or spoken of it is done so through a “monosexual framework” (6) and “claim that we don’t exist, or are rare, or are perverted, or are really on our way to something else” (Hutchins and Kaahumanu, 1991: 6). They go on to cite any reference to bisexuality within gay liberation and the women’s movement as “sensationalized” (6) and “gay people in heterosexual relationships are mentioned only within the research framework that there is no such thing as a bisexual and that their homosexuality is their only true sexuality” (Hutchins and Kaahumanu, 1991: 6).

Jan Clausen argues that bisexuality is “not a sexual identity” but an “anti-identity ... a refusal (not, of course, conscious) to be limited to one object of desire, one way of loving” (Clausen 1990, cited in Jagose, 1996: 69). Elizabeth Däumer also argues that bisexuality calls for an examination and a deconstruction of the bipolar framework of gender and sexuality (1992, cited in Jagose, 1996: 69).

Transsexualism for most of the twentieth century was dominated by a medicalised discourse. To distinguish the cross-dressers from the homosexuals Magnus Hirschfeld coined the term ‘transvestite’ in 1910 (Feinberg, 1996: 95), however, it was Havelock Ellis who distinguished cross-dressers from those who identified as female (Perkins et al, 1994: 5). Sex change operations came to the popular consciousness in 1952 with Christen Jorgenson (Billings and Urban, 1996: 100), but they had been performed since the 1930s (Pauly, 1968 cited in Billings and Urban, 1996: 100). In 1980 transsexualism, or gender

dysphoria, was included in the American Psychiatric Association's *Diagnostic and Statistical Manual* (Whittle, 2002: 19) six years after homosexuality was removed.

During the 1980s transsexuals began to politicise their position because of the predominantly medicalised view of their 'condition' and as Stephen Whittle says

There is little evidence until late 1980s and early 1990s that the people who were defined as *having* transsexualism participated in the discussion about the condition and its treatment. The recent contributions of transsexuals are very much at odds with the clinician's view that they are suffering from a mental disorder (original emphasis, Whittle, 2002: 19)

Critique of transsexualism as a condition and the process of accessing sex change operations "spawned transgender activists" (Califa, 1997: 224). Further, the ensuing 'transgender activists' of the 1980s and 1990s articulated "transgender" as an identity that refused to conform to the either/or options of male and female (Califa, 1997: 225), and extended the term to refer to an array of differently gendered bodies, identities and praxis:

Transsexuals, transgenders, transvestites, transgenderists, bigenders, drag queens, drag kings, cross-dressers, masculine woman, feminine men, intersexuals (people referred to in the past as 'hermaphrodites'), androgynes, shapeshifters, passing women, passing men, gender-benders, gender-blenders, bearded women, and woman body builders who have crossed the line of what is considered socially acceptable for a female body (Feinberg, 1996: x)

The implications of this taxonomic diversity meant that gender was seen as a flexible matrix within which one can transition, move or blur or obliterate boundaries, issues that I will explore later in this chapter.

Following on from these distinctive groups, some individuals saw the terms “gay,” “lesbian,” “bisexual,” and “transgender” as too restrictive to adequately describe their own identity and behaviour. While there is evidence to suggest that these terms and groups were able to blur themselves widely held assumptions embedded in these terms contradicted lived experiences. Subsequently some individuals adopted the term “queer” as an identity marker, to distinguish themselves from “gay,” “lesbian,” “bisexual,” and “transgender,” and these terms’ inadequacy to accurately describe real life experiences, and to reclaim a hitherto pejorative term.

Gay, lesbian, bisexual, transgendered and queer people have not necessarily been as delineated as this brief history may imply. Boundaries have been blurred, crossed and removed between these individuals, organisations and communities. During the 1990s and certainly in the first few years of the twenty-first century, gay, lesbian, bisexual, transgendered and queer individuals, organisations and communities have contributed to a broader community of coalitionist identity politics, coalescing under such umbrella terms as “GLBT,” “queer,” and “rainbow.”

2.2 Queer Theory

Queer theory adopts some of the ‘constitutional characteristics’ ascribed to queer, and applies them to a theoretical matrix of challenging institutionalised heterosexism, and gender binarism. According to Steven Seidman (1997) queer theory draws from French poststructuralism and the critical method of deconstruction (Seidman, 1997: 145). However, Seidman also warns that it is a mistake to “dismiss queer theory as merely academic” (Seidman, 1997: 160). Accounting for queer theory’s multifarious approaches demands, according to Hall, “a recognition of partiality, of tendentiousness, of epistemological limitations” (2003: 1). Hall argues that since queer theory is so diversified it warrants the use of the pluralised “queer theories” (5), which is not without merit. However, I will employ the singular to maintain lexical coherence. Rather than as a teleological prize to be held aloft after over a century of being in battle with medico-legal-political discourses embedded with inherent homophobia, queer theory does not

hold itself up as a cure-all nor is it without critique (Jagose, 1996: 101). Queer theory's nuances have been examined elsewhere (Jagose, 1996; Kirsch, 2000; Hall, 2003; Seidman, 1997), thus queer theory's valency in regards to this project will be my scope.

Within its deconstructionist heritage, queer becomes a verb, a 'queering' (Hall, 2003: 14; Kirsch, 2000: 33). Queer theory then is a way of looking, acting upon or uprooting previously held beliefs, opinions or even axioms, that were unproblematised or unproblematisable. Queer theory employs the tactic of 'reading' traditional systems: representations in popular culture (film, literature, and music); historical analysis; and the sciences. Enabling a queer reading of any discourse, within which heteronormative values are embedded, heterosexism is practiced and the assumption of gender binarism is enforced and unproblematised. Jagose posits queer's relevance for this project such that that queer "calls into question even such apparently unproblematic terms such as 'man' and 'woman'" (Jagose, 1996: 3). Further, Cranny-Francis et al argue that queering the gaze "works to destabilise divisive regimes based on binaristic thinking and perception" (Cranny-Francis et al, 2003). That is, queer and queer theory allow a re-inscription, reconceptualisation and a deconstruction of meanings of sex, gender and sexuality. From this position comes the understanding that what we come to know as sex, gender and sexuality, is called into question.

Arguably, one of the most influential thinkers of the latter half of the twentieth century is Michel Foucault. Foucault's work covers a wide area of thought and subsequently Foucauldian analysis has been applied to a range of theoretical fields. This project however, requires the attention of Foucault's views on 'power,' 'knowledge' and 'discourse.' Exploration of Foucauldian thought has been accomplished elsewhere (Mills, 2003), therefore, I give a specific offering of Foucault's 'power,' 'knowledge' and 'discourse' as a foreword to further analysis that will be undertaken in later chapters.

For Foucault power is more than just the repression of an individual. The term imbues an interrelationship between the repressor and the repressed, such that one cannot exist

without the other. Indeed, Foucault states that the repressed object comes into existence due to its repression

If power was never anything but repressive, if it never did anything but say no, do you really believe that we should manage to obey it? What gives power its hold, what makes it accepted, is quite simply the fact that it does not simply weigh like a force which says no, but that it runs through, and it produces, things, it induces pleasure, it forms knowledge, it produces discourse; it must be considered as a productive network which runs through the entire social body much more than as a negative instance whose function is repression (Foucault, 1979: 36)

Beyond Foucault's emphasis on power as a 'productive network' rather than 'a negative instance,' attempts to locate power are not restricted to formal institutions. Rather Foucault intended that power be understood as being experienced in multiple points in society. For Mills, Foucault "argues that power is a set of relations which are dispersed throughout society, rather than being located within particular institutions such as the State or the government" (Mills, 2003: 35).

For Foucault, "where there is power, there is resistance" (Foucault, 1990: 95), that is, power does not live in a vacuum. Therefore, our understanding of Foucauldian power necessitates a negotiation around this power-resistance axis. Annamarie Jagose (1996) describes resistance, like power, as "multiple and unstable; it coagulates at certain points, is dispersed across others, and circulates in discourse" (Jagose, 1996: 81). Sara Mills suggests that Foucault implies that if resistance is, by definition, inherently linked to power, "then this may be seen to diminish the agency of the individuals who do resist oppressive regimes" (Mills, 2003: 40). However, on the contrary, Mills identifies that what Foucault is saying is that not only is resistance "much more frequent than one would imagine," but also Foucault "manages to move away from viewing individuals as only passive recipients" (2003: 40).

Not dissimilar to resistance, 'knowledge' is considered not only within a power schematic, but also by using the same currency, such that Mills states that "Foucault describes knowledge as being a conjunction of power relations and information-seeking which he terms 'power/knowledge'" (Mills, 2003: 69). Mills goes on to claim that Foucault "also draws attention to the way that, in producing knowledge, one is also making a claim to power" (2003: 69). Another important dimension to 'knowledge' is that, for Kirsch (2000), Foucault's work seeks a substantial critique of current concepts that would lead to an unveiling of "low ranking" or "disqualified" knowledges, which hitherto had been "subjugated by powerful opposing forces that rendered them nameless" (Kirsch, 2000: 21). Moreover, these knowledges "easily fell into 'disuse' when confronted with more powerful dominators" (Foucault cited in Kirsch, 2000: 21). A quick navigation around 'knowledge' therefore highlights how Foucault's interest was not regarding what was 'known,' as much as it was "the processes which led to certain facts being known than others" (Mills, 2003: 68).

Jagose defines Foucault's use of the term 'discourse' as "the heterogeneous collection of utterances that relates to a particular concept, and thereby constitute and contest its meaning" (1996: 81). Its importance is emphasised in Foucault's *Archaeology of Knowledge* (1972) because it is through "discursive practice" that knowledge is spoken, and thereby specified by the speaking (1972: 182). Further, Kirsch (2000) highlights that Foucault's 'discourse' takes "on importance as a way of examining forces of domination and the regulation of knowledge" (Kirsch, 2000: 25). The Foucauldian peculiarity of the term 'discourse,' is not dissimilar to that of 'power' or 'knowledge.' As Jagose specifies

Just as he cautions against thinking that power demarcates only hierarchical relations, so Foucault insists that discourse is not simply for or against anything, but endlessly prolific and multivalent (Jagose, 1996: 81)

Helen Longino (1990) uses Foucault's discussion on 'discourse' to address the philosophical issues regarding the establishment of scientific knowledge.

He attends to the rules of formation of a discourse, the coemergence of a discourse and its object, and the network of social, political, and economical relations within and upon which the discourse takes shape ... It displaces the knowing (or believing) subject from the center of philosophical attention that it occupied from Descartes to Kant and makes questions about how an individual or group of individuals comes to believe or justifies a belief irrelevant (Longino, 1990: 202)

Foucault's work offers a compass by which to map and traverse such human pursuits as science. Moreover I shall use Foucault's insights into the interrelationship and interdependence of 'power,' 'knowledge' and 'discourse' as a critical conceptual tool in this current project, whereby the focus, at times, will shift from the object to the subject.

2.3 Gender Theory

In 1962 Thomas Kuhn said

Political revolutions are inaugurated by a growing sense, often restricted to a segment of the political community, that existing institutions have ceased adequately to meet the problems posed by an environment that they have in part created. In much the same way, scientific revolutions are inaugurated by a growing sense, again often restricted to a narrow subdivision of the scientific community, that an existing paradigm has ceased to function adequately in the exploration of an aspect of nature to which that paradigm itself had previously led the way. In both the political and scientific development the sense of malfunction that can lead to crisis is prerequisite to revolution (1962: 92)

Twenty-five years later in 1987 Grimm proposed that we were on the verge of a Kuhnian revolution of gender (1987: 84). However, eighteen years later in 2005 are we any closer to seeing any real changes to the ways we conceptualise sex and gender? Are we any closer to improving the lived experience of those who physically, socially and personally

challenge the ubiquitous assumption that there are two and only two naturally occurring and mutually exclusive sexes and genders?

In contemporary western cultures sex and gender are aspects of our society that have undergone considerable shifts in social currency over the past hundred and fifty years. Whether within popular or academic discourse sex and gender have become loci of much thought, praxis and epistemology. Examples of such discourses are virtually inexhaustible and appear in every arena of our lives. Having said that, in our society there is still the ubiquitous assumption that there are two and only two naturally occurring and mutually exclusive sexes and genders. Latter twentieth century and early twenty-first century gender theories are only recent manifestations of a trend toward greater articulation of a largely ignored yet seemingly infinitely diverse aspect of the human.

The theorisation of gender pivots around socio-political ramifications that are responding to the inference that the human species can be demarcated into either masculine or feminine aspects. Moreover, as will become evident in the coming chapters, gender is *the pivotal* aspect that appears to be the driving force behind the current intersex medical management. This section therefore overviews some of the key theories concerning gender, such as nature versus nurture debates, John Money's 'gender role theory,' the famous 'John/Joan' case, transgender theory, and feminism.

2.3.1 Biological Determinism and Social Constructionism

Biological determinists articulate the position that masculine and feminine qualities are inherently linked to one's biological configuration. That is one's sex: chromosomes, gonads, hormones and genitals determine one's gender behaviour and identity. Biological determinist thought, especially E.O. Wilson's *Sociobiology* (1975), has come under considerable scrutiny and criticism by gender theorists, and feminists in particular, because of the biological determinists' reliance on a 'biology is destiny' credo (Lowe and Lowe Benston, 1991: 56). Further, this position is "probably the most dangerous" (56) because "they claim that behavioural differences rooted in biological differences between

the sexes have led to the differences we observe in social roles. They all carry the message that woman's position arises from innate characteristics and that it would be very hard, and probably undesirable, to change" (56). What they are saying is that separating biological influences from social ones "may serve reactionary social and political purposes in certain social-scientific contexts" (Bleier, 1991: 249).

Simone de Beauvoir's "One is not born, but rather becomes, a woman" (de Beauvoir, 1949/1983: 295) is one of the first articulations of the theoretical position known as the social construction of gender. The social construction of gender has come to inform and shape the myriad of ways in which twenty-first century gender is theorised, politicised, conceptualised and practiced. de Beauvoir's axiom emphasises how gender is not innate but is inscribed upon the body by socially mediated discourses. The school of thought that permeates the social construction of gender therefore argues that being gendered is not a naturally occurring phenomenon, but instead is something that one 'becomes,' 'does,' and 'performs.'

West and Zimmerman (1987) have argued that members of society are "held hostage" to the "'doing' of gender" (1987: 126). Whereby to 'do' gender one must employ "a complex of socially guided perceptual interactional, and micropolitical activities" (126). Further, they emphasise how 'doing' gender is socially mediated; that is, while it is the individual who 'does' gender, it is done so in the "virtual or real presence of others" (126) consequently they conceive gender as an "emergent feature of social situations" (126).

Judith Butler's pivotal work *Gender Trouble* (1990) problematises the term 'woman' and its use by feminist discourse as denoting a common identity (1990: 3). Butler further positions gender as a "performative" (24) act underwritten by "regulation practices" (16) that ultimately casts its shadow upon 'identity' and the 'self.' Consequently Butler asks whether gender identity is not a "normative ideal" rather than a "descriptive feature of experience"(17). Gender as a socially mediated discourse that one 'becomes,' 'does,' and

‘performs’ begs the pivotal question that Butler asks: “If gender is constructed, could it be constructed differently?” (1990: 7).

2.3.2 John Money

Hird and Germon, in their analysis of how medical techniques discipline the intersex body (2001: 163) argue “that the concept of gender identity has had a profound effect on the medical management of intersexuals” (Hird and Germon, 2001: 168). Hence it is significant to map out those gender theories that have come to inform and shape the current intersex medical management. Perhaps the most central of these theories, is (with the assistance of John and Joan Hampson and Anke Ehrhardt) John Money’s Gender Role Theory.

John Money has been described as one of the greatest sex researchers of the twentieth century (Colapinto, 1997; O’Keefe, 1999: 20) and is best known for the coining of the term ‘Gender Role’ in the 1950’s, and the publishing of the ‘natural’ experiment of John/Joan in the 1970’s. These accomplishments have earned Money the respect of those involved in the fields of medicine, psychology and sociology (O’Keefe, 1999: 20). Money’s interest in the occurrence of intersex was established when Money, under the tutelage of George E. Gardner, M.D., was presented with a case of an intersex individual. In Money’s own words this encounter

Set me on an academic course that would lead to a Ph.D. dissertation on *Hermaphroditism: An Inquiry into the Nature of a Human Paradox* (Harvard University, 1952) which allowed me to spend several hours interviewing and testing the youth in question (Money, 1995: 19)

On a more personal level, colleague John Hampson described Money in a 1997 article as being “kind of a charismatic person, and some people dislike him. As a person, he is a little bit ... oh ... flamboyant; he might have been a little glib” (Colapinto, 1997).

Colapinto goes on to describe Money as “an acknowledged but discrete bisexual” (Colapinto, 1997).

In a study of 105 intersex children and adults Money (and John and Joan Hampson) sought to understand why more than 95% of people who were diagnosed with identical genital ambiguities and chromosomal makeup and who were raised as the opposite sex “fared equally well” (Colapinto, 1997).

In Money’s own words, there was an emphasis on understanding the interrelational mechanisms of ‘sex’

The first step was to abandon the unitary definition of sex as male or female, and to formulate a list of five prenatally determined variables of sex that hermaphroditic data had shown could be independent of one another, namely, chromosomal sex, gonadal sex, internal and external morphological sex, and hormonal sex (prenatal and pubertal), to which was added a sixth postnatal determinate, the sex of assignment and rearing (Money, 1955; Money et al, 1955). The seventh place at the end of this list was an unnamed blank that craved a name. After several burnings of the midnight oil I arrived at the term, *gender role* (emphasis added, Money, 1995: 21)

Money goes on to define what exactly is meant by “gender role”

The term gender role is used to signify all those things that a person says or does to disclose himself or herself as having the status of boy or man, girl or woman, respectively. It includes, but is not restricted to sexuality in the sense of eroticism. Gender role is appraised in relation to the following: general mannerisms, deportment and demeanour; play preferences and recreational interests; spontaneous topics of talk in unprompted conversation and casual comments; content of dream, daydreams and fantasies; replies to oblique inquiries and

projective tests; evidence of erotic practices and, finally, the person's own replies to direct inquiry (Money, 1995: 21-22)

Money's "Gender Role Theory" was more than a nomenclature for 'an unnamed blank that craved a name' it encompassed what was henceforth widely known as an infallible axiom for the medical profession, that is: children are born psychosexually undifferentiated; gender identity is fixed early in life; and, external anatomy must match gender identity (Hausman, 1995: 96-97; Dreger, 1998: 182; Fausto-Sterling, 2000: 63). So influential was Money's theory that its effects on the treatment of intersex children have lasted to this day, such that surgeons and endocrinologists raise children in whichever sex desired (Hausman, 1995: 102; Colapinto, 1997). These are issues that will be explored in subsequent chapters.

2.3.3 The John/Joan Case

John Money is perhaps most famous for what is widely referred to in the medical literature as the "John/Joan" case, a real life situation that Money exploited to exemplify the 'gender role theory.' In the late 1960s at age eight months a young boy, named "John" by Money, suffered a penis loss during a routine circumcision. Distraught by the accident, John's parents contacted Money after seeing Money on television talking about the success of reassigning the sex of transsexuals and children with ambiguous genitalia (Colapinto, 2000: 19). Money's prompt response was necessitated by the urgency with which the 'gender role theory' held for reassigning sex of children within the "gender identity gate" (Colapinto, 2000: 51), the point at two and a half years where gender identity was concretised. Now nineteen months, John's parents were still unconvinced and needed time to think. Despite their caution Money was keen to proceed. Subsequently, John's parents conceded and at the age of twenty-two months John was castrated, surgically altered to look female and raised as a girl named "Joan" (Colapinto, 2000: 53). What made this case even more striking was that Money was able to compare Joan's development to John's genetic twin "as an empirical control" (Preves, 2003: 96).

In 1972 Money revealed the initial findings of Joan's case to a meeting of the American Association for the Advancement of Science in Washington, DC. The story sparked much interest not only amongst Money's medical peers, but also in the mainstream media. For example, the story was covered in *Time* magazine. This was the same week Money's book *Man Woman, Boy Girl*, co-authored with Dr. Anke Ehrhardt was released (Money and Ehrhardt, 1972). The "twins case," as it was colloquially known, has become "the most well known and widely cited case in the intersex medical literature" (Preves, 2003: 95).

Money reported that John's sex reassignment as female and subsequent raising as Joan was a success. According to Money's initial and follow-up publications Joan took on the stereotypical role of a girl. Fausto-Sterling reports that

Money quoted Joan's mother to the effect that Joan had grown to love wearing dresses, that she hated being dirty, and that 'she just loves to have her hair set' (Fausto-Sterling, 2000: 67)

The "experiment of nature" (Kessler, 1998: 6; Preves, 2003: 96) was written up by Money as an example of any child's potential gender socialisation (Kessler, 1998: 6) and "unquestionable evidence of the value of success of surgical sex reassignment for intersex children" (Preves, 2003: 96). In other words the successful raising of John as Joan proved that Money was right. The influence of this new supporting evidence for the gender role theory would be widespread. Not only would "virtually all academic writing on sex and gender" refer to it (Kessler, 1998: 6), but also it would be in "the pediatric wards of hospitals around the world that the twins case would have its most lasting impact" (Colapinto, 1997). The 'lasting impact' is explored with an analysis of the current intersex medical management in Chapter 4.

2.3.4 “The Boy Who Was Raised as a Girl” - Critique of The John/Joan Case

In 1997, twenty-five years after the case was first publicised by John Money as a success, Milton Diamond and Keith Sigmundson (1997a) and John Colapinto (1997) announced to the world that it was not.

A tense professional relationship had existed between John Money and Milton Diamond since 1965, when Milton as a young graduate student was willing to question Money and the Gender Role theory (Colapinto, 1997). As a biologist, Diamond believed that gender expression was not neutral at birth, as Money had theorised, but was a factor of biology. Diamond says in the documentary *The Boy Who Was Turned Into a Girl* (Cohen, 2000)

Humans are a lot more complicated than just being a product of their upbringing. I saw no reason for humans to be that different [from animals]. Certainly we are influenced by our society, certainly we are influenced by our learning, but our basic inclination, our basic framework or predisposition we have, has to come from biology (Diamond, cited in Cohen, 2000)

For years Diamond was interested in knowing more about Money’s famous twins case. From the mid-seventies little was known of the follow-up situation of the case. According to Colapinto, Diamond would publish the following plea every year in *American Psychiatric Society Journal*: “Will whoever is treating the twins please report” (Colapinto, 1997). John/Joan’s psychotherapist, Keith Sigmundson, however, was reluctant to respond to Diamond’s request, stating simply “I was shit-scared of John Money” (Colapinto, 1997).

Sigmundson eventually relented and in 1994 introduced David Reimer (the ‘real’ John/Joan) to Diamond. The ensuing meetings and subsequent publications would reveal that at fourteen years of age “Joan” - that is, Brenda Reimer - had “decided to switch to living as a male” (Diamond and Sigmundson, 1997a: 300). David Reimer describes this period in Colapinto’s book “I was at that age where you rebel ... I got sick to death of

doing what everyone wanted me to do. I got to that point in my life, I knew I was an oddball, I was willing to live my life as an oddball. If I wanted to wear my hair in a mess, that's how I wore it. I wore my clothes the way *I* wanted to" (original emphasis, David Reimer cited in Colapinto, 2000: 165-166). Further, David says in Cohen's documentary

I was never happy as Brenda. Never. And I'd slit my throat before I go back to that (David Reimer, cited in Cohen, 2000)

Although David appeared to be living a successful life in Cohen's documentary (2000), David Reimer committed suicide in May 2004, after a series of tragic events, David was fired, divorced, and David's twin brother committed suicide. Diamond and Sigmundson found that David's unhappiness as Brenda was mirrored in the "clinical notes and the impression of the local physicians at the time" (1997a: 302), yet this went unreported. Ultimately Diamond and Sigmundson took the opportunity to argue against Money, and Money's gender role theory

The evidence seems overwhelming that normal humans *are not psychosexually neutral*, predisposed and biased to interact with environmental, familial, and social forces in either male or female mode (emphasis added, Diamond and Sigmundson, 1997a: 303)

Revelations about the truth of David Reimer's life did more to expose John Money's misplaced reliance on this case to support the 'gender role theory.' Diamond and Sigmundson went on to publish a set of 25 guidelines in 1997 to counter some of the medical treatment methods employed when "dealing with persons with ambiguous genitalia" (Diamond and Sigmundson, 1997b: 1046). They argued that "underlying our guidelines is the key belief that the *patients themselves* must be involved in any decision as to something so crucial to their lives" (emphasis added, Diamond and Sigmundson, 1997b: 1046). Further, Fausto-Sterling has claimed that Diamond and others "have gained a foothold ... in calling for new treatment paradigms - above all, postponing

immediate and irreversible surgery and providing counseling instead” (Fausto-Sterling, 2000: 70). These ‘new treatment paradigms’ are explored further in Chapter 5.

2.3.5 Transgender Theory

Transgender theory is a relatively recent addition in understanding gender. While originally referring to those people who transitioned from one gender to another, theorising transgendered bodies, experiences and identities now encompasses a broader trans palette. Trans theory takes into account: merging, blurring and an obliteration of genders; queering gender; third genders and spaces outside gender; living as gender outlaws; or gender fucking. Discourses that are of considerable significance for this present project.

While intersex communities are distancing themselves from a comparison to transgendered people and their identities, communities and discourses (see Chapter 5), the need to articulate the interrelationship between transgendered and intersex, where they converge as well as diverge, is imperative. It is especially necessary because firstly, some include intersex under the umbrella term transgender (Feinberg, 1997), and others claim that transgenderism/transsexualism is an intersex condition (Whittle, 2002: 90; W-o-m-a-n, 2004). Secondly, not unlike the interest evoked in gender theorists by intersex (Kessler, 1998: 5), transgendered people have similarly drawn the attention of gender theorists. Theorists who see transgender either as gender conformists (Garfinkel, 1967) or as potential gender revolutionaries (Grimm, 1987).

Trans bodies, experiences and identities, as historicised above, have been mediated through a medicalised discourse throughout the twentieth century as evident in their inclusion as gender dysphoria in the American Psychiatric Association’s *Diagnostic and Statistical Manual*. Yet it is Leslie Feinberg’s *Transgender Warrior* taxonomy, cited above, that more accurately maps out the contemporary trans body, experience and identity and its eruption into new, diverse and, at times contradictory trans bodies, experiences, and identities. Consequently today “transgender” has come to refer to a

broad array of trans bodies, experiences and identities that challenge the assumption that there are two and only two naturally occurring and mutually exclusive sexes and genders.

The transgender movement and transgender theory have enabled people whose bodies, experiences and identities fit within this trans schema, to achieve some socio-political currency. In some western countries, in particular Australia, anti-discrimination laws now exist. While it could be argued that mainstream media in 2005 has not moved far beyond what Katherine Cummings in 1993 called “Gee-whiz stories” (Cummings, 1993: 206), the influence of trans bodies, experiences, and identities on the way society views gender may be more encouraging.

West and Zimmerman’s demarcation of “sex,” “sex category” and “gender” (1987) have drawn attention to how one’s biological ‘sex’ characteristics do not necessarily correlate to the ‘sex category’ to which one has been assigned, lives or identifies, nor to the ‘gender’ one “does” (1987: 126). This disruption of continuity between sex, sex category and gender is exemplified through the lived experiences of people who transition from one sex, sex category and gender to the other or another sex, sex category and gender. For these transgendered people the social/personal issues that arise from a discontinuity of sex, sex category and gender are all too present.

For people who transition from ‘men’ to ‘women’ - also known as male-to-female, M2F, or transwomen - ‘passing’ is one of the principal concerns. The process of ‘passing’ as female engages discourses and praxis that are situated in social matrices of negotiation between one’s sex, sex category and gender, whereby it is the appearance of or assumptions about one’s sex, sex category and gender, to and by others. Undergoing sex reassignment surgery, that is to align one’s sex, with one’s sex category and gender, is not financially or physically viable for some transwomen. Therefore, does possession of a penis and testicles negate the claims by transwomen that they are women? For people who transition from ‘women’ to ‘men’ - also known as female-to-male transsexuals, F2M or transmen - one of the principal concerns is the phallus, its presence/absence, functionality, size, shape and colour. These considerations are very much negotiated

within personal matrices, whereby men that have absent or inadequate penises negotiate this absence or inadequacy in personal situations such as in intimate sexual relationships. For example, in Holly Devor's pivotal work *FTM Female-to-male Transsexuals in Society* (1997) 45 transmen discuss their experiences of transitioning from one gendered body to another. Devor concedes that these men would have preferred to have been born with penises, would like to have a penis and felt incomplete without them. Yet there is evidence that some transmen "believed that they were men and that they were males, *with or without that particular piece of flesh*" (emphasis added, Devor, 1997: 405-406). Within trans there is a visceral discourse underway. They are not just individuals negotiating identities; they are figuratively and literally looking at their bodies. Stephen Whittle's analysis of trans (2002) - in reference to 'gender outlaw' Kate Bornstein - reinforces this fact that the debate is outside gender

She proposes a play with gender partitioning to ultimately make the partitions meaningless. She is not offering a third sex, but she is creating a third space, a space outside gender (Whittle, 2002: 75)

The concerns of M2F and F2M contribute to the discourse of gender and gender theory. Both transmen and transwomen mirror Butler's contestation of what it means to be a 'woman.' Can women, who 'do not pass' as women, claim to be women? Can a man who does not have a penis, or does not have a penis that is functional and of a certain size, shape and colour, claim to be a man? What these questions infer, and these real life negotiations of sex, sex category and gender imply, is that one's sex, that is the genital, chromosomal, and gonadal configuration does not necessarily have to correspond to one's sex category or gender, nor one's perceived sex category or gender.

2.3.6 Feminism

While gender is theorised in multiple locations - biological determinist/social constructionist, gender role and transgender - feminists go further to articulate the real life socio-political ramifications of the splitting of human beings into two halves.

Feminism articulates a position that states that the binary system innately prioritises one sex/gender over the other, a prioritisation that invariably leaves women in the inferior position, as Humm indicates “the emergence of feminist ideas and feminist politics depends on the understanding that, in all societies which divide the sexes into differing cultural, economic or political spheres, women are less valued than men” (Humm, 1992: 1).

Not unlike other social change movements of the 1960s, the diaspora of feminism has left it occupying a myriad of socio-politico-theoretical locations. According to Rosemarie Tong’s seminal text *Feminist Thought* (1989) “No short list could be exhaustive, but many, although by no means all, feminist theorists are able to identify their approach as essentially liberal, Marxist, radical, psychoanalytic, socialist, existentialist, or postmodern (1989: 1). This ‘inexhaustive’ list has led to a pluralisation of feminism to feminisms. These conceptualisations have also given rise to Butler’s problematisation of the one common denominator to all forms of feminism, its subject: woman.

The very subject of women is no longer understood in stable or abiding terms. There is a great deal of material that not only questions the viability of ‘the subject’ as the ultimate candidate for representation or, indeed, liberation, but there is very little agreement after all on what it is that constitutes, or ought to constitute, the category of women (Butler, 1990: 1)

While changes in attitude to the role of women, and the recent rise of the Metrosexual has led to some rethinking of gender, colloquially gender would appear to be one expression of humanity that is incontestable. However, this analysis opens up the view that in fact there has been a continuous and at times contradictory theorisation of gender. Viewing gender through the scope of biological determinist, social constructionist, gender role, transgender or feminist theory, moreover, has catalogued a theoretical sphere of gender that exerts a large gravitational force over a broad range of issues. As the next chapters will contest, these influences often cross the path of the intersex movement and the current intersex medical management.

2.4 Disability

The long-term impact of sex assignment surgeries on the gender identities of intersexed children is not dissimilar to the impact of cochlear implant surgery on the identities of prelingually deaf children (Crouch, 1999: 42)

Campbell and Oliver (1996) have identified three influences that contributed to the emergence of the disability rights movement. First was the recognition by disabled people that: “neither party politics nor charitable and voluntary organisations were serving their interests appropriately or well” (Campbell and Oliver, 1996: 62). Second, the “civil rights movement and feminism, both of which [had] succeeded in getting the outlawing of discrimination on the grounds of race and gender onto the statute books” (Campbell and Oliver, 1996: 62). And, thirdly, “the emerging consciousness of disabled people, who were beginning to recognise that the problem of disability is externally located and that our exclusion from society is a human rights issue” (Campbell and Oliver, 1996: 62). This consciousness raising of people with disability led to the disability rights movement organising around and opposing: “among other things, their relegation to residential institutions, their exclusion from the labour market and the opportunity to earn a living wage, and their enforced poverty” (Thomas, 2002: 39).

Mike Oliver coined the ‘social model of disability’ which articulated that the ‘problem with disability is externally located,’ as noted above (Thomas, 2002: 39). With the disability rights movement there was a distinct shifting of the emphasis from the disability to the social sphere one finds oneself in. As Thomas states “restrictions of activity and myriad of disadvantages experienced by people with impairments could be placed at the door of society” (Thomas, 2002: 40). The social model of disability not only cemented issues of consciousness raising and discrimination, but also had a “revelatory and liberatory” effect on disabled individuals (Thomas, 2002: 40).

However, orbiting around the disability rights movement and its central issues of consciousness raising and discrimination are its satellite companions of Disability Theory

and Disability Studies that have uncovered a number of issues pertaining to de-medicalisation of disability, namely the emergence of disability-as-identity and narrative. A person's disability-as-identity has been widely exemplified by people with a hearing disability, or deafness. What has come to the fore is the position that these people, rather than seeing themselves as deaf, prefer to see themselves as Deaf. The capitalisation emphasises a shared sense of belonging, community and identity. As Davis states the Deaf see

Themselves as a linguistic subgroup like Latinos or Korean. They feel that their culture, language and community constitute them as a totally adequate, self-enclosed, and self-defining subnationality within the larger structure of the audist state. As such the Deaf do not regard their absence of hearing as a disability (Davis, 1995: xiv)

Adopting disability-as-identity is a reclamation of one's lived-experience, body and identity. A similar position is evoked by Frank (1995) who suggests that modernisation of illness has removed the 'voice' from those who are ill, subsequently "they need to become storytellers in order to recover the voices that illness and its treatment often take away" (Frank, 1995: xi). Investing energy into establishing one's own identities and narratives are attempts to engage "with hegemonic structures and practices" (Corker, 1999: 193), which Corker explains is necessary if the disability rights movement is to "increase both its prestige and its status" (Corker, 1999: 193).

What these discourses of identity and narrative are doing is distancing themselves from the historicised hegemonic medicalisation of disability, as Davis states the Deaf "see their state of being as *defined not medically* but rather *socially and politically*" (emphasis added, Davis, 1995: xiv). Further, the disability discourse destabilises the medical profession's assumption of impartiality and objectivity; indeed the socially laden view of medicine is uncovered

Medicine claims to be value-free and concerned with bodily functioning. Yet the history of medicine reveals an enormous set of treatments which ‘improve’ appearance (Marks, 1999: 67)

Moreover the “heavily medicalized” (Davis, 1995: 2) view of disability has “failed to understand dialectically its own position in the economy of power and control, and it failed to historicize its own assumptions and agency” (Davis, 1995: 2). Examples of this destabilising is illustrated by Crouch (1999) who states that “arguments have been advanced in support of foregoing cochlear implant surgery in order to open up the possibility of the child becoming a member of the Deaf community” (Crouch, 1999: 42). While I shall return to this issue, I’ll conclude by quoting Crouch. By making use of the Deaf community’s ability to disassociate itself with the prevailing medical discourse, Crouch goes on to conclude, with reference to the intersex movement, that

Great advances in understanding can be made when a condition is depathologized and people stop to listen to those who are subject to the medical technologies that are brought to bear on the assumed pathology (Crouch, 1999: 43)

2.5 Female Genital Mutilation

We protest the practices of genital mutilation in other cultures but tolerate them at home (Fausto-Sterling, 2000: 79)

The intersex literature makes reference to how concern over female genital mutilation (FGM) is not unlike the concern raised over intersex surgeries. Since the 1996 Congressional Bill in the United States to ban FGM there has been a concerted campaign to employ this legislation with regards to banning surgeries on intersex genitals (Preves, 2003: 93). Inspiration from the FGM movement has extended to the language of the intersex movement such that these surgeries are called “Intersex Genital Mutilation (IGM)” (Kessler, 1998: 80). The adoption of the debates surrounding female genital

mutilation by the intersex movement has been widely documented (Chase, 1998a; Kessler, 1998; Dreger, 1998; Preves, 2003).

Female circumcision has been defined by the World Health Organisation as comprising

All procedures involving partial or total removal of the female external genitalia or other injury to the female genital organs whether for cultural or other non-therapeutic reasons (cited in Gilbert, 1997: 5)

It is difficult to generalise issues surrounding female genital mutilation. FGM is often cited as an African custom (Chase, 1998a: 204), yet, it actually occurs in many countries (Boddy, 1998: 81). The World Health Organisation identifies four broad categorisations of FGM (Gilbert, 1997: 8), it may be performed at any age from birth to adulthood (Family Law Council, 1994: 8), and there are often many reasons for FGM being performed (Gilbert, 1997: 13).

The United States legislation passed in 1996 declares

- (1) The practice of female genital mutilation is carried out by members of certain cultural and religious groups within the United States;
- (2) The practice of female genital mutilation often results in the occurrence of physical and psychological health effects that harm the women involved;
- (3) Such mutilation infringes upon the guarantees of rights secured by Federal and State law, both statutory and constitutional;
- (4) The unique circumstances surrounding the practice of female genital mutilation place it beyond the ability of any single State or local jurisdiction to control ... Except as provided in subsection (b), whoever knowingly circumcises, excises, or infibulates the whole or any part of the labia majora or labia minora or clitoris of another person who has not attained the age of 18 years shall be fined under this title or imprisoned not more than 5 years, or both. (cited in Dreger, 1998: 258-259)

Further, Subsection “b” specifies

A surgical operation is not a violation of this section if the operation is (1) necessary to the health of the person on whom it is performed, and is performed by a person licensed in the place of its performance as a medical practitioner; or (2) performed on a person in labor or who has just given birth and is performed for medical purposes connected with that labor or birth (cited in Dreger, 1998: 259)

The President of Australian Androgen Insensitivity Syndrome Support Group, Tony Briffa’s submission to the NSW Anti-Discrimination Board (Briffa, 2003a), reports on how the Crimes Acts in various states in Australia under certain conditions “permit genital mutilation” (Briffa, 2003a: 14). The wording of these references is not dissimilar to subsection “b” of the U.S. law, that is, the conditions under which genital surgeries are permitted include when performed by a health professional, performed during or in the benefit of giving birth or in sex reassignment surgery (Briffa, 2003a: 14). Indeed, Kessler a leading social researcher and campaigner for the intersex movement, in regards to the U.S. legislation argues “that it could include genital surgery on intersexed infants” (Kessler, 1998: 81). Briffa goes on to say that the Australian Androgen Insensitivity Syndrome Support Group “believes ‘normalising’ surgical intervention on children with intersex conditions - including the removal of healthy gonads and ‘cosmetic’ surgeries - is prohibited by the Crimes Act 1900 (NSW)” (Briffa, 2003a: 14).

Attempts to align the intersex and the FGM movements have not gone uncriticised by FGM activists and campaigners. Specifically Chase (1998a) reports how Patricia Schroeder, the author of the 1996 U.S. bill, “received and ignored many letters from [Intersex Society of North America] members and Brown University professor of medical science Anne Fausto-Sterling asking her to recast the bill’s language” (Chase, 1998a: 204). Kessler presumes that the reluctance of FGM activists to consider a coalition with intersex activists is because it “would be seen as diluting the argument and

would mean confronting the American medical establishment at a time when it needs to be wooed” (Kessler, 1998: 81).

2.6 The Family

What constitutes ‘the family’ in our culture has been widely conceptualised and theorised (Rodger, 1996: 1). This project attempts to place emphasis on the interpersonal microcosm of ‘the family’ especially in regards to certain phenomena, namely illness, that has significant influence on ‘the family’ and its members. As will become clear in subsequent chapters, families, and parents in particular, play a pivotal role in intersex medical management. Consequently, what is of interest is the interrelationship between parents and other members of the family.

Psychoanalytical theory, according to Chodorow (1974), places emphasis on early infancy experiences in regards to the development of personality in children; further, this development is in no small way due to the subconscious influence of parental intentions (43). Coupled with this covert influence, parents and family (among others) play a significantly overt part in the early reinforcement of social norms, especially in relation to gender roles in children.

Research into illness indicates its significant and profound affect on the family (Strozier, 1996: 246), and this research has highlighted the role the family can play in a person’s illness. For example, John Rodger’s *Family Life and Social Control* (1996) introduces a range of theoretical perspectives that attempt to analyse family life, in particular application of systems theory in regards to the family’s reaction to illness. Namely, “family medicine,” whereby identification and treatment of medical conditions is taken from the family perspective (1996: 13). The emergence of this way of thinking has been attributed to “the increasingly well researched and documented connection between clearly defined medical conditions or problems and their associated family effect” (Rodger, 1996: 13). This research highlights the interdependence and reflexivity of family and a person’s illness, Rodger explains

The flow of influence from family members to a particularly ill member can have significant consequences for the prognosis of an illness ... Family attitudes to an illness and treatment programme can be crucial for supporting a patient's adherence to a medical regime or encouraging abandonment of a course of treatment (Rodger, 1996: 13)

This positioning of illness within the microcosm of 'the family' contextualises how the relationships within the family are not only influenced by a person with an illness, but how that person is in return influenced by the family - a significant interrelationship mechanism that will become evident in later chapters.

Conclusion

Traversing, albeit briefly, the ecological landscapes of the theoretical spheres above draw attention to the gravitational forces that play on intersex individuals. The reader will be able to identify these theoretical foundations as they thread their way through the subsequent chapters. For example contemporary queer's epistemological and historicised antecedents draw attention to the socio-political machinations of the contemporary intersex movement and the theorisations of gender will highlight the complexity of intersex lived experiences and the interplay with the medical management. However, the major source of influence of contemporary intersex is the medical profession. Before I explore this medicalisation of intersex in Chapter 4 it is prudent to explore not only its historical antecedents but also to ask how other cultures conceptualise intersex.

CHAPTER 3: HISTORICAL AND CROSS-CULTURAL

Introduction

3.1 Historical Research

3.2 Anthropological Research

Conclusion

Introduction

Any historical or anthropological research of intersex is complicated by a number of mitigating circumstances, some peculiar to the study of intersex and some found in any historical or anthropological scholarship. Firstly, one must consider the fact that intersex is varied, and not all of these variations present themselves with obvious outward signs, such as ambiguous genitals (an issue that will be explored in chapter 4). Therefore any historical or anthropological reference that may or may not be made toward a person's intersex status relies heavily on the socially embedded assumptions of the appearance of genitals and sex-linked characteristic. Secondly, historians or anthropologists often confound historical or anthropological research. Postmodern thought has drawn attention to the socially embedded assumptions that historical or anthropological researchers bring to their work, such that when one is 'looking' at historical or anthropological examples of intersex, the response of historical or anthropological researchers can be determined by many socially-driven and researcher-biased variables.

One of the most useful insights of late twentieth-century critical theory and reconceptualizations of historiography is that 'history' is always an artificial construct, one that depends upon numerous acts of interpretation, exclusion, and information shaping that reflect inevitably and indelibly the beliefs and biases of the historian or critic. (Hall, 2003: 21)

Because of the 'beliefs and biases of the historian,' queer bodies, behaviours and identities have been largely ignored, rewritten or obliterated in historical or anthropological research. Schuyf (2000) implies that homosexuality (and let us infer all queers) are not simply hidden from history but are hidden *in* history (original emphasis, 61). Hekma (2000) and Garber (1992) both discuss anthropologists' reluctance to confront queer bodies, behaviours and identities in the field

Anthropologists had and still have great difficulty in going beyond visible traces of same sex desires and exploring the details of same sex practices. They framed

public intimacies between same sex partners and cross-dressing as signs of homosexuality, while the absence of such public markers led them to believe there was no homosexuality (Hekma, 2000: 82)

This tendency to erase the third term, to appropriate the cross-dresser “as” one of the two sexes, is emblematic of a fairly consistent critical desire to look away from the transvestite as transvestite, not to see cross-dressing except as male or female Manqué, whether motivated by social, cultural, or aesthetic designs. And this tendency might be called an *underestimation* of the object (original emphasis, Garber, 1992: 10)

This current project therefore, assumes that ‘underestimations’ have taken place. What this means is that it offers a possible explanation for the paucity of references to intersex in historical or anthropological research. Further, it means that if intersex is referred to in historical or anthropological research we must decodify the terms and read between the lines.

What is presented here for the first time in one piece of work is an overview of references found in a range of historical or anthropological sources. For this current project I make the artificial demarcation of ‘historical’ and ‘anthropological’ research. ‘Historical’ research refers specifically to the Western European history, which includes an overview of intersex from Ancient Greece through to the ‘memoirs of a nineteenth century French hermaphrodite’ (Foucault, 1980) and the “age of the gonads” (Dreger, 1998). Further, the designate ‘anthropological’ research means all cultures not generally considered of Western European descent or influence. This will include the peoples indigenous to the geographical regions of North America, India, Papua New Guinea, Indonesia, Kenya, the Dominican Republic and China.

3.1 Historical Research

Historical commentaries of intersex are rare. The topic has not been isolated in any systematic or categorical manner, but has merely been recounted as, at best, somewhat anecdotal, or, at worst, in passing. This study has moved beyond the hope of finding such a text, and has been restricted to sifting through texts that deal specifically with sex, gender and sexuality - although these too are few and far between. This task has required a figurative and a literal translation of terminologies, meanings and identities that once may have referred to a range of persons in which our contemporary notion of the intersex person is included alongside that of the homosexual, bisexual, transvestite, transsexual or transgender person. The quest therefore is not to unravel *The History* of intersex, but a *hidden history* embedded in the dominant paradigm of 'history' that is on one level reluctant to investigate non-traditional sexes, genders or sexualities and on the other ignorant that such non-traditional sexes, genders or sexualities have been traversed by the human experience.

Having said this, Alice Dreger claims that intersex has occurred "throughout virtually every era of recorded history" (Dreger, 1998: 32). Western culture has conceptualised, regulated or institutionalised intersex in a myriad of ways (Edgerton, 1964: 1289; Fausto-Sterling, 2000: 33): from allegorical characters to living people (Dreger, 1998: 32). I now outline how in the West intersex has been conceptualised, regulated or institutionalised and how this has been tied to each historical era's conceptualisation, regulation or institutionalisation of sex, gender and sexuality.

Ultimately research into historical references of intersex is problematic because of the temporally shifting conceptualisation, regulation or institutionalisation of intersex. Contemporary intersex may not necessarily be considered intersex in the past. Often intersex has been referred to by other terms such as hermaphrodite, eunuch, or androgyny. Rather than posthumously translating these terms into intersex, they may be used interchangeably with intersex.

3.1.1 The Ancients (500 B.C. - 500 A.D.)

According to transactivist Leslie Feinberg in *Transgender Warriors* (1996) Roman historian Plutarch makes what could be argued, the first known, albeit figurative, reference to intersex: a hermaphroditic deity. Plutarch claims that a hermaphroditic deity referred to as The Great Mother was worshipped by transsexual priestesses, a practice that “dates back to Mesopotamian temple records from the middle of the third millennium B.C.E., and are also found in Assyrian, Akkadian, and Babylonian records” (Feinberg, 1996: 40).

However, perhaps the most commonly cited reference to intersex comes from the highly myth-based representations in Greek and Roman societies between 500 B.C. and 500 A.D. While Delcourt explains in *Hermaphrodite. Myths and Rites of the Bisexual Figure in Classical Antiquity* (1961) that “the origins of Hermaphrodite are extremely obscure” (Delcourt, 1961: 46), it is widely agreed that the etymology of the term ‘hermaphrodite’ is in the mythological culture of Ancient Greece. Feinberg goes further to suggest that “Greek mythology was ... filled with references to sex-change, intersex, and cross-dressing [and] many mythological heroes and gods cross-dress at one time or another, including Achilles, Heracles, Dionysus, and Athena” (Feinberg, 1996: 56).

Three myth etymologies of the word ‘hermaphrodite’ have survived to the twenty-first century. Two myths refer to the male child of the Greek Gods Aphrodite and Hermes. The first myth states how Aphrodite and Hermes’ male child was so beautiful that its sex could not be decided; therefore it was named Hermaphroditos (Fausto-Sterling, 2000: 32). The second myth involves a water nymph falling in love with their son and “Overcome by desire, she so deeply intertwines her body with his that they become joined as one” (Fausto-Sterling, 2000: 32).

The third mythic origin of the term ‘hermaphrodite’ appears in the *Symposium* by the well-known Ancient Greek philosopher Plato, recently popularised in the trans cult classic *Hedwig and the Angry Inch* (Cameron Mitchell, 2001). In a quest to understand

the origins of love, Plato philosophised, through the voice of Aristophanes, that originally there were three kinds of human beings: males, female, and hermaphrodites.

In the first place there were three sexes, not, as with us, two, male and female; the third partook of the nature of both the others and has vanished, though its name survives. The hermaphrodite was a distinct sex in form as well as in name, with the characteristics of both male and female, but now the name alone remains, and that solely as a term of abuse (Plato, 1951/1981: 59)

The physical nature of the hermaphrodite was described as such

Each human being was a rounded whole, with double back and flanks forming a complete circle; it had four hands and an equal number of legs, and two identically similar faces upon a circular neck, with one head common to both the faces, which were turned in opposite directions. It had four ears and two organs of generation and everything else to correspond. These people could walk upright like us in either direction, backwards or forwards but when they wanted to run quickly they used all their eight limbs, and turned rapidly over and over in a circle, like tumblers who perform a cart-wheel and return to an upright position (Plato, 1951/1981: 59)

The reason for the existence of three types of human beings is explained

Originally the male sprang from the sun and the female from the earth, while the sex which was both male and female came from the moon, which partakes of the nature of both sun and earth (Plato, 1951/1981: 59-60)

Subsequently these three races possessed great strength and vigor that made them very formidable, and prideful, which ultimately led them to attack the gods (Plato, 1951/1981: 60). Plato retells for us how the gods responded

So Zeus and the other gods debated what was to be done with them. For a long time they were at a loss, unable to bring themselves either to kill them by lightening, as they had the giants, and extinguish the race – thus depriving themselves for ever of the honours and sacrifice due from humanity – or to let them go on in their insolence. At last, after much painful thought, Zeus had an idea. “I think”, he said, “that I have found a way by which we can allow the human race to continue to exist and also put an end to their wickedness by making them weaker. I will cut each of them in two; in this way they will be weaker, and at the same time more profitable to us by being more numerous. They shall walk upright upon two legs. If there is any sign of wantonness in them after that, and they will not keep quiet, I will bisect them again, and they shall hop on one leg”. With these words he cut the members of the human race in half, just like fruit which is to be dried and preserved, or like eggs which are cut with a hair (Plato, 1951/1981: 59-61)

As a result, according to Plato, humans thereafter “yearned for the half from which it had been severed,” (Plato, 1951/1981: 60) so originated love.

Can these Greek myths be relied on to elucidate a certain position toward intersex? In what sense is Greek mythology a relevant lens through which we can view a ‘true’ attitude of The Ancients? It has been argued that Greek mythology was utilised as a depiction of the Greek world-view, such as creation of the world, heroic historical tales, indeed even the origin of love itself. Blundell, however, asks whether they are “just old wives tales” or the “expressions of the relationship between gods and humans, or as allegories of scientific or moral truths” (Blundell, 1995: 14). Dowden goes further to claim that it is a mistake to infer a direct relationship between the language of myth and historical data, stating that myths are “predominately fictional and ideological, not documentary” (Dowden, 1995: 44). Blundell posits the idea that while myths have an ahistorical quality they are influenced by the process of adaptation, such that Greek myths are generally composed some time after the events they purport to describe (Blundell, 1995: 15). Blundell goes on to reiterate the position that “to use myth as a

source of information about historical events and societies is a rather dangerous exercise” (Blundell, 1995: 15).

The etymology of the term ‘hermaphrodite’ and the representation of intersex in Greek society are not limited to myth explanations. Delcourt’s “inventory” (1961: xiii) of Greek representations of Hermaphroditic artwork contests two of the previously stated etymologies. Delcourt claims that the term originated from the depiction of the Greek Goddess Aphrodite in statues, called ‘herms,’ and that the creation of Hermaphrodite from two gods was “a later invention, to explain the name” (46). Delcourt suggests that while “literary evidence [of hermaphroditism] was meagre” (55), its representation in art is numerous: “statues and statuettes in bronze and marble, low reliefs and vases and sarcophagi, Pompeian paintings and gems” (58).

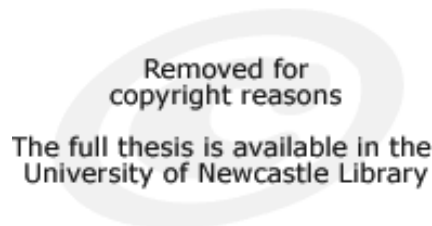


Figure 3.1. Statue of the Reclining Hermaphroditos [removed]

Brandt (1974) describes perhaps one of the most widely depicted statue of Hermaphroditos (Figure 3.1.)

As a blooming youth with female luxuriantly developed hip-muscles and male genitals. Especially beautiful are the sleeping hermaphroditos that have come

down to us; resting comfortably in a graceful attitude, which brings into full relief all the charms of the male-female body, the hermaphrodite lies half on his [sic] side on a couch adorned with a magnificent covering, the arms are crossed beneath the head. This type was especially popular, as the numerous replicas show (Brandt, 1974: 126)

Delcourt suggests also that “Hermaphroditos frequently appears in statues and herms, lifting up the garment to draw attention to the erect member” (Delcourt, 1961: 127), as in Figure 3.2.



Figure 3.2 God Hermaphroditos Depicted Lifting up Garment to Reveal Male Genitals

[removed]

However, caution is warranted when considering the artistic representations of intersex and the mythic Hermaphroditos, as Delcourt claims “many of these works are examples of *genre*-sculpture; the artist’s aim is to please, sometimes to amuse” (original emphasis,

Delcourt, 1961: 55). The *GLBTQ Encyclopaedia of Gay, Lesbian, Bisexual, Transgender and Queer Culture* (2001) supports this view

The Greeks (and Roman copyists) depicted the [hermaphroditic] figure lying down asleep in a pose that seems from the back to be a woman but from the front reveals the *confusing attributes* and *shocks* the viewer. This notion of the *shocking joke* emerges in Pompeian paintings that combine the hermaphrodite with a satyr or faun who *recoils in horror* at the sight of the "truth" about the object of his lust (emphasis added, GLBTQ, 2001)

Representing the hermaphrodite as ‘amusing,’ ‘shocking’ and ‘horrific’ contrasts with references to Hermaphroditos as worshipped in the average Greek home “as the good spirit of the house and private life” (Brandt, 1974: 126). According to Brandt the location of artistic representations of Hermaphroditos in the home explains why “we hear nothing of special sanctuaries or even temples of Hermaphroditos ... After the fourth century B.C. rooms in private houses, gymnasia, and baths were adorned with statues or pictures representing Hermaphroditos” (Brandt, 1974: 126).

While caution exists regarding the reading of Greek mythology as historical documentation some writers believe that they are indicative of a “moderate Greek attitude toward intersex” (Edgerton, 1964: 1289). Non mythic literature indicates that the real life attitude toward intersex in Greek and Roman societies is multi-layered and heterogenous.

As Plato claims above the name ‘hermaphrodite’ remains “solely as a term of abuse” (Plato, 1951/1981: 59). Delcourt explains what Ancient Greek societies believed regarding the birth of an intersex child

The whole community felt itself threatened by the anger of the gods. To avert its consequences they must first suppress the abnormal child, who was thus made to bear the sins of which he was the token (Delcourt, 1961: 43)

Subsequently these children were killed by exposure, drowning or burning (Delcourt, 1961: 45). Adult intersex individuals, too, when discovered, were led to the sea or burned (Delcourt, 1961: 44-45). The birth of intersex individuals in Rome fared no better. Edgerton claims that there too they were seen “as expressions of divine displeasure, as auguries of national disaster” (Edgerton, 1964: 1289), and were put to death (Edgerton, 1964: 1289; Epstein, 1990: 107; Dreger, 1998: 32). Further, Delcourt quotes Pliny saying in the first century B.C. that intersex individuals are “objects of jest” (Delcourt, 1961: 45). Yet this is not the whole story. Some writers, like Fausto-Sterling (2000), claim that in Pliny’s era “hermaphrodites became eligible for marriage” (2000: 33). According to Nederman and True’s research (1996) into medieval lawyers who took as their point of departure the texts of the classical Roman lawyers

Roman Law seems to have regarded the existence of hermaphrodites as a purely natural phenomenon ... there is no suggestion that an intersexed creature counts as anything other than fully human (Nederman and True, 1996: 512)

Transwoman Roughgarden contributes to this diversity of views regarding intersex. According to Roughgarden Roman lawyer Ulpian’s division of eunuchs included those who were born with genitals that did not develop past puberty, and who were considered to have genitals sufficient enough to be assigned male at birth. Roughgarden also states that in the early Roman Empire infants with genitals too ambiguous to be assigned were killed (Roughgarden, 2004: 352).

Whatever the reaction, the existence of intersex did not go unnoticed in the myths, art, worship or laws in Greek and Roman societies. However, we must turn our attention to how intersex influenced and was influenced by the sex and gender schema in Greek and Roman Society. The Greek and Roman world-view on sex and gender can be attributed to three principle players: Hippocrates (c. 430 B.C.), Aristotle (b. 384 B.C.) and Galen (c. 150 A.D). Their work would go on to influence European thought for the best part of the next two millennia.

The Greek and Roman conceptualisations, regulations and institutionalisations of gender were heavily based on a strict differentiation of social roles. Although these societies, especially Greek societies, are held up as the seat of contemporary democracy, “the lives of ordinary women remained restricted” (Katz, 1995: 161), furthermore, “the citizenry remained exclusively male” (Foxhall and Salmon, 1998: 30). Even when Solon in 594 B.C. was given the opportunity to reform the Greek city-state of Athens, “one of his first measures was to prohibit women leaving their houses at night, and the effect of this was to confine them more and more to their homes by day” (Miles, 1990: 71). In Rome too, women’s position was considered subordinate to that of men: “The Romans believed that all women, whatever their age or status, were characterized by certain traits: a feeble intellect, weakness of character, and overall, a general incapacity innate in the female sex” (Fraschetti, 2001: 3).

Women’s position in the Greek and Roman world-view of biological sex fares little better. Laqueur’s *Making Sex* (1995) considers the Greek and Roman world-view of biological sex a one-sex model (Laqueur, 1995: 25). That is, while the Greeks and Romans felt that men and women’s bodies were in essence the one sex, the female sex was an inferior version of the male sex, as Laqueur describes it “They have exactly the same organs but in exactly the wrong places” (Laqueur, 1995: 26). From a contemporary context, this view may not only appear naïve, but a result of the masculinist bias of the culture, as Harlow suggests

Most writing of the ancient world was done by men working within a system that held the male as the model for mankind and the female as somehow inferior to that ideal (Harlow, 1998: 156)

However, Miles refutes this posthumous reading, and in *The Women’s History of the World* (1990) states that this view “said no more than any man or woman of [this] age would have accepted as fact” (68).

We view the biological differences between the sexes in terms of sex differentiation. However, the Greek and Roman societies' theories focused on the failed female. Hippocrates, Aristotle and Galen speculated on two possible methods: 1) the concept of a predominate seed; and 2) the in-utero conditions (Gleason, 1995: 59). The 5th and 4th century B.C. *Hippocratic Corpus* were a collection of writings that addressed the nature of procreation, pregnancy, foetal development and childbirth (Harlow, 1998: 157). From these works we deduce that the Hippocratic tradition argued that

Both parents have male and female seed; the child's sex is determined by *whichever sperm prevails in quantity* ... Both parents produce strong (male-producing) and weak (female-producing) sperm, and weak sperm can overcome strong sperm by sheer volume, thus producing a female child (emphasis added, Harlow, 1998: 158)

In contrast to the Hippocratic view, Aristotle's "'one-seed' theory" (Laqueur, 1995: 38) of procreation, draws on a notion of internal heat. That is, "the woman is merely the passive incubator of his seed ... the male semen cooks and shapes the menstrual blood into a new human being" (Miles, 1990: 68). As Harlow points out "Aristotle's theory of generation hinged on the central principle that only the male parent, the father, has the power of generation" (Harlow, 1998: 159).

Hippocrates and Aristotle (Foxhall and Salmon, 1998: 159) undoubtedly influenced the work of the Roman Galen in the second century A.D. The Galenic tradition held that both the male and female produced seed and half the human race were 'mutilated' "because in essence a female offspring was a male who had not achieved its full potential due to being undercooked in the womb" (Harlow, 1998: 159). The determination of a child's sex therefore is reliant on two things

- 1) The opposition of male and female principles in the maternal and paternal seeds in combination with interactions between the left and right sides of the uterus
- 2) The concept of a grid system in the uterus (Fausto-Sterling, 2000: 33-34)

From this point of view Fausto-Sterling proposes that “thinkers in the Galenic tradition believed no stable biological divide separated male from female” (Fausto-Sterling, 2000: 34). Gleason concurs with this view of ambiguous demarcation of the sexes “an infant’s [sex] was not an absolute but a point on a sliding scale” (1995: 59). What this view ultimately meant was an increased possibility of intersex existing in this sex schema. As Murray reports

The elder Pliny (*Natural History* 7.23) included such cases of women who became men, including one he himself met who had become male on the day she wed a female. That is, the greatest of Roman natural scientists ... considered such metamorphosis as a verified empirical phenomenon (albeit a rare one) (Murray, 2000: 227)

Greek and Roman references to intersex is fragmentary and heterogenous. They conceptualised, regulated and institutionalised intersex within discourses of mythology, art, worship, law and a sex and gender schema. From this evidence however, we cannot conclude that intersex was considered a ‘normal’ part of Greek and Roman existence. Greek and Roman mythology, art, worship, law and the sex and gender schema are ultimately imbedded within very specific cultural positions. Therefore a posthumous reading of intersex is blurred. Hence the fragmentary and heterogeneous representation of intersex in Greek and Roman mythology, art, worship, law and the sex and gender schema is indicative of not only their tentative position in the mainstream discourses, but also the precarious real life experiences.

3.1.2 The Middle Ages (500 – 1500 A.D.)

Historical research of intersex in the Middle Ages is virtually nonexistent, one notable exception is Nederman and True’s *Third Sex: The Idea of the Hermaphrodite in Twelfth-Century Europe* (1996). Yet as the title suggests this work explores intersex in only a one hundred-year period. Jacquart and Thomasset’s *Sexuality and Medicine in the Middle*

Ages (1985), Laqueur's *Making Sex* (1990), and Cadden's *Meanings of Sex Difference in the Middle Ages* (1993) are three works that specialise in the period and are described by Nederman and True as being "useful" (1996: 502). However, Nederman and True insist that "none of these works treats intersex in a systematic fashion" (Nederman and True, 1996: 502). The paucity of detail and information on intersex from this time, as Nederman and True speculate, requires more investigation.

What is known of European societies in the Middle Ages is that they inherited a great deal from The Ancients. In particular their ways of conceptualising sex and gender is directly attributed to the influence of the Greek and Roman such as writers Aristotle and Galen (Jacquart and Thomasset, 1985: 48; Rigby, 1995: 246; Nederman and True, 1996: 502-503; Fausto-Sterling, 2000: 34). When turning attention to intersex it is of little surprise then to find the attitudes of Medieval Europeans reflect the contradictory nature of the Ancients.

Julia Epstein's *Either/Or - Neither/Both: Sexual Ambiguity and the Ideology of Gender* (1990) prior to discussion of 'sexual ambiguity and medical jurisprudence' in pre-Renaissance Europe, states that hermaphrodites in the early Middle Ages "were frequently put to death" (Epstein, 1990: 101). Moreover Epstein claims that intersex individuals were put to death by drowning because they "could not be assailed into conceptions of the natural" (1990: 107). Nederman and True, however, problematises Epstein's views on Medieval intersex individuals (1996: 501). While conceding that these views were held in the period, Nederman and True expand the Medieval view by claiming that this "by no means exhausts the range of premodern views regarding intersexuality" (1996: 501). Evidence suggests "that hermaphrodites were tolerated" (1996: 502) and that "medieval natural philosophers and physicians consistently adduced purely naturalistic explanations for the generation of hermaphrodites" (Nederman and True, 1996: 501-502). Alice Dreger, as a historian of intersex, reiterates this position and informs us that hermaphrodites in medieval Europe were not pathologised (cited in Kessler, 1998: 84).

Presently I must draw attention to the ways in which the Middle Ages conceptualised, institutionalised and regulated intersex. Following a review of the scant research that pivots around this period in western history it could be argued that there exists two distinct means of demarcating intersex in Medieval society: an anatomical/medical and a legal/moral view. Bridging these two, Nederman and True claim that there is a “common assumption: that the hermaphrodite constitutes a third and biologically distinct sex” (Nederman and True, 1996: 503).

Medieval natural philosophy, anatomy and medical narratives posit biological sex as “labile” (Bynum, 1992: 220) as such intersex was legitimised as a third category, a third axis in a “trisex model” (Nederman and True, 1996: 503). This pliable view of the biological sex and the trisex model is directly related to the Galen-influenced sex-determining theory, whereby it was argued that the position of the foetus in the uterus determines the sex of the child. According to Bynum, this allowed Medieval thinkers to conceptualise male and female along a continuum, and, at the very least, to ponder the question “why there are not at least as many hermaphrodites (midpoints on the spectrum) as there are males and females (endpoints on the spectrum)” (Bynum, 1992: 221). A speculation further reiterated by Nederman and True

The implication of this explanation of the process of sexual determination is clear: it is possible for a child ... to be neither male nor female, or in essence to have the combined natures of both (1996: 504)

This concept of intersex as a ‘midpoint,’ a third sex was reflected in the legal status of intersex individuals in Medieval Europe. According to Nederman and True the Bolognese civil jurist Azo did not consider intersex individuals “accidents” or “freaks” but rather as “unproblematically human” (Nederman and True, 1996: 513). Rigby tells of how in mid-thirteenth century England “people could be classified for legal purposes in two ways, firstly, into free and bond; secondly into ‘male, female or hermaphrodite’” (Rigby, 1995: 243). Moralists of the time similarly placed considerable time and effort into understanding the existence of intersex, such that “there was wide agreement that a

hermaphrodite was unique form, and not physically assimilable to, either male or female form” (Nederman and True, 1996: 506).

If biological sex was conceptualised in a trinary system, gender in contrast was bound by a distinct binary. Subsequently, as Rigby states, “even hermaphrodites were said to be closer to either the male or to the female pole, ‘according to the predominance of their sexual organs’” (Rigby, 1995: 243). Nederman and True support this view, “one may be born with the nature of the hermaphrodite, but one must be classified according to standard bifurcation of gender identity” (Nederman and True, 1996: 515). To reinforce the fact, according to Jacquart and Thomasset, not only did the Church force intersex individuals to choose to be either male or female, but “surgery could offer them the means of correcting the most visible anomalies” (Jacquart and Thomasset, 1985: 141). An offer that is eerily similar to that view of the current medical model, as will be seen in Chapter 4.

Historical research into the sexed and gendered lives of Medieval Europeans is fragmentary. Any conclusions made from this period in Western history must be done so cautiously. However, from the references above some tentative conclusions about the ways that medieval thinkers conceptualised, regulated and institutionalised intersex can be made. Firstly, it is clear that Medieval thought was certainly influenced by Greek and Roman writers. Secondly, by the time of the Middle Ages the Classical ‘one-sex’ had morphed into a ‘trisex model,’ a model that provides epistemological support for the natural occurrence of intersex. Thirdly, intersex individuals were provided a legal claim to be members of society, although the claims made by Epstein suggest that intersex individuals were put to death. Fourthly, while intersex individuals were provided for as a ‘third sex’ in the medico-legal schema of medieval society, they were expected to conform to a binary gender system.

3.1.3 From the Renaissance to Enlightenment (1500 - 1800's)

The 1500's are widely considered as the period in which European history began an era of new ideas. The Renaissance is seen as a time of great upheaval and change

The phenomenon of the Renaissance lay as much in the sheer diversity of its expression as in their unprecedented quality. Within the span of a single generation, Leonardo, Michelangelo, and Raphael produced their masterworks, Columbus discovered the New World, Luther rebelled against the Catholic Church and began the Reformation, and Copernicus hypothesised a heliocentric universe and commenced the Scientific Revolution. Compared with his medieval predecessors, Renaissance man [sic] appeared to have suddenly vaulted into virtually superhuman status (Tarnas, 1996: 224)

This diverse and unprecedented expression is mirrored in the greater attention given to intersex (Nederman and True, 1996: 500). While this epoch continues to contribute to the medico-legal discourse that preceded it, it further elucidates considerable interest in intersex via literature and by the end of this period through investigative pursuits of teratology and sexology. What is striking of these medico-legal and literary works is the first glimpse into the real life experience of intersex individuals. While they are affected by the context through which they are introduced, we can begin to deduce from these accounts some indication of how intersex individuals negotiated around their intersex status and its representation and regulation in society.

Knowledge of intersex individuals during 1500-1800 is often speculation that is based legal documents. In particular, this period of time appears to be dominated by accounts of those intersex individuals who are brought before legal institutions charged with 'sodomy' (Epstein, 1990: 109; Wilson, 1993: 83). Intersex is viewed through the lens of this legal milieu and the medical documentation that often accompanied, reinforced and indeed legitimated it. I have identified ten individuals in the historical literature that have been deemed transgressors of the social status which intersex individuals were awarded.

As Table 3.1. indicates these individuals are found on two continents and throughout the four centuries.

Century	Country	Name
1500s	Spain	Eleno/Elena de Desopedes
	New World	Thomasine/Thomas Hall
		Elvira de Cespedes
		Antide Collas of Dôle
1600s		Marie/Marinle Marcis
1700s		Michel-Anne Drouart
	Holland	Rsamus Væver
		Anne/Jean-Baptiste Grandjean
1800s		Levi Suydam
	France	Herculine Barbin

Table 3.1. Intersex Individuals during 1500-1800's

For the most part intersex individuals between 1500 and 1800 were permitted a certain, conditional, social status and protection. While it was widely understood that intersex individuals possessed bodies that were ‘ambiguous,’ they were required to “adopt either a male or female identity” (Brown, 1995: 174), a demarcation that ultimately was determined by the dominant sex characteristic

Every heire [sic] is either a male, or female, or an hermaphrodite, that is both male and female. And an hermaphrodite shall be heir, either as male or female, according to that kind of the sexe [sic] which does prevail (Coke of Littleton, cited in Friedli, 1988: 246)

Moreover, once they adopted and maintained this assignment an intersex individual was able to marry (Jones and Stallybrass, 1991: 90). Subsequently, at the core of ‘sodomy’ charges against intersex individuals of this period was not the intersex status, rather certain social transgressions, that is when an individual did not maintain the adopted sex the ‘sexe which does prevail.’ As Trumbach claims it was individuals who were found to

be switching from one gender to the other that invariably had a case of sodomy brought against them (Trumbach, 1993: 112-113).

Writers of 1500-1800 literature appear to have shown “a great deal of interest” (Wilson, 1993: 166) in intersex, so much so that numerous books were published that investigate the occurrence of intersex and other forms of so-called ‘monstrous births.’ Five such works include

- 1) James Paris’ *A Short History of Human Prodigious and Monstrous Births of Dwarfs, Sleepers, Giants, Strong Men, Hermaphrodites, Numerous Births, and Extream Old Age &c* published in the late 1700’s (Wilson, 1993: 90-91);
- 2) Jacque Duval’s *On Hermaphrodites, Childbirth and the Medical Treatment of Mothers and Children* (Fletcher, 1995: 40);
- 3) In 1750 George Arnaud published the *Dissertation on Hermaphrodites* (Friedli, 1988: 248);
- 4) *The Treatise of Hermaphrodite* published by Edmund Curll in 1718 (Trumbach, 1993: 117); and
- 5) Antonio de Torquemada’s *Jardin de flores curiosasi* in 1570 (Burshatin, 1996: 115)

Wilson claims that throughout this literary evidence a significant focus, especially during the sixteenth century, is placed on the ‘picture book’ genre, whereby an increased appearance of illustrations of intersex accompanied these works (Wilson, 1993: 166). In particular Wilson notes the works of Henricus Petri (Wilson, 1993: 65), Rueff (Wilson, 1993: 67), the *Histoire et Memoires de l’Academie des Sciences*, (Wilson, 1993: 166), and Paris (Wilson, 1993: 92), of the latter Wilson expands to indicate the wider implications of this ‘scientific’ view of intersex

This figure is equipped with a flap to demonstrate its anatomical details, and it has been suggested that this was probably the way in which hermaphrodites were exhibited to the public at the time. The accompanying account makes it clear that

the curiosity of the public was in no way inhibited and that this type of exhibit was frequently handled with very little consideration, although no doubt it was all done in the name of science (Wilson, 1993: 92)

It has been argued that the disproportionately high frequency of references to intersex during this period (Nederman and True, 1996: 500) is attributable to a fascination embedded in a general interest in a range of “monsters, monstrous births and other strange natural phenomena” (Friedli, 1988: 246). This interest led to the eventual establishment of ‘Teratology’: the study and classification of monstrous, abnormal and unusual births (by father and son Etienne and Isidore Saint-Hilaire) (Epstein, 1990: 113; Dreger, 1998: 35; Fausto-Sterling, 2000: 36). Coupled with increased ‘study’ of the physical occurrence of intersex, through the ‘picture book’ genre noted above, and the teratologists, this legacy of a new understanding of intersex, this new ‘science,’ according to Fausto-Sterling

Redefined such bodies as pathological, as unhealthy conditions to be cured using increased medical knowledge. Ironically, this scientific understanding was used as a tool to obliterate precisely the wonders it illuminated (Fausto-Sterling, 2000: 37)

This overview of the historical research shows that at times intersex has been considered nothing more than another expression of being human. While intersex itself was initially deemed a ‘natural’ variation, whereby intersex individuals were able to adopt a gender of their own choice, what we have witnessed is a change in the regulation of intersex individuals’ social status. The failure of some individuals to maintain this singular gendered social position brought intersex individuals under the scrutiny of the medico-legal system, namely legal charges of ‘sodomy,’ that were officiated over by medical declarations and diagnosis. At the end of the 1800’s a systematic interest in human anatomy, desire and behavior this led to the establishment of epistemological pursuits such as teratology and sexology. Moreover this institutionalisation meant that intersex was now regulated and conceptualised from a pathological point of view. These attitudinal and epistemological shifts during the 1500-1800’s have brought our historical

understanding of intersex up to the point where contemporary medical management develops what Dreger refers to as the “Age of the Gonads” (Dreger, 1998: 29).

3.1.4 Late 1800’s - Mid 1900’s

I will now trace the immediate precursors to contemporary medical attitudes towards intersex. To do this I turn to the comprehensive work of Alice Dreger *Hermaphrodites and the Medical Intervention of Sex* (1998). Dreger’s understanding of late nineteenth and early twentieth century French and British hermaphroditism begins with the suicide in 1868 of the now famous hermaphrodite Herculine Barbin. The significance of this death comes not just from the fact that Barbin’s memoirs (Foucault, 1980) were the only ones of their kind from a nineteenth century hermaphrodite (Dreger, 1998: 23), but because “Barbin shaped the biomedical treatment of human hermaphroditism for years to come” (Dreger, 1998: 28). According to Dreger it is this event that is the dawn of the “Age of the Gonads” (Dreger, 1998: 29).

Hitherto intersex individuals, such as those in Table 3.1, have survived to us today only because of their appearance in medico-legal documentation. Therefore, Herculine Barbin’s memoirs are unique in that they are the first first-person biographical account of an intersex individual to survive to contemporary times. Michel Foucault summarises Barbin’s life in the preface to the 1980 publication of these memoirs

Brought up as a poor and deserving girl in a milieu that was almost exclusively feminine and strongly religious, Herculine Barbin, who was called Alexina by her familiars, was finally recognized as being ‘truly’ a young man. Obligated to make a legal change of sex after juridical proceedings and a modification of his civil status, he was incapable of adapting himself to a new identity and ultimately committed suicide (Foucault, 1980: *xi*)

These few sentences from Foucault draw attention to the fact that emphasis is being placed upon Barbin’s negotiation (and unsuccessful re-negotiation) of identity. Barbin

was both ‘incapable of adapting himself to a new identity,’ and “was one of those unfortunate heroes of the quest for identity” (Foucault, 1980: *xii*). This research similarly mirrors the attention given by Foucault to this interrelationship between intersex and identity. Further, significance is pointed out by Dreger who insists that the development of medical management during the “age of the gonads” expressed concern over incorrect assignment of sex using Barbin’s life and death as illustration

The medical man reporting the case of Sophie V. specifically referred to Barbin’s suicide as reason to worry about forcing an unfamiliar new sex on a hermaphroditic patient. Meanwhile, Barbin’s case, with its scandalous sexual exploits, also pushed many medical men to try to seek out and prevent or end the ‘unnatural’ sexual associations (like Sophie V.’s marriage) caused by hermaphroditism (Dreger, 1998: 29)

Herculine Barbin’s memoirs are an outstanding autobiographical account of a nineteenth century intersex individual. Adding Dreger’s claim that Barbin shaped the biomedical treatment of human hermaphroditism for years to come (Dreger, 1998) it could be argued that these points alone would make the memoirs a source for analysis. Moreover, I suggest that these memoirs’ significance lies in their contribution to understanding the regulation and conceptualisation of intersex in the nineteenth century. Therefore this section offers an analysis of three thematic threads identified in Barbin’s narrative: hermaphroditism, gendered self and intimate relationships.

The main issue at hand within the memoirs is intersex, or in the terms of the day hermaphroditism. Initially references to it are vague and elusive as mere inferences to the unique physical situation. Barbin makes remarks of ill health and weaknesses (10), and offers almost as a preface to the disclosure, a warning, of sorts, that cautions the reader of what is to come, and its possible implausibility, Barbin asks that the reader “be convinced of my sincerity above all” (15). Barbin’s intersex status is only referred to indirectly as the “condition,” or in equally vague terms such as with a doctor’s decision “not to worry about *the matter* any more but to leave everything to time” (emphasis added, 19).

Eventually, Barbin's condition is finally and unambiguously referred to in a passage, here repeated in full, where Barbin describes the observation of the obvious physical differences to other young women

At that age, when all a woman's graces unfold, I had neither the free and easy bearing nor the *well-rounding limbs* that reveal youth in full bloom. My complexion with its sickly pallor denoted a condition of chronic ill health. My features had *a certain hardness* that one could not help noticing. My upper lip and a part of my cheeks were covered by *light down* that increased as the days passed. Understandably, this peculiarity often drew to me joking remarks that I tried to avoid by making frequent use of scissors in place of a razor. As was bound to happen, I only succeeded in making it even thicker and more noticeable still. My body was *literally covered in it*, and so, unlike my companions, I carefully avoided exposing my arms, even in the warmest weather. As for my figure it remained *ridiculously thin* (emphasis added, Barbin cited in Foucault, 1980: 26-27)

Barbin never acknowledges exactly any diagnostic terminology of the 'condition.' Indeed "science was unable to find an explanation for a *certain absence* and quite naturally attributed to it the kind of languor in which I was wasting away" (emphasis original, 39). However, two sentences draw the conclusion that the true nature of the condition was far from a mystery to Barbin. Barbin refers to two seemingly meaningful 'discoveries.' One in childhood

I confess that I was extraordinarily shaken when I read *Ovid's Metamorphoses*. Those who know them can imagine how I felt. As the sequel of my story will clearly show, this discovery had a special bearing on my case (18)

Whereby the phrases 'as the sequel of my story will clearly show' and 'special bearing on my own case' implies an understanding on Barbin's part in an interrelationship between

Barbin's own situation and that of the famous mythic hermaphrodite. The second meaningful discovery occurred after Barbin's gender reassignment was recorded in the *Annales de médecine légale*

Consulting [the *Annales de médecine légale*] I discovered that a similar case had occurred in 1813 ... if not under the same circumstances, at least with the same outcome (89)

Barbin pre-empts the inevitable gender reassignment with reports of a gendered discontinuity with Barbin's peers that goes beyond the physical differences noted above but reflect on the socially prescribed gendered roles. As an example Barbin adds to the memoirs the aversion to handicrafts and aptitude for study, in particular history (8), and notes that it is this "love of study [that] took my mind off the strange perplexity that had possessed my whole being" (26). This discontinuity between Barbin's propensity for a gender role and of the gender roles of Barbin's peers, is subsequently explained and justified in the narrative by later physical examinations. Here repeated in full are two occasions when Barbin undergoes physical examinations prior to subsequent gender reassignment. In both circumstances the conclusion is the same

You are here and now entitled to call yourself a man in society ... And so, the advice I am giving you is this: withdraw from the world and become a nun; but be very careful not to repeat the confession that you have made to me, for a convent of women would not admit you, this is the only course that I have to propose to you, and believe me, accept it (62)

And,

Frankly ... your godmother had a stroke of luck when she called you Camille. Give me your hand, *mademoiselle*; before long, I hope, we shall call you differently. When I leave you, I will go to the bishopric. I don't know what Monseigneur will decide, but I doubt that he will permit you to return to L. There,

your position [as a teacher] is lost; it is not tolerable ... [addressing Barbin's mother] It's true that you've lost your daughter ... but you've found a son whom you were not expecting (emphasis original, 78)

Following the first encounter Barbin appears shocked by the insinuation that one must undergo a reassignment of gender and responds by stating that "I was not prepared for such an outcome" (62) and "I decided to await events" (63). However, after the second examination Barbin seems resolved to the decision and comments

This inevitable outcome, which I had foreseen, had even desired, terrified me now like a revolting enormity. In short, I had provoked it, no doubt it was my duty to have done so; but who knows? (79)

In the earlier situation Barbin was cautioned that failure to change would result in a scandal. However, Barbin reasoned

He had proposed that I avoid a possible scandal in a way that would only create for myself an even more dangerous situation, which would have to end in an inevitable scandal (62)

Having resigned to the change Barbin again ponders the ramifications

Didn't this abrupt change, which was going to reveal me in such an expected way, offend all the laws of conventional behavior? ... Would [society] give me credit for an impulse that might pass for honesty? Wouldn't people try to falsify it instead and treat it as if it were a crime on my part? (79)

Despite these concerns Barbin was given "a new place ... in society" (80) and subsequently

The civil court ... ordained that a rectification be made on the civil status registers, which meant that I was to be entered there as belonging to the masculine sex, and at the same time I was to be given a new first name in place of the feminine one I had received when I was born (89)

Unfortunately the gender reassignment did not go without incident from idle gossip to reports in newspapers. Barbin's fears were thus realised "as always, the matter was considerably embroidered upon" (90) bringing into question Barbin's relations, in particular with one Mademoiselle Sara with whom Barbin shared a teaching position.

Barbin's situation was not to be resolved, having made the comment that Barbin would come to repent the 'duty' to undergo gender reassignment (81), this feeling is further expanded upon in the passage

And now, alone! ... alone ... forever! Forsaken, outlawed in the midst of my brothers! Ah! What am I saying! Have I the right to give that name to those who surround me? No, I do not. I am alone (98)

Barbin's 'new place in society' therefore was not without regret. The remainder of the memoirs is not only incomplete (98) but is, just as it begins, rife with references to suicide

This incessant struggle of nature against reason exhausts me more and more each day, and drags me with great strides toward the tomb ... It is no longer years that remain to me but months, days perhaps (103)

Barbin's change in gender role was not only necessitated by the 'condition,' but also by the fact that Barbin engaged in intimate relationships with three women. The first of which was when Barbin was 12, with Lea, who was seventeen at the time

I lavished upon her a devotion that was ideal and passionate at the same time. I was her slave, her faithful and grateful dog. I loved her with the same ardor I put into everything (10)

While the mutual attachment did not go unnoticed by others, it was because Barbin was held in such high esteem that the repercussions were minimal. Barbin describes their final embrace, “before going to sleep I had clasped my dear Lea in my arms, and the kiss that I gave her was as sad as a last farewell. I was going to lose her, too, no doubt forever; for our destinies could not reunite us” (14). The second “close friendship with a charming girl named Thécla” (27) occurred while Barbin was studying to become a teacher. During their attachment they “were always called the inseparables” (27). Once again their actions were not unnoticed and while not condoned, little was done to actively dissuade them. The third intimate relationship with Sara was by far the more elaborately described and occurred when Barbin was established with a teaching position. Sara was the daughter of Barbin’s employer and also a fellow teacher. On their meeting Barbin remarks “Sara herself took me to my room, which was next to her own, there she made so bold as to kiss me, thus winning my friendship completely” (43) and “on that day we began a relationship that was not slow to become a real attachment” (44).

Barbin makes numerous comments that indicate that the magnitude of this relationship exceeded those that had preceded it

I would lace her up; with an unspeakable happiness I would smoothe the graceful curls of her naturally wavy hair, pressing my lips now upon her neck, and now upon her beautiful naked breast (49)

The situation however, for Barbin was not without concern. Barbin is all too aware of how things would have been if the situation of Barbin’s life were different “I sometimes envy the lot of the man who will be your husband” (50). Further, Barbin calls attention to how the condition and the resulting situation prohibit a full disclosure of the attachment

“destined to live in the perpetual intimacy of two sisters, we now had to conceal from everyone the terrifying secret that *bound* us to each other” (emphasis added, 51).

Yet, as before, the attachment did not go unnoticed, in this case by Sara’s mother, Barbin’s employer. The situation seemed to call for nothing more than a passing caution, Sara was told “I must ask you to be more reserved in the future in your relations with mademoiselle [Barbin]” (56), as Barbin comments “we nonetheless continued to share the same bed” (56). Interestingly, the intimacy was so regarded, that Sara would take “pleasure in using masculine qualifiers for me ... ‘*Mon cher* Camille, I love you so much’” (58). After Barbin’s gender change, while the intimacies may have stopped, however, “my correspondence with Sara had not ceased” (95). Neither were Barbin’s relations with Sara’s mother spoiled. At Barbin’s departure Sara’s mother said, “Now, good-bye, dear *daughter!*” (emphasis original, 86).

As a real life biographical account, we are privy to some, until that point, unknown personal reflections by an intersex individual, namely obvious discontinuities between feelings, physical appearance and gender role. What is notable is that Herculine Barbin was by and large accepted among familiars. Yet this seemingly secure position in society was only tentative, and though able to find a place in society through love, work and family, the discordance Barbin felt in this role eventually led to an intervention by others into Barbin’s (re)position in society. Yet a ‘new place in society’ was not the answer, and it was a change that ultimately cost Barbin’s life. The memoirs end with a brief paragraph from Michel Foucault

In the month of February 1868, the corpse of Abel Barbin, who had committed suicide by means of a charcoal stove, was found in a room in the quarter of the Théâtre de l’ Odéon. He had left the manuscript of the preceding text (Foucault, 1980: 115)

According to Foucault the 1860’s and 1870’s was a period of intense investigations into different types of perversions including the attempt to establish the ‘true’ sex of intersex

people (Foucault, 1980: *xi-xii*). As discussed in Chapter 2 the late nineteenth century not only manifested a curiosity for perversions but also was motivated by a desire to ‘prevent’ and ‘cure’ these perversions (Dreger, 1998: 137).

In Alice Dreger’s *Hermaphrodites and the Medical Intervention of Sex* (1998) we read a thoroughly documented account of a period that Dreger calls the “Age of the Gonads”: 1870-1915 (Dreger, 1998: 29). Dreger analyses how the British and French investigated, conceptualised and represented intersex. In particular, this period witnessed the increased authority of biomedical experts to say what one’s body meant to one’s identity, and the decreased visibility of intersex persons outside the hospital, clinical and medical journal settings (Dreger, 1998: 11). This section shall recap some of the significant developments as seen by Dreger.

The “vague term” ‘hermaphrodite’ was still in common usage until the middle of the twentieth-century (Dreger, 1998: 31). Yet the term ‘intersexual’ did begin to make an appearance from the early 1900’s (Dreger, 1998: 4). Richard Goldschmidt is reported to have introduced the term ‘intersex’ in a 1917 article titled ‘Intersex and the Endocrine Aspect of Sex,’ in which Goldschmidt discussed varieties of intersex including hermaphrodites (Dreger, 1998: 31).

Dreger’s attempt to recount the steps of British and French investigations into intersex has uncovered what Dreger describes as “roughly three hundred commentaries and accounts of human hermaphroditism published in the scientific and medical literature of France and Britain from 1860 to 1915” (Dreger, 1998: 24). Yet with the sole exception of Barbin’s memoirs (Dreger, 1998: 24) any information provided by this literature is “filtered and shaped by contemporary biomedical observers and authors” (Dreger, 1998: 23). Most significantly Dreger describes these accounts as “a peculiarly masculine, biomedical view of masculinity, femininity and hermaphroditism” (Dreger, 1998: 24).

Having said this Dreger suggests that during this period there was not a unifying opinion of masculinity, femininity or intersex, such that “sex itself was still open to doubt”

(Dreger, 1998: 16). Further, the fact that many women were still being serviced by midwives (Dreger, 1998: 25) in the late nineteenth century is yet another indication of the plurality of thought. Knowledge of mid-wifery has largely been lost because according to Dreger “midwives did not share the same level of interest in publication that the professionalizing medical men did” and “I was obligated primarily to use indexes compiled by men often disinterested in the writings of midwives” (Dreger, 1998: 25).

Notwithstanding these limitations placed upon the literature referring to intersex, Dreger asks the question: How did it happen that a virtual explosion of human hermaphroditism occurred in the last few years of the nineteenth century? Dreger proposes that the answer lies among three important social changes: firstly, a rise in gynaecological and medical services (Dreger, 1998: 25); secondly, an increase in opportunities for publication (Dreger, 1998: 25); and thirdly, because this period saw a need for medical and scientific men to police those who “vigorously challenged sexual boundaries,” such as feminists, homosexuals and hermaphrodites (Dreger, 1998: 26).

Before exploring the medical and scientific men in the ‘age of the gonads’ I will look at how Dreger claims that these intersex individuals were visually and linguistically represented. The visual record of intersex people from the ‘age of the gonads’ has two distinctive and recognisable motifs. Firstly, the “reaching-hand” (Dreger, 1998: 47) (Figure 3.3.), that undoubtedly has links to the ‘picture book’ genre, discussed above. And secondly, ‘black bag over the head’ (Dreger, 1998: 49) motifs (Figure 3.4). Dreger claims that the ‘reaching-hand’ motif elicits for us the understanding that the frame of study is inclusive of both subject and the observer and secondly it is also culturally specific (Dreger, 1998: 47). In regards to the ‘black bag over the head’ motif it was intended to omit the person’s identity to protect their privacy, however, according to Dreger it ironically removes their humanity making them “seem even more data-like” (Dreger, 1998: 49).



Figure 3.3. “Reaching Hand” [removed]

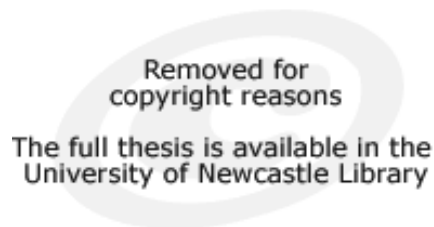


Figure 3.4. “Black Bag” [removed]

The usage of language is indicative of how intersex was viewed by scientific and medical men. In particular the use of pronouns in regards to intersex individuals, according to Dreger “may also have contributed to the objectification of hermaphrodites” (Dreger, 1998: 50). While the French almost always referred to intersex people as *le sujet* or *le malade* (‘the subject’ or ‘the patient’ - literally, ‘the ill one’) (Dreger, 1998: 50), the English, although sometimes remarking on the difficulty of the situation, either switched from one gender pronoun to the other, or “used the ungendered but unpleasant ‘it’” (Dreger, 1998: 50).

Dreger draws attention to and reminds the reader of the attitudes held by many medical and scientific men who investigated intersex. In particular they saw intersex as an “‘amusing’ subject” (Dreger, 1998: 59) and intersex individuals “as curiosities” (Dreger, 1998: 60). This can be seen by the account in the 2nd December issue 1882, of the *British Medical Journal* as reprinted by Dreger

Mr. Brian Rigden showed a [subject of] Spurious Hermaphroditism, seven months old. There was a large clitoris, not perforated, and labia without testicles. A small opening existed beneath the clitoris ... there was no visible vagina, and the finger in the rectum failed to detect an uterus ... This child was considered a female by the meeting. A very amusing and interesting discussion followed (Dreger, 1998: 59-60)

From such instances Dreger concluded that “obviously curiosity and a sort of voyeurism were part of what drew interest to the subject of hermaphroditism” (Dreger, 1998: 60). Amidst the ‘amusement’ Dreger has found more practical considerations that were taken on board. Namely

The kind of human hermaphrodite that most excited medical and scientific men was the one who stayed long enough to answer pressing questions - about menstrual signs, nocturnal emissions, family history, sexual desires and acts - but who also dies soon enough that the body could be located and secured, opened and preserved in drawings, photographs, wax replicas, and jars, to satisfy any observer’s curiosity (Dreger, 1998: 52)

Let us now return to the ways that medical and scientific men conceptualised masculinity and femininity, men and women and intersex. Dreger considers this period as a time when there was a concerted effort by biomedical experts to authorise themselves to determine what one’s body meant to one’s identity and a time when intersex became increasingly invisible outside the hospital, clinical and medical journal settings. In the midst of the ‘age of the gonads’ Dreger shows that indeed there was not always a single

perspective on sex, nor a single part of that body that revealed the 'true' sex (Dreger, 1998: 87). Yet, medical and scientific men "still retained the assumption that [the] gonads would somehow make themselves known to the investigator through other traits" (Dreger, 1998: 87). These 'other traits' that medical and scientific experts looked toward included: pubic and body hair, nocturnal emissions, ejaculations, menstruation, breast tissue, the pelvis, the entire skeleton, carnal desires and acts, the voice and even height.

While at the core of these investigations into intersex was the belief in a gonadally determinable 'true' sex, there also existed doubt as to the practical application of this belief. Some experts' attitudes got in the way of making a declaration of 'true' sex. Dreger tells of one French surgeon who "allowed an apparently same-sex union to continue rather than taking on the 'ungrateful role' of destroying a happy marriage by announcing mistaken or doubtful sex" (Dreger, 1998: 124).

Yet this sort of decision did not often go unchallenged (Dreger, 1998: 126). Franciszek Neugebauer (1856-1914) in 1903 "could cite no less than sixty-eight 'marriages between persons of the same sex, in consequence of such erroneous declarations'" (Dreger, 1998: 76). Dreger returns to the point that the pursuit of intersex individuals' 'true' sex was not just to satisfy the need to fit everyone into one of two naturally occurring sexes, but to prevent "accidental homosexuality" (Dreger, 1998: 76). This schema is not however, limited to just the medical and scientific experts of this period; Dreger informs us that "medical doctors, scientists, hermaphrodite's *parents*, and *other lay people* have historically been interested in sorting people according to their sexes to avoid or prevent what might be considered homosexuality" (emphasis added, Dreger, 1998: 8).

Identifying 'mistaken sex' and thereby identifying 'true' sex called into question both sexuality and sex. While heterosexuality was prioritised over homosexuality, being either a male or female was prioritised over being intersex. Herein lies one of Dreger's main points about the 'age of the gonads,' that is the determination of a persons' 'true' sex left less and less people as intersex.

The characterisation of human intersex into three types - male pseudohermaphroditism, female pseudohermaphroditism, and true hermaphroditism - is a theoretical taxonomy that dates back to the age of the gonads (Dreger, 1998: 36). The founder of what Dreger refers to as the constitution of the 'age of the gonads,' was Theodor Albrecht Edwin Klebs (1834 - 1913) (Dreger, 1998: 145). The Tri-nomenclature was categorised thus: If a person is found to have ovarian tissue then they are to be considered a female pseudohermaphrodite. If the person in question has testicular tissue then they would be considered male pseudohermaphrodite. If a person possesses both ovaries and testes, then that person is considered a 'true' hermaphrodite (Dreger, 1998: 36). The result of Klebs' system meant "fewer people counted as 'truly' both male and female, a trend that we see throughout the rest of the period" (Dreger, 1998: 146).

In the late 1890's George F. Blacker (1865-1948) and Thomas William Pelham Lawrence (1850 – 1936) adapted Kleb's system and conceded that a 'true hermaphrodite' could possess ovarian and testicular tissue in the one organ, ovotestes (Dreger, 1998: 147). Their work reassessed previous historical accounts of 'true' hermaphroditism and re-categorised them according to the new gonadally determined system of classification (Dreger, 1998: 146). This final onslaught rendered a large number of potential 'true hermaphrodites' invisible by means of being re-categorised as "spurious" (Dreger, 1998: 149). And ultimately, due to the very nature of determining 'true' sex "the only true hermaphroditism would exist on a microscope slide after the death or castration of the person from whom the sample came" (Dreger, 1998: 150).

3.2 Anthropological Research

Robert Edgerton's pivotal study *Pokot Intersexuality: An East African Example of the Resolution of Sexual Incongruity* (1964) makes two striking claims regarding anthropology in general and intersex in particular. Firstly Edgerton claims that the occurrence of "infrequently occurring phenomenon" (1297) like intersex is not mentioned in the notebook of anthropologists and "have the potential for suggesting and confirming hypothesis about cultural structures and processes" (1297). For Edgerton one 'cultural

structure and process’ is the assumption of normality, in particular the assumption of “a natural and normal world in which there are, and ought to be, biological males and biological females” (1298). In other words by looking at the ways that humans respond to the occurrence of intersex we can tell something about assumptions being made about being human. By taking an anthropological look at intersex I hope to not only add to the historical research reviewed above, but widen the scope of understanding contemporary western intersex.

If intersex has been all too frequently excluded from anthropological notebooks, and subsequently anthropological research, any conclusions are bound by this limitation. Nevertheless in the last forty years since Edgerton’s study, a wealth of anthropological knowledge has been accumulated. Some of this appears to investigate what Edgerton may call ‘infrequently occurring phenomenon,’ such as homosexuality and transgenderism. However, what remains obvious is a dearth of focus on intersex. This section offers a brief overview of the regulation and conceptualisation of intersex in a number of cultures from different geographical and cultural regions through Africa, Asia, Pacific Islands, and the Americas (Table 3.2, Fig. 3.5).

Country/Region	Community	Nomenclature
China	16 th and 17 th Century	‘False males’ and ‘False females’
Dominican Republic	Widespread	Guevedoche or ‘penis at 12’
India	Widespread	Hijras
Indonesia	Alor	Alurkaseni (individual)
Kenya	Pokot	Sererr
North America	Widespread	Two-Spirit
Papua New Guinea	West Sepik	Bimin-Kuskusmin
Papua New Guinea	South-East Highlands	Sambia

Table 3.2 Geographical Distribution of Anthropological Research of Intersex.



Figure 3.5. Community/Country with Examples of Intersex

3.2.1 Native North American

It could be argued that no other well-documented culture appears to have embraced and institutionalised as many sex, gender and sexuality categories as have the many communities of Native North America.

The ground American society occupies once may have been the queerest continent on the planet (Roscoe, 1998: 4)

Native North American communities are now forming new sex, gender and sexuality terms, behaviours and identities. In tandem with the burgeoning new understandings of Native North American communities are re-emerging traditional terms, behaviours and identities. Together they are not only challenging the western concepts of sex, gender and sexuality, but also offer contemporary Native North Americans a map on which to traverse the current psycho-social tensions between the past and present.

One site of tension exists with the nomenclature of 'berdache' or 'two-spirit.' Either has been used as an umbrella term to refer to gender types in a range of communities, extinct

and extant. However, these communities occupy different linguistic, epistemological and socio-political spaces. The term 'berdache' according to Roscoe "has been routinely used by anthropologists since the end of the nineteenth century" (Roscoe, 1998: 120). Williams claims that 'berdache' originated from French explorers who, on seeing the adoption of female dress by males, used the word 'bardache' as the only familiar term, which has clear homosexual implications (Williams, 1992: 10). 'Berdache' however, is seen largely as a derogatory term (Feinberg, 1996: 21; DRK 2000) and one that "does not speak to the many facets of the role" (DRK 2000). However, DRK (2000) supports the position put by Roscoe that by using the term 'berdache' you avoid the confusion over which particular term, behaviour, or identity in the diverse range of expressions is meant. Yet, in response many contemporary Native North American individuals and communities have adopted the term 'two-spirit' as an alternative. 'Two-spirit' is meant to evoke a spiritual essence lost in the term 'berdache' and regain some of the spiritual ground left behind by extinct traditional terms, behaviours and identities. Unlike Roscoe and DRK this research project prefers to employ the 'two-spirit' nomenclature as preferred by the people to whom it refers.

Having said this it must be stated that the term 'two-spirit' does not always translate to intersex (Callender and Kochems, 1983: 443; Roscoe, 1991: 25; Williams, 1992: 10; Herdt, 1993a: 64; Roscoe, 1998: 121). As Roscoe claims

While some berdache may indeed have been individuals born with anomalous genitals, the known incidence of such a condition is too rare to account for their numbers (Roscoe, 1991: 25)

Therefore in the majority of cases the focus of much anthropological research has not necessarily been the physical, but social and spiritual. Two repeated lines of inquiry are whether 'two-spirit' people are considered a "third-gender" and another revolves around the interrelationship between 'two-spirit' people and spirituality. This dualistic focus of anthropological research however, doesn't negate the fact that some references to 'two-spirit' people may indeed include the physically intersex. Williams speculates that some

references may infer “a combination in a physical sense, as in the case of hermaphrodites” (Williams, 1992: 21). Callender and Kochems (1983) and Roscoe (1998) are two examples of studies that provide analyses of cultures that linguistically distinguish between the physically intersex and other ‘two-spirit’ people. In particular the well-documented Navajo classify a special place for intersex people known as Nadle or nádleehí (Hill, 1935 cited in Edgerton, 1964: 1290; Callender and Kochems, 1983: 444; Williams, 1992: 77; Roscoe, 1998: 45).

If Native North Americans occupied the ‘queerest continent on the planet’ it is not surprising then to find examples of communities that provided for a linguistically distinct intersex nomenclature, such as Nadle. Although there is a propensity for anthropological research on Native American communities to focus on ‘third-gender’ and ‘spiritual’ roles there was nevertheless a space in these communities for intersex.

3.2.2 India

In India there is the potential for people to traverse a range of sex, gender and sexuality positions through the social-spiritual role of the ‘hijras.’ If we were to view this role through the lens of a contemporary western lexicon we could arguably find examples of transsexualism, transvestitism, homosexuality and intersex. Yet this translation vastly underestimates the complex and tense social-spiritual position occupied by hijras. This institutionalised social-spiritual role is not without stigma or controversy (Herdt, 1993a: 70).

Serena Nanda (1990) claims that the epistemology and ontology of the hijras in Indian society is multi-layered enabling the role to absorb a wide range of

Temperaments, personalities, sexual needs, gender identities, cross-gender behaviours, and levels of commitment without losing its cultural meaning (Nanda, 1990: 19-20)

Further, the hijras social role implies a certain physical defect impairing the male sexual function (Nanda, 1993: 380), and because mostly men become hijras they must go through an emasculation process whereby their genitals are surgically removed (Nanda, 1993: 383). However, some women who do not develop secondary female sexual characteristics, like breast development and menstruation can become hijras (Nanda, 1990: 15; Nanda, 1993: 380). While it may be tempting to map these experiences within western transexual or transgender lexicon or epistemologies, Nanda insists that the hijras do not see themselves as men or women but rather “not-men” (Nanda, 1990: 115; Nanda, 1993: 381).

This negating of the body through identity, is characteristic of hijras’ de-emphasis on the physical. Nanda claims that the hijras actively negotiate with cultural meanings, experience and organisation of their lives (Nanda, 1990: xxv), such that claims of being born hijras go beyond body experiences, as with transsexual or transgendered experiences. As Nanda explains

Although all hijras say, “I was born this way,” this cannot be taken literally to refer to a physical condition, although it *is* meant to refer to the innate essence of a person, which includes ... physical, psychological and moral qualities (original emphasis, Nanda, 1993: 381)

While the role of hijras ‘cannot be taken literally to refer to a physical condition’ we do find the existence and acceptance of a “small number” (Nanda, 1993: 399) of intersex individuals. Nanda insists that hijras communities do make a distinction between “real” and “made” hijras (Nanda, 1993: 381). With this distinction in place, the role of the hijras expands to allow the inclusion into their communities of children with ambiguous genitals

A child initially assigned to the male sex whose genitals are later noticed to be ambiguously male would be culturally defined as hijras, or potentially hijras (Nanda, 1993: 380-381)

Moreover, Nanda cites a widely held belief that if a child is born intersex, the hijras have a claim to it (Nanda, 1993: 399). Yet Nanda is unable to find any supporting evidence among the hijras who all joined their communities voluntarily (Nanda, 1990: xxiv).

An understanding of the hijras role is interdependent with that of Hinduism in India. The role of hijras is deeply embedded within the spiritual structure of Hindu worship, myth and cosmology. Through worship of the Mother Goddess Bahuchara Mata the hijras are bestowed divine powers through emasculation (Nanda, 1993: 373). Hindu myth incorporates the expression and idealisation of intersex and the representation of sex and gender transgressions. For example, Arjun, a hero of the epic Mahabharata, for a year braids his hair like a woman, dresses in female attire, participates in weddings and births and is portrayed as a vertically divided half-man, half-woman (Nanda, 1993: 375). In the Tantric sect of Hinduism the Supreme Being is conceptualised as one complete sex, containing male and female sexual organs (Bullough, 1976: 266; Nanda, 1993: 377). Bullough goes on to indicate that the gods Shiva, Krishna and Vishnu have all been depicted in hermaphroditic forms (Bullough, 1976: 266).

From these institutionalised positions in worship, myth and cosmology, the hijras role is imbued with a deeply ritualistic position. The divine powers bestowed upon them by Bahuchara Mata enables hijras to perform at and bless weddings and the birth of male children (Nanda, 1990: 1; Nanda, 1990: 4). Yet as Nanda claims the complexity of the role means that their position in society is a tentative one and can be equally viewed in a negative light

[Hijras] are also believed to have the power to curse a family with infertility and misfortune. And while their entertainments and requests for alms include praise, a refusal to pay leads to insults and curses. The ultimate weapon of a hijra is to raise her skirt and display her mutilated genitals, which is a source both of shame and insult for the audience, as well as a curse by which the hijras contaminate the potentially fertile with a loss of reproductivity (Nanda, 1993: 392)

Subsequently it could be argued that perhaps partly because of this inauspiciousness or their “blatant and bawdy flirting with men and their aggressive caricatures of feminine sexuality” (Nanda, 1990: 9) Indian society also mocks and fears hijras (Nanda, 1990: 8). This contradictory view of hijras in India does little to dismiss the role of the hijras. Whether the social-spiritual role engenders blessing or mockery, what is significant is the institutionalisation of intersex within the highly influential practice of Hinduism.

3.2.3 Indonesia

Comparative to other anthropological research, few references exist regarding Indonesia. Intersex has been shown to exist in two communities from the islands of Bali and Alor. According to Bullough (1976) Balinese religion places a high value on Syng Hyang Toenggol, who is a figurative intersex character who represents in Balinese cosmology the time before gods, before the separation of male from female (Bullough, 1976: 24). One Indonesian intersex individual, Alurkaseni, emerges from a study of “homosexuality” by Cora Du Bois (1944) in the east Indonesian Island of Alor.

Alurkaseni’s story is retold through anecdotal evidence told to Du Bois by Alurkaseni’s grandnephew (101) and “Malelaka the Prophet” (305) some twenty years after Alurkaseni’s death. Alurkaseni was raised as a girl named Tilamani, until the age of twelve. Tilamani’s new husband refused to maintain the relationship, because of Tilamani’s incapacity to have children. On return to the family Tilamani was raised as a boy, and renamed Alurkaseni. Trained as a hunter Alurkaseni soon earned great respect and became known for these abilities. At which point Alurkaseni “built himself a house and lived alone. He worked in the fields and cooked for himself. He could pound rice just like a woman” (102). When Alurkaseni was middle-aged the village arranged a marriage (102). Du Bois describes the subsequent situation as thus

Alurkaseni ... was neither a man nor a woman. He didn't have either a penis or a real vagina ... Kolmaukalieta went to live with Alurkaseni as his wife, although they couldn't sleep together (Du Bois, 1944: 305)

While brief and anecdotal this offers insight into the life of at least one intersex individual and how there are attempts to assign this person a position within society.

3.2.4 Papua New Guinea

Anthropological research on intersex in Papua New Guinea has been largely undertaken by Herdt (1987, 1990, 1993b), Herdt and Davidson (1988) and Poole (1981, 1996). The two communities that have been witnessed to include intersex are the Bimin-Kuskusmin of the remote West Sepik interior and the Sambia of the South-Eastern Highlands.

Poole (1981, 1996) claims the Bimin-Kuskusmin have an interrelationship between intersex and their "totemic" ancestors. Afek and Yomnok are two offspring of the original androgynous ancestor Goowpnuuk or Daarkhru (a giant lizard). Both Afek and Yomnok possess a penis-clitoris (*maiyob-mem fuun*) and breasts and are generally identified with the cassowary and spiny anteater (echidna), which are considered to be androgynous also (Poole, 1981: 159-160 n.16). Poole draws attention to how in a society that otherwise pays particular attention to "sharp, pervasive and powerful dichotomous boundaries between female and male" (Poole, 1996: 197) they also employ

Afek'aan maag'maak migiim men ("Afek's double-gendered children") - androgynous images both human and non-human - [who] are culturally elaborated in a number of social contexts and are most significantly embedded in the Bimin-Kuskusmin cultural imagination focused on notions of procreation and maturation and in contexts of myth and ritual in which gender is formed and transformed (Poole, 1996: 198)

The interrelationship therefore between myth and reality is of profound importance for intersex individuals whose physical configurations are seen

As sacred mark[s] of special and auspicious ancestral destiny. Once recognised, the yomnok 'min aiyem is deemed a powerful ritual repository of fertility, is specially initiated, is never allowed to marry or engage in sexual intercourse, and is adorned with special ritual markings distinctive of his [sic] status. The yomnok 'min aiyem becomes a celibate and solitary embodiment of androgyny (Poole, 1996: 209)

Another Papua New Guinea community, the Sambian, is deeply segregated along sex and gender divisions (Herdt and Davidson, 1988: 35). Sambians believe that while women have an innate natural essence, men must undergo oral homosexual inseminations to attain adult manhood (Herdt, 1987: 6). Accompanying these inseminations boys undergo harsh ritualistic initiations at several year intervals beginning at age seven and ending with marriage. At this point men are considered fully initiated (Herdt and Davidson, 1988: 36).

While Sambians focus on the division of the sexes, intersex individuals are incorporated within their society. Herdt claims that there is a “genetically high ratio of pseudo-hermaphroditism in the Sambian population (it is many times higher than in our society)” (Herdt, 1987: 86). Moreover, according to Herdt Sambians have created a third-sex category. This socially based category is regarded as neither male nor female, and is based on the genitals and other characteristics necessary to differentiate among the three sexes (Herdt, 1993b: 420). Known as kwolu-aatmwol, which infers a person’s “transforming into a male thing” (Herdt, 1993b: 436). The transformation indicates how the infant’s genitals are feminised at birth, and this intersex individual would be raised as female (Herdt, 1987: 86; Herdt and Davidson, 1988: 34). During puberty however, there is some virilisation and a slow development of secondary sex characteristics (Herdt and Davidson, 1988: 34).

As noted above all men progress through a specific initiation culminating with marriage (Herdt, 1987: 111). However, these rigorous ‘rites-of-passage,’ are designed such that intersex individuals are prevented from attaining full initiation and thus acquiring equal status with Sambian males (Herdt and Davidson, 1988: 41). In particular, intersex individuals are by-passed for initiation beyond the second stage (Herdt, 1993b: 438-439).

At a glance the Bimin-Kuskusmin and Sambian gender and sex systems seem a simple matter of separating and segregating the sexes. Yet the ways that Bimin-Kuskusmins and the Sambians institutionalise intersex is a clear indication of the complexity that lies beneath the surface of these cultures. While the Sambians tend to restrict full status to intersex individuals, by establishing an interrelationship with mythic beings and a third sex category the Bimin-Kuskusmins and the Sambians have incorporated intersex as another social category within their societies.

3.2.5 The Dominican Republic

Debate appears to surround the anthropological research regarding intersex in the Dominican Republic. An initial study conducted by Imperato-McGinley et al (cited in Herdt, 1993b: 429) has been heavily critiqued by Herdt (1993b). While neither research denies the existence and subsequent significance of intersex, the study by Imperato-McGinley et al works within a binary sex and gender framework, while Herdt proposes that a ‘third-gender’ exists.

In the ethnographic and anthropological literature the Dominican Republic is known for the occurrence of a rare form of intersex known as 5-alpha reductase deficiency syndrome. In general, not dissimilar to the Sambian kwolu-aatmwol, genetic males are feminised at birth and most raised as girls until puberty when virilisation occurs. Imperato-McGinley et al’s initial investigation concluded that at this point “‘in a laissez-faire environment, when the sex of rearing is contrary to the testosterone-mediated biological sex’ the biological sex will prevail and ‘override’ the social environment’s

gender socialization” (Imperato-McGinley et al cited in Herdt, 1993b: 426). That is, at puberty these girls will henceforth be raised as men.

Yet Herdt’s work has led to an alternative interpretation of these findings. Herdt’s conclusion is contrary to Imperato-McGinley et al’s employment of a binary sex and gender framework to understand the Dominican Republic’s intersex. Herdt claims therefore that the Dominican Republic has not only provided a word for individuals with 5-alpha reductase deficiency syndrome, known as *guevedoche* or “penis at 12,” but they have also established a third-sex/-gender role (Herdt, 1993b: 428). Unfortunately Roughgarden (2004) reports that medical doctors since have intervened and provided these communities with technology such that they can determine these individuals at birth and raise them as boys/men, and thus “the social category of *guevedoche* is now extinct” (2004: 386).

3.2.6 Kenya

Anthropological research of intersex on the African continent has been largely absent since Edgerton’s widely cited study on the *sererr* of the Kenyan Pokot (1964). Edgerton’s ethnographic interviews draw attention to the lives of Cheporr and Lazaro whose experiences seem “characteristic of other known intersex Pokot” (Edgerton, 1964: 1291). From these lived experiences Edgerton exposes a complex and contradictory society in regards to the regulation and conceptualisation of intersex.

The term ‘*sererr*’ means “male and female yet neither male nor female” (Edgerton, 1964: 1292), moreover, Edgerton claims that the word is not necessarily reflective of a positive position in Pokot society. While intersex individuals may be revered as “God’s wish” (Edgerton, 1964: 1291), the term is sometimes used as an insult (Edgerton, 1964: 1292) or intersex individuals are seen as freaks and consequently put to death (Edgerton, 1964: 1291).

Two socially significant facts may well link intersex with this tentative position in Pokot society: First, being the fact that among the Pokot “traditional dress exposes the genitals continually” thus one’s intersex status is unable to be hidden (Edgerton, 1964: 1294). Second, intersex individuals are unable to participate in the critical ‘rites-of-passage,’ such as sex-play, circumcision and reproduction necessary for members of Pokot society to reach maturity (Edgerton, 1964: 1295).

In contrast to these practicalities is a belief system that appears to care for intersex individuals. The Pokot have a belief in the omniscient being called Torurut, whose power extends to the condemnation of putting intersex children to death (Edgerton, 1964: 1295-1296). Despite the institutionalisation of this belief system anecdotal evidence provided through Edgerton’s interviews indicates that putting intersex infants to death can be easily justified by simply statements such as “these children are *not* the will of torurut” (original emphasis, Edgerton, 1964: 1296).

Intersex individuals, who survive infanticide, are able to obtain status in society through hard physical work and accumulation of wealth (Edgerton, 1964: 1296) as the life histories of Cheporr and Lazaro attest.

3.2.7 Sixteenth and Seventeenth Century China

According to Furth (1993) there is evidence of intersex in China during the sixteenth and seventeenth centuries. A systematic categorisation and study of ambiguous births in medical and informal literature (480) Furth argues can be categorised alongside the contemporary intersex (489). Reflections on intersex were used to understand certain aspects of daily life by authors, historians, medical writers, and philosophers. This research provides insights into reproductive health, cosmology and the gender system of the day (Furth, 1993: 480).

Furth uncovers a reference in Li Shih-chen's *Systematic Materia Medica* to the Chinese categorisation that distinguishes five types of 'false females' and five types of 'false males' (Table 3.3).

	False Males	False Females
1	'natural eunuch'	'corkscrew'
2	'bullock' (castrated)	'striped'
3	'leaky'	'drum'
4	'coward'	'horned'
5	'changeling'	'pulse'

Table 3.3 Categorisation of 'false males' and 'false females' in C16-17 China

Of the 'false female,' only one is not related to genital abnormalities: the 'pulse' refers to irregular menses. The 'drum,' was popular in folklore and known as 'stone maiden' and involved an impenetrable hymen (cited in Furth, 1993: 481-482). Furth goes on to state that in everyday language the name 'stone maiden' could not only refer to a range of genital abnormalities but also was used in popular idiom as a figure of fun, an old crone or termagant wife (Furth, 1993: 491). Of the 'false males' only one, the 'changelings,' are said to be 'two forms' endowed with abilities "that echos [sic] old Chinese legends of hermaphrodites as fantastic beings with superabundant erotic capabilities" (Furth, 1993: 482).

In regards to broader Chinese conceptualisations the appearance of figurative and metaphoric intersex was not uncommon. In particular, conceptualisations of sex and gender were based on the Chinese cosmology of Yin and Yang whereby, "sexual difference [is] a relative and flexible bipolarity in natural philosophy" (Furth, 1993: 479). Moreover, this "natural philosophy would seem to lend itself to a broad and tolerant view of variation in sexual behavior and gender roles" (Furth, 1993: 481). This would appear to indicate an inclusion of intersex as a naturally occurring phenomenon, as Furth claims "the physically anomalous person is fully human" (Furth, 1993: 482). Yet Furth states that the only description of an intersex infant is that found in a short story which "demonstrates the social impossibility of intermediate status" (Furth, 1993: 490).

In sixteenth and seventeenth century China a flexible natural philosophy institutionalised a nomenclature of five types of ‘false’ women and men. This categorisation and the inference made by Furth that intersex were ‘fully human’ offers evidence to suggest that the Chinese offered a socially regulated and conceptualised intersex status.

Conclusion

This overview of historical and anthropological research indicates a large array of regulations and conceptualisations of intersex and intersex individuals. At times the evidence is hidden in history, contradictory, influenced by the ‘beliefs and biases’ of the researchers, and perhaps ‘underestimated.’ However, what remains constant is that intersex occurs in a wide range of socially embedded ways throughout history and across cultures.

Historical research has revealed that intersex has been worshipped as a figurative deity and revered as a mythic creature. Intersex individuals have been abandoned as a sign of evil, deemed a natural part of the human sex continuum, permitted to choose a gender and marry, charged with sodomy, accepted by familiars, and pathologised. Since there is a dearth of anthropological research, which is at times contradictory, what is necessitated is further research before any conclusive statements can be unequivocally made. However, in the interim we can, albeit cautiously, conclude that in at least seven communities, across a number of geographical regions, intersex is regulated and conceptualised into a myriad of socially embedded categories, that perform mythic, cosmological, spiritual, and ritualistic roles. But, no matter the reaction, react we have. Whether negative or positive, historically or cross-culturally, we have pursued knowledge that has somehow and by some means attempted to find *a place* for intersex and intersex individuals in society.

CHAPTER 4: MEDICINE AND INTERSEX

Introduction

- 4.1 Categories of Intersex
- 4.2 Contemporary Diagnosis of Intersex
- 4.3 Contemporary Treatments of Intersex
- 4.4 The Medical Encounter
- 4.5 Surgical Intervention and Intersex

Conclusion

Introduction

A medicalised discourse of intersex as pathology has dominated the conceptualisation of intersex in the twentieth and twenty-first centuries. This contemporary view of intersex has been inherited from its historical antecedents, such as the ‘age of gonads’ as discussed in Chapter 3. Under review in this chapter therefore are the ways in which the medicalisation has coalesced into the current intersex medical management, namely, categorisation, diagnosis and treatment of intersex. Further, I investigate how intersex individuals and parents of intersex individuals are advised, and the assessment and ‘follow-up’ procedures in place. Presently however, I wish to draw attention to a shift in terminology. Hitherto emphasis has been placed on the term ‘intersex’ as an appropriate nomenclature, in the medical view ‘intersex condition’ is more prevalent. In addition those whom I have referred to as ‘intersex individuals’ are most often referred to as ‘patients.’

4.1 Categories of Intersex

As I indicated in the previous chapter a tri-nomenclature system of classification was inherited from Theodore Klebs in the late nineteenth century including true hermaphrodites, male pseudo-hermaphrodites and female pseudo-hermaphrodites (Preves, 2003: 26). Over the past hundred years this taxonomy has expanded and the demarcation of intersex is such that we are now aware of many more intersex conditions.

Within the literature intersex had been widely considered as a relatively rare occurrence. Recent investigations into frequency ratios have called this into question. So how common are intersex conditions? Intersex is more common than is publicly thought. An oft-quoted survey of the medical literature from 1955 to 1998 by Blackless et al (2000) has suggested, “1.7% of all live births do not conform to a Platonic ideal of absolute sex chromosome, gonadal, genital, and hormonal dimorphism” (161). In Fausto-Sterling’s report of this same study the caution is raised that this “should be taken as an order-of-magnitude estimate rather than a precise count” (2000: 51). Indeed, it is an “average from

a wide variety of populations, the number is not uniform throughout the world” (Fausto-Sterling, 2000: 53).

The subsequent intersex literature rounds this 1.7% into either 1% or 2% of the population (Frequency, 2002; Dreger, 1998: 42; Kessler, 1998: 135n4; Hausman, 1995: 204n32), or provides a more conservative estimate. In addition, the incidences of ambiguous genitalia at birth that may or may not receive surgery also fluctuates between either 1 in 1,000, 2 in 1,000 (Frequency, 2002; Briffa, 2003a) or 1 in 2,000 (Toomey, 2001: 38; Philips, 2001: 38; Lilford and Dear, 1987 cited in Blackless et al, 2000: 161). To demonstrate this relatively high frequency some authors juxtapose these statistics with other more widely known conditions: cystic fibrosis (1 in 2,500) (Toomey, 2001: 38; Dreger, 1998: 43) and albinism (1 in 20,000) (Fausto-Sterling, 2000: 53).

Felicity Haynes in *Unseen Genders* (2001: 4) states that there are over 70 multiple variations of morphic evidence of intersexualities. Conte and Grumbach (1989, cited in Fausto-Sterling, 2000: 277 n. 15) also have established a demarcation of different conditions. According to the Intersex Society of North America’s website the more commonly occurring intersex conditions include: Androgen Insensitivity Syndrome (AIS), Congenital Adrenal Hyperplasia (CAH), 5-Alpha-Reductase Deficiency (5-ARD), Klinefelter’s Syndrome (47XXY), Turner’s Syndrome (45XO) (ISNA, 2002) and Fausto-Sterling adds Hypospadias to this list (Fausto-Sterling, 2000: 51).

4.1.1 Androgen Insensitivity Syndrome (AIS)

Androgen Insensitivity Syndrome (AIS) is an inherited genetic condition (Fausto-Sterling, 2000: 52) occurring in between 1 in 13,000 (ISNA, 2002) and 1 in 20,000 individuals (Haynes and McKenna, 2001: 215). AIS can be either in a complete (CAIS) or partial (PAIS) form (Blackless et al., 2000: 153). AIS individuals possess XY sex chromosomes, and are insensitive to testosterone (O’Keefe, 1999: 36). Because of their inability to react to testosterone the external genitals are typically feminised (Dreger, 2000: 38). Internally, people with AIS possess undescended testes (Preves, 2003: 28) that

have a relatively high chance of becoming cancerous (Dreger, 2000: 38), but not until after puberty (Fausto-Sterling, 2000: 65). AIS individuals are raised as girls (Haynes and McKenna, 2001: 215) and usually develop a female gender identity (Fausto-Sterling, 2000: 64). Hines et al (2003) report that

CAIS women in our study reported female-typical gender identity, heterosexual erotic interests, and female-typical gender role behavior in adulthood. They were as likely to be married or living with a male partner as female controls. We also found that they were conventionally feminine in personality characteristics (Hines et al, 2003: 97-98)

At puberty AIS individuals develop some secondary feminised sex characteristics, breast development, pubic and axillary hair distribution and feminine body shape (Dreger, 2000: 38). However, menstruation does not occur (Haynes and McKenna, 2001: 215). Internally the AIS individual does not possess a uterus, fallopian tubes, cervix or upper part of vagina, nor do they possess epididymis, vas deferens, or seminal vesicles (Haynes and McKenna, 2001: 215). Consequently they are infertile (Haynes and McKenna, 2001: 215).

Partial AIS is said to occur in 1 in 130, 000 individuals (ISNA, 2002). Partial AIS individuals will have the partial ability to react to testosterone and will have ambiguous external genitals: phallic tissue larger than a clitoris but smaller than a penis, and a partially fused labia/scrotum. Partial AIS individuals will undergo feminised breast development at puberty, along with a small amount of pubic and axillary hair (HealthyPlace, 2000a). If AIS is diagnosed in infancy a number of procedures may be performed: removal of testes, vaginoplasty, and/or either complete or partial clitorrectomy.

According to the ISNA web site (2002) the mother of an AIS individual is a carrier with her XY children having a 50 percent chance of being an AIS individual. Most AIS individuals should be able to locate other AIS individuals among siblings or maternal

relatives. Some AIS individuals or families with AIS individuals have sought a prenatal diagnosis to determine the likelihood of passing AIS onto children. At 9-12 weeks gestation AIS can be determined by chorionic villus sampling (sampling tissue from the foetal side of the placenta). By the 16th week it can be detected by ultrasound and amniocentesis.

4.1.2 Congenital Adrenal Hyperplasia (CAH)

Congenital Adrenal Hyperplasia (CAH) is a genetically inherited condition (Haynes and McKenna, 2001: 215) whereby one or more of six enzymes involved in the making of steroid hormones fail. CAH occurs in between 1 in 13,000 births and 1 in 20,000 births (Haynes and McKenna, 2001: 215). Most CAH individuals have an XX karyotype with either an enlarged clitoris or near complete masculinisation of external genitals (Preves, 2003: 27), with ovaries (Dreger, 2000: 38) and other typical female internal organs allowing reproduction (Preves, 2003: 27). Surgical intervention involves the feminisation of external genitals, for example, a clitorectomy and/or vaginoplasty.

Unlike most intersex conditions CAH's inhibition of salt metabolism may consequently be life threatening and require treatment with cortisone. There are many grades of CAH, 80% are "salt losing CAH" requiring "urgent treatment as a potentially life threatening condition" (Conway, 1999). CAH is detectable in-utero and according to Fausto-Sterling is the only preventable intersex condition

The genes that cause CAH are well characterized, and several approaches to detecting their presence in the embryo now exist. A woman who suspects she may be pregnant with a CAH baby (if she or someone in her family carries CAH) can undergo treatment and then get tested. I put it in that order, because to prevent masculinization of an XX-CAH child's genitalia, treatment (with a steroid dexamethasone) must begin as early as four weeks after conception. The earliest methods for diagnosis, however, can't be used until the ninth week. For every

eight fetuses treated for CAH, only one will actually turn out to be an XX child with masculinized genitals (Fausto-Sterling, 2000: 54-55)

Fausto-Sterling states that treatments prevent “premature growth stoppage and extremely early puberty” (2000: 55) and allows CAH individuals “to become fertile females in adulthood” (2000: 59). However, cortisone produces significant dependence and other side effects, and is not usually recommended because it has not been established in rigorously controlled trials (2000: 55).

4.1.3 5-alpha-Reductase Deficiency

While 5-alpha-reductase deficiency (5-ARD) appears to be relatively common in certain populations as discussed in Chapter 3, there appear to be no gene or population frequencies available (Blackless et al, 2000: 153). 5-ARD is a result of the inability to convert prenatal testosterone into dihydrotestosterone because of a lack of the enzyme 5-alpha reductase. Consequently individuals are born with feminised genitalia: what appears to be a clitoris, labia and small vagina (O’Keefe, 1999: 39). At puberty 5-ARD individuals no longer require dihydrotestosterone and rely solely on testosterone to masculinise the genitals (Dreger, 2000: 39). That is, 5-ARD individuals experience an increase in muscle mass, a lowering of the voice, growth of the penis, sperm production and some pubic and axillary hair growth, but little or no facial hair growth.

4.1.4 Klinefelter’s Syndrome

Klinefelter’s Syndrome individuals have a 47-chromosome configuration karyotype 47 XXY. The extra X chromosome may come from either parent. Other less common variations include 48,XXYY; 48,XXXY; 49,XXXXY; and XY/XXY mosaic (Author Unknown, 2003). The frequency of Klinefelter’s Syndrome is reported to be between 1 in 500 and 1 in 1, 000 males (Frequency, 2002; www.genetic.org, 2003; Medical Questions, 2002). These individuals present less than average masculinised characteristics and usually there is some feminisation at puberty, such as breast growth

(O'Keefe, 1999: 38; Kessler, 1998: 167; HealthyPlace, 2000a). They have less than average testicles and penis, no sperm production and atrophied vas deferens (Bucar, 1999; HealthyPlace, 2000a; Kessler, 1998: 167; O'Keefe, 1999: 38). Other characteristics, according to www.genetic.org (2003) include: being tall, having decreased facial hair, and an increased risk for speech and language problems that may lead to shyness and low self-esteem. There are no universal treatment programmes due to lack of research and variability of condition (<http://47xxy.org/>, 2003). For most, testosterone levels will be low, as such Hormone Replacement Therapy (HRT) will be prescribed to mimic natural testosterone cycles (<http://47xxy.org/>, 2003). HRT can be administered through intramuscular injections, skin patches, gels, implanted pellets or oral pills (<http://47xxy.org/>, 2003).

An informal Internet survey of 66 people with Klinefelter's Syndrome by Bill Bucar (1999) (Table 4.1) found that people with Klinefelter's Syndrome tended to be non-heterosexual (66.7%), male (84.8%), University educated (60%) and employed (72%).

4.1.5 Turner's Syndrome

While Fausto-Sterling implies that Turner's Syndrome individuals are commonly said to lack an X chromosome (2000: 52), and therefore possess a 45 XO karyotype, O'Keefe suggests that Turner's Syndrome individuals may in fact include a combination of chromosomal configurations: XO, XX and XY (1999: 37). Occurring in 1 in every 2,500 births (Abramsky et al, 2001: 463; ERC, 2001), the characteristics of Turner's Syndrome individuals include: short stature (Fausto-Sterling, 2000: 52; O'Keefe, 1999: 37; Abramsky et al, 2001: 463), incomplete ovaries (Fausto-Sterling, 2000: 52; O'Keefe, 1999: 37), webbed neck, and sometimes heart problems and educationally slow (O'Keefe, 1999: 37). Further, Abramsky et al notes that Turner's Syndrome is common at conception but 98% of foetuses are miscarried (2001: 463).

Characteristic	Variable	Statistic
Karyotype	47XXY	89.4%
	46XY/47XXY	6.7%
Sexual Orientation	Non-adult	4.5%
	Heterosexual	39.7%
	Homosexual	33%
	Bisexual	21.7%
	Transsexual	6%
Gender Identity	Male	84.8%
	Female	4.8%
	Intersexual	9.5%
	Unsure	3.2%
Education	University	60%
	High School	20%
	Never Completed H.S.	10%
	Still in School	10%
Occupation	Professional	32%
	Technology	30%
	Self-Employed	10%
	Unemployed	4%
	Disability	6%
	Retired	8%

Table 4.1 Results from survey of report of Klinefelter's Syndrome by Bill Bucar (1999)

4.1.6 Hypospadias

Hypospadias is a condition whereby the urethral opening or meatus on a male-type penis is not positioned directly at the tip of the glans. In severe forms the meatus can be found anywhere along the shaft of the phallus and even at its base, hence causing difficulties with urination. A study of men who were admitted to hospital for non-hypospadias related conditions, indicates that only 55 percent of men have a meatus that opens in the 'normal' position (Kessler, 1998: 42, Fausto-Sterling, 2000: 57). Many of the 45 percent never realised they were urinating differently (Fausto-Sterling, 2000: 57). The most

commonly performed penile surgery is for hypospadias (Kessler, 1998: 49-50) with up to 300 different procedures being described in the medical literature (Fausto-Sterling, 2000: 62). According to Fausto-Sterling

Except for the most minor forms of hypospadias all involve extensive suturing and, on occasion, skin transplants. A male-assigned child may receive as many as three operations on the penis during the first couple of years of life, and even more by the time puberty hits. In the most severe cases, multiple operations can lead to densely scarred and immobile penises, a situation one physician has dubbed “hypospadias cripple” (2000: 62)

Kessler reports that the rate of hypospadias is 1: 200 male births, yet more rarely 1: 10,000 births the hypospadias is an indication of an underlying intersex condition (Kessler, 1998: 42), the Androgen Insensitivity Syndrome Support Group Australia (AISSG, 2001) indicates that 1 in 2,000 births have hypospadias.

4.2 Contemporary Diagnosis of Intersex

Diagnosis of an intersex condition can occur at any time in a person’s life: prenatally (e.g. CAH and AIS), at birth (e.g. hypospadias), during puberty (e.g. 5-ARD) or in adult-life (e.g. Klinefelters syndrome and AIS). However, the medical literature appears to be dominated by references to at-birth diagnosis. This section explores the criterion that the medical profession uses to diagnose intersex conditions, paying particular attention to at-birth diagnosis, where there is a propensity for diagnosis based on the observation of at-birth ‘ambiguous genitalia.’

Most fetuses and babies with an extra sex chromosome are not identified because there are usually no indications for karyotyping. However, a sex chromosome anomaly is sometimes detected prenatally when amniocentesis is performed to exclude Down’s syndrome or other serious chromosomal anomalies (Abramsky et al, 2001: 463).

According to Fausto-Sterling several approaches to detecting the presence of genes that cause CAH in the embryo now exist (2000: 54).

The phrase “ambiguous genitalia” is often used in the medical literature to refer to the genitals of intersex infants. However, as Kessler insists “ambiguous genitals are described ambiguously” (1998: 33). Like most intersex conditions the occurrence of ‘ambiguous genitalia’ rarely poses a threat to a child’s life yet it is referred to as a “social emergency” (Meyers-Seifer and Charest, 1992 cited in Dreger, 2000: 162; Coran and Polley, 1991 cited in Holmes, 2002: 159; Crouch, 1999: 30), a “neonatal psychosexual emergency” (Kessler, 1998: 34) and a “neonatal psychosocial emergency” (McGillivray, 1992 cited in Holmes, 2002: 159).

When ‘ambiguous genitals’ are observed, a team of experts is immediately assembled (American Academy of Pediatrics, 2000: 141; HealthyPlace, 2000b; Rangescroft et al, 2001) consisting of paediatricians, endocrinologists, gynaecologists, urologists, geneticists, and psychologists, to assess the infants’ “true sex” (Dreger, 1998: 29), for whom immediacy and accuracy of the diagnosis is paramount (Kessler, 1998: 15; Diamond and Sigmundson, 1997b: 1046). The process of diagnosing and subsequent assignment of ‘true sex’ involves the employment of a variety of techniques (Diamond and Sigmundson, 1997b: 1046; Kessler, 1998: 18; Fausto-Sterling, 2000: 56; American Academy of Pediatrics, 2000: 138; Radio National, 2002/2003) and may take months to complete (Kessler, 1998: 19; Fausto-Sterling, 2000: 57). Techniques that involve the examination of an infant’s internal organs and chemistry include cytologic screening, chromosome analysis; assessing serum electrolytes; hormone, gonadotropin, and steroid evaluation; digital examination; and radiographic genitography (Kessler, 1998: 18). Examination of an infant’s external appearance includes an evaluation of the size and shape, absence or presence of the genitals.

Despite the ambiguity surrounding the phrase ‘ambiguous genitalia’ some contemporary physicians employ quantifiable measurements to assist in assignment of a ‘true sex.’ However, historically, these measurements have not been available for both sexes. While

a 1916 medical text gave size ranges for penises and testicles, it is not until the 1980's that clitoral values appeared (Kessler, 1998: 42). Despite the presence of quantifiable standards, according to Kessler, other contemporary physicians: "are more likely to refer to the average clitoris in food terminology, such as a pea or small bean" (1998: 43). These contemporary, albeit sporadically applied, standards - what the intersex movement sardonically refers to as "phall-o-metrics" (Fausto-Sterling, 2000: 59) - are based primarily on the size of the phallic tissue. A 'clitoris' must be between .2 and .85 centimetres in length; and, a 'penis' must be between 2.5 and 4.5 centimetres (Kessler, 1998: 43). Leaving those with phallic tissue of lengths between .9 to 2.4 centimetres in "phallic limbo" (Fausto-Sterling, 2000: 60) and susceptible to surgery.

Size is not the only thing that matters. A small penis, or micropenis, is not just simply a small phallus, it must have a urethra and a meatus (Kessler, 1998: 41). The positioning of the meatus is rigorously policed, the determination of which "requires waiting until the baby voids" (American Academy of Pediatrics, 2000: 139). As mentioned above, according to Fausto-Sterling (2000: 57), the ideal penis is regarded as having a urethra opening at the very tip of the glans, and any position contrary to this is designated the medical term "hypospadias." Hypospadias is consequently "treated by constructing a new urethra through to the tip" (Dreger, 1998: 184) even though only 55% of men are considered 'normal' (Kessler, 1998: 42).

There is evidence to suggest that some physicians do not assign a 'true sex' solely on basis of the physical appearance of the patient, but the decision is influenced by social factors. In Kessler's study of six physicians it is indicated that the decision to assign a child one sex or the other was ultimately guided by the team coordinator's field of speciality (1998: 27). Fausto-Sterling (2000) describes two functional assessments considered in the process of determining phallus adequacy: Young boys should be able to pee standing up and thus 'feel normal' during little-boy peeing contests; and, adult men, need a penis big enough for vaginal penetration during sexual intercourse (57). Moreover, when the medical literature refers to the appearance of the penis, there is regular mention of its appearance in "locker room" (Kessler, 1998: 69).

For the American Academy of Pediatrics, concern is with fertility potential, capacity for normal sexual function, endocrine function, and malignant change (2000: 139-140). It must be noted that in 2002, Robert Blizzard critiqued the American Academy of Pediatrics (AAP) guidelines. Blizzard's assessment of these and other recently published works concerning the treatment of intersex conditions draws attention to the continual need to remain aware of changes to these protocols: "In my opinion, one should be cautious about using the currently published AAP guidelines without knowing that more recent guidelines exist and may be preferable" (2002: 620).

4.3 Contemporary Treatments of Intersex

After infants, adolescents or adults are diagnosed with an intersex condition, the medical profession will prescribe any number of surgical and/or hormonal treatments. Not unlike the diagnosis of intersex conditions, the decision to recommend a particular treatment is not outlined by a universally accepted set of guidelines. Therefore, these decisions can be based on any number of contributing factors. For example, 90 percent of these infants are assigned the female sex. This highly skewed assignment of sex is attributable to a limitation in surgical techniques, as one physician expressed it: "you can make a hole but you can't build a pole" (Chase, 1998a: 192; Holmes, 2002: 169; Preves, 2003: 56).

4.3.1 Hormones

In cases when an infant has a micropenis, and is assigned male, hormones may be prescribed to boost the growth of the penis. However, these children do not have a secondary growth at puberty and the adult is left with the same-sized penis as they had as a child (Kessler, 1998: 68).

Endocrine treatments assist in the development of masculinised and feminised characteristics in individuals assigned the male and female sex respectively. For individuals assigned male, hormones will encourage increased penis size, hair

distribution and body mass. For those assigned female they will encourage breast development, and menstruation can occur for some individuals following estrogen treatment (HealthyPlace, 2000b). Further, hormones must be taken throughout life, because individuals raised as male will need to maintain masculinised sexual characteristics, and for individuals raised as female these hormones will protect against osteoporosis and cardiovascular disease (HealthyPlace, 2000b).

Individuals with Klinefelter's Syndrome usually have low levels of testosterone, as discussed above. One common treatment protocol

Involves administering depot testosterone, a synthetic form of testosterone, by injection once a month. The dose gradually needs to be increased and given more frequently as the boys get older. Treatment should result in normal progression of physical and sexual development, including pubic hair growth, an increase in the size of the penis and scrotum (but not the testes), beard growth, deepening of the voice, and increase in muscle bulk and strength (Author Unknown, 2003)

Individuals with the more common form of CAH, that is, 'salt losing CAH,' are considered in "adrenal crisis" (Conway, 1999), and hence need "very urgent treatment" (Conway, 1999). According to Conway

The object of cortisol treatment in CAH is to replace inadequate production of cortisol by the adrenal glands allowing the body to recognise normal levels of cortisol in the body, which reduces the need of the adrenal gland to produce excessive amounts of testosterone (Conway, 1999)

4.3.2 Surgery

After a diagnosis has been made and the 'true sex' determined, a surgical procedure will be prescribed to construct the genitals to conform to the expected appearance of typical male or female genitals. According to the Intersex Society of North America (ISNA)

website the “total number of people receiving surgery to ‘normalize’ genital appearance is one or two in 1,000” (ISNA, 2002). As discussed in Chapter 2 ‘normalising’ surgery is predicated on John Money’s Gender Role theory, that assumes that a child cannot grow up successfully as a male or female unless their genitals corresponds to what is traditionally expected of males: penis, scrotum, and testes; and females: clitoris, labia and vagina.

The medical literature is populated with numerous surgical procedures. However, it is imperative to detail some of these that dominate the current medical management of intersex. Few terms are universally employed to refer to the surgical procedures. ‘Genitoplasty’ refers to any surgery on the genitals, ‘clitoroplasty’ and ‘phalloplasty’ both refer to surgery on the phallic tissue, for individuals being assigned a female sex either of these two terms may be used. If the individual is being assigned a male sex then only ‘phalloplasty’ is employed. Clitoroplasty may be accompanied by surgery on the labial-scrotal tissue, called ‘monsplasty’ or ‘labioplasty’ (Kessler, 1998: 47). It is also important to remain mindful that, according to Fausto-Sterling: “From 30 to 80 percent of children receiving genital surgery undergo more than one operation. It is not uncommon for a child to endure from three to five such procedures” (2000: 86).

As reported above, because of the difficulty of constructing penises (phalloplasty) only ten percent of infants born with ambiguous genitals are assigned to the male sex. When assigning individuals to a male sex, the most readily accessible issue is not reported as a health issue. Fausto-Sterling states what is of central concern is “how the penis functions in *social interactions*” that is, “whether it ‘*looks right*’ to other boys, whether it can ‘*perform satisfactorily*’ in (*heterosexual*) intercourse” (emphasis added, 2000: 58). These are social considerations that are inherently in keeping with the aforementioned gender role theory.

Phalloplasty may involve any number of procedures employed when physicians encounter penises that are bent, buried in an abnormally developed prepuce, or with the glans not proportional to the shaft. However, the large majority of surgeries involve the

repositioning of the urethral opening to the tip of the glans (Kessler, 1998: 49). Fausto-Sterling reports that: “there are over 300 surgical ‘treatments’ described in the medical literature for hypospadias ... A male-assigned child may receive as many as three operations on the penis during the first couple of years of life, and even more by the time puberty hits” (2000: 62).

As previously stated it has been often said “you can make a hole but you can’t build a pole” (Chase, 1998a: 192; Holmes, 2002: 169; Preves, 2003: 56). The socially considered decision to assign an infant with ambiguous genitals as male is based on an assessment of ‘social interactions,’ ‘looking right,’ ‘performance’ and ‘heterosexuality. Female’s genitals are also aesthetically assessed. The ‘phallo-metric’ standards mentioned above, while not universally adopted, indicate this preference for visually acceptable genitals as prescribed by the gender role theory. Kessler illustrates: “One physician who has operated on intersexed infants for over twenty years was not [aware of the ‘phallo-metric’ standards] - he told an interviewer that ‘overall appearance is most important’” (Kessler, 1998: 43). While the emphasis is on the aesthetic, it is a skewed emphasis. There are many more surgical procedures to alter the appearance of *the clitoris* than there are to alter the appearance of *the labia*. Compared to discussions surrounding clitoral appearance labia variation seems to be more permissible: “Texts say that the labia should not be completely fused, but a minor degree of posterior fusion is tolerable, and the labia majora are not required to completely cover the minora” (Kessler, 1998: 44).

Three surgeries to alter the appearance of the clitoris include: clitorectomy (clitoridectomy); clitoral reduction; and, clitoral recession (resection). In the “early days of surgical treatment” clitorectomies were more common, because doctors reasoned that female orgasms were vaginal not clitoral (Fausto-Sterling, 2000: 61). Further, all erectile tissue was amputated because of complications associated with tissue sloughing (Kessler, 1998: 47). By the 1960’s, understanding of the female orgasm shifted, such that physicians attempted to reduce the clitoris. In this operation the surgeon cuts the shaft of the elongated phallus, sometimes with wedge incisions, and sews the preserved glans and two dorsal nerves back onto the stump (Fausto-Sterling, 2000: 61; Creighton and Minto,

2002). The third procedure clitoral ‘recession’ or ‘resection’ reinforces the notion of ‘looking’ (Kessler, 1998: 45). This technique does not involve any amputation at all. The surgeon hides the clitoris under a fold of skin (Kessler, 1998: 45; Fausto-Sterling, 2000: 61).

I have already stated that there is some tolerance to variations in labial structures, and that the majority of focus is on clitoral size and appearance. However, some intersex females are born with incomplete, imperfect, or absent vaginas (Kessler, 1998: 48). More specifically, in its place there is typically a small pouch or dimple that is 1 to 4 cm in depth (Foley and Morley, 1992: 73). Known as ‘vaginal agenesis’ it occurs in between approximately 1: 5,000 and 1: 7,000 female births (Foley and Morley, 1992: 73). According to Foley and Morley 90% of individuals with vaginal agenesis fulfil the criteria for Rokitansky-Kuster-Hauser syndrome, whereby they possess a 46, XX karyotype, functioning ovaries and in except for about 5% of people an absent uterus (1992: 73).

Vaginoplasty is one of the most common surgeries performed on intersex individuals (Fausto-Sterling, 2000: 86). Two methods exist to create a neovagina. One, the nonsurgical Frank procedure, was developed in 1938, and involves the gradual dilation of the vagina (Foley and Morley, 1992: 74; Kessler, 1998: 49). The other surgical procedure is called McIndoe split-thickness skin-graft vaginoplasty. The neovagina is lined with the individuals’ own skin either from the abdomen, intestine or buttocks (Kessler, 1998: 49). Variations in the method include using the internal cavity that already exists, while others create a semiexternal sheath from partially sutured labia (Kessler, 1998: 49).

4.4 The Medical Encounter

Some within the medical profession profess to fully inform their patients and parents. However, as will be explored in Chapter 5, some have questioned their version of ‘the truth’ (Kessler, 1998: 29). The current medical management is predicated on John Money’s gender role theory, which states that patients and parents need to be told

specific details about the diagnosis and treatment to adequately manage intersex conditions. Dreger indicates this view of “telling [patients] all we know will just lead to gender confusion that all these surgeries were meant to avoid” (Dreger, 2004) (refer to Table 5.1 page 139). For parents too, there appears to be a concerted effort to include them in the need to maintain a certain level of knowledge

Because a child’s psychological schema developed in concert with his or her body image, Money and the Hampsons insisted, early genital surgery was imperative. A child’s body parts had to match his or her assigned sex. Money, and the Hampsons, and those who followed their lead argued, it was *even more important for the child’s parents* (emphasis added, Fausto-Sterling, 2000: 63)

The parents’ role in the process and the difficulty in attaining their consent are emphasised later by Fausto-Sterling who says “modern management manuals devote a *great deal of thought* to how to get parents to go along with suggested treatments. Clearly it is a matter of *great delicacy*” (emphasis added, Fausto-Sterling, 2000: 92).

If the information to patients and parents has been questioned what then are they told? After interviewing six physicians Kessler highlights four ways physicians “normalise” (Kessler, 1998: 22) the intersex condition, diagnosis and treatment to parents. First, physicians teach parents usual foetal development and explain that all foetuses have the potential to be male or female (1998: 22). Second, the normalcy of other aspects of the baby is stressed (1998: 22), such as stating that the baby is healthy but has a mild defect not unlike a mole or a hemangioma. Thirdly, physicians emphasise that the ambiguity lies with the child’s genitals not the gender (1998: 22). That is, physicians explain that there is a mishap in the natural development of their child. As Fausto-Sterling describes “doctors inform parents that the infant has a ‘birth defect of unfinished genitalia,’ and that it may take a little time before they’ll know whether the child is a boy or a girl” (Fausto-Sterling, 2000: 50). Fourthly, parents are told that social factors are more important to gender development than biological ones (1998: 23).

Kessler reports that one physician explains to patients that “sex organs are different in appearance for each person, not just those who are intersexed” (cited in Kessler, 1998: 29). Fausto-Sterling indicates how other physicians attempt to de-emphasise difference “all efforts should be made to discourage any feeling of sexual ambiguity” (2000: 64).

Suzanne Kessler reveals what physicians say to parents in the “period of ambiguity” (1998: 21), that is, the period between the birth and the assignment of sex/gender. Physicians apparently encourage parents to postpone announcement of gender and to treat their child as gender neutral, even giving the children a gender neutral name (1998: 21). One geneticist advised parents to insert “child of” (1998: 21) on the birth certificate. In one case “parents filled out two birth registration forms, one for each gender, and they refused to sign either until a final gender assignment had been made” (1998: 21). An endocrinologist told of a story of parents who said that they had had twins, when the child’s gender was determined they announced that one twin had died (1998: 21). In another scenario when parents are advised to not discuss their child’s gender Kessler remarks “parents are asked to sidestep the infant’s gender rather than admit that the gender is unknown” (1998: 22).

An Australian publication titled “Your Child with Congenital Adrenal Hyperplasia” (Warne, 1989) implies it is designed to assuage parental concerns. The 32-page booklet informs the reader (parents) of the biological consequences of CAH, treatments and the chances of inheriting CAH. Warne also offers a ‘normalising’ explanation

People with CAH enjoy excellent health once treatment has been started, and live to a *ripe old age*. They can do anything they want to do, including *marrying and having children*. To maintain this state of good health, they do need to take medications, but this becomes *accepted as part of life* ... There are many conditions much worse than CAH. CAH is a nuisance, but *not a handicap* (emphasis added, Warne, 1989: 3)

Inclusion of cartoon illustrating that hormones can be taken in tablet form reinforces that hormone treatment can be accepted as a ‘part of life.’

Two pages illustrating the way that neonatal genital development occurs precedes information on surgical treatment. Warne informs us that “girls with CAH need surgery to reduce the size of the clitoris to normal, separate the fused labia, and to enlarge the vaginal entrance” (1989: 22). Further, Warne indicates that surgery around the vagina will mean “there is scar tissue there” and giving birth may be difficult and require a Caesarean operation (1989: 23).

4.5 Surgical Intervention and Intersex

4.5.1 Review of Intersex Medical Management Literature between 1974 and 1995

Assessment of surgical intervention is, at best, vague. Fausto-Sterling explains “there exist no consistent or arguably scientific standards for evaluating the health and psychological wellbeing of the patients in question” (Fausto-Sterling, 2000: 95). Assessment of the ‘success’ of intersex medical management is the aim Suzanne Kessler’s review of genital surgery follow-up studies between 1974 and 1995 (Kessler, 1998). In response to that project, Kessler says, “it is not easy to extract from the medical studies exactly what criteria are used to measure success” (1998: 54). Following a summarisation of Kessler’s work in the next section I extend this review by analysing articles published between 1996 and 2004.

Kessler’s review of twelve feminisation surgeries identified four categories of criteria: clitoral appearance, clitoral sensitivity (sexual responsivity), vaginal size and complications (1998: 54). According to Kessler’s review clitoral appearance is the first criterion mentioned in surgeons’ reports (1998: 54). Indeed, the acceptability of the appearance is reported to be responsible for satisfactory psychological adjustment. However, as Kessler says, there is no evidence for this correlation nor is there any indication that patients have corroborated this with their own assessment of this

acceptability (54-55). So removed from the equation are parents that Kessler further indicates that it is apparently not uncommon for reports to include vague statements such as “the parents were satisfied with the results of the genital surgery” (Kessler, 1998: 55).

Another criterion for assessment Kessler identified in the medical literature is clitoral sensitivity or sexual responsivity. For decades assessment of sexual responsivity was through self-reports, yet there appears to be some uncertainty as to how these self-reports were presented “one gets the sense that patients’ remarks were collected rather casually. Outcomes are mixed” (Kessler, 1998: 56). Kessler infers that physicians are reluctant and sometimes avoid asking patients about their sexual experience

Other researchers, who appear hesitant to ask their patients straightforward questions, display their naiveté when they describe why erotic response cannot be assessed: “[Some patients] of marriageable age are still single, and any relevant conclusion regarding the erotic response of the glans is hard to determine” (Kessler, 1998: 56)

Towards the end of Kessler’s review period less studies relied on self-reports as “researchers have measured calibrated nerve-conduction responses to electrode stimulators” (Kessler, 1998: 55). Kessler exemplifies this through one study

That measured pudendal-evoked potentials before and after erectile tissue from the enlarged clitoris had been removed touted the surgical procedure because it preserved nerve conduction in five of six intersexed infants. The authors were cautious in extrapolating from this finding when they said that the technique ‘*may* permit normal sexual function in adulthood’ (original emphasis, Kessler, 1998: 57)

The third criterion of assessment is vaginal size. Adequacy is determined by the vagina’s ability to engage in “at least nonpainful intercourse with a ‘normal-size’ penis” (Kessler, 1998: 58). While physicians deem these vaginas ‘adequate’ Kessler states that “there is

no assurance that they were judged adequate from the women's point of view" (1998: 59). One method employed in post-vaginoplasty is dilation of the neo-vagina, usually by the parents, and as Kessler says

Nowhere in the medical management literature is there a discussion of the repercussions of repeated vaginal dilation of a daughter by her parents (1998: 59)

A final criterion of assessment is complications. If complications are discussed at all in the literature they are referred to as "minimal" (Kessler, 1998: 61). Kessler reports that almost all intersex children who had vaginal surgeries in infancy were diagnosed with stenosis, which required further surgery (61). Other complications included scarring, growth of hair at the introitus and high incidence of urinary-tract complications (61).

Kessler's review also includes follow-up studies on masculinisation surgeries. As noted above (4.1.6) the most common phalloplasty is to correct hypospadias. In Kessler's review attention is drawn to the "hypospadias cripple" (1998: 69) a term the medical literature coined to refer to males whose penises do not look or function better after genital surgery. A follow-up study of hypospadias correction surgeries between 1985 and 1992 concluded that there was a high incidence of fistulas, and with almost half requiring more than one surgery (69). While surgery was described as having "excellent cosmetic and functional results" (69), not unlike the genital surgeries on females "no criteria for excellent functioning were provided" (Kessler, 1998: 69). A review of five other follow-up studies revealed results similar to that found in the genital surgery on females, that is "criteria for success are only vaguely alluded to, with reports noting whether the urinary function after surgery is 'satisfactory' or 'unsatisfactory'" (Kessler, 1998: 70). According to Kessler one study indicated that their criteria was an assessment of "the force, quality, and direction of the urinary stream" (Kessler, 1998: 71). In regards to concern for post-phalloplasty appearances, it appears to be not unlike that for females, "a group of researchers who have examined hundreds of boys and men with hypospadias claims that the 'surgery never produces a perfectly normal penile appearance'" (Kessler, 1998: 71).

4.5.2 Review of Intersex Medical Management Literature between 1996 and 2004

With the intention of extending and updating Kessler's work I reviewed medical papers between the years 1996 to 2004. These papers were deliberately selected for their focus on gender, sexuality and surgical outcomes. Although I cannot argue that my findings completely mirror Kessler's some striking similarities exist, namely the consistent vagueness.

I have noted above how the medical literature is not explicit in its methods of acquiring information about the success of surgical outcomes. In my review I identified four ways that information pertaining to the assessment of gender, sexuality and surgical outcomes is acquired: patient report (8), parent report (4), medical observation (6) and/or psychologist (2). While this review uncovered a broad list of methodologies, the fact that the majority of studies did not consult patients primarily or at all supports that medical management has not changed.

The eight studies I describe as employing 'patient report' methodologies included questionnaires, tests and interviews. These studies enquired about participants' own adult and childhood gender role/behaviour, well being, sexual orientation, sexual function, sexual satisfaction, intelligence, satisfaction with sex of rearing, body image, relationship status, opinion/knowledge of treatment(s) and parenting issues. The four studies I have described as 'parent report' drew their conclusions from parental testimonials (mostly mothers).

The six papers that employed 'medical observation' used examinations designed to acquire physical and 'cosmetic' data. Physical data included measuring the stretched penis/clitoris, the breast tissue, determining the presence of the prostate gland, distribution of hair growth, and depth of vagina using graduated dilators. Cosmetic data (if discussed) was assessed through interpretation of these physical measurements and/or conferring with colleagues. The two papers that employed the services of a psychologist

appeared to be motivated by trying to “define the true gender identity” (Berenice et al, 1996: 77) and “prevent the development of cross-gender identification” (Slijper et al, 1998: 28). These psychologists employed methods of long-term counselling, interviewing the patients and administered gender-based psychological tests.

Another similarity of this review with Kessler’s is the use of vague language. Central is the lack of dialogue to illustrate the discourse that has taken place between the intersex individual (or their parents) and the researcher. Researchers do not offer evidence of or elaborate what they are talking about, as if the intersex individuals are absent from the studies. For example Slijper et al (1998) refers to gender role behaviour in boys as assessed by a psychologist

Although deviant behavior was not in evidence in the boys, their behavior was *not very assertive*. The boys were *fearful and bothered* about the smallness of their penis (emphasis added, Slijper et al, 1998: 130)

In regards to implementation of surgical procedures and supportive hormonal treatment Berenice et al’s use of some words reinforces this vagueness

It seems *intuitively obvious* that surgical correction of the hypospadias and cryptorchidism (when present) should be undertaken *routinely*, but when and how to intervene with supplemental hormonal therapy is *unclear* (emphasis added, 1996: 70)

This assumption surrounding ‘intuitive obviousness’ extends to apparent ‘normalising’ language in regards to physical measurements. Assessment of the “cosmetic appearance” (Migeon et al, 2002: 3) of the male genitalia in adulthood is often determined by the accumulation of three measurements (penis length, testes size and corporal bodies). The final ‘assessment’ is “evaluated independently” (3) and “then agreed on by 2 physicians” (3), both of whom were among the listed authors. The three measurements are then designated through a tri-scale nomenclature. If all three were deemed within the “normal

range” (3) cosmetic appearance was rated “good” (3), if one of three was deemed abnormal it was rated “fair” (3), and if two or all were deemed abnormal, it was designated “poor” (3). Creighton et al (2001) admit that “no standard methodology exists for genital cosmetic assessment” (2001: 124), and proceed to define their own tri-scale nomenclature which is not dissimilar to that of Migeon et al (2003), that is ‘good,’ ‘satisfactory’ and ‘poor.’ They do provide insight into the means of assessment. Namely, through genital proportions and symmetry, pubic hair distribution, clitoral hood size and shape, glans clitoris shape and clitoral body size and prominence, labial positions and proportions, vaginal introital position and appearance and genital skin quality (Creighton et al, 2001: 124). These criteria were assessed against what Creighton et al refer to as “normal values for clitoral and vaginal size” (2001: 124) citing Adkins’ “Female Genital Tract” (1997) as its source.

It is also evident that there is self-acknowledged vagueness and uncertainty among medical professionals. In regards to the descriptions of micropenises Gad et al (1997) state “the related terminology has been controversial” (96). The aetiology of this uncertainty is cited as being with patients

The appropriateness of this type of sex assignment in 46, XY individuals with a small phallus and perineoscrotal hypospadias *has been questioned in response to accounts of individuals* who were raised female and report dissatisfaction in adolescence or later with female rearing (emphasis added, Migeon et al, 2002: 1)

What exactly are the accounts of these ‘female-reared’ intersex individuals? Similarly Minto et al (2003) acknowledge that uncertainty in regards to surgical intervention is bound not only be intersex individuals’ ‘dissatisfaction’ but also by ethics

The practice of feminising genitoplasty has created considerable controversy, and is associated with many ethical dilemmas (Minto et al, 2003: 1253)

Researchers draw a line under this uncertainty and argue for further research

The effects on sexual function of surgical removal of parts of the clitoris are unknown ... Our aim was to assess the effects of surgery on sexual outcome in this population (Minto et al, 2003: 1252)

While a more in-depth investigation would be warranted, I will limit my next discussion to a brief report of the findings. Several papers sought to analyse any psychosocial problems arising from the medicalisation of a person's intersex status. Although Sandberg et al (2001) found an association between hospitalisation and increased internalisation problems and that there is some correlation between low school performance and poor cosmetic appearance of post-surgery boys with hypospadias, their study "provides a more positive picture" (472) than previous studies. For example, "the level of behavior problems was not different between hypospadias severity subgroups" (Sandberg et al, 2001: 472). Creighton et al (2001) report retrospectively on genital surgeries between 1979 and 1995, stating that these outcomes are substantially poorer than in previous studies (127). Wisniewski et al (2000) offer insight into the wishes of CAIS women in terms of increased disclosure, support and access to and negotiation of 'treatment.' The views of these women coincide with CAIS advocacy groups, which I will elaborate in the following chapters.

In terms of gender there is evidence of counter-normative, normative and transitioning gendered behaviours and identities. Hall et al (2004) claim to be the first study to find a correlation between genotype and both physical and behavioural masculinisation of girls with Congenital Adrenal Hyperplasia (CAH), moreover masculinisation is a feature of CAH (2004: 423). However, this is one of the studies noted above who gathered their data from mothers. Meyer-Bahlburg et al (2004) also investigated gender identity in CAH individuals and they too support this finding. They add that the marked masculinisation of gendered behaviour did not indicate an associated masculinisation of gender identity nor gender confusion or dysphoria (102). This finding, they say, contrasts with previous studies. Hines et al (2003) supports previous studies of women with CAIS and argued that they are neither less masculine nor more feminine than controls (99). In a study of

individuals with 5-ARD (Berenice et al, 1996) changing one's social sex (female-to-male) is reported from 10 out of 13 postpubertal subjects. As noted above this is a distinctive feature of the condition. Hormonal treatment accounting for some increased masculinised characteristics: prostate and penis growth, increased body and facial hair and enhanced libido and sexual performance (71). In Wisniewski et al the majority of participants did not believe that a third gender category was appropriate for intersex individuals (2000: 2668), a finding that, if nothing else, indicates an openness to the topic.

The findings in this review of medical management literature between 1996 and 2004 are not dissimilar to those in Kessler (1998). There appears to be a general continuation of vagueness in terms of assessing what is considered 'normal' genital appearance and 'successful' surgical intervention. I also argue that there is evidence to suggest that in this period changes have taken place. Firstly, I have identified some self-reflection among intersex medical management professionals. Secondly, there are references to the intersex movement. Thirdly, there are additions and corrections to previous research that elucidate a clearer understanding of the contemporary medicalisation of intersex. However, there are still problems with the medical management's assessment of surgical outcomes.

Conclusion

This chapter has endeavoured to unveil how intersex has been regulated and conceptualised. In the past century intersex has been dominated by a medicalised discourse inherited from its historical antecedents. A review of the literature by Kessler and myself highlights that there are certain ways in which the medicalisation of contemporary intersex has occurred. This chapter has highlighted a number of ramifications of this medicalisation. Firstly, intersex has been categorised into many different 'intersex conditions,' secondly, intersex individuals are referred to as 'patients,' thirdly, intersex patients have been diagnosed and treated by many diagnostic and treatment procedures, such as hormonal, chromosomal and digital examinations and surgeries and hormonal replacement therapies. Fourthly, physicians have informed

parents of intersex patients through a ‘normalising’ paradigm. Fifthly, these diagnostic and treatment procedures and information to parents are synergistic with John Money’s gender role theory. Finally, assessment and follow-up studies of these procedures, when done at all have been done without scientific rigor and have reinforced the medical and normalising discourses surrounding and dominating the management of intersex. The next chapter will take up the increasingly vocal intersex movement’s response to these six aspects of the contemporary medicalised view of intersex.

CHAPTER 5: THE INTERSEX MOVEMENT

Introduction

- 5.1 The Intersex movement
- 5.2 Goals of the Intersex movement
- 5.3 Outcomes of the Intersex movement
- 5.4 Intersex vis-à-vis Transgender
- 5.5 Intersex Identity vis-à-vis Male and Female

Conclusion

Introduction

Hitherto I have focused attention on the conceptualisation of intersex through the lens of historical, anthropological and medical discursive fields. However, in the last decades of the twentieth century and the first years of the twenty-first century another view has found a voice: intersex individuals themselves. Where previously the only voice that offered a first-hand account of the real life experiences of intersex individuals was that of Herculine Barbin in the nineteenth century (Foucault, 1980), we now find an array of locations within which to hear the voices of intersex individuals.

Quick on the heels of socio-political movements such as feminism, gay liberation, the queer movement and the disabilities rights movement, as discussed in Chapter 2, intersex individuals have formed their own socio-political movement and demanded and gained their own voice. The intersex movement has coalesced around the core issue of challenging and problematising the current intersex medical management. Moreover, they are challenging and problematising the contemporary regulation and conceptualisation of intersex. What is ascertained from the intersex movement literature is that the intersex movement is not monothematic, their demands have been pluralised and diversified over the ensuing years. This analysis of the intersex movement literature therefore highlights a range of opinions and demands being voiced.

Before I proceed, the use of the term ‘intersex movement’ can not be used without clarification. For the purpose of this current project any analysis of the intersex movement in this chapter is limited to literature that is authored by intersex individuals and their supporters (family members, medical professionals, sociologists and gender scholars) who question the medical management of intersex. As such, the use of the phrase ‘intersex movement’ establishes a discursive field bounded by a specific community of individuals. Yet, this community can not be easily mapped out as a simple geographical location, temporal zone, epistemological or socio-political sphere.

This chapter will briefly explore the evolution of the intersex movement and its array of diverse issues, demands, and subsequently achievements. Moreover, this chapter will elucidate the subsequent discourses the intersex movement has entered, namely transgenderism, and the ramifications of the existence of intersex on debates around alternative sex and gender identities.

5.1 The Intersex movement

It has been argued in Chapter 2 that the intersex movement has taken much influence from its socio-political antecedents, feminism, gay liberation, the queer movement and the disabilities rights movement. It would be remiss to assert that the evolution of the intersex movement has resulted from a supra-individual social force that swept through the latter part of the twentieth century. What seems obvious is that intersex individuals have come forward to express their discontent and anger with the medical management of intersex and used the apparently successful epistemological tools of preceding socio-political movements; tools that ultimately worked toward a similar goal of challenging the dominant medicalised discursive field.

It could be argued that it is too soon to map out the aetiology of this nascent intersex movement. That is to say that the intersex movement literature appears to have given little attention to it, preferring to focus on its principal demands. What is clear is that North American Cheryl Chase appears to be the groundbreaker with the founding of the Intersex Society of North America (ISNA) in 1993. While, as will become evident, other individuals or groups attempted to start intersex advocacy based groups in the 1980s, none appear to have the longevity of ISNA. Subsequently, this analysis will be brief, since the literature seems to sparingly refer to the origins of intersex organisations, and focuses more on the main aim of advocating a change in the current medical management of intersex.

Therefore this current analysis will place considerable focus on North America and the ISNA in particular, with some attention also given to other areas of the world. As this

present project emphasises an understanding of intersex in Australia I will provide an overview of the development of the Australian intersex movement. But any analysis at this point of time is arguably premature and thus it is recommended that further historical research be undertaken.

5.1.1 Australian Intersex Groups

In Australia it could be argued that the most vocal organisation is the Androgen Insensitivity Syndrome Support Group Australia (AISSG). While the organisation deals specifically with AIS, they cater for and advocate on behalf of a range of intersex. However, they are not the only intersex organisation in Australia. The AISSG website links' page lists seven groups, four of which appear to be Australian: Klinefelter's Syndrome Support Group Queensland, Klinefelter Support Group Victoria, Turners Syndrome Association of Victoria Inc (<http://www.turnerssyndrome.org.au/>), and Congenital Adrenal Hypoplasia Support Group Australia (CAHSGA) (<http://home.vicnet.net.au/~cahsga/>). The website of the Victorian Turner's Syndrome Association Inc. claims that the association was formed in 1984 and is a "support group to help Turner's individuals, their families, partners and friends to discuss their feelings, concerns and any sensitive issues that may arise" (Victorian Turner's Syndrome Association Inc., 2001). The website offers newsletters, mailing lists, advice and medical information.

According to the Congenital Adrenal Hypoplasia Support Group Australia (CAHSGA) website, their vision "is to provide support and educational information in order to assist individuals and families affected by CAH in Australia to maximise their health and wellbeing, and to advocate for and promote the interests of those affected by CAH." The CAHSGA website has information pertaining to definitions of CAH, information for people with CAH such as advice, links and treatment. Further, the website states the CAHSGA's eleven aims

1. Represent the views and goals of individuals and their families affected by CAH.

2. Provide support for the parents of newborn children with CAH in Australia.
3. Provide educational resources for the parents of newborn children with CAH.
4. To encourage and assist parents of children with CAH to promote independence and self-reliance in their children.
5. Provide support and education for those affected by CAH to manage their disorder as they mature into adulthood.
6. To facilitate communication between those affected by CAH throughout Australia.
7. To encourage and support research into CAH.
8. To support, where appropriate, the work of endocrinologists throughout Australia.
9. To monitor world-wide trends in the management of CAH and disseminate information on contemporary best practice in the treatment of CAH to members and health professionals.
10. To lobby health care professionals to involve those affected by CAH in decision making regarding the appropriate management of CAH.
11. To lobby medical groups for changes in medical practice that reflect world's best practice in order to optimise the management of CAH in Australia.

The short-lived Intersex Network of New South Wales (INNSW) was put together for the 2002 Sydney Mardi Gras parade. According to co-founder Lee Brown (1957-2004), however, it was not “a big success” (personal correspondence, 2003). Consequently soon after the parade the network “quietly folded” (personal correspondence, 2003). In *Polare*, the magazine published by the Gender Centre, Sydney, the INNSW advertised their organisation in two editions in 2002. They stated that the INNSW was “an information, lobby and peer support group for people dealing with intersex conditions” (INNSW, 2002a: 9; INNSW 2002b: 10). They stated that their aims were

1. To end non-consensual medical intervention on intersex children unless their condition is life-threatening
2. To provide sources of healing for people dealing with the trauma of childhood intersex surgery

3. To provide information on intersexuality for anyone who asks for it
4. To work towards community awareness and acceptance of the diversity of intersex conditions
5. To enjoy our lives as the people we are and to put the past behind us

In regards to the INNSW website (<http://www.angelfire.com/realms/isnetwork/>) Brown states

There was a website I put together when I still had some hope left that something might get started but I haven't looked at it in months and doubt it's still there (personal correspondence, 2003)

As of June 2003 the INNSW website was no longer available.

Androgen Insensitivity Syndrome Support Group Australia (AISSG) while based in Melbourne is a National organisation, which according to the website is a peer support, information and advocacy group for people affected by AIS and/or related intersex conditions, and their families. The website claims that AISSG also provides support to those with Partial and Complete Gonadal Dysgenesis, MRKH (also known as Vaginal Agenesis), 5 α -Reductase Deficiency, 3 β -Hydroxysteroid Dehydrogenase Deficiency, 17-Ketosteroid Reductase Deficiency and 17 β -Hydroxysteroid Deficiency.

AISSG is made up of an elected board and state representatives, with members meeting in November every year. AISSG membership is available at a small annual cost. Reports of the annual meetings are made available in certain editions of *dAISy*. *dAISy* is AISSG's biannual newsletter that is mailed out to members (editions between 2000-2003 are now available on-line). The welcome by Antoinette in the April 2000 edition of *dAISy*, states that this is the "new look of our AIS Support Group Newsletter." Because the AISSG website doesn't offer copies of any newsletters prior to 2000, we are not privy to how many earlier copies there have been. This mystery seems to be shared by those involved in AISSG. In 2003 Tony Briffa refers to *dAISy* as turning three "as we know it." Implying

that the current members of the board are unsure of the exact date that the newsletter was conceived.

Some uncertainty also surrounds the date that the group started. Kessler claims that the development of Australian Support groups was “simultaneous to [Intersex Society of North America’s] development” in the United States (Kessler, 1998: 79). Yet, according to North American Intersex Activist, and founder of the ISNA Cheryl Chase, it is claimed that it was not until 1996 that Australia had a chapter of AISSG (Chase, 1998b: 215), originally based in England. However, because these authors are situated in the United States a more reliable source comes from an article by an unnamed author in the March 2001 edition of *dAISy*. The author implied that an Australian group for people with AIS has existed since 1986, initially known as the AIS Discussion Group, it is subsequently reported that the name “AIS Support Group Australia” has been in usage since 1990.

By the September 2000 edition of *dAISy*, the AISSG website had been created, and in the March 2001 edition it was reported that the website was recognised by the National Library of Australia as being of significant cultural value. Quoting from an unnamed author “I understand that this means that anything included in the site will be available for future generations to see. It also means that our personal stories of living with AIS and other related intersex conditions will live on” (Author Unknown, 2001).

The March 2001 edition also published for the first time the “Aims of the AIS Support Groups Australia.” These aims include

- To put parents and people with AIS and related conditions in touch with each other in a safe and confidential environment and encourage them to seek support and information.
- To reduce the secrecy, stigma and taboo surrounding AIS and other intersex states, by encouraging doctors, parents and society to be more open
- To encourage the provision of psychological support within the medical system, for young people with AIS and their parents

- To put parents and people with AIS in touch with others and to encourage them to seek support and information
- To increase the availability of information on AIS both verbal (from health professionals) and written (from the support group and other sources)
- To encourage improvements in the treatment for men and women with AIS in both surgical and non-surgical means

Within this edition is advertised a “private” on-line discussion list called AIS People Club, co-established by Australian Tony Briffa and Renee from the USA. In the March 2003 edition it is reported that an AIS brochure (Figure 5.1.) had been launched.

The AISSG extend their reach of assistance beyond the immediate contact with intersex individuals and their families. The AISSG has become a regular fixture within the public domain by addressing public forums, submitting anti-discrimination recommendations and appearances in the media. AISSG President Tony Briffa has made public appearances at events that include but are not limited to the “Neglected Communities” forum as part of the 2003 Lesbian and Gay Sydney Mardi Gras, and a public forum dealing specifically with intersex issues at Adelaide’s Lesbian and Gay Cultural Festival in 2003 “Feast.” Also in 2003, on behalf of the AISSG, Tony Briffa compiled three anti-discrimination submissions in regards to how intersex individuals are covered by the law in New South Wales (Briffa, 2003a), the Australian Capital Territory (Briffa, 2003b) and South Australia (Briffa, 2003c).

In 2000, Tony Briffa, then known as Antoinette Briffa, appeared on Channel Nine’s *60 Minutes* programme. Again in 2003, the AISSG’s contact details were aired directly after the showing of Andrew Cohen’s documentary “The Boy Who Was Turned Into a Girl” (2000) on SBS television.



Figure 5.1. “Support and information for those affected by Androgen Insensitivity Syndrome and similar conditions” Brochure distributed by AISSGA (2002)
[removed].

As previously mentioned the aetiology of the AISSG Australia has not gone uncontested. Regardless of whether it has its origins in 1986, 1990 or 1996, what is evident is that the AISSG has been the most vocal organisation in Australia in recent years. Raising the voices of intersex individuals in the public sphere, namely the law, public television and gay, lesbian and queer forums.

5.1.2 International Intersex Groups

There are few writers who refer to non-America intersex groups, and they do so briefly. What I can discern is the existence of intersex groups in: Asia, Australia, Canada, Germany, England, Europe, Japan, Netherlands and New Zealand (Chase, 1998a: 197; Chase, 1998b: 215; Chase, 1998b: 216; Dreger, 1998: 200; Fausto-Sterling, 2000: 298 n.18; Kessler, 1998: 79).

I contacted 38 groups that provided support and information to either non-specific intersex issues (6) or provided information about Androgen Insensitivity Syndrome (15), Congenital Adrenal Hyperplasia (3), Hypospadias (1), Klinefelters (4) or Turner's Syndrome (9). The groups were located on many continents or islands, for example, North America (7), New Zealand (4), Asia (Japan, Singapore and India) (4), Africa (3), the United Kingdom (7) and Europe (8). Yet it must be noted that this is a conservative number because it indicates those contacted for the purpose of this study, and some organisations were omitted from the study due to not being accessible via the Internet and consequently electronic mail.

In Germany the formation of the Genital Mutilation Survivor's Support Network and Workgroup on Violence and Pediatrics and Gynecology, was predated by the Intersex Support Network Central Europe. According to Kessler the name change "reflect[ed] the fury of its political evolution" (Kessler, 1998: 79). In England a mother of a girl with AIS formed the Androgen Insensitivity Syndrome Support Group (AISSG) in 1988 (Chase, 1998a: 197). Initially a self-help group for parents, it began to attract many women with Androgen Insensitivity Syndrome. According to Chase the publication in 1994 of two letters in two leading British medical journals "led to a swell of visibility and participation" in AISSG (Chase, 1998b: 215). Kessler reports that the English AISSG published their first newsletter *ALIAS*, in 1995 and they adopted goals not unlike those in ISNA (Kessler, 1998: 79). Chase briefly mentions the existence of the Hijra Nippon in Japan who organise for the benefit of mutual support and in opposition to medical abuse (Chase, 1998b: 216).

5.1.3 North American Intersex Groups

The establishment in 1993 of the Intersex Society of North America (ISNA) has been widely documented (Chase, 1998a; Chase, 1998b; Kessler, 1998; Lehrman, 1999; Fausto-Sterling, 2000; Mason, 2002; Torassa, 2003; Turner, 1999). Prior to this references to the existence of other intersex organisations in the United States are few and far between. ISNA founder, Cheryl Chase says

When I first began organizing ISNA, I met leaders of the Turner's Syndrome Society, the oldest known support group focusing on atypical sexual differentiation, founded in 1987 (Chase, 1998a: 199)

In 1987, Toby a self-identified 'neuter,' attempted to initiate contact with others by establishing "Finding Our Own Ways" (Kessler, 1998: 77). Toby is quoted as saying the group's purpose was to

Discover and explore ways of being ourselves, in a setting free of pressure to define ourselves in terms of maleness and femaleness ... to support ... non-traditional gender identification as legitimate and non-pathological, and [to provide] a source of education for the public and professionals (Toby cited in Kessler, 1998: 77)

Kessler reports that Toby claimed

That there were fewer than two dozen members of the support group but no other 'neuters.' It is unclear what response Toby got to his/her solicitation for new members and newsletter subscriptions. No second issue of the newsletter was forthcoming, and I have heard nothing more from Toby or this embryonic movement (Kessler, 1998: 78)

Cheryl Chase moved to San Francisco in 1992 “based entirely on my vague notion that people living in the ‘queer mecca’ would have the most conceptually sophisticated, socially tolerant, and politically astute analysis of sexed and gendered embodiment” (Chase, 1998a: 196). What prompted Chase to make the first move to establish ISNA? Chase refers to talking indiscriminately to others finding six intersex individuals, two of whom escaped medical intervention, and thus decided to start a support network (Chase, 1998a: 197). Another significant moment may have been in 1993 when Anne Fausto-Sterling published “The Five Sexes: Why Male and Female Are Not Enough” in *The Sciences*. Fausto-Sterling concurs: “I like to think that my article was one important stimulus” (Fausto-Sterling, 2000: 79). Chase responded by writing a letter to the editor asking other intersex individuals to write and make contact (Torassa, 2002).

Initially wanting to hear from people with matching experiences, Chase was intrigued by the differences and the similarities

When I first began to seek out other intersexuals, I expected, I wanted, to find people whose experience exactly matched mine. What I have discovered is that in one sense we are very different - the range of personalities, politics, and anatomies in our nascent intersexual movement is broad. Some of us live as women, some as men, some as open intersexual. Many of us are homosexual if that term is narrowly understood in terms of the social gender roles of the partners. Some of us have never been sexual. But, in another sense, our experiences are surprisingly coherent: those of us who have been subjected to medical intervention and societal invisibility share our experience of it as abuse (Chase, 1998b: 216)

Chase proceeded to advertise ISNA in the media. While not getting much attention from medical professionals (Kessler, 1998: 78) who “treated [Chase] largely as a kook and a fanatic” (Torassa, 2002), Chase received responses from many intersex individuals (Chase, 1998a: 197; Kessler, 1998: 78) “relieved to find someone else like them” (Torassa, 2002).

In 1994 ISNA began distributing its first edition of the newsletter *Hermaphrodites with Attitude*. As a welcome it states

Long promised, long delayed, but here it is. ISNA has its own newsletter. I hope that many of you will contribute short articles, stories, poetry, and illustrations so that the next issue can be even more a collaborative effort

Who are we? In the 16 months since ISNA was founded, we have responded to hundreds of inquires from intersexuals, therapists, educators, parents, physicians, academics and journalists. The Intersex Society mailing list now reaches intersexuals in five countries and in 14 of the United States

As technology developed during the 1990's Chase made use of the increasingly popular Internet and in 1995 created the ISNA website (<http://www.isna.org>) (Chase, 1998a: 197, Kessler, 1998: 78, Torassa, 2002).

It wasn't long until they made their presence known through other forums. "The first recorded instance of intersex public protest in modern history" (Chase, 1998a: 200) occurred on October 26th 1996 (Turner, 1999: 457). Chase explains "the direct action group Transsexual Menace helped an ad hoc group of militant intersex individuals calling themselves 'Hermaphrodites with Attitude' plan and carry out a picket of the 1996 annual meeting of the American Academy of Pediatrics in Boston" (Chase, 1998a: 200). Their list of demands of the Paediatricians included

Avoidance of unnecessary genital surgery, family counselling with regard to the child's future medical needs and options, complete disclosure of medical files, referral of the adolescent intersexual to peer support, and the fully informed consent of the intersexual youth to any and all medical procedures (Turner, 1999: 457)

As Kessler highlights by 1997 there had been a distinct shift in focus for ISNA “from recruiting and supporting members to directly influencing the medical community” (Kessler, 1998: 79). ISNA increased its activities and visibility during 1997 with a demonstration outside the Columbia Presbyterian Hospital in New York City (Kessler, 1998: 79) and participation in the Second National Gender Lobbying Day in Washington, D.C. “to educate members of Congress about intersex genital mutilation” (Turner, 1999: 457).

Kessler states that the effort to attract the attention of the media was paying off. Prominent articles appeared in the *New York Times* and *Newsweek*, a segment on ‘Dateline NBC’ and more significantly with the invitation and participation of ISNA representatives at professional meetings, and being written about in professional newsletters. Kessler adds

Physicians were asking that their colleagues rethink their stances about intersexuality, a possibility that I didn’t imagine when I first began writing about intersex in the late 1980s (Kessler, 1998: 79)

Chase reflects on some other changes

Since ISNA has been on the scene, other groups with a more resistant stance vis-à-vis the medical establishment have begun to appear ... in 1996, [a] mother who had rejected medical pressure to assign her intersex infant as female ... formed the Hermaphroditic Education and Listening Post (HELP) (Chase, cited in Fausto-Sterling, 2000: 81)

In 2002 Chase resigned as executive director of ISNA, according to Torassa “She said she wants to make sure the group develops other leadership” (2002). Chase’s nine-year commitment and contribution to ISNA and to the lives of intersex individuals has not gone unnoticed. Dr. Jorge Daaboul, a pediatric endocrinologist at Children’s Hospital of Oakland states

[Chase's] organization really ranks up there with the various civil rights organizations of the 1960's and 70's ... She has brought the subject of intersex really to the forefront of my profession, where it had been nowhere before (cited in Torassa, 2002)

Personal narrative from intersex individuals also praise Chase, ISNA and *Hermaphrodites with Attitude*

Reading Cheryl [Chase's] letter ... and talking with her/him was a life-changing event. Learning that my experiences and feelings were not so different from other people ended the absolute isolation I had felt (David, 1995: 5)

Hopefully in joining ISNA I can understand my feelings better (Charles/Cathy, 1995: 9)

Thank you, thank you, thank you so the best Christmas present I've ever had or ever could have. As soon as I saw the title *Hermaphrodites With Attitude* I cried aloud for sheer joy. I mean, I've known that there were people like me, but to find that they also have *attitude*; that they also are ready to stand up and shout, 'I'm here, I'm angry and I'm not going to take it any more!' It's better than real, it's better than anything I dreamed, it's sheer paradise on earth. No more secrets, no more shame, guilt, dread, fear, self-loathing or hatred. Finally I can say, 'I'm hermaphrodite, I'm intersex, I'm transgender, I'm queer and damn proud,' as the tears of joy and belonging stream down my face (original emphasis, Lee, 1995: 10)

Other recent changes to ISNA include the cessation of *Hermaphrodites with Attitude* and in 2001 the birth of "ISNA News" and a more proactive stance, going beyond the initial 'recruiting and support.' The website states

The Intersex Society of North America is *devoted to systemic change* to end shame, secrecy, and unwanted genital surgeries for people born with an anatomy that someone decided is not standard for male or female. *We urge physicians* to use a model of care that is patient-centered, rather than concealment-centered (emphasis added, ISNA, 2002)

The aetiology of the world wide intersex movement can not be easily determined. However, there is apparently a universal focus on the provision of information, support and a forum through which intersex individuals can share their experiences. By far the most widely cited organisation is Intersex Society of North America, however, in Australia, the Androgen Insensitivity Syndrome Support Group, has had a great impact on increased awareness and addressing issues within the public sphere. Collectively the intersex movement has agreed on the need to address the issues faced by many if not all intersex individuals, the ubiquitous and dominant medicalisation of contemporary intersex.

5.2 Goals of the Intersex Movement

The intersex movement has evolved over the past decade from a forum for support and shared experiences to a proactive and politically motivated tool. As the intersex movement increased its vocal capacity and political weight it also coalesced its aims and objectives. The procedures employed by the medical profession, the surgical and hormonal intervention of intersex dominated the twentieth century. However, these procedures have only recently undergone some form of critique. A critique that has not only come from external sources such as the intersex individuals, gender theorists, family and friends of intersex individuals, but have also come from within the medical profession. Despite the different lenses through which these groups view issues surrounding intersex they share common demands.

Alice Dreger (2004) has assembled some of the main arguments that posit the intersex movement's demand for a paradigm shift. That is, a shift, away from a "concealment-centered model" to a "patient-centered model" (Table 5.1).

Key Points of Comparison	Concealment-Centered Model	Patient-Centered Model
What is Intersex?	Intersex is a rare anatomical abnormality which is highly likely to lead to distress in the family and great distress for the person with an intersex condition. Intersex is pathological and requires immediate medical attention.	Intersex is a relatively common anatomical variation from the 'standard' male and female types; just as skin and hair color vary along a wide spectrum, so does sexual and reproductive anatomy. Intersex is neither a medical nor a social pathology.
Is Gender Determined by nature or nurture?	Nurture. Virtually any child can be made into a 'boy' or a 'girl' if you just make the genitals look convincing. It doesn't matter what the genes, brain, hormones, and/or prenatal life are/were like.	Both, surely, but that isn't the point. The point is that people with intersex conditions ought to be treated with the same basic ethical principles as everyone else – respect for their autonomy and self-determination, truth about their bodies and their lives, and freedom from discrimination. Physicians, researchers, and gender theorists should stop using people with intersex conditions in 'nature/nurture/ experiments or debates.
Are intersexed genitals a medical problem?	Yes. Untreated intersex is highly likely to result in depression, suicide, and possibly 'homosexual' orientation. Intersexed genitals must be 'normalized' to whatever extent possible if these problems are to be avoided.	No. Intersexed genitals are not a medical problem. They may signal an underlying metabolic concern, but they themselves are not diseased; they just look different. Metabolic concerns should be treated medically, but intersexed genitals are not in need of medical treatment. There is no evidence for the concealment paradigm, and there is evidence to the contrary.
What should be the medical response?	The correct treatment for intersex is to 'normalize' the abnormal genitals using surgical, hormonal, and other techniques. Doing so will eliminate the potential for parents' psychological distress.	The whole family should receive psychosocial support (including referrals to peer support) and as much information as they can handle. True medical problems (like urinary infections and metabolic disorders) should be

		treated medically, but all non-essential treatments should wait until the person with an intersex condition can consent to them
When should treatments designed to make a child's genitals look 'normal' be done?	As soon as possible because intersex is a psychosocial emergency. The longer you wait, the greater the trauma.	ONLY if and when the intersexed person requests them, and then only after she or he has been fully informed of the risks and likely outcomes. These surgeries carry substantial risks to life, fertility, continence, and sensation. People with intersex conditions should be able to talk to others who have had the treatments to get their views.
What is motivating this treatment protocol?	The belief that our society can't handle genitals ambiguity or non-standard sexual variation. If we don't fix the genitals, the child with an intersex condition will be ostracized, ridiculed, and rejected, even by his or her own parents	The belief that the person with an intersex condition has the right to self determination where her or his body is concerned. Doing 'normalizing' surgeries early without the individual's consent interferes with that right; many surgeries and hormone treatments are not reversible. The risks are substantial and should only be taken if the patient has consented.
Should the parents' distress at their child's condition be treated with surgery on the child?	Yes, absolutely. Parents can and should consent to 'normalizing' surgery so that they can fully accept and bond with their child.	Psychological distress is a legitimate concern and should be addressed by properly trained professionals. However, parental distress is not a sufficient reason to risk a child's life, fertility, continence, and sensation.
How do you decide what gender to assign a new born with an intersex condition?	The doctors decide based on medical tests. If the child has a Y chromosome and an adequate or 'reconstructable' penis, the child will be assigned a male gender. (Newborns must have penises of 1 inch or larger if they are to be assigned the male gender.) If the child has a Y chromosome and an inadequate or 'unreconstructable' penis according to doctors, the child will be assigned a female gender and surgically	The parents and extended family decide in consultation with the doctors. This approach does not advocate selecting a third or ambiguous gender. This child is assigned a female or male gender but only after tests (hormonal, genetic, diagnostic) have been done, parents have had a chance to talk with parents and family members of children with intersex conditions, and the entire family has been offered peer support. We advocate

	<p>‘reconstructed’ as such. If the child has no Y chromosome, it will be assigned the female gender. The genitals will be surgically altered to look more like what doctors think female genitals should look like. This may include clitoral reduction surgeries and construction of a ‘vagina’ (a hole).</p>	<p>assigning a male or female gender because intersex is not, and will never be, a discreet biological category any more than male or female is, and because assigning an ‘intersexed’ gender would unnecessarily traumatize the child.</p> <p>The doctors and parents recognize, however, that gender assignment of infants with intersex conditions as male or female, as with assignment of any infant, is preliminary. Any child may decide later in life to change their gender assignment; but children with intersex conditions have significantly higher rates of gender transition than the general population, with or without treatment. That is a crucial reason why medically unnecessary surgeries should not be done without the patient’s consent; the child with an intersex condition may later want genitals (either the ones they were born with or surgically constructed anatomy) different than what the doctors have chosen.</p> <p>Surgically constructed genitals are extremely difficult if not impossible to ‘undo,’ and children altered at birth or in infancy are largely stuck with what doctors give them.</p>
<p>Who should counsel the parents when a child with an intersex condition is born?</p>	<p>Intersex is a psychosocial emergency that can be alleviated by quick sex assignment and surgery to reinforce the assignment. Professional counseling is suggested but typically not provided. Peer counseling is typically not suggested or provided.</p>	<p>Intersex is a community and social concern requiring understanding and support. Counseling should begin as soon as the possibility of intersex arises and/or as soon as the family needs it. Professional counsellors trained in sex and gender issues, family dynamics, and unexpected birth outcomes</p>

		should be present. Families should also be actively connected with peer support.
What should the person with an intersex condition be told when she or he is old enough to understand?	Very little, because telling all we know will just lead to gender confusion that all these surgeries were meant to avoid. Withhold information and records if necessary. Use vague language, like ‘we removed your twisted ovaries’ instead of ‘we removed your testes’ when speaking to a woman with AIS.	Everything known. The person with an intersex condition and parents have the right and responsibility to know as much about intersex conditions as their doctors do. Secrecy and lack of information lead to shame, trauma, and medical procedures that may be dangerous to the patient’s health. Conversely, some people harmed by secrecy and shame may avoid future health care. For example, women with AIS may avoid medical care including needed hormone replacement therapy.
What’s wrong with the opposing paradigm?	Parents and peers might be uncomfortable with a child with ambiguous genitalia. Social institutions and settings like locker rooms, public restrooms, daycare centres, and schools will be brutal environments for an ‘abnormal’ child. The person with an intersex condition might later wish that his or her parents had chosen to have her or his genitals ‘normalized.’	The autonomy and right to self determination of the person with an intersex condition is violated by the surgery-centered model. In the concealment model, surgeries are done without truly obtaining consent; parents are often not told the failure rate of, lack of evidentiary support for, and alternatives to surgery. Social distress is a reason to change society, not the bodies of children.
What is the ideal future of intersex?	Elimination via improved scientific and medical technologies.	Social acceptance of human diversity and an end to the idea that difference equals disease.
Who are the proponents of each paradigm?	John Money and his followers, most pediatric urologists and pediatric endocrinologists, and many gynecologists and other health care practitioners	Intersex activists and their supporters, ethicist, some legal scholars, medical historians and a growing number of clinicians.

Table 5.1 Alice Dreger’s “Shifting the Paradigm of Intersex Treatment” (2004).

The intersex movement’s literature can be condensed to five main goals: 1) Re-evaluate surgical and hormonal treatments, 2) Reassessment of the current sex/gender determination process, 3) Increased number of follow-up studies, 4) End ‘a culture of silence’ and the ‘paradigm of deceit’ and 5) Counselling and peer support.

“Stop infant genital surgery” (Fausto-Sterling, 2000: 79). This statement elucidates the central attitude of the movement. In Dreger’s comparative table above “intersexed genitals are not a medical problem ... intersexed genitals are not in need of medical treatment” (Dreger, 2004). According to Creighton and Minto “genital surgery is one of the most controversial interventions in current intersex management” (2001: 1265).

Criticism has been levelled at the surgical treatments because of the negative side effects, such as they “carry substantial risks to life, fertility, continence, and sensation” (Dreger, 2004) and because surgery “causes extensive scarring, requires multiple surgeries, and often obliterates the possibility to orgasm” (Fausto-Sterling, 2000: 80). The negative side effects have been more than physical. Sharon Preves’ pivotal work *Intersex and Identity* (2003) documents how participants “who had genital surgeries emphasized that the very operations that were intended to assuage feelings of difference only served to deepen their sense of alienation” (Preves, 2003: 78). Further, Preves’ participants

Reported that they received three messages about themselves through medical sex assignment: (1) that they were objects of medical interest and treatment; (2) that they were not to know what was wrong with them or why they were receiving medical treatment; and (3) that such procedures were in their best interest and should remain uncontested and undisclosed (Preves, 2003: 62)

According to Fausto-Sterling, even a group of physicians concede that “the trauma of such surgery might partly cancel out its intended benefits” (Fausto-Sterling, 2000: 86).

The current attitude of medical professionals insists on immediacy rather than accuracy or satisfactorily successful surgical intervention and assignment of sex. As Cheryl Chase states

A number of surgeons have expressed - in conversation and in private correspondence, though not in professional publications - the conviction that *any*

surgical intervention, no matter how damaging to sexual function or how poor the cosmetic result, is better than leaving an intersexed child unaltered (Chase, 1999: 150)

However, because of the aforementioned negative side effects of surgery, the intersex movement argues that these surgical treatments be postponed until the child is able to give informed consent to the irreversible procedures (Wilson and Reiner, 1999: 126). As the Intersex Society of North America's website states

No surgery should be performed unless it is absolutely necessary for the physical health and comfort of the intersexual child. We believe any surgery that does not meet these criteria to be essentially elective cosmetic surgery which should be deferred until the intersexual child is able to understand the risks and benefits of the proposed surgery and is able to provide appropriately informed consent (ISNA, 2002)

Criticism of the patient-centered protocol implies that the intersex movement condones the raising of gender-neutral children. However, Morgan Holmes responds to this claim

Intersex activists are not suggesting that children be raised without a gender identity ... Suggesting that early cosmetic surgery should be postponed is not equal to arguing that children should be raised as radical gender experiments. The necessity of a clearly defined social role is not at issue. The medical insistence that the gender assignment of the intersexed children has to be *sutured* down surgically is, however, very much at issue (Holmes, 2002: 160)

Surgical intervention is implemented after a team of specialists has determined which sex the child is assigned. This sex, and subsequently gender, assignment has been largely criticised because of its reliance on social rather than medical concerns (Fausto-Sterling, 2000: 58; Crouch, 1999: 32; Groveman, 1999: 35; Kessler, 1998: 12). As Dreger outlines above a child is assigned the male gender if its penis is larger than an inch and deemed

‘adequate.’ Adequacy is categorised through possible future social situations. As Fausto-Sterling describes it

Young boys should be able to pee standing up and thus to ‘feel normal’ during little-boy peeing contests; adult men, meanwhile, need a penis big enough for vaginal penetration during sexual intercourse (Fausto-Sterling, 2000: 57)

Again intersex activists insists that “intersexed children should be labeled male or female” (Chase, 1999: 148) yet while conceding it is “radical,” they support a position that challenges the need to surgically correct discordance between the body and gender identity (Chase, 1998a: 198).

It is argued that any future patient-directed reassignment of sex and gender can be performed. As Wilson and Reiner state “It is also increasingly clear that children can come to recognize their differing gender identity from the infancy-assigned identity without major psychological collapse or psychiatric illness” (Wilson and Reiner, 1999: 127). Fausto-Sterling also supports this position by stating that it is “clear that children adjust to the presence of anomalous genitalia and manage to develop into functioning adults, many of whom marry and have active and apparently satisfying sex lives” (Fausto-Sterling, 2000: 95).

As discussed in Chapter 4, the current medical model cites follow up studies to support surgical intervention and sex/gender assignment. However, “there are few empirical investigations to back up this claim. In fact, the studies gathered to build a case of medical treatment often do just the opposite” (Fausto-Sterling, 2000: 93). As previously discussed, assessment of clitoral surgery is largely based on the criterion of cosmetic success, rather than clitoral function, as Fausto-Sterling states “The inadequacy of the evaluations is glaringly obvious” (Fausto-Sterling, 2000: 80).

The argument made by medical professionals that intersex children raised with ambiguous genitalia are “doomed to lives of misery” (Fausto-Sterling, 2000: 94) is not

substantiated by the literature. Suzanne Kessler's research has shown that "There are no published studies on how these adolescents [who are not told the truth] experience their condition and their treatment by doctors" (Kessler, 1998: 30). Further, Wilson and Reiner insist that "there are no studies that document the psychological impact of secrecy versus open discussion" (Wilson and Reiner, 1999: 125).

Cheryl Chase considers the argument that medical professionals believe that "criticisms of former patients are irrelevant because 'surgery is now better'" (1999: 1467). However, as Chase states "there is no evidence to indicate that children operated on with current techniques will have better long-term outcomes than those operated on 10 or more years ago" (Chase, 1999: 147).

As Dreger's not too subtle categorisation implies the 'concealment-centered' model describes the active omission of information pertaining to an intersex individuals' intersex status. As a consequence of surgical intervention and the subsequent assignment of sex and gender, according to the Intersex Society of North America a "conspiracy of silence" (ISNA, 2002) and according to Groveman a "paradigm of deceit" (1999: 27) has surrounded people with intersex conditions.

The 'concealment-centered' model believes that intersex individuals should be told "very little" about their status, because "telling all we know will just lead to gender confusion that all these surgeries were meant to avoid" (Dreger, 2004). However, the result of being told 'very little' "culminates in experiences that are almost universally tragic" (Groveman, 1999: 27).

Suzanne Kessler illustrates these 'universally tragic' experiences. A pediatric endocrinologist recounts telling a 14 year old adolescent female with androgen insensitivity

That her ovaries weren't normal and had been removed. That's why she needed pills to look normal ... I wanted to convince her of her femininity. Then I told her

she could marry and have normal sexual relations ... [Her] uterus won't develop but [she] could adopt children (cited in Kessler, 1998: 29)

Kessler then offers the opinion of a urologist “on this handling of the counseling” (29).

It sounds like a very good solution to it. He's stating the truth, and if you don't state the truth ... then you're in trouble later (cited in Kessler, 1998: 29)

Kessler ponders this response

This is a strange version of ‘the truth,’ however, since the adolescent was chromosomally XY and was born with normal testes that produced normal quantities of androgen. There *were* no ovaries or uterus (original emphasis, Kessler, 1998: 29)

Kessler concludes by saying, “technically, these physicians are lying” (Kessler, 1998: 29). These lies have become all too common components of intersex narrative (Preves, 2003: 73). Secrets have a way of being found out, as Wilson and Reiner state “children have a particular knack for recognizing when something is being withheld from them, especially when scars, appearance, and frequent doctors' visits document that something about them *is* different” (original emphasis, Wilson and Reiner, 1999: 125).

As will be explored in Chapter 6, intersex narrative has revealed that intersex individuals' lives are “permeated with the disastrous consequences of secrecy and lies” (Preves, 2003: 29). For example, feelings of isolation, stigma and shame (Wilson and Reiner, 1999: 125; Preves, 2003: 63) and “self-doubt, anxiety and fear” (Holmes, 2002: 167). Further, as Preves says these are “the very feelings that such procedures attempt to alleviate” (Preves, 2003: 63). Further, Preves insists that knowing ‘very little’ led participants of Preves' study to develop

Their own explanations for their physical differences that revolved around a self-derived diagnosis. For example, in an attempt to make sense of their families' shame, several imagined they had terminal illnesses or disorders too freakish to comprehend, let alone discuss (Preves, 2003: 74)

Another significant goal of the intersex movement is putting intersex individuals and their families in contact with information and peer support groups. Apparently it is one goal that the two sides of the debate share (Yronwode, 2000). The Intersex Society of North America's website states that "contacting others through the Intersex Society has been a life-changing, or even life-saving, experience" (ISNA, 2002). This life-changing or life-saving experience is supported by Preves' study which argues that the lack of peer support "only served to further an individuals difficulty in formulating a coherent and stable self-concept because they had few if any accurate points of social comparison" (Preves, 2003: 75). The ISNA website goes further to say that the "ISNA provides a safe space for us to develop and express healthy identities as intersexuals" (ISNA, 2002).

These five universal goals of the intersex movement have drawn a line under the dominant medical management and identified a number of flaws in its assumptions, procedures, applications, assessments and ultimately its outcomes for intersex individuals. The intersex movement has offered its own opinions on the medical model in the light of their own lived experiences and research. Rather than advocating for the total abolishment of a medical intervention, and advocating the raising of intersex children as gender-neutral, the intersex movement is campaigning for a shift in the medicalised focus. A paradigm shift that will encompass a "Patient-Centered Model" that would not only better serve the medical profession, but will also offer a space for choice, democracy and struggle regarding intersex.

5.3 Outcomes of the Intersex movement

The contemporary intersex movement began with the establishment of organisations and support groups in the late 1980's and early 1990's. Therefore if we have seen over fifteen

years of collective campaigning and action, what outcomes has the intersex movement achieved? On a personal level more and more intersex individuals have increased their knowledge, acceptance and camaraderie concerning their intersex status. Some of these personal achievements will be discussed in the next chapter. However, presently I will focus on some of the systematic changes influencing the ways that western culture regulates and conceptualises intersex, and more significantly changes to the medical management that has taken place as a direct result of the intersex movement.

The five goals articulated by the intersex movement, as outlined above, have had an influence on the medical profession. Indeed this is one location where the intersex movement has achieved significant, albeit gradual changes. These changes to medical practice will be discussed presently. However, two recent changes will be discussed to illustrate how the concerns of the intersex movement are being heard in the non-medical sphere. Namely, policy changes in the International Olympics Committee and the Australian Department of Foreign Affairs. Both illustrate how systematic change can be driven by greater awareness of intersex issues and how the intersex movement has already produced significant outcomes.

5.3.1 Olympics

The modern Olympics have recently addressed the concerns raised by the intersex movement by challenging its own systematic configurations of sex and gender dualism. Until the 1960's the Olympics had relied on athletes to decide for themselves whether they would compete as males or females. One famous case came to light in 1957 when Hermann Ratjen admitted to competing for Germany under the name Dora Ratjen in the 1936 Olympics encouraged by the Nazi Youth Movement (Author Unknown, 1996; Lehrman, 1999; Dreger, 2000: 7). Despite the gender switch Hermann/Dora came fourth (Author Unknown, 1996).

At the height of the cold war in the 1960's some concern was raised as to the sex of some of the Eastern European competitors, "especially two Soviet sisters who won gold medals

at the 1960 and 1964 Olympics” (Author Unknown, 1996). Consequently, at the European Championships in 1966 and the Pan-American Games in 1967 female competitors were asked to parade in front of a panel of officials to ensure that they were indeed female (Author Unknown, 1996; Lehrman, 1999). Subsequent complaints about these parades as degrading (Fausto-Sterling, 2000: 3) led to the implementation of the Buccal Smear test at the Mexico City Olympics in 1968. Cells are scraped from athletes’ inner cheek to determine that genetically these females had two X-chromosomes (Author Unknown, 1996, Lehrman, 1999). In 1992 the test was modified using the polymerase chain reaction to SRY, that codes for male determination (Author Unknown, 1996).

How many people have failed the sex test? According to Patrick Schamasch, the International Olympic Committee’s Medical Director, “the answer is totally confidential as it affects the intimacy of the athletes” (personal correspondence, 2003) further

I can only tell you that in both summer and winter games, some athletes have been discovered having some medical abnormalities in terms of chromosomes. This had been revealed to them by the gender verification and this has helped them to discover their disease and to be treated. Gender testing on a large scale has been suspended in 1999 prior to the Games in Sydney (Schamasch, personal correspondence, 2003)

Despite the ‘confidentiality as it affects the intimacy of the athletes’ there appears to be some evidence to suggest a relatively high frequency of women’s disqualification on the basis of having failed the sex test. While Chase (1998b: 216) and Author Unknown (1996) cite 1: 500 and 1: 500-600 respectively, Lehrman (1999) specifies that in 1992 at the Barcelona Olympics five women out of 2,406 and at the 1996 Atlanta games eight women didn’t pass the sex test.

In 1998 Cheryl Chase wrote “To this writer’s knowledge, only one person treated in this way has thus far been willing to speak openly about her experience” (Chase, 1998b: 216). Maria Patiño was Spain’s top women’s hurdler. In 1988 Patiño failed the sex test. Just

prior to competing, Patiño was advised of the results and encouraged to fake an injury. Patiño refused. Not long after the press discovered the results. Fausto-Sterling recounts what happened next

Within months after returning to Spain, Patiño's life fell apart. Spanish officials stripped her of her past titles and barred her from further competition. Her boyfriend deserted her. She was evicted from the national athletic residence, her scholarship was revoked, and suddenly she had to struggle to make a living. The national press had a field day at her expense. As she later said, 'I was erased from the map, as if I had never existed. I gave twelve years to sports' (Fausto-Sterling, 2000: 1)

Patiño was convinced that she was indeed a woman and decided to fight the IOC. Having the condition Androgen Insensitivity Syndrome, Patiño underwent examinations to determine whether the pelvic structures and shoulders were feminine enough to compete

After two and a half years the International Amateur Athletic Federation (IAAF) reinstated her, and by 1992 Patiño had rejoined the Spanish Olympic squad, going down in history as the first woman ever to challenge sex testing for female athletes (Fausto-Sterling, 2000: 2)

The 2000 Sydney Olympics saw the first Olympics since the 1960's where being a woman was no longer determined by having two X-chromosomes. As President of the Androgen Insensitivity Syndrome Support Group Australia says

The International Olympic Committee stopped performing these tests for the Sydney Olympics specifically because women with AIS are clearly women with absolutely no physical advantage over non-AIS women yet their chromosomes are 46XY (the typical male pattern) (Briffa, 2003a: 11-12)

5.3.2 Australian Department of Foreign Affairs

Australian Alex MacFarlane is believed to be the first in the world to have a passport that acknowledges an intersex or intermediate identity as opposed to a male or female identity. In 2002 MacFarlane challenged the Australian Department of Foreign Affairs' policy of having only an M or an F box to designate one's sex, insisting that choosing either box would be lying "I should not have to commit fraud due to departmental production in-adequacies" (MacFarlane cited in Butler, 2003: 8). The Department initially refused because it stated that its computers could only deal with two choices. However, MacFarlane persisted and after several months of correspondence and an enquiry from the media they relented, thereby added the option of an X

The X signifies unspecific sex or intersex and is the only other sex category allowed under International Civil Aviation Organisation guidelines for machine-readable passports (Butler, 2003: 9)

5.3.3 Rethinking Intersex

While it is conceded that it is still the minority position (Mason, 2002), it has been widely noted that more and more within the medical profession have begun to rethink their attitude toward intersex. Yet, there have been some changes in medical intervention procedures as a direct result of the intersex movement (Fausto-Sterling, 2000: 114; Yronwode, 2000; Preves, 2001: 540). Three principal areas of real change include: 1) physician-established guidelines and advocacy groups; 2) attitudinal shifts; and 3) the intersex voice is being heard in medical journals and at medical conferences.

One of the more notable physician-established guidelines are those from Diamond and Sigmundson, who in 1997 published a set of 25 "guidelines for dealing with persons with ambiguous genitals" (1997b: 1046). These guidelines were drawn up in response to queries from physicians who wrote to Diamond and Sigmundson following their published work of a follow-up study to the famous John/Joan case (1997a), discussed in

Chapter 2. However, they appear to have had little universal impact, since, as Preves states several years later, “nothing formal is in place” (Preves, 2003: 152).

The formation of North America Task Force on Intersex (NATFI) in January 2000 however, has been seen by Preves as a site of possible future guidelines (Preves, 2003: 152). The task force itself is indicative of significant change within the medical profession. The committee is made up of specialists from various medical fields, ethicists, and members of intersex advocacy organisations

The committee represents the first ‘decision-making body’ to bring patients and doctors together on the topic of medical treatment of sexual variation (Preves, 2003: 150)

Preves indicates that one of the key indicators of change (2003: 150) is the fact that NATFI is supported by a number of influential American medical organisations. These organisations include, the American Academy of Pediatrics, the American Urological Association, the American Academy of Child and Adolescent Psychiatry, the American College of Medical Genetics, the Lawson Wilkins Pediatric Endocrine Society, the Society for Fetal Urology, and the Society of Genitourinary Reconstructive Surgeon (Preves, 2003: 185 n. 11).

According to Kessler by asking their colleagues to change their views is one success of the intersex movement (Kessler, 1998: 79). This position is supported by Preves “clinicians are beginning to reform their practices and are claiming to be far less eager advocates of surgical interventions on intersexed infants and children” (Preves, 2003: 153). Preves goes on to illustrate this attitudinal shift with the following example

This shift was notable in the NATFI council member and pediatric urologist Yuri Reinberg’s 1999 grand rounds presentation at the University of Minnesota’s Medical School. During his presentation and discussion thereafter, *several noted proponents of intersex surgery spoke of their newfound reluctance* to perform

genital operations on infants and children due to adult intersexuals' critiques of sexual dysfunction and inappropriate sex assignment (emphasis added, Preves, 2003: 153-4)

Dreger, who quotes Dr. David Thomas a pediatric urologist at the 1997 meeting of the American Academy of Pediatrics, provides a further example of this acknowledgement of the medical profession's shift in attitude

I feel like Daniel stepping into the lion's den. I recognize this may not be a popular message for this audience ... But I wonder whether we shouldn't be rethinking the philosophy for early vaginal reconstruction (cited in Dreger, 2000: 194)

Lehrman (1999) illustrates this attitudinal shift as a result of talking with intersex individuals. Pediatric nurse practitioner Katherine Rossiter stated in a nursing journal in 1998 that intersex activists represent only a minority, however, Rossiter recants this position after "listening to what real people say and their arguments" (Rossiter cited in Lehrman, 1999). While Rossiter's following comment that "I've become muddy mishmash in my thinking," indicates a tenuous relationship, it does demonstrate a dialogue between medical professionals and the intersex movement.

Anita Natarajan came under considerable critique for winning an ethics essay competition (Fausto-Sterling, 2000: 299 n.27). The essay, published in the Canadian Medical Association Journal (Natarajan, 1996b), defended the practice of lying to patients about any medical intervention on infants with ambiguous genitalia. However, the critique did not go unnoticed by Natarajan, who later the same year published a letter stating that it was "enlightening to read the thoughts of women with AIS concerning their dealings with physicians" (Natarajan, 1996a: 1833). Natarajan's view is another indication of how simply a change in attitude is achieved after interaction with intersex individuals' real life stories. Natarajan wrote

I feel that an ethics essay competition open to medical students, rather than practising physicians, is a way to capture the thoughts of developing professionals before they undergo the years of clinical experience needed to practice medicine. I see writing an opinion essay with feedback from readers as a vital part of shaping the views of a clinically inexperienced medical student ... I fully recognize that I still have a great deal of training to go through. Your constructive feedback on this complex issue has been a valuable part of my medical education (Natarajan, 1996a: 1833)

Phil Gruppuso Director of research in pediatrics at Rhode Islands Hospital and Professor of biochemistry at Brown University also concurs with the way that change is achievable once a dialogue is open

I was a pediatric endocrinologist and very much in the mainstream. Anne Fausto-Sterling was a colleague and became a friend. I started thinking: I'm a scientist, look at the evidence, look at the follow-ups. I looked at the evidence, and the evidence that this genital surgery is a good idea is just - junk. There is no such evidence that doing surgery on infant genitals for appearance's sake, surgery without consent and which frequently results in sexual dysfunction - there's no evidence at all that this is a good thing. And I am unwilling to harm patients to protect the reputations of physicians who are fine academics and thoughtful men, but who were - mistaken (Gruppuso, cited in Bloom, 2002: 125)

Another vital shift in the attitude of the medical profession has been allowing intersex individuals to express themselves within, literally, the very walls of the medical establishment. That is, allowing intersex individuals to voice their concerns in medical journals and at medical conferences. In 1994 an anonymous author wrote to the *British Journal of Medicine* expressing their views on and recommendations for treatment of intersex (Author Unknown, 1994). This letter set a precedent that was to soon follow with extensive involvement of intersex voices in forums that hitherto were devoid of any real sense of the lived experience of intersex individuals. Intersex individuals were being

invited to participate in medical conferences and write for medical journals (Kessler, 1998: 79; Preves, 2003: 151) but not without resistance (Turner, 1999: 473). More significantly, beyond allowing intersex individuals to address their own issues in these forums, Preves asks us to

Consider the 1998 publication of the *Journal of Clinical Ethics* special issue on intersex, which brought together essays written by intersex activists, scholars and physicians in one volume (Preves, 2003: 151)

The same edition, according to Yronwode, “ultimately recommend[ed] major changes” (2000).

The aforementioned outcomes of the intersex movement are by no means exhaustive. However, they offer considerable weight to the argument that it is relatively easy to instigate change and to prompt a significant paradigm shift in the way that intersex is regulated and conceptualised. The changes in the Olympic Committee and the Australian Department of Foreign Affairs have set significant precedents for not only our knowledge of intersex individuals and intersex identities, but also for the ways that we regulate and conceptualise sex and gender. However, for the most part the intersex movement is campaigning to stop and alter the current medical management. This quick overview of some changes indicates how this has been successful. It is indicative of how the intersex movement consists of voices other than intersex individuals. Such that medical professionals themselves are calling for changes to the current medical management. They have seen for themselves the ramifications of these procedures through intersex individuals’ real life experiences. Subsequently they have changed their minds.

5.4 Intersex vis-à-vis Transgender

As intersex has increased its presence within the public sphere it has increasingly drawn the attention of gender and queer activists, scholars and organisations who see within the

intersex discourse not only kindred spirits, but also a means of adopting intersex individuals, identities, epistemologies and issues within their own discourses.

Gender theorists are intrigued by intersexuality (often referred to as ‘hermaphroditism’), an idea symbolizing complexity and fluidity (Kessler, 1998: 5)

In recent years the transgender movement has adopted ‘intersex’ within its nomenclature (Feinberg, 1996: x) and its aetiology (Whittle, 2002: 90; W-o-m-a-n, 2004). However, this incorporation of intersex under the umbrella term ‘transgender’ has not gone uncontested (Koyama, 2002; ISNA, 2002; AISSG, 2002b, 2003; Briffa, 2003a). A significant portion of the intersex movement is now attempting to distance themselves from the transgender movement and its attempts at appropriating ‘intersex’ and intersex issues.

As discussed in Chapter 2, the transgender movement initially campaigned for increased access to sex change operations and support services. However, as more and more transgender people voiced their needs, there came awareness that transgender people did not form a unified monothematic project. What was in fact needed was increased acknowledgement of the range of transgenderisms experienced by transgender communities. As discussed in Chapter 2 the term ‘transgender,’ as an umbrella term, includes a range of gender and sex diversity as demonstrated by Leslie Feinberg’s taxonomy

Transsexuals, transgenders, transvestites, transgenderists, bigenders, drag queens, drag kings, cross-dressers, masculine woman, feminine men, intersexuals (people referred to in the past as ‘hermaphrodites’), androgynes, shapeshifters, passing women, passing men, gender-benders, gender-blenders, bearded women, and woman body builders who have crossed the line of what is considered socially acceptable for a female body (Feinberg, 1996: x)

That is, the newly formed transgender movement quickly shifted its focus from issues around sex change operations to collectively unifying the plethora of gender and sex variant persons. That is, a coalescing of those who have begun to voice their concerns with heteronormativity and the assumption that there are two and only two naturally occurring and mutually exclusive sexes and genders.

Transman Stephen Whittle suggests that some transgendered people wish to distinguish themselves from the broader transgender community “by claiming some sort of intersex disorder such as Klinefelter’s Syndrome” (2002: 90). In recent years in Australia a tense debate has recently erupted. Within several trans forums transsexualism is claimed to be an intersex condition. One such example can be found on the “Australian W-o-m-a-n Network” (2004) website

Our implacable opposition to any distinction being drawn between the significance of transsexualism and other intersexual conditions in legislation as it is a denial of the very essence of the decision of Chisholm J in *Re: Kevin* and, subsequently, the Full Court of the Family Court in the appeal of that decision, to hold us as something apart from, or less worthy of consideration than, other citizens who similarly experience variations in their sexual formation (W-o-m-a-n 2004)

According to Andie Hider, the medical liaison officer for the AISSG Australia, the apparent recent appropriation of intersex, by ‘non-intersex individuals,’ has occurred only after “the public profile of intersex conditions was raised and the intersex community began to achieve widespread support” (Hider, 2004: 1). It has subsequently been critiqued by a number of intersex organisations who adamantly state that the use of the term ‘intersex’ by transgender organisations and individuals, is “quite simply, incorrect” (AISSG, 2003). The Androgen Insensitivity Syndrome Support Group Australia has drawn up a ‘fact sheet’ (Table 5.2) to “highlight the differences between the two groups” (AISSG, 2002b).

	Intersex	Transsexualism
Definition	One of the many long-established biological conditions where a child is born with reproductive organs, genitalia and/or sex chromosomes that are not exclusively male or female.	A recognised medical condition where people are born with completely male or female body but with a 'brain sex' of the opposite gender.
Terminology	The previous word for intersex is hermaphrodite.	Transsexualism is also referred to as 'gender dysphoria' or 'gender identity disorder.'
Diagnosis	Biologically determined	Self identified condition
Gender Identity Issues	Approx 5 to 10 % of people with intersex conditions have some question about their gender identity, and often this is a direct result of earlier inappropriate medical treatment.	100% of transsexuals have gender identity issues and reject their biological sex.
Sex of Rearing	People with intersex conditions are preliminarily assigned a sex or rearing at birth if there is an obvious ambiguity as to the child's sex. A decision is made for them. Others with intersex conditions are diagnosed late when they fail to menstruate etc.	100% of transsexuals are raised from infants as their obvious biological sex. No doctor would support raising a biologically complete male or female as the opposite sex.
Biological or Psychological?	Long established biological condition	Long established psychological condition.

Treatment	Children and infants with intersex conditions endure repeated examinations and medical procedures including orchidectomies, vaginoplasties and hormone treatment without their consent. A standard of care does not exist, but treatment is generally based on invalidated research from the 1960s.	Transsexuals receive treatment as adults under the HBGDA Standards of Care and give full disclosure and consent to any medical intervention. Care is specifically taken to ensure mistakes are not made.
Fertility	People with intersex conditions cannot reproduce without medical intervention except in extremely rare circumstances.	Most transsexuals are naturally able to reproduce. (Many do prior to rejecting their biological sex).
Issues	Treatment of children with intersex conditions, support for parents, accurate and timely diagnosis, and access to medical specialist.	Legal status of their self-identified gender, particularly for amendments to their birth certificate and for the right to marriage.

Table 5.2 Comparison Between those with Intersex Conditions and Transsexualism
(AISSG, 2002b).

According to the President of AISSG, Tony Briffa, the misrepresentation of transgender or transsexual as an intersex condition has ten ‘adverse affects’

1. Reduces the legal rights of people with intersex conditions in the law reform process by incorrectly including them in transgender legislation;
2. Confuses the community about what intersex conditions are;
3. Increases the confusion, shame, stigma and taboo experienced by parents of children with intersex conditions (with the added risk of affecting the relationships with their child);

4. Forces people with intersex conditions to withhold their medical condition to others (sometimes including medical professional) in fear of being taken as being transgender;
5. Compromises the work of intersex support and advocacy groups by circulating misinformation about intersex conditions, gender identity and the legal status of people with intersex conditions;
6. Fails to recognise the rights of people with intersex conditions to represent themselves;
7. Perpetuated old-fashioned, offensive, stereotypical views of ‘hermaphrodites’;
8. Disrespects and ignores the differences between transgender and/or transsexual people and those with intersex conditions;
9. Makes role models of successful adults with intersex conditions invisible; and
10. Complicates the gender affirming process for those with intersex conditions who were raised in the wrong sex (Briffa, 2003a: 17)

The tentative relationship between the transgender movement and the intersex movement is further illustrated in Sharon Preves’ study (2003). Preves highlights how intersex individuals are reluctant to divulge information about their sex change for fear of being seen as transgender and consequently being “assessed more blame for changing genders” (Preves, 2003: 114)

For example, when Peggy transitioned from her male gender assignment back to her original, infantile sex assignment of female in her early twenties, she was concerned that she would be incorrectly assumed to be a male-to-female transsexuals. This concern motivated her to conceal her history of gender change (Preves, 2003: 114)

And similarly there is concern expressed by the Intersex Society of North America that “too often, intersex people’s unique needs are made invisible or secondary when ‘intersex’ becomes just another subcategory of ‘transgender.’ It is for this reason that we

prefer to have ‘intersex’ spelled out explicitly rather than have it ‘included’ in transgender” (ISNA, 2002).

Another distinguishing feature between transgenderism and intersex is the interrelationship between these communities and individuals and the medical profession. That is transgender people voluntarily undergo surgical and hormonal treatments while intersex surgical and hormonal interventions are non-consenting (Turner, 1999: 471-472). The website www.transfeminism.com states

Intersexuality is not about whether or not something is biologically rooted, but about *how our bodies are treated by the medical authority* as we grow up and live. While some transsexual people are in fact also intersexed, most transsexual people do not experience involuntary medical ‘treatment’ to ‘correct’ their physical sex, for example (emphasis added, www.transfeminism.org, 2002)

Another feature that distinguishes transgender and the intersex communities and individuals is the fact that for intersex individuals’ gender is not always an issue, as the Androgen Insensitivity Syndrome Support Group Australia website states

Unlike transsexualism and/or transgender where 100% of people have gender identity issues, *only a small portion of people with intersex conditions* (probably about 5-10%) *have an issue with their gender*. The vast majority of these cases are due to the assignment of an inappropriate sex of rearing in a child with an intersex condition, and these individuals can have their birth certificates fully corrected in all states in Australia (emphasis added, AISSG, 2003)

The way that the intersex movement is wary of inclusion of ‘intersex’ in ‘other’ discourses is further evident by their reaction to the inclusion of ‘intersex’ within queer discourses, for example through addition of ‘I’ to the acronym “GLBT.” This recent extension of the acronym “LGBT” to “LGBTI” is indicative of an awareness that intersex is in some way relevant to lesbian, gay, bisexual and transgender discourses. Coalescence

of these individuals and groups under “LGBTI” adds strength to arguments against heteronormativity and sex and gender binarism. Queer discourses see intersex as the physical embodiment of their claims. Previously I cited those within the intersex movement who do not condone the raising of children as gender neutral. However, others are willing to align themselves with counter-heteronormativity and counter-dualism discourses adding their voices and support to “LGBTI” and a queer project.

What is seen by some as a collaborative effort to align voices toward a common goal is seen by some within the intersex movement as an appropriation of the intersex experience for purposes not voiced by intersex individuals or the intersex movement. For example, number six in Emi Koyama’s *Suggested Guidelines for Non-Intersex Individuals Writing about Intersexuality and Intersex People* (2002) states

Do not conflate intersex experiences with lesbian, gay, bisexual or trans (LGBT) experiences. You may understand what it might feel to grow up ‘different’ if you are part of the LGBT community, but that really does not mean you understand what it means to grow up intersexed (Koyama, 2002)

The Intersex Society of North America’s website after posing the question: “Should we add an ‘I’ to our LGBT organization?” states

This is a question each organization needs to ask itself, because if you are going to add an ‘I,’ you should be serious about doing advocacy for intersex people - adding the ‘I’ should not be just a fashion statement. Educate your members about issues intersex people face, and when you are ready to commit to fighting the stigmatization and erasure of intersex people along with homophobia, biphobia and transphobia, give us a call (ISNA, 2002)

5.5 Intersex Identity vis-à-vis male and female

Let me say outright that I believe that intersexed children should be labeled male or female (Chase, 1999: 148)

Criticism has been levelled at the intersex movement and its demands for changes to the current intersex medical management because it is thought that they want to raise children as “radical gender experiments” (Holmes, 2002: 160). Despite recent stories like Australia’s Alex MacFarlane, mostly the intersex movement has made it clear that they do not condone the raising of children as ‘radical gender experiments.’ However, as adults, there is evidence of adopting ‘intersex’ vis-à-vis ‘male’ or ‘female’ gender identities.

Comparisons between 30 years of gay liberation and the nascent intersex movement have been made (Kessler, 1998; Chase, 1998a; Turner, 1999). Kessler remarks that “much of the language of intersexuals has decidedly been formed by the history of the gay movement” (Kessler, 1998: 83-84). Kessler goes on to quote Cheryl Chase as comparing “coming out as intersexual in the 1990s with coming out as gay in the 1950s” (Kessler, 1998: 84). Stephanie Turner claims in *Intersex Identities* (1999) that

Intersexed people are continuing a theoretical and strategic trajectory begun by feminists, gays and lesbians, transpersons, and queer theorists with regard to questions of sexual and gender identity. Thanks to the work of these groups during the last 25 years, intersexuals have an intellectual foundation that permits them to resist being reduced to the normative categories of sex and gender. As a result, they are better able to establish their intersex identities on their own terms (Turner, 1999: 458)

This suggestion that intersex individuals need to be given space to ‘establish their intersex identities on their own terms’ can be witnessed within the diverse intersex movement literature.

Tony Briffa the President of the AISSG Australia has reported that 5-10 percent of intersex individuals have issue with their gender assignment. Briffa goes on to say that some of them “identify as having a gender that is both male and female. Hence, they are intersex in both sex and gender” (Briffa, 2003a: 12). As Kessler tells it, an intersex identity appears to have arisen from “knowledge of having been treated as neither completely female nor male” (Kessler, 1998: 84).

The use of phrases like ‘intersex identity’ by the intersex movement, however, needs to be examined. There appears to be subtle and almost imperceptible distinctions between use of ‘intersex’ as a third categorisation of sex/gender and as a collective coalescence of a group of people with shared biographies. Cheryl Chase posits the politicisation of intersex identities as a product of “transforming intensely personal experiences of violation into collective opposition to the medical regulation of bodies” (Chase, 1998a: 189). Further, Kessler does not see intersex identities as being “adopted for political reasons but [as] a direct outgrowth of surgical experiences” (Kessler, 1998: 86). As part of a comparison with the antecedent gay liberation movement Turner attaches significance to ‘intersex’ as identity “so that closeted intersexuals can have a better chance of filling in the gaps of their personal histories by gaining access to their own medical records” (Turner, 1999: 474).

Delineation of the use of ‘intersex identities’ is evident through the use by members of the intersex movement who perceive the need to adopt ‘intersex’ as a personal identity, as a modifier to their identity or as a gendered identity. For example, a study of 66 people with Klinefelter’s Syndrome (Bucar, 1999) found that of those surveyed 9.5% answered that their gender identity is “intersex” (Table 4.1). While expressions of ‘intersex’ identities are seen in intersex narratives and will be further elucidated in the following chapter, it is perhaps pertinent to isolate a few stories to illustrate this point.

For some, ‘intersex’ solves some life-long dilemmas. David (1995) has been able to articulate the delineation of environmental influences and personal self-reflections, such

that adopting 'intersex' encompasses some apparently contradictory identities and experiences

What I am now more able to do is to say 'yes' to my intersexuality without having to say 'no' to other aspects of my reality, other aspects of myself. I was 'brought up' to think of myself as male, and many influences in my environment have reinforced this perception, even if I am not comfortable with this image. I am saying 'yes' to intersex, 'yes' to my masculinity, and 'yes' to the fluid and receptive femininity that has enriched my life with its non-linearity and intuition. And this has given me an ease and comfort that did not seem possible when I tried to deny any of these parts (David, 1995: 5)

Intersexed is a new self-label ... Before I came to use this term I had for many years vaguely thought of myself as both male and female, or as a pseudo-hermaphrodite (original emphasis, Slocum, 1995: 6)

The interrelation between one's body and one's sense of self, appears also to be a source of coming to adopt 'intersex' as a better expression of that relationship.

I'm not seen as a girl or a boy in the flesh. I look half-and-half, and mentally I feel the same (Author Unknown, 2001: 4)

My body feels androgynous ... I no longer feel 'caught between.' I am a unique blend of my female and male essences, and I expect to continue evolving on that level" (Cameron, 1999: 96)

For some, intersex has been coupled with traditional gendered terms to express a blending of identities

Yes, I regard myself as a woman - but I am an intersex woman ... there is a multi-faceted complexity to my sense of self which the two labels imposed by society cannot embrace (MacDonald, 2000)

And Morgan Holmes agrees

What is even more difficult than identifying one self as a member of the community 'woman' is attempting to define one's identity as an intersex/woman. The task requires taking back an identity which has been made illegitimate by culture and have been stolen through surgery (Holmes, 1996: 139)

Intersex identity as an alternative to a 'male' or 'female' identity is a controversial position. Those who support it are in a minority within the intersex movement. While not altogether dismissing the experience, comments such as that made by Cheryl Chase: "Let me say outright that I believe that intersexed children should be labeled male or female" (Chase, 1999: 148), make it clear that the intersex movement's emphasis is elsewhere. As Sharon Preves concludes

Will the category and identity 'intersex' disappear altogether if doctors stop treating, studying, and classifying children in this way, or will this category continue to expand further into academic and social realms until its presence is solidified in a way similar to the presence of transgender, gay, or alcoholic identities? Focusing less on articulating the category 'intersex' may indeed be a step in the right direction toward the ultimate goal of focusing less on gender and sexual categorizations ... the clear message from my research is to decrease sex and gender categorization rather than to create yet a third rigid sex or gender line for us all to ponder (Preves, 2003: 154)

Conclusion

In a relatively short period of time intersex individuals have coalesced into a strong, diverse and successful movement. Making its first tentative moves over fifteen years ago in disparate corners of the world, the intersex movement now exists in and coordinates amongst many countries across the world. Despite the immensity of the movement it manages to agree on one particular point: they demand the cessation and change to the current intersex medical management. Yet it is not a monothematic movement, they have articulated a range of issues, and set a number of goals. In part this has been a successful movement with a number of significant changes being implemented. For example, we have seen recent changes in the attitude of medical professionals and within the current medical management. Further, there have been changes to the Olympic Committee's policy of what constitutes a 'woman' and the Australian Department of Foreign Affairs' demarcation of sex from two to three categories in the Australian passport system.

The intersex movement has drawn considerable attention from and been appropriated into gender and queer spheres, activities that have not gone uncontested by the intersex movement. Further, there has been significant, if not universal, articulation and adoption of 'intersex' as a gender identity as distinct from 'male' or 'female' within the intersex movement narrative. It is to this narrative that we now turn our attention. While this chapter focused on the goals, outcomes and ramifications the intersex movement has made, the next chapter will analyse what intersex individuals have said, a somewhat scarce if not ignored project in the intersex movement literature thus far.

CHAPTER 6: INTERSEX NARRATIVES

Introduction

6.1 Forums of Intersex

6.2 Narratives of Intersex

Conclusion

Introduction

As previously implied our view of intersex until recently has been skewed by the lens through which we looked: historical, anthropological or medical. With the sole exception of *Herculine Barbin*, intersex individuals' real life experiences were told as 'the other.' As part of the burgeoning intersex movement and as a reaction to the distortion and dearth of real life experiences, intersex individuals have recently come forward to tell their own stories. The intersex movement literature has been largely interspersed with non-intersex supporters, whom by and large we have left in Chapter 5. This chapter, I argue for the first time, contains solely the voices of intersex individuals. I offer a sample of these voices found in a wide range of forums: newsletters and 'personal story' pages on the Internet, gay, lesbian and queer anthologies, transgender discourses, intersex texts and mainstream media.

What becomes evident in this analysis is that the voices of intersex individuals pull along the same three thematic threads. That is, I have concluded that what intersex individuals are mostly talking about relate to issues of 'discovery,' 'reaction by others' and 'reflections.' I ascertain that these three themes represent how intersex individuals talk about: firstly, 'discovery' of their intersex status; secondly, the 'reaction by others' to their intersex status; and finally, how these intersex individuals 'reflect' on certain lived experiences; namely the medicalisation of their bodies and their own sense of self.

Alice Dreger (1998: 170) asks the question: why are intersex autobiographies suddenly appearing in relatively large numbers? Dreger offers two responses: the electronic-media technological revolution and postmodernism. As we will see through this chapter, there is a great deal of intersex narrative on-line. However, Dreger's answer is focused more towards the influences of postmodern thought, than the reliance on simple access to technological means of communication and expression.

Dreger epilogues the pivotal historical analysis of nineteenth century French and English hermaphroditism with an analysis of "postmodern intersexuality" (1998: 170). Dreger

suggests that postmodernity has had five key influences in the “emergence of intersexual autobiography” (170). Firstly, postmodernism has seen the valuing of voices previously considered non-authoritative. Secondly, postmodernism has brought with it the recognition that there can never be a single, self-evident, ‘true’ story to be told about a life, disease, or condition. Thirdly, postmodernist sufferers often share a sense that their bodies have been ‘colonized’ by medicine in ways that impel them to resist and object. Fourthly, postmodernism challenges the doctor-patient balance of power and the ‘doctor as saviour’ motif. And finally, postmodernism has allowed intersex individuals the ability to see their “plight” as a sign of the social times, and not inherent in or necessary to their bodies (Dreger, 1998: 170-172).

Through analysis of the forums within which intersex narratives are found, and the identification of thematic threads I argue that ultimately neither these forums nor my own analysis is beyond influence on the ‘voice’ of intersex individuals. Moreover, I argue that no matter how focused I am on offering a postmodernist work, allowing intersex individuals to speak for themselves, these narratives are not and cannot be read as unedited.

6.1 Forums of Intersex

Before progressing into an analysis of the thematic threads, I shall presently take some time to consider the forums within which these intersex narratives are found. Namely, newsletters and ‘personal story’ pages on the Internet; gay, lesbian and queer anthologies; transgender discourses; intersex texts and mainstream media. I argue that these narratives are articulating more than just a postmodern ‘voice.’ These forums are codified with meanings concerning underlying trends in the intersex movement. The language, intent and content of these narratives are imbued with knowledge possessed by the respective authors in regards to the context within which the narrative is heard. Intersex activist Michael Noble states about a paper given at Adelaide’s Gay and Lesbian Festival in “Feast” 2002

[This paper] was *targeted to an audience* which had little, if any, prior knowledge of intersex and therefore the complexities of intersex were simplified for this purpose (emphasis added, Noble, 2002)

Therefore I argue here for a decodification of these narratives for not only what they tell us about the voice of intersex individuals, but also underlying author-biased trends and contexts. Further, I make note of and problematise the embedded and codified intersex narratives in these discursive fields, because a similar codification will be done in my own study in the following chapters. I argue therefore that despite the problems associated with narrative codification, it is a necessary tool to assist in conceptualising intersex. Therefore, this chapter works as a signpost to possible complications in this current project.

6.1.1 Internet

As Dreger speculates (1998: 170) the role the Internet has played in the emergence of intersex narrative is a significant one. Hence as intersex organisations' newsletters have increasingly become available on-line, and many intersex organisations host websites contain personal narrative pages, this forum appears to be fairly imperative to my analysis.

It may be arguable that decreased cost and increased access to the Internet has had a correlation with the increasing number of intersex organisations that upload their newsletters on-line. Regardless of the reason, the result is that a larger and geographically far-reaching audience can now download newsletters hitherto only available in hardcopy and to members. Yet this project did identify some intersex organisations' websites that have maintained fee-paying-members-only access to their websites and newsletters.

Subsequently I have chosen the newsletters *Hermaphrodites with Attitude* and *dAISy*, from Intersex Society of North America (ISNA) and Androgen Insensitivity Syndrome Support Group Australia (AISSG) respectively. Not only because these two organisations

are the largest in their respective geographical regions, but also because their on-line accessibility is not limited to members. However, the focus of this project on two newsletters is not solely for practical reasons. Epistemologically and socio-politically, these newsletters appear to have a reflexive relationship with their organisation whereby they share similar discursive fields, such that changes that are witnessed in the newsletters appears to be seen in the changes to the intersex movement, and vice versa.

An example of this is the Intersex Society of North America's *Hermaphrodites with Attitude* founded in 1994 by Cheryl Chase. The newsletter hoped that many readers would contribute short articles, stories, poetry, and illustrations. A point reiterated by Chase in 1998 is that *Hermaphrodites with Attitude* is "a forum for intersexuals to tell their own stories" (1998a: 198). The first three editions included contributions from 18 individuals sharing their stories and experiences. However, by the fourth a "special edition" featured responses to an article by Dr David Sandberg. Subsequently only one contribution, a letter to the editor, offered a view not related to the 'special issue' topic. Henceforth, editions of *Hermaphrodites with Attitude* (Fall 1997, Summer 1998 and Fall 1999) and then its successor *ISNA News* (2001-present) stopped publishing personal accounts and concentrated more on "news" relevant to readers and the aims of the ISNA.

This shift in focus appears to reflect a similar shift in their goals as put forward by Chase in 1998 who stated that the "immediate goal" of the movement was to "create a community of intersex people who could provide peer support" and the "long-term and more fundamental goal" is to change the way intersex infants are treated (Chase, 1998b: 197-198). I argue therefore, the newsletter *Hermaphrodites with Attitude* mirrors this shift from the 'immediate goal' to the 'long-term and more fundamental goal' in the movement itself. That is as the movement developed through the 1990s their 'immediate goal' was displaced in favour of the 'long-term and more fundamental goal,' and with that there was a decline in real-life stories in the newsletter.

dAISy is a twice-annual newsletter produced by AIS Support Group Australia, based in Melbourne. Unlike its North American counterpart, only certain editions are available on-

line. Further, *dAISy* continues to encourage submissions of a personal nature. As with AISSG, as discussed in Chapter 5, *dAISy* provides information relevant to intersex other than AIS. In the April 2000 edition, as part of the welcome, Antoinette invites members to contribute articles to the newsletter. Alongside personal narratives there is a wealth of information contained within each edition of the *dAISy* newsletter, ranging from updates regarding developments in treatments, to reprinted articles found in mainstream media. It must be noted that while each edition of *dAISy* has numerous stories from people with intersex, some have come from people living outside Australia.

It could be argued that the AISSG has kept its focus on peer support. While the AISSG has been involved in making considerable inroads into understanding intersex in the public sphere, as discussed in Chapter 5, their focus, as *dAISy* indicates, appears to be dualistic. That is, it remains a forum through which intersex individuals can express their voices and have a voice within a socio-political arena. This is not to say that the ISNA doesn't have this focus. Rather I argue that this is a distinction that needs to be made between the North American and Australian intersex communities.

On-line publication is not limited to newsletters. With recent advancements in, and increased accessibility to Internet technologies, it is not surprising that many intersex individuals are telling their stories on-line via personal homepages. Notable in an analysis of intersex websites are the presence of pages and links to pages dedicated to the telling of personal stories. Underlying influences regarding publishing their own 'voices' on-line are the inherent issues regarding autonomy and privacy, the ability to publish instantaneously, and the fact that on-line publishing enables access to geographically and socially disparate audiences. The establishment of websites for intersex support groups aimed directly at intersex individuals appear to have begun with the ISNA website in 1996, a phenomena that has since migrated to most intersex Internet websites. While it is arguable that the Internet is a reliable source of information, it cannot be ignored that the Internet has reached a larger group of people than had been previously by other electronic or print media.

There exists outside the newsletter and website discursive fields intersex voices in a range of very different forums. This project has demarcated these into categories of anthologies, transgender discourses, intersex texts, and miscellaneous mainstream media. I argue that each forum has very specific socio-political reasons for including the voices of intersex individuals. What follows therefore is an overview of some of these reasons, and what I believe to be a necessary contextualisation of the intersex voice within these ‘other’ forums.

6.1.2 Anthologies

Among the 51 stories of North American queer youth in Amy Sonnie’s *Revolutionary Voices* (2000) one sole voice identifies as a “queer boi of mixed heritage (human-melting-pot-style) and intersexed physicality” (Hanley, 2000: 34). Editor Sonnie reinforces the placing of emphasis on the telling of the stories of queer youth - by queer youth, for queer youth. Thereby becoming ‘experts’ in their own narratives

Thank you for picking up *Revolutionary Voices*, a creative resource collection *by and for* queer and queer and questioning youth. A first-of-its-kind anthology, this book was created as a forum for today’s queer youth movement to address the issues that shape our lives ... and in a world that constantly tries to speak for us, this book asserts that we are our own experts. That *we* can speak for ourselves (original emphasis, Sonnie, 2000: xi-xii)

To underline *Revolutionary Voices*’ ‘first-of-its-kind’-ness from other anthologies, Sonnie states that

Revolutionary Voices attempts to open up this dialogue for youth: to move beyond the coming-out testimonials and recognize the process we go through in questioning, understanding, and *requestioning* our identities as queers (original emphasis, Sonnie, 2000: xi)

This intersex narrative therefore is firmly embedded within a queer and queer youth discourse, whereby intersex is queered. It is indicative of a generation of youth who not only need to express their identities, but to actively ‘question, understand, and *requestion*’ queered identities, and use such anthological forums to articulate these identity negotiations. While only one intersex story (Hanley, 2000) emerges in this anthology, it offers a profitable excursion into what Sonnie refers to as a ‘queer youth movement.’

Finding the Real Me (O’Keefe and Fox, 2003) offers a “window of understanding into the world of sex and gender diversity” (xvi) to “anyone who has even the remotest interest in human nature, as well as for clinicians, academics, employers, and the families and friends of sex and gender diverse people” (xvi). Again “Peter’s Story” (Häberle, 2003) stands as a lone intersex voice. It allows a glimpse into the life of a person whose intersex status was unknown until adulthood, whose surgical and hormonal intervention was a welcome relief to years of “going around like a zombie because I did not dare talk about what was really bothering me” (101).

6.1.3 Transgender Discourses

I have discussed in Chapters 2 and 5 how recently the term ‘transgender’ has come to be employed as an umbrella term to include a range of sexes and genders and sex and gender boundary challengers; how this trend has adopted intersex under the rubric, and further, how this appropriation has not gone uncontested by the intersex movement, particularly in Australia. Intersex individuals believe that their issues and those surrounding transgenderisms are different, and consequently intersex individuals need a voice that is distinct from that of transgendered people. Yet, there remains the presence of intersex narrative within transgender discourses.

Three key transgender discourses that have drawn some attention include Leslie Feinberg’s *Transgender Warriors* (1996), Dr Tracie O’Keefe’s *Sex, Gender and*

Sexuality (1999), and Haynes and McKenna's *Unseen Genders. Beyond the Binaries* (2001). The latter two are texts by Australian authors.

Rather than being texts that explore the issues of intersex, these texts utilise intersex in a broader context of understanding sex and gender expressions, in particular transgender expressions. *Unseen Genders. Beyond the Binaries* (2001) is a collection of essays that has two aims. Firstly, in part it is a collection of "stories of those who have resisted categorization as either male or female in many diverse ways, and of their isolation and invisibility in a society that pathologizes and excludes them" (2001: 11). Secondly, the contributions in this work "speak to the questions that emerge from a poststructuralist critique of binary logics" (Haynes, 2001: 11).

Feinberg prefaces *Transgender Warriors* (1996) with the clarification "since I am writing this book as a contribution to the demand for transgender liberation, the language I'm using in this book is not aimed at *defining* but at *defending* the diverse communities that are coalescing" (1996: ix). This position is counter to the appropriation project previously identified in transgender discourses, even Feinberg's own nomenclature cited previously. Further, Feinberg claims that *Transgender Warriors* is not an exhaustive history of the transgender experience, but is rather a "fresh look at sex and gender in history" (1996: xi) and asks the questions "have all societies recognized only two sexes? Have people who traversed the boundaries of sex and gender always been so demonized?" (1996: xi).

In Dr Tracie O'Keefe's *Sex, Gender and Sexuality* (1999) readers interested in alternative sex and gender expressions are provoked

The new categories of individuals who identify as having more than one sex, neither sex, or belonging to the third sex have a great deal to contribute to our own debates about how we view ourselves. If, like me, you are fascinated or curious about the human condition then READ AND ENJOY! (original emphasis, 1999: ix)

The ‘fascination’ of these authors, and the suggested fascination in their audience, implies that sex and gender, and its alternative expressions, are intrinsically linked to the issues of intersex. There is the assumption that the existence of intersex comes to the aid providing supporting arguments and alternative examples of real life experiences of alternative sex and gender categories, behaviours, and identities. While I do not argue that this position is unfavourable to intersex people it may also be viewed as an appropriation of intersex for a different gender political project. That is to say it problematises the boundary between intersex and transgender discourses. As shown in Chapter 5, some intersex advocates regard this as problematic.

6.1.4 Intersex Texts

In recent years some academic texts have specifically dealt with the myriad of issues concerning intersex. As a result, these texts have been well received by intersex individuals and organisations, and have been made ‘recommended reading’ lists on a number of intersex websites. Subsequently most of these texts have been included as part of the intersex movement literature. The most often cited texts are Suzanne Kessler’s *Lessons from the Intersexed* (1998), Alice Dreger’s *Intersex in the Age of Ethics* (1999) and *Hermaphrodites and the Medical Intervention of Sex* (1998), and Anne Fausto-Sterling’s *Sexing the Body* (2000). More recently one other text has been published that has yet to make its mark in the broader intersex literature. While I cite Sharon Preves’ *Intersex and Identity* (2003) here I shall postpone an analysis of Preves’ work because it is has been central to my project of interviewing intersex Australians, a point that shall be clarified in later chapters.

Although intersex texts such as Kessler, Dreger, Fausto-Sterling, and Preves focus on the myriad of issues pertinent to intersex, as those discussed in previous chapters, they employ intersex narrative sporadically so they can highlight those issues. That is to say that they codify the narrative to occupy a contextual space in their investigations into the regulation and understanding of intersex. I do not suggest that the context distorts the narrative to a point where the narrative is obliterated out of its original meaning,

However, I do argue that academic investigations such as these tend to embed narrative within theoretical debates, rather than allowing the voices to speak for themselves.

Suzanne Kessler in *Lessons from the Intersexed* (1998) openly states that this piece of work is codified for a certain audience

This book introduces and *interprets the medical literature on intersexuality for scholars and students in the area of gender studies*, thereby contributing to feminist theory on the social construction of gender and providing a *scholarly context* for understanding the contemporary intersexual movement (emphasis added, Kessler, 1998: 9-10)

In one sentence Kessler acknowledges that intersex is ‘interpreted’ for its audience in a ‘scholarly context.’ Therefore the author’s ‘interpretation’ of intersex narrative enables them to ‘contribute’ to feminist theory. If only all examples of intersex narrative interpretation were as easily decoded.

Alice Dreger’s two pivotal intersex texts *Intersex in the Age of Ethics* (1999) and *Hermaphrodites and the Medical Intervention of Sex* (1998) approach the issues from two distinct perspectives. *Intersex in the Age of Ethics* contains some previously published articles from an edition of *The Journal of Clinical Ethics* on intersex (Dreger, 1999: ix), including the work of physicians and researchers in the area of intersex, caregivers, partners, and parents of intersex persons and the stories of the intersex individuals themselves. Therefore what is of interest to my current project are the main issues identified in the narratives of the ten intersex contributors: Angela Moreno, Sherri Groveman, Martha Coventry, Howard Devore, D. Cameron, Kim, Hale Hawbecker, Kiira Triea, Heidi Walcutt and Sven Nicholson. Namely, these essays allow intersex individuals to speak for themselves. Further, what I witness is a collaboration of those who see the way that intersex is currently managed by the medical profession as problematic. Hence it could be argued that *Intersex in the Age of Ethics* (1999) is, if not

the but certainly, *a* critical piece of work that captures the depth and diversity of the intersex movement.

Hermaphrodites and the Medical Intervention of Sex on the other hand is “a history of the biomedical treatment of human hermaphrodites in France and Britain in the late nineteenth and early twentieth centuries” (1998: 10). Dreger goes on to say that the book “tells of the story of the encounters of two groups of people” ‘hermaphrodites’ and “men of medicine and science” (1998: 10) in this period of time. However, the work by Dreger’s own confession goes beyond “one particular chunk of history” (13), such that Dreger came to the “delayed revelation” (14) that the work needed to be contextualised not only in contemporary times, but also with contemporary intersex individuals in mind.

I had to at least ask living intersexuals for feedback on my work, because my work was in a profound way more about them than about anyone else except perhaps doctors and scientists (1998: 14)

As inferred in the introduction to this chapter, Dreger’s historical analysis is epilogued by the critical understanding that the current mode of expression for intersex individuals is interrelated to postmodernism, in particular postmodernists’ emphasis on the ‘voice.’ Hence what I witness here in Dreger’s insistence that ‘I had to at least ask living intersexuals for feedback on my work’ demonstrates this understanding of the need to embed intersex individuals’ own voices within the work. Subsequently I find in the epilogue four examples of understanding the text through the real life experiences of intersex individuals. Namely, Diane Marie Anger, Martha Coventry, Cheryl Chase and Sven Nicholson, whose stories, in keeping with the broader theme of ‘medical intervention of sex,’ are retold in the context of how their ‘sex’ was ‘intervened’ by ‘men of medicine and science.’

Anne Fausto-Sterling’s *Sexing the Body* (2000) is another pivotal work that contributes to the understanding of the regulation and conceptualisation of intersex and the current medical management and the development of the intersex movement. Indeed Fausto-

Sterling's role in the intersex movement has been long standing. Especially since the publication of the 1993 article "The Five Sexes: Why Male and Female are not Enough" in the journal *The Sciences*, which ultimately inspired a course of action that led Cheryl Chase to form the ISNA (Chase, 1998b: 215). Here Fausto-Sterling contextualises the book in the preface by stating that this is "a narrative accessible to a general audience *and* a scholarly work intended to advance discussion and arguments within academic circles" (emphasis added, 2000: ix). While Fausto-Sterling achieves a significant insight into the understanding of intersex, there is a focus on 'sexing the body.' So while a third of the chapters investigate intersex ("That Sexe Which Prevaileth," "Of Gender and Genitals: The Use and Abuse of the Modern Intersexual" and "Should There Be Only Two Sexes?") the presence of narrative from intersex individuals is not widespread. However, their presence is felt, and I endeavour to elucidate their voices from the text.

6.1.5 Mainstream Media

Any analysis of the provision of intersex narrative in what I have demarcated as 'mainstream media' would be too extensive to embark on in this current project. In recent years, a growing awareness of and interest in intersex issues has led to an explosion of such articles. This explosion has left splinters of intersex narrative throughout the public sphere. Through the inclusion of these intersex narratives I argue that intersex individuals are having their voices heard in the mainstream, away from a distortion influenced by their inclusion in intersex, gender or academic forums discussed above. What results is an emphasis on the narrative that reflects intersex individuals' need to express their concerns to a broader audience, such that what we see is a diversity of opinions regarding the medical management of intersex, the real life experiences of intersex and the ramifications of intersex on such social systems as gender. What I have included therefore is a broad range of articles from various sources: science and academic journals (Author Unknown, 1994; Chase, 1998a; Holmes, 2002), on-line sources (Lehrman, 1999; Mason, 2002), magazines (Nussbaum, 2000; Philips, 2001; Toomey, 2001), radio (Swan and Fry, 2003), and documentaries (Mortimer, 2002).

6.2 Narratives of Intersex

I have intentionally employed a postmodernist tool of allowing intersex individuals to speak for themselves. However, the preceding analysis of intersex narratives offers a caution to the claim that one can present the ‘voice’ of intersex individuals. I argue that the preceding analysis is necessitated by the fact that one needs to be wary of this context. The context of this portion of my study is to present a content analysis of intersex narrative. I argue therefore that this piece of work maintains its initial postmodern paradigm of offering intersex narrative in their own voice, but also allows a tentative interpretation of these narratives into three thematic threads: ‘discovery,’ ‘reaction by others’ and ‘reflections.’ I identified these themes throughout the forums within which intersex narrative existed. While I argue that these themes are artificially constructed, they are significant in increasing an understanding of the issues relevant to intersex individuals. Moreover, these themes appear to correlate to the intersex movement literature identified in Chapter 5.

6.2.1 Discovery

A significant portion of the intersex movement critiques the current intersex medical management. Through an analysis of this via their own lived experiences, intersex individuals have identified a ‘conspiracy of silence’ and a ‘culture of deceit’ embedded within the intersex medical management. Silence and deceit that has not only distorted ‘the truth,’ but has left many intersex individuals ignorant of their intersex status. One thread I have identified within intersex narratives revolves around the issue of ‘discovery.’ That is, discovery narratives address issues of ‘knowing’ one is different, accessing information via the Internet, inadvertent uncovering of intersex status via medical texts or records, and significantly, the revelations of discovery of ‘other’ intersex individuals and intersex organisations.

Following Wilson and Reiner statement quoted earlier “children have a particular knack for recognizing when something is being withheld from them” (1999) there is evidence in

the discovery narratives that indicate that intersex individuals have an intuitive awareness of being ‘different’

I really awakened about a year ago, though I realize that my awakenings has had many stages. Some time before the onset of memory, I awakened to the knowledge that I was different (Triea, 1994: 1)

I cannot remember a time when I didn’t know I was different. I believe I am intuitive most of the time. One of my earliest recollections regarding my syndrome is sitting in the bathtub weeping. I was weeping there, waist-high in water, at the age of 6 or 7, because I felt betrayed. I was positive that I was ‘supposed’ to be a boy and my mother wouldn’t tell me (Fran, 2002: 4)

From an early age I felt my personal history was out of the norm, that I looked a bit different, felt a bit different and was treated differently than most females. This was never acknowledged. My doctors said only trivial things to me, my parents avoided any mention (and probably any thought) of my difference (Slocum, 1995: 6-7)

I knew I was different from the moment I was capable of thought ... I knew that *something was weird and off*. There were dark, secret, clandestine appointments once a year in New York where they looked between my legs. *I knew there was something horrible there* that wasn’t talked about (original emphasis, Max cited in Mason, 2002)

The World Wide Web has been cited by intersex individuals as a source of first discovering information regarding their intersex status

In March of 2000, I was home alone on a Friday night (surprise!) and was playing around on the computer. I thought I would try and find out why I didn’t have any pubic hair (Isn’t this something everyone does?) I did several searches and kept

winding up at websites for male patterned baldness. Then I remembered that the doctor on the East Coast had used the word ‘gonads.’ I did a few searches and wasn’t really getting anywhere and then suddenly I found a website for Androgen Insensitivity Syndrome. I read everything there and realized it was me they were talking about! It was me! They described every aspect of my body. There were personal stories, many of them had led similar lives and had the same surgery and had been lied to as well. It was shocking, it was horrifying and it literally blew the top of my head off. I was genetically male? How could that be? How could that possibly be? I kept on reading all through the night, I printed out reams of pages. I couldn’t soak in enough information. I figured out that I had Complete Androgen Insensitivity Syndrome. I had a name for it (Renee, 2000)

This past summer I started digging and searching on the [Internet]. But I couldn’t come up with anything. I’d type in key words like ‘missing periods’ or ‘women not menstruating’ etc. Nothing concrete would come up. Then it was only in the last month I was searching at work one weekend, I typed in the word ‘gonads,’ and a whole slew of hits came up. Then I found words like Androgen Insensitivity Syndrome and WOW it just hit me between the eyes. Did I have this, is this what it was? No way? XY chromosome in a female? My head was spinning. I just couldn’t get enough. I read more and more and more and website upon website. Then I came across the Australian AIS website and read all the biographies. Their stories fit me a T. the puzzle was coming together after 33 years of wondering. I downloaded a whole pile of documents and had them ready when I went to see my doctor for my next HRT shot. I just couldn’t believe it (Fran, 2002: 8)

When I turned 40 I discovered the Internet. One of the first things I did was type the words ‘hermaphrodite’ in my browser. My life changed forever from that moment. I discovered that I have PAIS and the truth about what that really was right in front of me. I found all kinds of people and web sites full of information. I finally began my quest for truth and started healing from the wounds caused by the secrets kept from me (Hastings, 2003: 4)

While the medical profession is reported to have been reluctant in divulging information regarding individual's intersex status, discovery narratives cite medical texts, records and professionals as inadvertent sites of disclosure.

After several weeks of poring over medical texts and comparing the appearance of my body with the clinical photographs, I reached a firm diagnosis: testicular feminization. Not an oophorectomy, as my parents had told me. The doctors had removed my - *testes*. Alone and frightened, in the deserted stacks of the medical library in the wee hours of the morning. I learned that I was a 'male pseudo-hermaphrodite' (Carden, 1995: 2)

At the beginning of my process of coming out as intersexual, I chose to examine again the three pages of medical records that I had set aside for fifteen years. The word 'hermaphrodite' was horribly wounding; it drove me to the brink of suicide ... This second coming out was far more painful and difficult ... no ... help was available to reclaim my intersexuality. The only images found were absolutely pathologized cases histories in medical texts and journals, close-ups of genitals being poked, prodded, measured, sliced, and sutured, full body shots with the eyes blacked out (Chase, 1998b: 206)

Ultimately, I unearthed the truth about having AIS in a medical school library when I was twenty by researching the possible causes for my primary amenorrhea and lack of pubic hair (Grovesman, 1999: 26)

Angela and her parents tried hard to forget the surgery ... She'd gone into therapy for an eating disorder ... and her therapist encouraged her to write for her medical records. She did, and after three weeks during which she feared that the records had been sealed or lost, or that the hospital simply would not release them, they came: twelve pages, of which all Angela could grasp at first was that her pelvic type was consistent with that of an adolescent male. After her gynecologist helped

her to decipher the medical terminology, Angela concluded that she probably has PAIS. The records showed that the ‘ovaries’ the doctors has excised were actually undescended testes, which do pose a significant risk of cancer if not removed. But while there were at it, the doctors extended their sense of urgency to her disturbingly long clitoris, and removed it too, for reasons having nothing to do with the potential for cancer, “I guess they assumed everyone was horrified by my outsized clit as they were,” she says (Bloom, 2002: 116-117)

Searching for the truth, I went to my home to visit the family doctor of twenty years, only to be told that I was born a transsexual basically, and left me to walk out without any support given. Confused, Angry and not knowing what to do, I spoke to a doctor where I worked, and was directed to Garry Warne. Thankfully, someone who greeted me with open arms and a friendly smile, and sat me down to inform me correctly of AIS (Kylie, 2000)

Then in February 1973 [my husband and I] were married and moved to Florida to his first duty station in the U.S. Air Force. I had never been away from home and the homesickness was more than I could handle. I developed panic attacks, and though I didn’t know what they were at the time I know now. My parents and a state Senator from our home state helped us get a Compassionate Reassignment back to our home state. During the time we were writing letters and filing papers for this Compassionate Reassignment we came across some papers that pertained to me and my condition. There black and white were the words under diagnosis, ‘Bilateral Gonadectomy.’ I immediately called my parents and questioned them on this and of course they denied it and tried to convince me I was mistaken and that the papers had been on someone else, but my new husband and myself had read them and there was NO MISTAKE. I called my urologists and he at first also denied any knowledge and tried to give me answers he had given me all those years ago after my surgery, but finally he realised that I wasn’t going to stop digging until I knew the truth, so he told me the whole truth. I was devastated

because my physical appearance was female and I had always been told I was a girl and I had always thought of myself as a girl (Virginia, 2001)

When I was ten I found the word ‘hermaphrodite’ in a book on Greek myths and looked it up. A thrill of excitement ran through me upon finding the definition. There was a word for what I was, what I felt myself to be inside my head. I knew what my body looked like - a girl’s body, though large and sturdy for my age. I knew that my mother wanted me to be - something pink and fluffy and delicate, something I was never quite able to manage, being something of a tomboy. And now I knew what I really was - the secret ‘me’ no one else knew. Then I realized that this word referred to a mythical creature. How could I be one? It was quite impossible. I should just go by what my eyes could tell me, not what my heart already, somehow, knew (Kaldera, 1998: 227)

I’d had a number of different tests done on me to find out what this other thing was. They said to me, ‘There’s something that you’re not telling us, what is it?’ And I finally owned up to the fact that I’d had a bilateral mastectomy, and the surgeon who had carried that out had done a very good job, because it was almost imperceptible, and it was only after much more scrupulous checking over of my body that someone noticed the minute scars, and they carried out a karyotype which is an analysis of the genetic structure of my body and found that I had the 47XXY chromosomes (Somers quoted in Swan and Fry, 2003)

Following experiences of silence and deceit one significant process intersex individuals reported in the narratives is the discovery of others like them, and organisations that were able to support them.

Reading Cheryl [Chase’s] letter ... and talking with her/him was a life-changing event. Learning that my experiences and feelings were not so different from other people ended the absolute isolation I had felt (David, 1995: 5)

I would like to pass along some of my impressions of my first ISNA meeting ... I sat and listened in rapt wonder as others talked effortlessly about things that I had kept hidden from everyone, even myself. Near the end I was able to talk briefly about some of my problems. Later, staying with some of the local members of the group, I was able to unburden myself of some of the emotional baggage that I've been carrying around for most of my 34 years (Walcutt, 1995-1996: 12)

I am blown away, it is almost too much to take in. Yes, we do exist, there are others like me, we have a shared history and shared experiences. I feel an enormous sense of relief, of excitement, of happiness. There are others like me and others who deeply desire the need to be just who they are. It is not such a rare condition after all (David, 1994: 4)

Thank you, thank you, thank you so the best Christmas present I've ever had or ever could have. As soon as I saw the title *Hermaphrodites With Attitude* I cried aloud for sheer joy. I mean, I've known that there were there people like me, but to find that they also have *attitude*; that they also are ready to stand up and shout, 'I'm here, I'm angry and I'm not going to take it any more!' It's better than real, it's better than anything I dreamed, it's sheer paradise on earth. No more secrets, no more shame, guilt, dread, fear, self-loathing or hatred. Finally I can say, 'I'm hermaphrodite, I'm intersex, I'm transgender, I'm queer and damn proud,' as the tears of joy and belonging stream down my face (Lee, 1995: 10)

I found the subjects to be covered in the newsletter [*dAISy*] in a comprehensive, informative and honest way that was empowering for people like myself whose journey into the intersex world is still unfolding. Through showing a dialogue in which medical professionals were being engaged and so effecting real change it illustrated to me how we can all participate in this process at this level, and signified a way forward that is assertive and yet not confrontational. A range of personal intersex experience was portrayed in way that was inclusive and positive (David, 2002: 20)

Finally to be told the truth, answered all the questions so simply. A feeling of relief was felt to finally discover I was not abnormal, and there were others who felt the same! (Kylie, 2000)

I went to my first support group meeting and for the first time in my life lived amongst others just like me, talked to them, cried with them and cared deeply for them all (Andie, 2002)

At first I was terribly vexed by this issue of identity. My earlier experiences of coming out as a lesbian helped me to see the solution to my predicament. The terms homosexual and lesbian, as with the term intersex, were inventions of medical discourse used to pathologize disapproved sexualities. I must proudly assert my identity and insist that the medical construction of intersexuality as disease is oppression, not science. I must find others who share my experiences - others who will speak out with me. A community can provide emotional and logistical support for its members and mount a much more powerful resistance than individuals acting alone (Chase, 1998b: 212)

These narratives counter the prevailing medical management that filters disclosure on a 'best interests' basis.

6.2.2 Reaction of Others

Within the intersex narratives medical professionals and parents occupy central roles. Narrative is used as a forum to express how the behaviour, use of language and provision of information by doctors and parents affected intersex individuals' lived experiences. I argue therefore that the reaction of others, namely medical professionals and parents, comprise a second thematic thread in intersex narratives. Intersex narrative is a means of describing how medical professionals reacted to their patients' intersex status and gives

us insight into the medical management, and the physical outcomes, side-effects and complications that occurred.

My genitals were severely damaged by a series of surgeries during infancy and childhood. Because my penile urethra was surgically constructed, I had frequent urinary infections, which produced urinary discomfort and occasional bladder and kidney infections. As a young adult, I thought that I could shop for better, more modern surgery that would undo some of the damage to my urinary tract (Jeff, 1995: 5)

I underwent the mastectomy at the age of 14 and even though I suffered intense pain at the time, it was my decision and so I felt a little more in control of my life ... My first recollections of surgery were at about the age of 6 when I remember being separated from my family to go into hospital. I didn't understand what it was all about, all I did know was that I felt a deep sense of separation and guilt, perhaps I had done something wrong that made my parents dislike me in some way, and this was why I needed to be operated on ... My clinic visits were very humiliating as I remember, I would have to strip below the waste and have doctors poke and prod at me, all done with the consent of my mother, and what I now see as childhood sex abuse (Graham, 2002)

The gruesome procedure had the same outcome every week: urine passed freely but painfully immediately after the procedure; then the stricture clammed up again a few hours later. Again and again my father had to drive me to the physician's home in the evening in order to open me up again (Nicholson, 1999: 201)

When I was eleven ... I had three operations to repair [the] hypospadias (Nicholson cited in Dreger, 1998: 178)

One thing I hated, occasionally the school doctor and nurse would visit and class by class they would line the boys up and check for head lice and God knows what else. Part of this examination was to check that the boy's testicles had descended. They used to randomly check some of us, and a couple of times, I got away with it. Then came the time it was my turn to get caught. Picture this: a whole class of boys lined up in the hall, told to strip to underpants. I left on my shirt as I was developing breasts at this time and was very shy about it. Along comes this doctor (supposedly) and plunges his hand down my underpants in order to have a look, this was done in front of the class, though it is fair to say that they would not be able to see my penis. I felt that I had been completely humiliated, that is until later when I was summoned to the head masters room, where he tried to tell me I was not normal like other boys! As if I did not know. This never happened again and in today's climate I feel that the practice was tantamount to child abuse (Tony, 2000)

In reality though these rooms always had people in them, doctors, someone to take the photographs, sometimes a nurse to help the poor child take their clothes off and place them on the chair, always on a chair. Sorry dear you have to take all your clothes off. For all those people allowed in to view the show and tell, my parents were never there. I only recently found out that my parents didn't even realise this was going on, never consented to their child being used as a training aid for future generations of medical professionals. This is one thing that I don't know if I will ever be able to forgive the medical profession for doing (Andie, 2002)

At about one and a half years [of age] I was taken to Princess Margaret Hospital for 'investigative surgery.' I don't know what inspired them to look inside - I assume my penis wasn't normal. About seven months later they cut [my penis] off (David, 1999: 125)

When vacation was over, I would return to school, often not yet healed from the latest surgery. Sometimes I went back to school with tubes coming out of me, and stiches and scars, and I couldn't walk well. They made arrangements for me to use the teacher's rest room. I have no idea what they told the teachers (Devore, 1999: 80)

Whenever I went in for examinations as a child and later when I started hormonal treatment, doctors seemed to be perversely fascinated with my genitals. They would make me sit in frog-legged position, and invite teams of earnest interns to come in and look at me while I was naked on the cold metal examination table, the shame on my face unnoticed by them as they talked about me in the third person and looked at me close, peering at me as if I were a bug under a microscope (Hawbecker, 1999: 112)

[My GP] referred me to a gynaecologist who examined me thoroughly and quizzed me about my sex life - a traumatic experience for a naïve and sheltered virgin. I was told that I would need an operation to remove the gonads. I was studying O level biology and was surprised by this reference but there were more important things to consider at the time. I saw myself as female and came to think of gonads as the medical profession's generic reference for my ovaries. In hospital a nurse told me that surgeons did not remove ovaries from girls my age. I met my new consultant and in front of his medical staff and nurses he told me that they were not ovaries that I was sterile. The operation followed and I began taking hormone replacement therapy drugs normally prescribed for menopausal women (Author Unknown, 1994: 542)

Then of course the many horrible, tense visits to the pediatric endocrinologists to have my genitals gawked, fondled and stared at by hordes of what I perceived to be nasty, despicable men (Anger, 1997 cited in Holmes, 2002: 169-170)

For the first seven years of my life, I was passed from doctor to doctor, and I remember that they all wanted to do the same thing: look up my crotch. I am sure that most children visiting the pediatrician weren't continually removing their underpants and spreading their legs. I know this because *after* my surgical alteration, I went for the usual booster shots, look-down-your-throat routine that the other kids got (Holmes, 1994: 5)

Now at 37 I feel optimistic about the future. At the time of diagnosis I wasn't given any counselling to support me with my fertility, let alone any of the other issues that all AIS people have to face. This experience is of course common for many of us (Sarndra, 2001)

At some stage in the next year or so I was put in hospital where I believe I was to be made more like a female. A doctor I hadn't met before came in to tell me what they planned to do. That was when I said I didn't want that. He left the room without saying anything, and the endocrinologist came down a bit later and said he was going to refer me to a psychiatrist. That was the ultimate insult. Having first been denied by doctors my physical sexuality, it seemed my mental state was also going to be determined (David, 1999: 126)

The doctors told my parents that with such small genitalia it would be impossible for me to function as a male and that surgery has to be performed so that I could be raised as a girl (Hawbecker, 1999: 111)

My consultant did what he could but there were several events which increased my despair. I was admitted to hospital for adhesions and a nurse asked me if I had previously had a penis. I was seen by a psychiatrist at his office in a maternity hospital with a heavily pregnant doctor participating. I was seen by a psychosexual counsellor who tried to take me apart and reconstruct my psyche, a process which nearly caused a mental breakdown (Author Unknown, 1994: 542)

It was precisely my treatment and how it was inflicted on my being which really damaged me more than anything else and prevented me from having what I think of as a 'normal' happiness ... I never uttered a peep about being intersexed to anyone, not a word. Ever. It was something that I seemed completely incapable of doing. It was unthinkable to even think about doing such a thing. Talking means death. Intersexed people don't talk (Triea, 1997, cited in Holmes, 2002: 169)

It's kind of a strict club in this country to be a man, with very rigid rules to qualify ... It doesn't matter if you're XY. If your penis is too small, you lose it (Hawbecker cited in Lehrman, 1999)

In communication with patients/parents medical professionals placed an emphasis on individuals' intersex status that was mapped out in the narratives. For some a key feature of their lives is the way in which medical professionals spoke of their patients' intersex status

"If not for the two essential Hawbecker characteristics, denial and procrastination," he tells a large audience in one of his occasional public speaking engagements, "I would be sitting here a very, very, very angry lesbian. The doctors told my parents I had a very, very small penis. My parents said, 'Do we have to do anything about it now?' And when the doctors hesitated, my parents took me home and wouldn't bring me back." Doctors told the Hawbeckers that their son was deformed and, if not treated surgically would probably kill himself from shame when he entered childhood. "I didn't," he says. For a moment, he is visibly uncomfortable, and saddened both by what might have happened and by the actual difficulties of his physical condition "you could look at my genitals and find them pathetic, or" - and he smiles - "you can look at them as my wife and I do and find them ... adorable. But they are mine, they are intact, and I will be grateful for the rest of my life to my parents for their decision to let me be" (Hawbecker, cited in Bloom, 2002: 118)

The pediatric endocrinologists repeatedly advised [my parents] that I did not need to know the truth. They told my parents some horror story about a girl like me who had peeked at her file once while the doctor was out of the room and then killed herself. My mother asked the doctors specifically if they thought I would benefit from any type of counseling. They discouraged her from pursuing it (Moreno, 1999: 138)

They told me that my ovaries hadn't developed properly and if left would become cancerous (Angela cited in Mason, 2002)

The message was conveyed to me in many ways: Take the pill, your questions are irrelevant, do not ask them. It became quite clear over time that my body was a frightening and dangerous thing ... It also became clear that something was not being discussed and that this little tomboy, who just want to play soccer and read, was the source of heartbreaking despair for his doctors and parents (Kristi cited in Mason, 2002)

I was born physically intersexed and was medically assigned as male. If you like, I transitioned at an early age, without my consent. Like many intersexed people, neither I nor my parents were given any information regarding my condition or treatment ("trust us, we're doctors, this is all for the best, you wouldn't understand the big words we use"), I was one of those who slipped through the net of follow-up medical care and only uncovered the truth in later life, slowly and painfully, after a lifetime of confusion and conflict and undiagnosed health difficulties as I refused to go anywhere near anyone in a white coat for several decades (MacDonald, 2000)

I had learned a long time ago that my parents and health care professionals did not want to hear what I had to say or thought. I can tell you how many times I had heard phrases like these when I would protest any kind of treatment. I would be told 'We are doing this to save your life' or 'We are doing this to make you

normal.’ These phrases are not reassuring or comforting. These phrases tend to tell a child that you do not care what they think and what others want to do to your body is right. Most children are told that if they do not want another person to touch them then they do not have a right to touch them. In a hospital situation anyone can come in and do anything to the child and the child can not say no. I can remember a scenario like this one happening many times in my life. I would be in the hospital or the doctors office and the doctor would come in with their residents say hi to my mom and maybe or maybe not acknowledge me. Then after saying hi to my mom they would pull down the sheets, raise my night gown and remove my panties. After doing of all this without asking they would force my legs apart so that they could examine me. There could be as many as eight or ten residents standing around my bed. They would then examine me whether I wanted it or not or resisted. Imagine what this does to a child’s psyche. This had happened to me hundreds of times over my lifetime. This is like being raped over and over again with your parents in the room and bringing you to the rapist. I have termed this medical rape which is allowed to go on unprotested since it is by medical professionals who will say that they are trying to save the child’s life (Danette, 2003)

At this point they reconsidered their labelling of my gender. [John] Money now decided that I was a ‘failed male,’ i.e., female. My ‘true sex’ had been discovered ... They shifted gears; now they worked to prepare me for initiation into the Vagina Club (Triea, 1999: 142)

A significant critique of the medical profession takes place in a discourse the intersex movement has labelled a ‘conspiracy of deceit.’ This deceit is mirrored in the ‘reaction by others’ narratives, where intersex individuals report how medical professionals have omitted or distorted information of their intersex status.

My parents, like so many others of their generation, trusted the medical profession to do what was right for their child and because what they were told because they

were never allowed any doubt. Like me, my parents had now been drawn into a deception that would self-perpetuate for the next 24 years (Andie, 2002)

I certainly wasn't told the truth at Buffalo as a patient. It was not until December of 1995 that I got the truth - that I had been diagnosed with gonadal dysgenesis, that surgeons at Buffalo Children's had removed my testes, and that all the staff there had conspired to lie to me, telling me that I was female but that my nonexistent ovaries and uterus were 'underdeveloped' (Walcutt, 1999: 199)

I found a doctor who told me he was an expert. When I asked to see photos of his previous work, or talk to others he had done genital surgery on, he said he couldn't do that because of those patient's privacy, and he doubted any doctor could put someone in touch with previous patients as I was requesting (Jeff, 1995: 5)

Like many - if not most - who are born intersexed I was lied to about my condition and suffered terrible shame and humiliation regarding the 'big ugly secret' of my condition (Gossar, 2003: 6)

In 1970, when I was 7 years old, I was brought to a doctor. The reason was never fully explained, but the primary focus of these visits was my penis (Randy, 1995: 11)

I would sit with a psychologist for about an hour, and she would talk to me about very general concepts of being different. She told me that I was female, but my ovaries and uterus had been 'underdeveloped,' and that I would need to take pills ... if I wanted to have puberty like other girls (Walcutt, 1999: 198)

A few years ago I had occasion to see a urologist. While the urologist was taking my history I told him I had been born without testicles. The urologist asked me why this was so. My response was that I did not know, but I was also surprised by

his question. I was surprised because it had never occurred to me that in fact my condition could be the result of some syndrome or that there could be a 'why.' Until that day I honestly believed I was the only one on earth born so freakish; why else would my condition have been shrouded in so much secrecy and shame? The secrecy and shame imposed upon me caused me to feel isolated and alienated for much of my life. Eventually the urologist's question provided the impetus to learn more about what I had worked so hard to bury and escape from in my day to day life. Escape was not possible though because as soon as I undressed I was reminded again that I was a freak (Gossar, 2003: 6)

Intersex individuals cited their parents' behaviour, use of language and provision of information in the 'reaction by others' narratives. Some intersex individuals report that their parents were 'freaked out,' 'alarmed' and 'horrified' to see their child's obvious intersex status. 'Reaction by others' narratives include quotes from parents, or discussed how parents refused to refer to their child's intersex status

My mother freaked out and dragged me to the doctor, who diagnosed a hormone imbalance and put me on female hormones. No more shape-shifting; I was stuck with just being a girl again. My condition, for the record, is an intersex condition known as secondary congenital hyperplasia, but those are just words. It doesn't reveal the wonder and mystery of all that I am (Kaldera, 1998: 228)

My mother caught a glimpse of me as I bathed one day ... She tried very hard not to let on how alarmed she was, but of course a twelve-year-old girlchild just senses these things. When the pediatrician examined me the next day she was also obviously alarmed (Moreno, 1999: 137)

It was 1967, I was a 12 year old girl, and I will never forget the day and the look of horror on my mother's face. I was stepping out of the shower, reaching for a towel, when my mother entered the room and pointed to a lump on my groin and said, 'Oh my God, what is that?' It turned out it was an inguinal hernia,

containing an undescended testicle. But I would not find that out until 32 years later (Renee, 2000)

Twenty five years ago, as my girlfriends were getting their periods, I was told a lie. It went something like this: ‘When you were born, your ovaries were twisted. And a very smarty doctor discovered this because he saw that you had hernias. Well, these twisted ovaries were at risk of becoming cancerous. So, to prevent this from happening, when you were just a baby, they removed your ovaries, to make sure that you didn’t develop cancer.’ ... Something in this story just didn’t make sense ... A few weeks later my mother took me to a reproductive endocrinologist. He wrote a prescription for Premarin, told me I would have to take it for the rest of my life, that I would never have babies and never have a menstrual cycle. From that day forward, no one in my family has ever again spoken to me about my medical condition. Not my parents and not my elder brothers, one of whom is a medical doctor and one of whom is a clinical psychologist (Carden, 1995: 2)

When I was 12 years old I heard those terrible words that are very familiar to intersexed people, ‘you will never be able to have children.’ That was some of the most devastating news I have ever heard. Nothing else the Doctor told me that day registered at all except that. I was in physical and emotional pain and just wanted to go home and cry. My mother, trying to make me feel better immediately told me ‘*you can always adopt.*’ Hearing that didn’t help me at all, it was not a comfort. That was such a small Band-Aid to put on such a huge wound. I hurt for years because of what happened that day. **I stumbled through life not really knowing why I couldn’t have children but forever thinking that no one would ever want to marry me and I will be alone for the rest of my life.** (original emphasis, Hastings, 2003)

I do remember being taken to numerous doctors as a young child from the age of 5. I was never given a reason why I was being examined. I don’t remember questioning it, if I did I don’t remember being given an answer that is memorable

... I was told that I had been born with an inguinal hernia and it would have to be corrected. I was also told I would have to take female hormones the rest of my life so I could develop breasts and have all the female curves etc. ... I questioned 'WHY' but my parents said that is just the way it is. Naturally as a girl at that age I wasn't concerned about this because you have all faith and confidence in your parents and feel that they would never do anything to your detriment ... I don't blame [my parents] for having the surgery performed but I DO blame them for not telling me the WHOLE TRUTH especially when I was around the age of 13 or 14 when I could have understood it all better I believe (original emphasis, Virginia, 2001)

I was told as I was growing up that something was 'not quite right down there.' But I was also told not to ask too many questions. I thought it must be something horrible ... My mother just told me that I should always use a cubicle to change at school and that nobody but a doctor was ever allowed to touch me (Melissa cited in Toomey, 2001: 36-38)

I know I should have been male, I have never felt female, although I look more female than male. My childhood carried on in this manner, until I reached my early teens. Then came the inevitable, all my classmates were starting their periods, and I was left out. From this day, I consider my life to be a lie. All my mother ever said was that I would never have periods, and obviously no children, and not to tell anyone (Sue, 2002: 10)

When I was 11 yo, my mother and step-father told me one night that I had no womb (and could never have children), wouldn't menstruate, and that I didn't have a vagina (yet). No mention was ever made about my gender (except to reinforce the lie of my femaleness) or my testes that had been removed, or to explain the operations I'd had (Shorona, 2003)

My father and my doctor had the same sensible response when I asked what sex I really was: ‘You had children, isn’t that proof enough?’ (Coventry, 1999: 72)

My mother said, “Everything was done to make sure that you were a boy” *What she meant by this, I didn’t really understand*. But I believe that things were done to me (original emphasis, Carl cited in Mason, 2002)

My father said “We did a lot of things for you when you were born. You should be thankful” ... I don’t know if I can thank him for it now (Carl cited in Mason, 2002)

[My mother] said she thought the truth would upset me ... She told me for the first time that doctors had thought I was a boy when I was born, and that she and my father had named me Nicholas [But when doctors pumped dye through her genital tract when she was three weeks old, they discovered Melissa had a womb and ovaries] My parents were told I was a girl after all, but that I would need surgery to ‘normalise’ things (Melissa cited in Toomey, 2001: 38)

My parents were indifferent to, and have never acknowledged, my obvious hermaphroditism (Harris, 1995: 6)

I expect it’s all been fairly difficult for my parents, brothers, relatives and everyone I’ve known, to come to terms with my past, and they probably had, and have still, as many doubts and unanswered questions as I did (David cited in O’Keefe 1999: 126-127)

I know my parents had what they thought was my best interest in mind when [the surgery] occurred but there is still tension as a result of it. I really think it has made my relationship with them strained. I have tried to bring it up as an adult but they refuse to discuss the matter. To my mother’s credit, I think there is a lot of

guilt over it and she doesn't know how to express it. But I also think she doesn't understand my anger over it either (Betsy, 2003)

My mother was told by doctors to be honest with me as she could while I grew up. My older sister was told she would have babies 'here' (as her tummy was being rubbed) and I was told I would adopt. At a very young age, I had no trouble accepting this fact. My mother claims she knew that I was sterile but that she did not know I was CAIS. I did not and do not believe her. She knew. My mother is a registered nurse. She knew. **This entire topic was never discussed in my home, shrouding it with shame and secrecy, in my mind.** My parents did nothing to prepare me for any of what I might encounter in AIS life. Part of that is due to, I believe, the fact that I am their daughter, plain and simple. I believe they saw me as 'whole.' What difficulty could there be? (original emphasis, Fran, 2002: 4)

I have kept in close touch with my cousin [who has the same condition], and whenever either of us feels the need for a shoulder to cry on we always have each other. The sad part of all this is that we also have an uncle who is now in his 70s with the same problems, but who has had to go through life without the help and support that we now both have, it is sad that he will not open up to us despite the fact that he is aware that we all have the same condition. If we had been born to life in a wheelchair or something similar, then we would have been allowed to communicate with each other, but as we were born with ambiguous genitalia then it was a taboo subject, something to be ashamed of and not talked about with each other at an earlier stage of our lives, then we could have found so much support and reassurance between ourselves ... I just wonder how many more relatives I have with the same condition, and how many of them would welcome a shoulder to cry on, instead of all the secrecy and shame that the family have placed on our predicament. The stories that I have heard makes me wonder that if I was given more support as I was growing up and had the condition explained to me, or at least as much as they knew, then maybe I would not be as screwed up as I am now, and would not have had to go through the living hell of it all. The thing that

screwed me up more than anything else was the fact that every body else was aware of the condition except for those that were affected, and who it concerned the most (Graham, 2002)

I was taken to the doctor and within days, surgery was scheduled, for what I was told was a hernia repair. When I awoke from surgery, my parents were standing next to the bed. I lifted up the sheet, and saw two identical incisions, one on the left, one on the right. I said to my parents, ‘Why do I have two scars?’ My mother, without missing a beat, said, ‘They also removed your appendix.’ I didn’t know it at the time, but 32 years of lies and shame had just begun (Renee, 2000)

For intersex individuals one’s intersex status does not exist in a social vacuum. That is to say that while they may not be privy to information regarding their intersex status, the ways others react to their status is a compass that points - sometimes literally - to their ambiguous genitalia and other physical signs of their intersex status. For many intersex individuals it is those in their social sphere, those privy to the information denied intersex individuals, who are central to many traumatic lived experiences.

6.2.3 Reflections

Thus far I have cited narratives that focus on discovery and the reactions of others, namely medical professionals and parents. I argue that intersex narratives are also locations of reflection for intersex individuals. This third and final thread takes into account these individuals’ reflections on issues such as the medical management, personal feelings and issues of self-identity; namely sexuality, gender, and alternative gender and/or intersex identities.

Medical management appears in intersex narratives not only as expressions of lived experiences, but also as the subject of critique and analysis. Intersex individuals scrutinise this from their own perspectives and offer up a view that is imperative to any reconceptualisation of contemporary intersex.

I was an interesting lab rat. I call myself a lab rat because that is how intersexed kids are treated. Tested, photographed, tested again, photographed some more (Tria, 1997, cited in Holmes, 2002: 169)

I also wonder why they refused to help me become my real self when I began asking for help at age of 12. That's when I finally told doctors I wasn't a girl (Briffa, 2002: 10)

It wasn't until October of 1988 that I got a call from Dr. Diamond inviting me to participate in a seminar that he was teaching to medical students on intersexuality. I accepted his offer to attend the weekly classes somewhat tentatively. I was worried that he wanted me there as a specimen (as he had happened in the past with Doctors who had called in their residencies to have a looksee). I soon realized that my fears with Dr. Diamond were unfounded. In retrospect, I feel that he wanted me there to help me unlearn the misinformation I had encountered for a lifetime regarding intersex conditions and particularly my condition. In that class, I discovered that many others had suffered similar mistreatment and been subject to secrecy regarding their own body like I had (Watson, 2000)

The most critical variable to achieving a better outcome for intersex patients is not surgical management followed up with platitudes and half-truths, but instead is the provision of resources for parents to be thoroughly educated about what intersex is, and to work through any anxiety or guilt they feel about having an intersex child (Groveman, 1999: 25)

It has occurred to me that the way that intersexness has been (mis)managed in the twentieth century is analogous to the assimilation policies the Australian Government had (and has) in regards to Indigenous Australians - absorb them, hidden them, deny their existence. This assimilation attempt is often stated to be a form of genocide (Shorona, 2000)

Nonconsensual surgery cannot erase intersexuality and produce whole males and females; it produces emotionally abused and sexually dysfunctional intersexuals. If I label my postsurgical anatomy female, I ascribe to surgeons the power to create a *woman* by *removing* body parts; I accede to their agenda of ‘woman as lack’; I collaborate in the prohibition of my intersexual identity (original emphasis, Chase, 1998b: 214)

If they had just let me pee sitting down, neither I nor my family would have had to suffer all of that - the expense, the pain, the repeated surgeries, the drugs, the repeated tissue breakdowns and urine leaks. It would have been just fine to have a penis that peed out of the bottom instead of the top, and didn’t have the feeling damaged (Devore, 1999: 81)

In further search for understanding, I read through huge medical volumes with black and white photos of infants, like insects tackled to a board for study. And to my dismay, most of these photos were followed by an image of their surgical ‘correction.’ The clitoris was removed and only space remained where beauty once grew, like a forest being clear cut and left with only stumps, empty and desolate. I was thinking about how it would feel to touch that unresponsive flesh ... thinking about how it would feel if that flesh were between my own legs ... thinking about how another fraction of an inch could have destined me to the same fate (Kim, 1999: 99)

All this talk about surgery made me wonder what makes doctors so certain that women want a small clitoris, and want it badly enough to sacrifice sexual responsiveness to alter it. In a society where men pride themselves on possessing a large penis, why would women view their bodies differently. Whose perception of beauty and attractiveness are surgeons basing these decisions on? (Kim, 1999: 100)

I don't feel the medical establishment has the right to determine which of our bodies are socially acceptable (Kim, 1999: 100)

I go blank when people tell me that 'in other cultures, intersexed people were respected as Shamans.' This knowledge was of absolutely no value to me at all when I was 14 and faced with either hormonal mutation and surgery or vaginoplasty. But there must be some truth in it, because I can think of no other reason why they would invest so much energy in my genitals. They must have been profoundly awed by my genitals! Since they were different from normal genitals, they must be more powerful (Triea, 1999: 142-143)

In retrospect, I wish that the operations had never happened, that I had simply been allowed to live out my life with the plumbing system originally given to me by my creator (Nicholson cited in Dreger, 1998: 179-180)

When I discovered I had AIS the pieces finally fit together. But what fell apart was my relationship with both my family and physicians. It was not learning about chromosomes or testes that caused enduring trauma, it was discovering that I had been told lies. I avoided all medical care for the next 18 years. I have severe osteoporosis as a result of a lack of medical attention. This is what lies produce (Unknown author cited, Fausto-Sterling 2000: 299 n.27)

I was assigned a female because they didn't think I had a viable penis. At 17 months, the small phallus was a clitoris. I hadn't changed but their perceptions had (Max cited in Mason, 2002)

Narratives are more than just a telling of stories of lived experiences, intersex individuals use it to express their feelings. Invariably they express very strong emotions about their lives, the medicalisation of their bodies, and other issues that relate to their intersex status.

The biggest humiliation was when we were shown into a hall that was full of doctors, and bombarded with personal questions. Both my [CAIS] sisters found this unnerving and the talking was left to me. At that time my sisters were 5 and 6 years old, and I was 11. That experience scarred me emotionally for life, we were made to feel like freaks although at that time none of us had been told the reason. I can never go into crowded places, without those memories flooding back (Sue, 2002: 9)

I have come only very slowly to an awareness of my intersexuality, because of the secrecy and shame that surrounded me as a child, and it has not been easy to accept, even tentatively, that I am a hermaphrodite (David, 1995: 4)

I was devastated. Not that I was intersex, but that I had been lied to (Melissa cited in Toomey, 2001: 38)

I would like to illuminate what it has meant for me to grow up as a mutilated, intersexed woman. I want to write about stolen physical potential, emotional harm, and the loss of years within a potentially legitimate identity/community of queer and intersex culture. It is a robbery and loss that I share with a mostly silent and invisible population, and I hope that telling my story will draw out the potential for others to recognize 'kin' instead of remaining in the poverty of isolation (Holmes, 1998: 221)

But you don't hear the real me, and you don't see the real me. I present myself in a certain manner - a 'fitting' manner, so you will feel comfortable with me. I speak in an appropriate voice, saying acceptable things for the sake of stress-free social intercourse. The real me has been 'othered' by you and your heterosexual hegemony. I do not have a place other than one that is in hiding; I have been bound, gagged and masked (David, cited in McFarlane, 2001: 22)

But I'm kind to myself when I can't quite tell the whole truth, as all intersexuals should be. We have lifetimes of shame to overcome and, for most of us, this has been a secret that we have guarded with our lives and at great expense. Coming out as a hermaphrodite has its own precious timing. You can't peel the chrysalis off a butterfly and expect it to survive any more than we can speak out, or even face our own truth, before we are ready (Coventry, 1999: 76)

[The treatment by doctors] had me questioning my own existence as a person, male or female (Anger, 1997 cited in Holmes, 2002: 169-170)

It is disorienting when you have always considered yourself female to learn that you have XY chromosomes and once had testes. It is equally disorienting when you have always considered yourself loved and cared for to discover that your parents and doctors have lied and left you to your own devices to discover this truth (Grovesman, 1999: 26)

Coming to terms with my true sex, a sex barely recognized by humanity outside of freak shows and medical oddities, took years of work and soul-searching (Kaldera, 1998: 228)

In regards to issues of self-identity, intersex individuals were reflective of how their intersex physiology, history and medicalisation influenced, changed or reinforced their sexuality and/or gendered identities. Further, there is scope within the 'reflective' narratives for intersex individuals to contemplate alternative gendered identities, including the adoption of an 'intersex' identity.

While intersex individuals came to question their sexuality, others gained strength from it and others saw it as an opportunity to express non-traditional sexuality identities.

I feel in between male and female. I don't really know what 'masculine' feels like, but I don't feel like the 'feminine' that I see in my Mom and my sisters,

either. Because my family was so against homosexuality, I always tried to deny my lesbianism, I hoped to marry, adopt children as the counsellors at Buffalo Children's [Hospital] suggest. But I was never really attracted to men, and then I would see a girl, and feel this intense attraction (Walcutt, 1999: 200)

I personally feel like 'a straight woman trapped in a gay man's body' (Cameron, 1995: 9)

Embracing my love for women not only makes me happy, it is the thing that I had been waiting for to give me the courage to look at my body, and at who and way I truly was, without turning away. I could never have found my intersexual self until I had found and loved my sexual self (Coventry, 1999: 75)

My sexual orientation had not changed - I was still attracted to men (Cameron, 1999: 94)

There are some of us who perceive ourselves to be bisexual, there are a number who see us as heterosexual, male to female relationships. Others who see themselves as I like I do, if I'm making up to a women, gosh, I keep on checking myself as to whether I'm actually a lesbian. It's a dilemma, because the language doesn't allow for a difference in understanding as to who we are (Somers quoted in Swan and Fry, 2003)

I also had to come to terms with my sexual preference. I call myself pansexual because bisexual implies that there are only two genders (Kaldera, 1998: 228)

The medicalisation of intersex attempts to align one's body to one's assigned gender. For intersex individuals gender is often an aspect of their lives that is not easily negotiated. 'Reflection' narratives include intersex individuals' negotiation of gender.

Finally, at age 29, after years spent wandering in an emotional quagmire, I made the mammoth switch to becoming a man. I did it cold turkey, almost overnight. I just stopped taking the estrogen and let my beard grow in (Harris, 1995: 6)

Most of my life (I am 46 at present) I have endeavoured to feel female. Most of my childhood my parents, especially my mother, labored to instill in me a female identity. These efforts have had some effect. I present myself as a woman, have many womanly attributes and am treated by and large as a female. Unfortunately this struggle has almost exhausted me. All this time I have labored to prove something which is in some sense not true and at best a terrible simplification of a rather complex state of body and mind (Slocum, 1995: 6)

Though I was on testosterone injections for years, until a prostate operation, I have always had feminine feelings. I have never been interested in a sex change, life is difficult enough trying to be somewhat (as I am) male (Charles/Cathy, 1995: 9)

When I was born my sex was unknown until genetic tests were performed. The test came back that I am a female but mentally I am male like (Danette, 2003)

I'm probably also the worst nightmare of the average parent of a CAH child. Doctors tend to tell parents that their children will definitely be normal females, especially if they're properly mutilated. They're wrong. I'm living proof. At the age of 30, after years of suffering, I changed gender from female to male ... What I ended up doing, for personal and medical reasons, is transitioning to a male somatic physiology - in other words, I got a partial sex change. I am much, much happier. I realized that this is not the answer for all or even most CAH women - disclaimer, - but it has to be acknowledged that a small percentage of us will have been so masculinized, mentally, that we aren't really women any more from the neck up, as it were. I know that I'm not an anomaly (Raven, 2003)

I was to take these hormones off and on for the next dozen years until the doctors finally became worried and made me stop. In the meantime, terrified of the near hysterical reaction of my mother to any hint of crossing gender boundaries ... I decided to forget what I was. I repressed my bisexuality ... got married, and proceeded to put my body through hideous round of hormone treatment in order to have a child. I felt it was necessary to prove, once and for all, that I was a real female. The hormone treatment left me sterile, still depressed, with a premature infant - and nothing had changed. I still didn't feel female. I'm grateful that my daughter came into existence, but the price I paid for her was high (Kaldera, 1998: 228)

Either I was going to swap over and live my life as a female or suicide, so I swapped over (Rhian cited in Somers and Haynes, 2001: 35)

The first few years of testosterone replacement therapy, I had the sensation of 'reverse menopause' combined with the feeling that my female persona was dying. It was an overwhelming time of confusion, yet confusion was mixed with discovery ... Now my body appeared very masculine and I was told that, to further 'improve the effect,' I could have testicular implants and have my breast tissue removed. I chose not to have surgery ... In 1991, my sex drive began to diminish significantly. I feared that my testosterone replacement therapy had failed. I started to think of the testosterone as a poison in my system. I started to get back in touch with my female side - and realized that I had never completely lost her. Emotionally and spiritually, I have always felt more feminine, and I began to doubt that correctness of the decision I had taken, in 1976, to find out what being a male was like (Cameron, 1999: 93-94)

I am a successful attorney with a good salary. I identify as a man, and do not have a difficult time playing the part, as a matter of fact, I am actually glad that I was born the way that I was. I view it as a secret challenge that I have overcome, like climbing Everest; it has given me a lot of self-esteem, to know that I have not let

my physical condition negatively affect me, and that I have not used it to claim any special victims status either ... My physical condition has not stopped me from enjoying the truly wonderful things in life - a perfect sunset, a sumptuous meal, the laughter of a close friend, or the softness of my lover's kiss. I am glad to be who I am (Hawbecker, 1999: 113)

I very happily engage in sex whenever I can. You have to be creative, and not focus on genitals ... My penis does everything you'd expect a penis to do - it's just small (Hawbecker cited in Lehrman, 1999)

I guess I've never really felt like I fell neatly into the camp of guys. I love to cook. I love to take care of things around the house. I hate the three stooges and I don't like football (Hawbecker cited in Lehrman, 1999)

[If I was raised as a woman] I think [I'd] be OK. I could've done 'girl' too. I could be happy that way, too. That's what's mind-boggling (Hawbecker cited in Lehrman, 1999)

Coming to terms with what my body wanted was another hard issue. I function best on testosterone - no depression, no lethargy, better physical health. My brain was somehow bathed in it while I was still a fetus, creating my endocrinal disorder ... I need it to be healthy. Letting the male hormones take back my body pushed me into a category I hadn't expected - that of female-to-male transgender (Kaldera, 1998: 228-229)

The doctors have told me that I will need further surgery if I am to have sexual relations however, to this date I have not even had a boyfriend let alone a sexual relationship. I feel that the reason I have not the relationship is that I probably feel embarrassed [sic] about it. I also feel that I have been cheated of something and that males don't want only half a female, I also feel more male than female (F.P. cited in Holmes, 2002: 170)

I would have preferred to stay in between or to be a girl until I was old enough to determine what I wanted in life. I would have avoided a lot of problems that way (Carl cited in Mason, 2002)

I also feel very good [post-treatment], especially because I am no longer floating between two genders like I was before. I feel as one gender (Häberle, 2003: 101)

This reflection on gender extended to considering how their gendered experience was not confined to the criteria set down through medical management. Nor do notions of a gender dichotomy suit their lived experiences. Further, there is evidence in the intersex narratives that intersex individuals ‘reflect’ on the possibility of alternative identities, such as adopting an ‘intersex’ identity.

I am chromosomally male, a pseudohermaphrodite. These two phrases pervaded my rational thought. I did not think I was female. I did not think I was male. I did not know what I was (Author Unknown, 1994: 542)

My Name is Kira Triea. I am intersexed, my karyotype is XX, and I was raised as a male until age thirteen (Triea, 1994: 6)

I was always a very small, feminine child. I knew I wasn’t female, yet I never felt male either (Rosenthal, 2001)

What I am now more able to do is to say ‘yes’ to my intersexuality without having to say ‘no’ to other aspects of my reality, other aspects of myself. I was ‘brought up’ to think of myself as male, and many influences in my environment have reinforced this perception, even if I am not comfortable with this image. I am saying ‘yes’ to intersex, ‘yes’ to my masculinity, and ‘yes’ to the fluid and receptive femininity that has enriched my life with its non-linearity and intuition.

And this has given me an ease and comfort that did not seem possible when I tried to deny any of these parts (David, 1995: 5)

I consider myself gender neutral somewhat a mesh of the two sexes (Danette, 2003)

Although I describe myself as female, I now define myself as intersexed (Renee, 2000)

I am more than a male. I am XXY and I have always known that I have a complex blend of male and female within my being, which has always manifested in my sense of self and also in my physical appearance (Noble, 2002)

I speak as someone who was born with Androgen Insensitivity Syndrome, raised as female, and as someone who has come to identify as intersexed. Intersexed is a new self-label. I have arrived at this naming through my association with the Intersex Society of North America. Before I came to use this term I had for many years vaguely thought of myself as both male and female, or as a pseudo-hermaphrodite. It seems to me that intersexed is a good neutral, collective term that associates me with those who share my specific physical difference, and also with a larger group of people who have had to struggle with gender difference and have faced a gender-rigid world, just as I have (Slocum, 1995: 6)

I know I should have been male, I never felt female, although I look more female than male ... I settle now for being intersexed (Sue, 2002: 10)

At this point in my life I have resolved most of the painful issues associated with being born neither male nor female. In fact I have come to embrace my uniqueness and would not change anything other than my early medical treatment (Gossar, 2003: 6)

However, given the choice of "male," "female," "intersex," I would unhesitatingly select "intersex" - but society does not give me that option so I select "female." I do so with deep reservations, gritting my teeth at a society which will not accept my right to simply be who I am (MacDonald, 2000)

Yes, I regard myself as a woman - but I am an intersex woman ... there is a multi-faceted complexity to my sense of self which the two labels imposed by society cannot embrace. My desire was not to transition into female - it was to transition out of male. Period (MacDonald, 2000)

Right now my greatest struggle is to accept myself as a desirable, even marriageable human being. By that I mean people in our culture grow up expecting to marry a man or a woman, even if they're gay. They don't expect to marry someone who is intersexed, let alone someone who defies the system of sex and gender on which our society is based. Not only am I physically androgynous, but I also staunchly believe that our expected gender roles are mere constructions (Hanley, 2000: 36)

Many intersexuals share my sense of queer identity (Chase, 1998b: 216)

Well, I'm a shaman, a pagan priest(ess) of the Dark Goddess and the Lord of the Dead. Thousands of years ago, I might have been seen to be a shaman at puberty, been acknowledged and valued for the living, breathing, magical, mythical beast that I am. Those of us in the gender community who consider ourselves shamans such as myself and my [male-to-female transsexual] wife, are starting to move. We want our birthright back (Kaldera, 1998: 231)

What is even more difficult than identifying oneself as a member of the community 'woman' is attempting to define one's identity as an intersex/woman. The task requires taking back an identity which has been made illegitimate by

culture and has been stolen through surgery (Holmes cited in Feinberg, 1996: 139)

I think there is a continuum of Male ... to ... Female; like shades of gray from black to white (Cameron, 1999: 91)

I no longer feel 'caught between.' I am a unique blend of my female and male essences, and I expect to continue evolving on that level (Cameron, 1999: 96)

For example, if one is to look at various forms, such as the driving licence, what sex are you, male or female? I always enter that, first thing last, which asks me about my sex, I circle both boxes, male and female and I put the word 'androgynous' and I say 'Contrary to popular belief, there are people who are a mix of sexes and genders, and in this case could be called androgynous or intersexed ... And it raises a few eyebrows, but the interesting thing about that is that they do ask me, and then they get very serious and actually say, 'Well, we're really glad to have been opened up to this one' (Somers quoted in Swan and Fry, 2003)

We have been denied our gender-blending identities - and (often) bodies - to 'make our lives easier' (i.e. More like theirs), rather than helping to create a space where we can be safely more fully ourselves (Shorona, 2000)

Conclusion

The intersex movement would not exist if it were not for the story telling of intersex individuals. The sharing of their isolation, exclusion, pain and trauma has allowed them to coalesce firstly as a means of self-support, then as a political movement to challenge amongst other things the current medical management. Intersex narratives map out contemporary regulations and conceptualisations of intersex. By employing a similar postmodern tool as Dreger, we allow intersex individuals to speak for themselves. It is an attempt to shift the dominant medical discourse to an intersex discourse.

However, I have argued that despite these good intentions a purely postmodern project is virtually untenable. On perusal of the voices of intersex individuals in a number of different forums, of which I have provided a sample above, it was notable that the embeddedness of intersex narratives within these forums has had considerable influence on the narrative. Hence a process of decodification of the context was necessary to discern the intersex narrative inside. The process of decodification was made easier in some cases where the self-reflective author willingly admitted to their reasons for utilising intersex narratives. The decodification of intersex narratives enabled the voices to be heard.

I conclude, therefore, that while it may well be impossible to offer a purely postmodern analysis of intersex narrative, certain forums that included intersex narrative to support and clarify issues regarding sex, gender and sexuality and intersex were able to do so without distortion of the intersex individuals' voice. Such that, despite caution regarding the appropriation of intersex narratives for the authors' own agenda, these embedded narratives and the author's reflexivity ultimately contribute to the broader project of understanding contemporary regulation and conceptualisation of intersex. This conclusion is fundamental to my current project. I will continue to implement a postmodern tendency to allow intersex individuals to speak for themselves. Yet I do so based on the aforementioned conclusion. That is, as will be seen in ensuing chapters, my agenda and context may well be an influential factor in an understanding of the regulation and conceptualisation of Australian intersex individuals.

Leaving these meta-considerations aside for a moment, I have witnessed in these narratives three threads that are woven through specific forums that coalesce as an intersex movement. Located in intersex narratives are stories that tell us about intersex individuals' discovery of their intersex status, the reactions of others to this status and how these intersex individuals reflect on certain lived experiences; namely the medicalisation of their bodies and their own sense of self. Cheryl Chase began a journey to discover others hoping to find stories that matched their own, however, Chase soon

realised that every intersex individual has their own story to tell. I hope that I have done justice in reflecting just a small sample of the diversity of the lived experiences of contemporary intersex individuals.

CHAPTER 7: STUDY OF INTERSEX AUSTRALIANS

Introduction

7.1 Theoretical Frameworks

7.2 Methodological Design

7.3 On Reflection

Conclusion

Introduction

To complement the hitherto content analysis of the intersex movement, through intersex literature and intersex narratives, this project included an empirical study element to enhance its aims of exploring the social identities and relationships of Australian intersex individuals. Therefore this chapter presents the theoretical framework and the methodological design of this research project. The theoretical framework is informed by feminist, postmodern and queer theory.

As a social science researcher enrolled in the Australian higher education system of the early twenty-first century it is impossible to avoid being influenced by feminist, postmodern and queer theories. Their contributions to methodological thought and praxis have heavily guided the initiation, development and implementation of a qualitative methodological design. That is, I have deliberately placed an emphasis on the following:

- 1) Subjects telling their own stories in their own voices
- 2) Self-reflection and subjectivity of the researcher
- 3) An appreciation of the hitherto largely overlooked yet inherently diverse, ambiguous and contradictory human condition, especially in regards to sex, gender and sexualities.

This study places emphasis on the advantages of doing qualitative research. I will address how the initiation, development and implementation of a qualitative methodology is an extension of the theoretical background of this study. The methodology of this project was implemented in three phases: Key Informants, Initial Interviews, and Follow-up Interviews. This chapter will inform the reader of practical decisions and conceptual processes that established this methodological design. I shall discuss research limitations and reassessments during the processes of research design. Finally, these processes will be discussed with a reflection on specific issues within the study of intersex Australians. Namely the role of intersex organisations and community groups, and the views of

intersex organisations, community groups and individuals in regards to the term ‘intersex’ and intersex research.

7.1 Theoretical Frameworks

7.1.1 Feminism

Feminism is not a monolithic project that is mapped out along distinct geographical, sociocultural or temporal axes. However, it could be argued that feminism is unified by an analysis of masculinist assumptions in our social universe, and as such feminism has embarked on an analytical trajectory orbiting contemporary medicine. Considering the considerable influence that medicine has had on the conceptualisation and regulation of contemporary intersex it is necessary to launch a feminist analysis into orbit around intersex.

While feminism is applicable to intersex through this medicalisation of intersex there is also an unavoidable interrelationship between the lived experience of intersex individuals and feminism. Feminism is more than a theoretical tool to expose masculinist assumptions. Feminism is an extension of the lived experience of women. That is, women’s lived experiences have informed the sociocultural, political and historical aetiology of feminism. I apply a feminist framework to a study of intersex Australians because out of the thousands of infants born with ambiguous genitals 90% are surgically assigned female (Hendricks cited in Chase, 1998b: 210; Newman, 1991 cited in Holmes, 2002: 169; Creighton and Minto, 2001: 1265; Preves, 2003: 56). As intersex activist Morgan Holmes states

What many intersexed persons, myself included, have in common with women is that we also live in this world ‘as women.’ We were raised as women, to be accorded only whatever rights and privileges women can manage to obtain, within the confines of her race and class in patriarchy (Holmes cited in Feinberg, 1996: 139)

Arguably contemporary feminism does more than challenge masculinist assumptions and express the lived experiences of women. Late twentieth and early twenty-first century feminism is perhaps best defined as ‘feminisms.’ An extension of this plurality has come to include non-women as feminists. While “men-as-feminists” has not gone uncontested, there is general acknowledgement that men are able to support the feminist project. Further, in this era of delineation of what it means to be a “woman” or a “man,” one generally does not need to have a body-sex/mind-gender continuity to be ascribed an identity, for example, Butler’s problematisation of ‘woman’ (1990) and the transgender movement’s view that there are men without penises and women without vaginas. Therefore, it could be argued that one does not necessarily have to identify as or have the lived experience of a woman to employ feminist tools. Feminism goes beyond innate or inherent femaleness. Thus I argue that it is possible for a non-woman researcher to apply a feminist framework.

Feminisms’ diversity, plurality and delineation perhaps are the best indication of the real life experiences of women. In addition, it goes some way to support the notion that feminists do not practice a perfect feminism. Indeed, it has been observed that feminism in general and feminist methodology in particular has in-built biases that go beyond the notion of a ‘women’s experience’ and are perhaps universal. Ramazanoğlu and Holland state

Feminists are no more immune than other social researchers to arrogance, ignorance, complacency, academic insecurity, power hunger or limited capacities for self-knowledge, empathy or patient listening (2002: 109)

So while this current project employs feminism as part of its research framework, it does so cautiously. There are inherent and problematising capacities and limitations to feminism. Problems that in turn influence and affect feminist thought, feminist praxis and feminist methodologies. Yet the ability of feminism to embrace self-reflection and meta-analyses of its own limitations and strengths offers scope to adopt in this project. However, the key influences of feminism to critique masculinist assumptions and to offer

a link to the lived experiences of intersex individuals makes feminism an ideal theoretical platform from which an analysis can emerge.

7.1.2 Postmodernism

The social universe is also orbited by the analytical trajectory called postmodernism. Postmodernity is perhaps best described as a critique of ‘modern’ thought that has dominated the western mind over the past three hundred years. This modernist project endeavoured to evoke the belief that human existence was not only knowable but could be knowable through a process of rational, systematic and scientific progress. Postmodernity, however, calls into question the assumption that socio-political phenomena are ‘natural’ and ‘normal’

At the heart of the modern west is the culture of the Enlightenment. Assumptions regarding the unity of humanity, the individual as the creative force of society and history, the superiority of the west, the idea of science as Truth, and the belief in social progress, have been fundamental to Europe and the United States. This culture is now in a state of crisis. Signs of cultural turmoil are everywhere: in the resurgence of religious fundamentalism, in the declining authority of key social institutions, in the enfeeblement of western political ideologies and parties, and in the cultural wars over literary and aesthetic canons and paradigms of knowledge. A broad social and cultural shift is taking place in western societies. The concept of ‘postmodern’ captures at least certain aspects of this social change (Seidman, 1994: 1)

Firing postmodern weapons upon social theory and social inquiry in particular shatters the illusion of a ‘knowable’ social universe. According to Denzin (1994) postmodern social theory calls into question the notion of society as anything but an amalgamation of “the interactions of individuals. Society is then surreptitiously read from the actions of those people” (Denzin, 1994: 187). This postmodernist shifting of attention away from grandiose considerations toward ‘smaller’ ones is well articulated by Steven Seidman

Postmodernists aim to explore universalism as illusionary and as erasing, submerging, or marginalizing sociocultural diversity; they champion the values of individuality, locality, diversity, and ambiguity as the conditions of a democratic society (Seidman, 1997: 1)

The questioning being undertaken by the contemporary intersex movement of the current medical model mirrors this. Preference is given to individual considerations, that is the needs of intersex individuals, over generalised theories and practices, such as the medical model.

7.1.3 Queer Theory

Where feminism critiques the masculinist assumptions of society, and postmodernity challenges the emphasis on a knowable social universe, queer theory locates and offers alternatives to the inherent heteronormativity embedded, reinforced and perpetuated in contemporary western societies. Not unlike feminism and postmodernity queer theory's analytical trajectory is deep and broad. Some of queer's characteristics include being a celebratory reclamation of a historically pejorative word (Epstein, 1996: 153; Berry and Jagose, 1996: 5); a catch-all term to refer collectively to lesbian, gay, bisexual, transgender, transsexual and other non-heterosexually-orientated identities and behaviours (Seidman, 1996: 11; Epstein, 1996: 153; Berry and Jagose, 1996: 5); and queer is employed to deconstruct heterosexist assumptions embedded in institutions, discourses and epistemologies (Stein and Plummer, 1996: 134; Kirsch, 2000: 33; Hall, 2003: 14).

Because "indeterminacy is considered one of queer's greatest charms" (Berry and Jagose, 1996: 6) queer has become an invaluable commodity within social science research due to its ability to embrace, understand, and negotiate around the complex and contradictory nuances of human nature, especially in regards to notions of sex(es), gender(s) and sexualit(ies). Application of queer theory to intersex is significant for two reasons.

Firstly, intersex is perceived to be an embodiment of queer theory's challenge to the assumption that there are two and only two naturally occurring and mutually exclusive sexes and genders. Secondly, intersex challenges the homosexual/heterosexual binary.

While the appropriation of intersex by queer and queer theory discourses has not gone uncontested the fact remains: intersex is queer. Through two key aspects the intersex discourse takes its place in a queer discourse. Advocating the assigning of children to one gender or another on the surface appears to reinforce the demarcation of individuals into one of two sexes or genders. However, allowing infants with ambiguous genitals to grow up free of surgical intervention advocates bodies that are differentiated from their gender assignment. Another unavoidable queer aspect of the current intersex movements' claims is that they advocate allowing these children the option of undergoing a sex change later in life.

Therefore, despite the reluctance of some within the intersex movement to align themselves with queer I argue that it is unavoidable. Intersex is queered. By accepting a demarcation between gender-of-rearing and physical configuration, and by supporting sex changes, the intersex movement does in fact coincide with queer theory's project of challenging the assumption that there are two and only two naturally occurring and mutually exclusive sexes and genders.

The existence of intersex also calls into question heteronormativity. Heteronormativity is the insistence that heterosexuality is 'normal' and the assumption that everyone is heterosexual unless otherwise stated. Through intersex the very terms 'heterosexuality' and 'homosexuality' are problematised. They are predicated on the desires for a person who is either the same (homo) or the opposite (hetero) sex or gender. The existence of intersex poses the question: When one's own gender or sex is uncertain or malleable then how do we assign sexuality to it?

These comments do not attempt to impose a theoretical position onto a movement or individuals. Such a position would undermine that movement's and those individuals'

autonomy. What these above arguments suggest instead is the unavoidable necessity to include queer theory as part of this present study's framework. Queer theory offers an invaluable lens through which the complexities and contradictions of intersex can be viewed.

The current research framework therefore employs three theoretical positions - feminist, postmodern and queer theory - that offer this project an insight into the machinations of masculinist, knowable and heteronormative assumptions embedded in western cultures, and how these assumptions effect the lived experiences of intersex individuals.

7.2 Methodological Design

Investigation of social knowledge has historically been facilitated through qualitative research methodologies. When employing feminist, postmodern and queer theories, there appears a further emphasis on acquisition of social knowledge through qualitative methodologies. Joshua Gamson (2000: 348) stresses that there has been a long and intertwined interrelationship between the study of sexualities and qualitative research. A relationship bred from a critique of positivist research (348). In addition, Gamson identifies that

Qualitative methods, with their focus on meaning creation and the experience of everyday life, fit especially well with movement goals of visibility, cultural challenge, and self-determination (Gamson, 2000: 348)

A qualitative research project necessitates more than a shared goal with its research framework. How does a feminist, postmodern and queer theory framework influence a qualitative methodological design? I have adapted three critical aspects of a feminist, postmodern and queer theory framework to this methodological design. Firstly, self-reflection and meta-analysis, secondly, acceptance of multiple and at times contradictory positions and thirdly, I have adapted a prioritisation of individual voices over an authoritarian discourse.

As indicated in Chapter 1 analysis of a researcher's place in the social research text and indeed in the epistemological and interpretative layers of social research is not new (Fontana and Frey, 2000: 661). I employ a dimension of self-reflection in this project that enables the reader to identify the researcher's voice as distinct from the intersex voice. I argue that no acquisition of social knowledge can be a purely objective pursuit. Coupled with the researcher's gender, sexuality, racial ancestry, education, financial position, religion, and ambition, the researcher's personal interests in intersex adhere to the text. Therefore at the core of this research I flag a personal and professional desire to investigate the possibility of alternative and pluralised genders.

The second aspect I have adapted from the theoretical background is the understanding that at times human existence is 'knowable' only through analysis of multiple discourses. These discourses are neither mutually exclusive nor free from contradiction. Such as the opposing and contradictory debates that now define "Feminisms." So too I have identified epistemological tensions within the intersex movement and literature and amongst intersex individuals. The debates between the intersex community and queer and transgendered communities over the appropriation of the term 'intersex,' and debates within intersex communities about whether 'intersex' is a 'condition' or an 'identity' are notable sites of epistemological tension. I embrace the tensions as a necessary aspect of not only this project and its subject matter but as an inherent quality of human existence.

Finally, I have already discussed a prioritising of an individual's voice. Traditionally western societies have been dominated by authoritarian discourses, whereby groups of individuals have had their stories told by 'others.' The medicalisation of intersex is just one example. Because of this history of having their stories told by 'others,' I have argued that the intersex voice must be understood in terms of its contextualisation, whether within a medical, gender, or activist discourse. I also argue that while this contextualisation denotes a certain level of author-directed interpretation, it does not negate the validity of the intersex voice as indication of intersex issues. As I discuss in the following chapter, through an analysis of this project's context I add another space within which intersex issues can be voiced.

This theoretical background has led to the development of a methodological design that includes three phases: key informants, interviews and follow-up interviews. Phase One involved liaising with key informants within the Australian intersex movement. Phase Two employed an open-ended interview of intersex Australians. Phase Three was an extension of Phase Two interviews, whereby participants were interviewed again after reflection on previous responses. The basis of this methodological tool is informed from what I am calling an intersex-guided methodology. This intersex-guided methodology employs a two-fold epistemological schema.

The first sought to isolate contemporary Australian intersex issues. Australian intersex organisations and community groups were contacted and informed of the study. Through liaising with these organisations and community groups rapport was established with stakeholders, who were invited to become Key Informants. As Key Informants they were asked to reflect and suggest issues that were relevant to their positions within the intersex movement.

The second schema involved the employment of interviews. Interview questions were compiled with information discerned from three sources: the aims of the study, Key Informants' input and the intersex literature. A follow-up interview was conducted to meet a number of requirements. Firstly, it allowed interviewees the opportunity to add to or edit their own responses. Secondly, the follow-up interview took into consideration a duty-of-care, giving interviewees the opportunity to raise any issues that may have arisen post-interview. Finally, it gave the interviewees the chance to reflect on a summary of all initial interviewees' responses.

I have already discussed how decisions to take one particular course of study and not another is based on the researcher's own subjectivity. Further, I have claimed that this subjectivity is a pivotal source of motivation for any form of social research. I take this opportunity to explore one way this study embraces its subjects' autonomy, agency and right to self-determination.

The intersex literature consists of intersex activists and scholars writing for non-intersex activists and scholars who are interested in studying intersex individuals. One such example is that of intersex activist Emi Koyama's *Suggested Guidelines for Non-Intersex Individuals Writing about Intersexuality and Intersex People* (2002). I argue that Koyama's 'guidelines' mirror a feminist, postmodern and queer theory framework. The guidelines are embedded with considerations of agency, reflexivity, and autonomy firmly within a discourse of 'the other.' Whereby 'the other,' is not the researched, but the researcher. That is, the 'non-intersex individuals writing about intersexuality and intersex people,' a group to which this researcher belongs. Because of their significance in the formulation of the current methodological design, I here reproduce Koyama's eleven 'guidelines' in full

1. **Recognize that you are not the experts about intersex people, intersexuality, or what it means to be intersexed; intersex people are.** When writing a paper about intersexuality, make sure to center voices of intersex people.
2. **Critically approach writings by non-intersex "experts" such as doctors, scientists, and academics about intersexuality or intersex people** if you decide to quote or cite them. That is, consider what the author's perspective and agenda are, and where his or her knowledge comes from.
3. **Do not write about intersex existence or the concept of intersexuality without talking about the lives and experiences of intersex people as well as issues they face.** Do not use intersex people merely to illustrate the social construction of binary sexes.
4. **Do not judge the politics and narratives of intersex people or movement based on how useful they are to your political agenda (or agendas).** Intersex people are no more responsible for dismantling gender roles or compulsory heterosexuality than anyone else is.

5. Be aware that writings by intersex people are often part of conversations within the intersex movement and/or with other communities, including the medical community. **Realize that intersex people's words may be addressing certain constituencies or political agendas for which you do not have access to the full context.**
6. **Do not conflate intersex experiences with lesbian, gay, bisexual or trans (LGBT) experiences.** You may understand what it might feel to grow up "different" if you are part of the LGBT community, but that really does not mean you understand what it means to grow up intersexed.
7. **Do not reduce intersex people to their physical conditions.** Depict intersex people as multidimensional human beings with interests and concerns beyond intersex issues.
8. **Focus on what looking at intersexuality or intersex people tells you about yourself and the society, rather than what it tells you about intersex people.** Turn analytical gaze away from intersex bodies or genders and toward doctors, scientists, and academics who theorize about intersexuality.
9. **Do not represent intersex people as all the same.** How people experience being born intersex is at least as diverse as how people experience being born non-intersex, and is impacted by various social factors such as race, class, ability, and sexual orientation, as well as actual medical conditions and personal factors. Do not assume that one intersex person you happen to meet represents all or even most intersex people.
10. **Assume that some of your readers will themselves be intersex, and expect that you may be criticized by some of them.** Listen to intersex people when they criticize your work, and consider it a gift and a compliment. If they thought

that you had nothing to contribute, they would not bother to engage with you in the first place.

11. No writings about intersexuality or intersex people should make light of the immediate crisis: five children are being mutilated every day in the United States alone. Think about what you can do to help stop that.

Shifting emphasis onto researcher as ‘the other’ initially polarises the role of the researcher. At one end the re-emphasis is disempowering the researcher or distances the researcher from the work, and at the other it calls into question the researcher’s validity to do social inquiry. Rather, I argue that it allows the researcher to employ a greater empathy to the issues of the researched. In this present case, the researched, that is intersex Australians, is a population that has drawn considerable empathy-free attention.

7.2.1 Intersex Australians as Study Participants

Estimating population sizes of alternative sex, gender and sexuality communities has historically been a difficult task. Sociological and anthropological estimates of the occurrence of homosexuality have not gone uncontested, but in Western cultures it has fluctuated around ten percent, a figure colloquially attributed to the Kinsey Report. Recently the occurrence of transgenderism in Australia has been estimated to occur in 1: 24,000 males and 1: 150,000 females (Ross cited in Perkins et al, 1994).

Due to the ‘culture of silence’ that surrounds intersex the number of intersex Australians is impossible to determine. However, based on the estimate provided by Fausto-Sterling that 1.7 % of a given population are intersexed I argue that with a population of 20 million people there are 340, 000 intersex Australians. Employing open-ended qualitative interviews in a methodological design it was estimated that between 6 and 12 interviews would constitute a valid sample of the population.

The three phases of this study drew upon two significant groups within the intersex community and movement: firstly, individuals active in intersex organisations and community groups and secondly, intersex individuals who access these organisations and community groups. Stakeholders were identified as members of the intersex community who were experts in issues pertaining to the intersex community and whose input would assist in guiding the direction of the study. Intersex individuals who access intersex organisations and community groups were identified as possible interviewees because of their familiarity with intersex and intersex issues. That is, this study was conscious of not sampling from a population that had not yet discovered their intersex status, or those who had recently been diagnosed. Rather those who sought out information through established organisations and community groups, with the assumption that these people accessing these service providers would have access to support and counselling elsewhere or through these established organisations and community groups.

7.2.2 Informants

The process of establishing key informants underwent considerable change through the development of Phase One. Initially it was proposed that a Reference Group would be established with key stakeholders from organisations and community groups within the intersex movement. It was intended that this reference group would meet twice to discuss some key issues that were relevant to their respective organisations and community groups and to reflect on the subsequent interview phases. However, contact with at least one key stakeholder from five organisations, either by phone or email, resulted in a reassessment of Phase One. Key stakeholders were either not geographically located in the same area, were no longer active in the intersex movement or reluctant to participate in a study of intersex persons. As a result Phase One was redesigned to include a set of open-ended questions (Appendix A) that were sent via email to those who agreed to become Key Informants. Eight questions were asked regarding issues that were pertinent to the original aims of the study.

7.2.3 Recruitment

Key Informants' responses to Phase One questions were consulted in developing methods of recruiting participants. Two methods of recruitment of interviewees were employed: advertising and snowballing. An introductory letter (Appendix B) was emailed to key Australian and International organisations and community groups that were determined to have an interest in intersex issues and who have intersex members. Although this was designed as a study of intersex Australians, international organisations and community groups were chosen because of the increased globalisation of the intersex movement and the increased access to technologies such as email and the Internet. It was assumed that international organisations and community groups might have Australian members or have websites that may be visited by Australians.

As discussed in Chapter 5 the World Wide Web has had a significant influence on the aetiology of the intersex movement. The Internet has provided a space through which intersex individuals can share their lived experiences with others. As intersex narrative in Chapter 5 indicates the Internet is accessed as an initial point of contact and as a continuing resource for information and support. Subsequently the Internet is identified as a site for recruiting from a sample population that would be familiar with information and support networks. Further, email was identified as means to make correspondence with key informants and interviewing the intersex individuals easier. While advertising, recruiting and correspondence via the Internet offered a range of advantages it was not without its problems.

Recruitment of participants took place online. International intersex organisations and community groups agreed to advertise this study on their websites. This study sought those intersex individuals who knew enough about their intersex status to seek out further information and support online.

Assessment was made regarding accessing potential interviewees through Internet discussion groups (e-groups). These e-groups are designed as virtual spaces for intersex

individuals to discuss issues pertinent to their lives. While it could be argued that these e-groups would offer an invaluable site of recruitment it was decided that contact with these e-groups would infringe upon e-group participants' privacy. As I sought to establish rapport with sample population this means of recruitment would not be conducive to inviting interviewees.

The initial letter sent to organisations and community groups introduced the researcher and the study and asked the organisation or community group whether they would be willing to advertise the study to their members. Accompanying this letter was advertising material to be made available to potential interviewees (Appendix B). The advertising material included information introducing the study and myself, potential interviewees were informed that they could choose one of three methods of being interviewed: face-to-face in person or on the phone, written or audiotape. No face-to-face interview options were included due to the geographical dispersion of the sample population.

7.2.4 Interviews

In 1956 Benney and Hughes (1977) wrote that sociology is the science of the interview. They emphasised that this is so in two ways; firstly, the interview is an essential "digging tool" (1977: 215) of the sociologist and secondly, sociologists' subject matter is interaction, conversation (216). Sociology, and by default the interview, have not gone uncontested by feminism, postmodernity and queer theory. Since the 1950's sociology has undergone considerable transformation, self-reflection and meta-analysis, not the least of which is through gender and sexuality theories. For example, Steven Seidman's queering of sociology (1997) has drawn the social researcher's attention to 'classical' sociologists' privileged gender and sexual position (1997: 84). Further, I argue that the assumption that sociology is a 'science of the interview' crumbles under the scrutiny of postmodernity. Postmodernity challenges the assertion that human existence is firstly, 'knowable' and secondly, knowable through a rational and procedure-driven science. Although the interview is seen as a qualitative procedure, its aetiology and application is

imbued with scientific connotations. Therefore as a ‘digging tool’ it is not unproblematic. I will discuss some problems embedded in this study later.

In addition, feminists have viewed the interview ‘conversation’ and the interviewer’s role and responsibility with some scrutiny. Reinharz (1992) cites sociologist Ann Oakley’s own self-reflection and change of focus as a feminist engaged in ‘scientific’ enquiry. Oakley argued for a new model of interviewing that placed emphasis on intimacy, self-disclosure and “believing in the interviewee” (cited in Reinharz, 1992: 26). As Reinharz argues

Guiding this new model was a proposed feminist ethic of commitment and egalitarianism in contrast with the scientific ethic of detachment and role differentiation between researcher and subject (Reinharz, 1992: 27)

Traditionally interviews are bound by hierarchical researcher-researched structures with the researched occupying the subordinate position (Fontana and Frey, 2000: 645). Feminist thought has made a significant contribution to our understanding of this structure. Olesen insists that the researched are active in the research, such that they have become ‘researchers’ themselves

For they, along with the researchers, construct the meanings that become ‘data’ for later interpretations by the researcher (Olesen, 1998: 317)

My placement of focus on interviews is done cautiously. Hence I place attention on establishing a relationship with and evoking a sense of ownership amongst the researched rather than on most effective ‘scientific’ means of acquiring social knowledge. Establishing sociology as the ‘science of the interview’ places emphasis on this process as authoritarian and implies a hierarchical interviewer-interviewee structure. For my current intentions it is necessary to elucidate the issue of how an ‘interview’ is perceived by a wider audience, in particular intersex Australians. I argue that the interrelationship

of the interview with ‘science,’ ‘research’ and ‘institutions’ contributes to its problematic nature. The interview in this case is bound within a specific context. That is, a university.

The interview schedule (Appendix C) was constructed through an evaluation of three sources: 1) consideration of the initial aims of the study; 2) consultation with Phase One participants; and 3) the intersex literature with particular reference to Sharon Preves’ pivotal study of intersex persons in the United States of America (2003). What follows is an overview of this consideration, consultation and comparison and its results.

The two principal aims of this project are: 1) to explore the social lives, identities and relationships of intersex people; and 2) to understand the ways that intersex Australians compare to those living overseas. The aims of this study are informed by a review of the current intersex literature. The aims are to explore some of the areas of interest to the researcher raised in the literature and areas that were absent or only briefly mentioned in the literature. In regards to issues of social lives, identities and relationships the literature was forthcoming in exploring - albeit sporadically - some of these concerns. However, there are no studies that explore social lives, identities and relationships for intersex Australians.

Key Informants’ responses to consultation regarding establishing Phase Two of this project provided invaluable insights into how to proceed. While one Key Informant’s responses were largely discarded due to confusion of ‘intersex’ with ‘transgender,’ the confusion itself provides insights into the ways that these terms are being used interchangeably, and therefore reinforces the need for this project to clearly define to whom this project directing its recruitment.

Coming across Preves’ book *Intersex and Identity* (2003) over a year into my project it was clear that Preves’ themes and my own are similar. It soon became clear that a comparative analysis of intersex Australians with those overseas was imperative. Further, the subsequent adoption of some of Preves’ interview questions validates claims of comparison.

Preves flags for the researcher-in-the-field numerous considerations regarding methodology, results and ramifications in the chapter titled “Methodological Appendix” (2003: 159). One significant aspect Preves’ book is reflection on how participants were “investing their trust and their life stories in my hands so that I could do it and them some justice” (172). Preves engenders in the reader a responsibility that relates to any research that attempts to hear individuals’ own voices. It is in this vein that this current project attempts to respect individuals and not to distort their voices by viewing them through too many social research instruments.

The introductory letter to the study informed interviewees of the study’s aims and defined ‘intersex’

For the purpose of this study ‘intersex’ refers to people who were born with ambiguous genitals, gonads or chromosomes or who may or may not have Turners Syndrome, Klinefelters Syndrome, Androgen Insensitivity Syndrome, Congenital Adrenal Hyperplasia or Hypospadias. Therefore, this does not include people with gender dysphoria, transsexuals or cross dressers

It was seen as imperative that a definition was installed within the structure of the interview schedule because of the concerns raised by some Phase One participants, who believe that some respondents may not be intersex for the purpose of this study, but are in fact transsexual and/or transgender. As one participant from Phase One remarked

One first needs a method to ascertain that the person does have an intersex condition and not just “identify” as intersex. These people are usually transsexuals who have a strong desire to have an intersex condition in order to explain their gender identity disorder (Key Informant C, 2003: 2)

The same participant reinforced the need to include a definition by stating

Your study will run the risk of being discredited if it includes non-intersex participants (Key Informant C, 2003: 2)

The interview schedule is composed of four question sections: “Introductory Questions,” “Intersex Conditions,” “Surgical or Hormonal Treatments” and “Identity.” In “Introductory Questions” participants are asked demographic information, within “Intersex Conditions,” they are asked specific questions about their intersex status. In the “Surgical or Hormonal Treatments” section, participants are asked questions regarding any surgical or hormonal treatments they may or may not have had; and finally, as the title infers “Identity” asks participants to reflect on different aspects of self-identity.

To enable consistency between Preves’ American study and this current project a brief questionnaire was adapted from Preves’ interview schedule (2003: 162) and made up the “Introductory Questions.” Consequently participants’ were asked the following demographic questions

- 1) How old are you?
- 2) What is the highest level of education you completed?
- 3) What kind of work do you do?
- 4) What is your current romantic relationship status?
- 5) What is your religious or spiritual identification?
- 6) What is your racial or ethnic identification?

Under the question heading “Intersex Diagnosis and Treatment” Preves remarks “Even though I included only two questions in this initial interview section, interviewees’ responses to them were often lengthier than for other questions during the interview. The first question alone often elicited a half-hour response” (Preves, 2003: 162). These two questions are

- 1) When and how did you first become aware of your intersexuality?

- 2) Did you receive any medical intervention related to intersex? If so, tell me about that (Preves, 2003: 162)

As Preves indicates the American participants give a certain amount of epistemological weight to these areas, thus the first of these questions was adapted into our first two “Intersex Condition” questions

- 1) At what age did you find out about the intersex condition?
- 2) Can you tell me a bit about how you found out about the intersex condition?

The second of Preves’ questions was adapted into our third set of issues “Surgical or Hormonal Treatments.” While Preves study did not directly explore the issues of familial relationships, this study was interested in asking interviewees directly about their interrelationships with their families. Therefore I posed the following questions

- 1) If your parents/family know about your intersex condition, can you tell me a bit about how they reacted?
- 2) Can you tell me about your relationship with your partner/parents/family since you found out about your intersex condition?

The “Surgical or Hormonal Treatments” section of interview sought to explore explicitly the way that participants’ intersex condition was treated and how they feel about this

- 1) Can you tell me a bit about any surgical or hormonal treatment you may have had as a direct result of your intersex condition?
- 2) Can you tell me a bit about how you feel about these surgical or hormonal treatments?
- 3) Can you tell me a bit about how you would feel about your life if you did not have these surgical or hormonal treatments?

In regards to “Identity” it must be noted that the terms ‘gender’ and ‘sex’ in our society are often colloquially perceived as referring to the same thing. While gender scholars may refer to ‘sex’ as a biological category and define ‘gender’ as the behavioural expression of one’s sex, lay communities may not be privy to such distinctions. A point raised by Key Informant A

You need to be clear, and also explain in detail the difference between sex and gender. Many people believe they are the same thing – but when they refer to their gender identity, they are actually referring to perception of their sex. Also you need to be mindful that our language is limited to the polar binaries, and so the identities of many intersexed people are beyond language – so they distil their identities down to the binaries – which then does not reflect their inner identities (Key Informant A, 2003: 2)

Preves’ questions incorporated phrases that went some way in identifying and articulating the differences between ‘sex’ and ‘gender.’

Preves asked

- 1) How do you, personally, define your *sex at birth* (sex assignment)?
- 2) I’d like to talk with you now about your gender. How do you define your gender?
- 3) How do you *express this gender identity to others*? (emphasis added, Preves, 2003: 162)

Initially this present study’s research design included an option to tick a box: Female; Intersex; Male; Transgender or Other (Specify) and the question: “Can you tell me about how you feel about the sex/gender that your doctor and/or family assigned to you?” After reconsideration the success achieved by Preves design I adopted a similar one.

A similar process of comparison was undertaken with the issue of sexual orientation. The initial design of this present study appeared to inadequately convey the nuances necessary for this issue. As a result I followed Preves' questions

- 1) I am also interested in issues of sexual orientation. How do you characterize your sexual orientation?
 - 2) What have been the most significant events that helped you to develop your sense of gender and sexual identity?
 - 3) Has your sexual identity changed over time? If so, tell me about this
- (Preves, 2003: 162)

However, I believe that not enough attention was placed on the possibility of participants who have undergone a shift in how they 'defined their gender identity' and 'expressed their gender identity to others.' Therefore, there is the addition of the question

- 1) Has the way you see your gender identity, or the way you express your gender identity to others changed over time? If so, tell me about this.

The interview structure is a multifaceted matrix. It is more than a process of interviewees replying to questions asked by an interviewer. Narrative theory argues that an interviewee's responses are not necessarily 'true' reproductions of individuals' life history but are mediated stories. Subsequently the methodological design has employed a secondary interview phase. This is not designed to 'catch-out' inconsistencies in interviewees responses, rather as a means of allowing interviewees an active role in an accurate and full representation of their life histories. As such a second interview enables interviewees to reflect on, add to or edit their initial responses.

Phase Two interviewees were invited to take part in a follow up interview. They were sent an introductory letter (Appendix D) informing them of the follow-up phase and asking whether participants would rather be sent the follow up information via postal or email. The follow-up interview package consisted of the participants' original interview

responses, a list of themes collated from all original interview responses (Appendix E) and a set of further interview questions to clarify any ambiguities I identified (Appendix F). Participants are asked to reflect on the responses given in the original interview phase and to make any relevant omissions, additions or corrections to these responses. Further, participants are asked to respond to the additional questions asked by the researcher (Appendix F).

7.3 On Reflection

Development and employment of a theoretical and methodological platform onto which is transposed an investigation of issues pertaining to intersex Australians necessitates the understanding and implementation of tools that extend beyond the epistemological interest and reach of a researcher. This current project prioritises an emphasis on the ‘object’ of research as an integral part of the methodological and theoretical background to the investigation. This position has been informed from feminist, postmodern and queer theory thought. The attention is then given not to the researcher-as-authority, but to the participants under study. Further, the de-emphasis on the researcher-as-authority opens up the work to considerations of researcher-embeddedness, epistemology plurality and contradiction, individual agency and subject-as-expert.

Subsequently the development and implementation of a qualitative methodological design that incorporates this theoretical framework must consider more than the researcher’s aims. While the researcher’s areas of interest are inherently embedded within the methodology’s design and implementation, there is considerable input into the eventual direction of the study from the sample population. On more than one occasion I have invested in a degree of reflexivity with and deferred opinion to stakeholders in the sample population, allowing participants to guide the foci of the study. Yet at the same time maintaining awareness of and adherence to the original premise of the study, that is the social lives, identities and relationships of intersex Australians.

Hence, the methodology was designed with this background as a guidepost. At each stage of the development and implementation of the methodology stakeholders and participants themselves are active in the consultation process. The establishment of the Key Informants is an integral part of insuring against mis-representation. I argue that these Key Informants, from organisations and community groups that offer support and services to intersex Australians, would have first-hand experience with and knowledge of issues facing the sample population. Interviewees are given the opportunity to actively engage with their own responses. Phase Three of the methodology invited interviewees to re-read, edit or add to their own initial interview transcripts and further they are invited to reflect on broader issues being raised by other interviewees via a summary of all interviewees' responses.

However, the design of the project was not without flaws. Certain issues were raised that have to some extent led to biases being embedded within the results. While the results of this project are detailed in Chapter 8, presently I shall reflect on three considerations that accompanied the development and implementation of the methodology. First, there was reluctance on the part of the sample population to collectively identify with or coalesce under the term 'intersex.' Secondly, participants were cautious in engaging with 'research.' Finally, there was an overwhelming feeling from both the researcher and participants that the sample population is 'over-researched.'

Despite the macroscopic propensity for the medical and academic literature and the intersex movement to coalesce under the term 'intersex,' there is reluctance by intersex people to identify on a microscopic level with the term 'intersex.' Often the sending of advertising material to intersex organisations and community groups was met with requests for the removal of the term 'intersex.' I argue that this is indicative of service providers' belief that those who access their services not only do not identify themselves as 'intersex,' but also these service providers believe that people accessing their services would actively disassociate themselves from anything that uses the term 'intersex.' As one service provider responding to initial advertising material says

I'm not surprised to hear that it's been a bit of an uphill road getting responses from intersex folk. My experience with many adult CAH women over the years (technically born 'intersex') is that they don't particularly like the intersex label so shy away from things related to this topic. Even offering information and support services as we do I find it hard to make and hold contact with these people (Mann, 2003: personal correspondence)

Potential interviewees contacted me querying their eligibility to participate in the study. That is to say they did not identify themselves with the study's use of the term 'intersex.' Not only does not-identifying with 'intersex' problematise the use of 'intersex' as a term under which a coalition of disparate groups of people are calling for social action and change, but it also places considerable tension on this study's claims of validity. The very nature of the intersex movement relies on an inclusivity politick which now appears misleading. As one key stakeholder says

It is also somewhat politically popular currently to include hypospadians in the intersex 'movement,' ala ISNA (Jasper, 2003: personal correspondence)

Another aspect of the reluctance to align with 'intersex' is objection to the recent trend of attaching 'intersex' issues to a broader queer agenda. The presence of 'intersex' voices and epistemologies in queer academia, activism, nomenclature and cultural events, for example the addition of "I" to the acronym "GLBT," appears to contradict and misrepresent the desires of people who do not see themselves as 'intersex.' If there is a reluctance to align with a term such as 'intersex' - and the implications that are associated with it - then asking intersex persons to align with queer discourses appears to be far removed from the identity politics of this group of people.

That is not to say that intersex persons do not have gender or sexuality issues. Intersex persons may undergo gender transition in adulthood - 24% of Preves' sample now lived in a gender different to the sex that they were medically assigned (2003: 8). Intersex persons can identify as gay, lesbian or bisexual (Briffa, 2003a). As these points indicate

there does appear to be a need to discuss these issues among intersex persons, but contextualised within certain non-queer discourses.

Another consideration relevant to the process of developing and implementing this research is the medicalisation of contemporary intersex. The almost universal experience of regular visits to and examinations by doctors gives weight to intersex persons' reluctance to volunteer for further investigation. I am well aware of the emotional effect the terms 'university,' 'study' and 'researcher' has on potential participants. A significant factor in the development and implementation of even a 'qualitative' methodology was the attitude held by some stakeholders that intersex people are reluctant to volunteer for studies. Some key informants indicated that there is the view that intersex Australians have been over-researched. While it is argued that there are no studies of the social lives, identities, and relationships of intersex Australians, there has been considerable study of intersex persons within a medicalised context. One of the key issues facing intersex persons today is the medicalisation of their lives and bodies. More significant is the psychological trauma this medicalisation has caused in many intersex people. Subsequently there is a negative attitude towards the medical profession.

It is the view of this researcher that the distinction between the medical profession and academic social science is not clear in mainstream society and the association of a study with an institution such as a University causes it to be no different to those studies aligned with hospitals. And while I am a *social* researcher, the terms that I employ, like 'study,' 'research,' and 'university' would seem to be enough in themselves to remind intersex persons of feelings of abuse, mistrust and secrecy. Hence I argue there may be transference of this attitude toward medical research into a reluctance to participate in social research.

Conclusion

Social inquiry aimed at the intersex population necessitates the employment of theories and methodologies that engender sensitivity to its subject matter. Applying feminist,

postmodern and queer theories in a research framework enables an understanding and critique of masculinist, universalist and heterosexist assumptions institutionalised in the West, assumptions that are also institutionalised within Western medicine. Hence the medicalisation of contemporary intersex necessitates the employment of feminist, postmodern and queer theories. This background has drawn attention to the emphasis of this research project on the voices of intersex persons. While the study is guided by researcher's motivations there were considerable inputs from stakeholders and individuals from the intersex community. The researched are active participants in the study, even 'co-researchers.' The three-phase methodology employed assisted in this endeavour and allowed multiple sites of co-research. The intersex-guided methodology assumed that intersex persons were experts of their own issues, as advised by Koyama's guides for non-intersex researchers.

The intersex-guided methodological design however, was not without problems. On reflection on the aforementioned theoretical background and methodology design certain considerations were made during the implementation of the project. Stakeholders' knowledge of and familiarity with intersex specific issues proved an invaluable insight into the limitations in accessing intersex persons. Yet, as requests to remove the term 'intersex' from advertising material access was at times controlled by stakeholders. I argue that stakeholders from intersex organisations and community groups act in a "gatekeeper role." As gatekeepers stakeholders monitored use of terminology, researchers' motivations and intentions and the psychoemotional affect of research on intersex persons.

CHAPTER 8: FINDINGS

Introduction

8.1 Co-Researchers - Intersex Stakeholders

8.2 Hearing Voices - Intersex Australians

8.3 Intersex Voices - Revisited

Conclusion

Introduction

‘Coming out’ as a person with an intersex condition and then reaffirming my true self by changing to live as a male made life difficult in areas of work, political life and societal activities, but it was a challenge I took on and feel I have been fairly successful (Chris, 2003: 2)

A quote such as this by Chris is an indication of the strength and tenacity of some intersex Australians not to let their intersex status stand in the way of achieving personal goals. However, there is no one quote that captures the breadth of lived experience of all intersex Australians interviewed in this study. Intersex Australians that participated in this study face a diverse range of issues. These are issues that are not dissimilar to those articulated in the intersex literature and intersex narratives. Yet like most lived experiences they are unique. This chapter informs the reader of those issues as expressed by two groups of intersex Australians. Firstly, this study drew upon the professional and personal experiences of stakeholders from organisations and community groups that offer information and support to intersex Australians. Secondly, I have analysed the voices of eight intersex Australians as they reflect on and discuss their intersex status, their intersex history and their familial, sex, gender, and sexuality identities and relationships.

As I have discussed previously intersex research must be contextualised. This research project is contextualised by its theoretical framework and methodological design. As discussed in the previous chapter I have deliberately employed a feminist, postmodern and queer theory framework and a qualitative methodological design. In addition I argued that the intersex voices heard within this chapter are bound by certain considerations unique to an intersex population. That is, the role of intersex organisations and community groups as ‘gatekeepers,’ a reluctance of some intersex organisations, community groups and individuals to support the use of or identify with the term ‘intersex,’ and a reluctance of intersex individuals to undergo further study. I flag these considerations once again so that the reader is mindful that no acquisition of social

knowledge is a purely objective pursuit, nor can it be conducted without influences from either the researcher or the research process.

After an exploration of the issues raised by the intersex individuals I conclude this chapter with a collation of themes identified in the two interviews. The socio-political and theoretical ramifications of these thematic threads on intersex individuals, the intersex movement, intersex medical intervention, queer and gender theory and the future of Western conceptualisations of intersex will be discussed in the following chapters.

Assessment of this study's validity is a present priority. The study aimed to interview between 6 and 12 intersex Australians from across a large geographic location; an objective achieved. Eight initial and four follow-up interviews were conducted with intersex Australians who were located in the South-Eastern, Southern or Western regions of Australia or were currently residing overseas.

Assuming that 1.7 % of a population are intersexed (Fausto-Sterling, 2000) and given that Australia has a population of 20 million people it is estimated that there are 340, 000 intersex Australians. Our sample size of eight interviewees constitutes a .00235% of this population of intersex Australians. While this figure appears to be statistically low I argue for the purposes of a qualitative study eight interviewees is sufficient to address the aims of the project. That is, I am undertaking an investigation into the social lives, identities and relationships of intersex Australians and doing a comparison between Australian and International intersex individuals. Although Preves' study (2003) interviewed 37 intersex individuals, this is from a possible population of four and a quarter million intersex Americans. Taking into consideration financial, geographical and temporal limitations it is argued that this is a valid sample size of the estimated population of intersex Australians that is comparable to an American study of similar issues.

A significant complication embedded within this research project was the failure to conduct face-to-face interviews. While the interview, as a tool of the sociologist, has not gone unproblematised, I posit that the interview enables the interviewer to engage in a

one-on-one situation with the subject and this situation establishes rapport and engenders confidence in the interviewer-interviewee relationship. Further, conducting face-to-face interviews would have increased the validity of qualitative research that pertains to the social lives, identities and relationships of intersex Australians. Yet, when one is relying on a subject to talk intimately about personal experiences, especially subjects as intimate as one's genitals, surgical history and familial, sex, gender and sexuality identities and relationships, anonymity can at times be a beneficial inducement to the revelation of intimate details. Therefore, this failure to conduct any face-to-face interviews, while unfortunate, was not perceived as detrimental to the validity of the work.

The limitations of the secondary aim of this project, namely a comparison of intersex Australians with those overseas, meant that it was imperative that this project achieved a representative sample from a geographically dispersed population. While the researcher is based in a large regional centre in New South Wales (an east-coast state), all interviewees were either from South-Eastern, Southern or Western regions of Australia or were currently residing overseas. Subsequently interviewees were sent written questions.

8.1 Co-Researchers - Intersex Stakeholders

The intersex literature and narratives flag intersex organisations and community groups as sites of epistemological power. Individuals involved in Australian intersex organisations and community groups are seen as pivotal contributors to any investigation of social identities and relationships of intersex Australians. They have an expertise in identifying issues garnered from their in-situ position as service providers offering information and support to intersex Australians.

Australian intersex organisations and community groups were invited to become Informants in Phase One. As discussed in Chapter 7 several stakeholders declined to become part of this study, however, three stakeholders consented and became the three Key Informants of the study. Contact with Informants was maintained through email correspondence and phone conversations.

Known as Informants A, B and C they were asked eight questions pertaining to issues of identity, situation of intersex in Australia, and their views on this current project. What follows is an outline of their responses. However, while these Key Informants are anonymously referred to as Informants A, B and C, some background information is perhaps necessary. Informant A is an intersex activist, Informant B is a surgeon and Informant C is the coordinator of an intersex support group. As discussed in Chapter 7 Informant B's responses seemed to at times confuse intersex issues with those of transgendered Australians. Their responses are included here.

8.1.1 Gender Identity

Key Informants were asked to reflect on two areas of gender identity. One referred to the fact that in the intersex literature gender identity is not considered a major issue for intersex individuals. Informant A saw gender identity as an issue in relation to one's biological sex "If the somatic (physical) sex is not questioned by the person, then probably one's gender is not questioned either. Gender identity usually is only questioned when one's somatic sex is brought into question" (Informant A, 2003: 1). Informant B believes that Gender Identity is a major issue that is tied to their relationship with wider society.

The major issues surrounding the change in Gender Identity relate to their deeply felt conviction of their core identity. Many have tried to do everything possible to function in society as members of their biological sex but eventually the conviction that their core identity is opposite to that of the biological sex becomes overwhelming and irrepressible. In my experience with transgender people the ability to function sexually in the opposite desired gender role is relatively of much less importance than their perception of their gender identity (Informant B, 2003: 1)

However, we must reinforce the fact that Informant B's responses are influenced by the misrepresentation of transgenderism as an intersex condition. Informant C informs us that gender identity is only an issue for about 5% of intersex adolescents and adults, and lists some of the reasons for these issues.

- An incorrect choice in the sex of rearing (a choice has to be made and sometimes doctors get it wrong),
- People being raised with little or no information about their condition - hence making them very suspicious about themselves, their past treatment and why they have regular medical examinations, surgeries etc., and
- Being anatomically different to others (not being able to menstruate, have children, having atypical genitalia etc) raises questions about one's true sex. This may have a flow-on affect to that person's identified gender (Informant C, 2003: 1)

Key Informants were also asked to reflect on issues for people who are questioning or changing their gender identity. Informant A insisted that there is an emphasis on the individuals' "innate knowledge" (Informant A, 2003: 1) of self, "that their assigned sex is not the sex they were born as" (Informant A, 2003: 1). This view is reinforced by the claim that these considerations are not an issue of gender per se, "but a physiological sex issue" (Informant A, 2003: 1). While Informant B declined to answer this question, Informant C was forthcoming with five major issues.

- The ability to physically change given the limitations of their intersex condition,
- The ability to reverse previous unwanted medical intervention including surgeries and hormone treatment,
- Confusion from the transsexual/transgender community about what intersex conditions are and not wanting to be confused as a transsexual person,
- Not having a strong sense of gender identity as either a male or a female, but wanting to get on with life in whatever gender is easiest,

- Being unsure what the future holds for them and whether they will be accepted in a society that knows very little - if anything - about intersex conditions (Informant C, 2003: 1)

8.1.2 Intersex Issues

I also sought to understand how stakeholders saw the current situation for intersex Australians. Key Informants were asked to draw upon their experiences as part of the intersex community and asked what they thought were important issues relevant to the lives of intersex Australians. Informant A identified two issues related to medical management.

Medical reforms are not happening at the same rate as countries with visible intersex activism organisations. Standard medical management programs persist in Australia and are not being questioned (Informant A, 2003: 1)

In addition Informant A believes that “Intersexed people are not as organised collectively in Australia - so the message is not getting out as effectively” (Informant A, 2003: 1). Informant B does not think that there are any particular issues that are peculiar to Australian people with intersex conditions (2003: 1).

In contrast to Informant A, Informant C sees Australia as a world leader in medical treatment, a fact attributed to “the openness of Australian culture and the considerable efforts of the AIS Support Group Australia” (Informant C, 2003: 1-2). Informant C illustrates this point by stating that

People with intersex conditions in Australia can have their birth certificates corrected if desired, have reasonable access to experienced and sensitive clinicians, have access to progressive peer support organisations, a network of genetic counsellors, national intersex community meetings etc (2003: 1-2)

8.1.3 Future Directions

Key Informants were also asked to reflect on the future directions of support groups and service providers. Informant A hoped that more people will “come out of the closet and tell their stories, organise into support and activist groups, work more closely with the medical profession” (Informant A, 2003: 2). Informant B’s response is again indicative of their confusion between intersex and transgender issues.

Within the next ten years I think that there will be improved services and support groups for transgender people as some State governments in Australia are already moving progressively to review and improve services (Informant B, 2003: 1)

Informant C was quite explicit with the future of intersex support groups and service providers

I think intersex support groups are already on the right track, but medical service providers will start treating intersex patients more holistically. This will include providing truth disclosure to parents of children with intersex conditions and adults with these conditions, considering all options prior to surgical and hormonal intervention (including not intervening at all), providing counselling and encouraging peer support (Informant C, 2003: 2)

Informant C adds “it should be noted that some doctors are already using these progressive guidelines in Australia” (Informant C, 2003: 2).

8.1.4 Informant Contributions to this Study

The theoretical considerations undertaken in the previous chapter expressed the argument that this study sought to make intersex Australians co-researchers. The final section of the Phase One questions asked the Key Informants to contribute to the development and implementation of the study. Firstly, they were asked to consider the aims of the project,

namely issues related to identity and a comparison of Australian and international intersex issues. Informant A reminded the researcher to be careful with the use of the terms 'sex' and 'gender' and their discontinuities with real life experiences.

Many people believe they are the same thing - but when they refer to their gender identity, they are actually referring to perception of their sex. Also you need to be mindful that our language is limited to the polar binaries, and so the identities of many intersexed people are beyond language - so they distil their identities down to the binaries - which then does not reflect their inner identities (Informant A, 2003: 2)

In addition Informant A states that there is a difference with Australian and international intersex persons, whereby "Australian intersexed people are not so forward in 'coming out'" (Informant A, 2003: 2). Further, they witness an international, in particular American, influence in support and information services, what Informant C refers to as an "intersex US style." Further, Informant A claims that this influence extends "even to the point of assuming that the medical/social procedures/laws/legislations of US are the same as they are in Australia" (Informant C, 2003: 1).

Once again Informant B's response implies a lack of distinction between intersex and transgendered Australians: "I think that the two aims of your study are most appropriate and potentially would be helpful to service providers, support groups and transgender people themselves" (Informant B, 2003: 1). Informant C indicates a concern regarding establishing a "viable number of people with intersex conditions" (Informant C, 2003: 2) as a sample size of the population for the study into identity. In addition Informant C was unclear about the relevance of comparing Australian and International intersex issues.

As my co-researchers I was interested in knowing what they considered important and what issues they thought this study should investigate. Informant A suggested a focus on medical management in Australia, such as intervention procedures, what is available, who does it, where it's done, and follow-up management (Informant A, 2003: 2).

Informant B states “I think that it would be valuable if your study could include some measure of the extent of discrimination against transgender people in the workplace and amongst general health service providers” (Informant B, 2003: 1).

Informant C makes reference to ‘transgenderism as intersex’ discourse, whereby the intersex movement calls into question the appropriation of the term ‘intersex’ by the transgender movement. Informant C advises that “one first needs a method to ascertain that the person [does] have an intersex condition and not just ‘identify’ as intersex. These people are usually transsexuals who have a strong desire to have an intersex condition in order to explain their gender identity disorder” (Informant C, 2003: 2).

Informants were asked to comment on possible methods of recruitment. Informant A advises that the technique known as snowballing has the strength of acquiring confidence in potential interviewees.

Contacting intersexed people who have friends who are intersexed. Being mindful of confidentiality issues, reluctance to be interviewed and continuing the ‘objectification’ of the people. Being sensitive to the suffering and trauma of intersexed. You need to be vouched for by intersexed people you know (2003: 2)

Informant B suggests contacting “transgender support groups” (2003: 1). While Informant C is cautious against contacting transgender support groups

Work with intersex groups and not through transgender groups such as the Gender Centre in NSW. Your study will run the risk of being discredited if it includes non-intersex participants (Informant C, 2003: 2)

To further explore the prospect of subjects as co-researchers, Informants were asked to make any further comments. Since both Informant A and C have given extensive thought to this I shall quote them in full.

You will be impeded by both intersexed people themselves and the medical profession if you pursue this avenue. Intersexed people are wary of being objectified and exploited and subjects for study. What can you offer these people in return – their lives and stories will be furthering your academic career, what benefits can you provide to them in return? How can you make their co-operation worth while? The medical profession often does not want people poking around their procedures as it may unmask their medical mismanagement and/or rock the boat. Need to be critical without attacking too much – need co-operation not confrontation (Informant A, 2003: 3)

I note that you have advertised your research in the Gender Centre newsletter “Polare”, which will probably result in non-intersex people requesting to participate in your study. You may be aware that there is a small but growing number of people with gender identity disorder (transsexualism) who incorrectly claim it to be an intersex condition. I believe this may regrettably adversely affect your research and compromise its validity (Informant C, 2003: 3)

I strongly suggest your research include a method of validating a person's intersex status in order to ensure its integrity (Informant C, 2003: 3)

Phase One participants were able to assist me in identifying a few key issues relevant to the study. These contributions were invaluable in the design, initiation, and implementation of Phases Two and Three.

8.2 Hearing Voices - Intersex Australians

Eight (8) individuals consented to being interviewed. Interviewees contacted the researcher via post or email. As no interviewees were geographically located near the researcher, that is interviewees lived in South-Eastern, Southern and Western regions of Australia and overseas, all interviews were conducted via answering written questions. As will be discussed later not all Phase Two interviews underwent a follow-up interview.

This was due to two reasons, either initial interview responses were received as product of a ‘snowballing’ technique and therefore were anonymous, or interviewees did not consent to a follow-up interview. Interviewees were given gender-neutral pseudonyms by the researcher: Chris, Jamie, Kerry, Leigh, Lou, Mel, Pat, and Terry. The interview schedule included four sections of between three and seven questions. This section details the eight Phase Two participants’ responses. Details are catalogued in their respective sections, while demographic information ascertained from the “Introductory Questions” is contained in Table 8.1.

8.2.1 Introductory Questions

Participant	Age	Education	Employment	Relationship	Religion	Ethnicity
Chris	33	Degree	Professional	Single	Rmn Cath	Malt/Aust
Jamie	35	Year 12	Administration	Married	Pagan	White
Kerry	40	Degree	Professional	Single	None	Br. Aust
Mel	48	Degree	-	-	-	-
Terry	37	Degree	Service	Single	Spiritual	Celt. Aust
Pat	44	Post-Grad	Student	Single	Buddhist	Celt. Aust
Lou	73	Degree	Professional	Married	Anglican	Anglo-Sax.
Leigh	20	Year 12	Service	Relationship	Buddhist	No Answer

Table 8.1 Phase Two Participants’ Demographic Information

8.2.2 Intersex Condition

8.2.2.1 At what age did you find out about the intersex condition?

The lived experience of intersex individuals as intersex individuals was under consideration, therefore I asked about the age at which interviewees discovered their intersex status. Three respondents (Chris, Kerry and Jamie) indicated that knowledge of their intersex status was vague during childhood and adolescence.

I found out different bits and pieces from various sources from the time I was 6
(Chris, 2003: 1)

At some time around the age of 5 with some understanding although something was wrong earlier due to having to have surgery (Kerry, 2003: 1)

I realised that there was something different about me during adolescence (Jamie, 2003: 1)

Chris, Jamie and Terry each said that by their twenties they knew of their condition.

I only found out the true nature of my condition ... in December 1999 (Chris, 2003: 1)

In my early 20's I began to learn a little more about my circumstance (Jamie, 2003: 1)

Terry was 28 when they found out (2003: 1). Lou was 65 years old when they found out about having Complete Androgen Insensitivity (CAIS) stating that “this was due to being kept in ignorance also the silence that pervaded the condition” (2004: 1). Pat had been incorrectly diagnosed at 21 with hypogonadism. It was not until 35 years of age that Pat was diagnosed with Klinefelters Syndrome (2003: 1). Leigh is the only participant who has known of their condition for “as long as I can remember” (2004: 1).

8.2.2.2 Can you tell me a bit about how you found out about the intersex condition?

Disclosure of one's intersex status has received considerable attention in the intersex literature and in intersex narratives. Chris elaborates how different aspects of their intersex status were found out in different ways. At 6 “I learned I couldn't have children because I overheard my parents talking about me” (2003: 1). At 7 Chris was told they had to have “‘tissues’ removed from my groin. What I didn't know was the tissues they removed were my healthy testes” (2003: 1). At 11 Doctors told Chris that they would not be able to have periods (2003: 1). At 16 Chris found out about having 46XY

chromosomes, even though Chris was being raised as a girl (2003: 1) by “‘borrowing’ my medical records off the counter at the hospital and seeing my karyotype” (2003: 1). Chris describes this as “an incredibly emotional incident for me” (2003: 1). Yet Chris does expand this by stating that between the ages of 11 and 30

I was lied to by my doctors about my condition. They repeatedly told me my body does not respond to androgens and that I have to be a girl. I was also denied access to testosterone treatment to compensate for their removal of my healthy testes when I was 7 (2003: 2)

Chris admits to “only [finding] out the true nature of my condition from reading a website in December 1999” (2003: 1). Kerry was “told the basics” (2003: 1), but Kerry’s hypospadias “was never really discussed from an early age” (2003: 1). Jamie found out from a “magazine article in a woman’s magazine” (2003: 1).

Terry began noticing differences “between myself and my brothers very early in life” (2003: 1), with these differences leading to “issues with my body” (2003: 1). Notably a “lack of strength and coordination ... avoiding sport ... I hid my body away” (2003: 1), refusing to “go into change rooms, to swim at baths, to have relationships, to be seen by my family or friends naked” (2003: 1). Terry “experienced internal trauma that lasted until the late twenties” (2003: 1) and was “filled with fear that someone would see me naked” (2003: 1). Terry goes on to say that

I feared telling my parents because I thought they might think I didn’t think they loved me enough to tell them earlier and as the years past the fear just increased (2003: 1)

At 27 Terry “managed enough courage to go to the sexual health clinic” (2003: 1). Describing the experience as “the most difficult day of my life and I nearly didn’t get there” (2003: 1). Terry had blood and seminal fluid tests in 1993 and was diagnosed in

1994, learning of being infertile in the same month (2003: 1). At which point Terry “felt I knew enough to tell my parents” (2003: 1).

Leigh’s mother “was very open and told me from the start everything she could” (2004: 1). Lou found out from a magazine in a doctor’s surgery (2004: 1). For Pat the failure of the treatments for the effects of hypogonadism and the resulting dissatisfaction highlighted the need to get a second opinion, at which point the diagnosis of Klinefelters was made (2003: 1).

8.2.2.3 If your parents/family know about your intersex condition, can you tell me a bit about how they reacted?

Familial relationships have played an important role in regards to disclosure, surgical assignment and continual support. Attention has been given to how members of intersex individuals’ family have reacted to their intersex status. Chris’ parents were “devastated” (2003: 2), explaining “my mother was particularly withdrawn and relied on doctors to advise her on what was the best treatment for me” (2003: 2). Chris’ mother is still not over what happened, and Chris believes that “this has irreparably damaged our relationship” (2003: 2).

For Kerry and Jamie discussion with parents and family never took place. Kerry says “parents are obviously aware [and] siblings may know but the subject never arises” (2003: 1) and Jamie remarks “it was never discussed within my family” (2003: 1). Jamie’s mother never took Jamie for treatment “I lived in shame enclosed in a wall of alienation. I still don’t know why my mother was afraid to help me” (2003: 1). Although Lou’s parents are deceased their family is “unphased” (2004: 1). Pat reports that their parents were deceased at time of diagnosis (2003: 1) but siblings were “as relieved as I for diagnosis enable physical and psychological history to be explained” (2003: 1).

Terry’s mother “was mostly concerned with my infertility and that I felt that I couldn’t tell them” (2003: 1). Terry says “she wasn’t angry but begun I believe her own grieving

period. Knowing of my inner pain for so many years etc” (2003: 1). Terry’s father “never [took] much interest in my having [Klinefelters Syndrome] since diagnosis and the initiations of treatment” (2003: 2). For Terry it was odd that “dad thought the most important thing for me in receiving HRT should be increased libido” (2003: 2). Since diagnosis however, Terry’s father

Has seemed to think I should ‘move on’ and as I find out more about the condition and attribute issues and events from my childhood to having Klinefelters Syndrome he just says ... ‘oh many people experience that’ as if he doesn’t want me think of myself as different ... but it doesn’t allow me discuss it further with him (2003: 2)

Unlike other respondents for Leigh “they [the family] all have known since I was a baby, as have friends of the family” (2004: 1). Leigh says, “they are all supportive and open about it” (2004: 1).

8.2.2.4 Can you tell me about your relationship with your partner/parents/family since you found out about your intersex condition?

Another aspect of intersex individuals’ familial relationships is the way that these relationships have been affected, developed or enhanced by the discovery of the intersex status. Chris describes the experiences as very positive, in particular “My siblings have been very understanding” (2003: 2). Further, Chris says

‘Coming out’ as a person with an intersex condition and then reaffirming my true self by changing to live as a male made life difficult in areas of work, political life and societal activities, but it was a challenge I took on and feel I have been fairly successful (2003: 2)

Kerry has not had a relationship “because of the hypospadias” (2003: 1) and states that the relationship with family is “normal” (2003: 1). Kerry believes that the condition is

never discussed “because my mother feels guilty I was born this way” (2003: 1). Kerry further remarks, “It is something I have to deal with by myself” (2003: 1).

Jamie has only recently re-established relations with family in the past year after staying away for seven years (2003: 1). One of Jamie’s sisters has also been diagnosed with AIS, allowing them to talk more openly with each other over recent years, Jamie says that since they lived in different areas of the city during their teenage years they “had no opportunity to support each other” (2003: 1). In regards to Jamie’s husband

Well he was aware that I had a medical condition before we considered our intimate relationship. We were both apprehensive about our physical relationship. We have had no difficulties, I am obviously one of the fortunate ones (Jamie, 2003: 1)

Leigh (2004: 1) and Lou (2004: 1) both have supportive relationships with their respective partners. Leigh’s partner is described as “extremely supportive” (2004: 1), “amazingly understanding” (2004: 1), “open and curious” (2004: 1) and “things are going very well” (2004: 1). For Lou “my husband married me knowing I had an unknown gynaecological condition and that we would only be able to adopt. Since knowing the truth it hasn’t made any difference” (2004: 1).

Terry’s first relationship was at age 29 and lasted 2 ½ years (2003: 2), an experience that allowed Terry to realise “my body issues were irrelevant and we enjoyed both an active and explorative sexual relationship and supportive emotional connection” (2003: 2). Since then Terry has had three relationships, lasting no longer than six months (2003: 2). Jamie describes having spent many years developing skills in avoiding relationships, and thereby missing out on the social skills and knowledge of women and relationship development (2003: 2). Pat is not in a relationship but remarks that their family is far more accepting of “my personal idiosyncrasies - especially in relations to my fluid sex and gender identity” (2003: 1).

8.2.2.5 Summary

For most participants disclosure of the intersex status in childhood was vague or absent. For most participants the method of disclosure was through their own investigation or was being told half-truths from parents/doctors. For most participants their parents did not know or reacted negatively. Some participants indicated a good relationship with their partner. Some participants have not had sexual relationships because of their status. Others indicated having good relationships with family members.

8.2.3 Surgical and Hormonal Treatment

8.2.3.1 Can you tell me a bit about any surgical or hormonal treatment you may have had as a direct result of your intersex condition?

The current intersex medical treatment has dominated the intersex literature and intersex narratives. In particular how one's intersex status has drawn the attention of the medical profession and what diagnostic and intervention procedures have intersex individuals undergone. In regards to diagnosis, Chris describes their condition as

PAIS [Partial Androgen Insensitivity Syndrome]. I was born with 46XY chromosomes, atypical genitalia (including small phallus/large clitoris, vagina, hypospadias and descended testes), no uterus, no ovaries and healthy testes (2003: 2)

Procedure	Age
Laparotomy	2 Months
Shifted Testes	2 Months
Vaginoplasty	2 Years
Vaginoplasty	7 Years
Castration	7 Years
Vaginoplasty	15 Years
Oestrogen Treatment	11-29 Years

Table 8.2 Chris' Surgical and Hormonal Procedures.

Chris has undergone six surgical procedures between 2 months and 15 years of age, and had taken oestrogen between 11 and 29 years (2003: 2) (Table 8.2). Chris further states that

Although I took oestrogen infrequently, I had to have it to prevent osteoporosis. I also had to try to accept being a female which is what I was told I had to do (2003: 2)

Kerry was “born with midshaft (moderate) hypospadias” (2003:1) and underwent three surgical procedures. The first surgery at age 2 was to straighten chordee (2003: 1), the second at age 4 to close the midshaft opening (2003: 1) and the “third procedure was performed but I don’t know any details” (2003: 1). On arrival in Australia Kerry was seen by a doctor “for undescended testicle which did not require surgery” (2003: 1).

Jamie has had no treatment (2003: 1) and adds “I am fearful of invasive surgical procedures” (2003: 1). Terry began fortnightly injections of Sustenon Testosterone HRT in 1994 [28 years of age] (2003: 2), and explains that

I had a lot of difficulty maintaining adherence as I was required to attend a surgery every two weeks. At one stage over about two years I was having injections every six weeks. I had a testosterone test and the test suggested my levels were acceptable so I continued in this way ... I later learned the test the doctor gave was inaccurate and I had probably continued to be under throughout the years (2003: 2)

In 2003 Terry began applying patches daily, describing it as being “great” (2003: 3). Leigh was “given many surgeries in the first 3 years of my life” (2004: 1), describing them as

Cosmetic as when I was born I looked like a female ...[tests] showed I was male so they did corrective surgery to fix everything and made me look male (2004: 1)

In Leigh's tenth year at school they underwent further corrective surgery "to neaten things up a bit" (2004: 1). Leigh had regular hormone treatments for the following two years (2004: 1). Lou had been born with hernias which were removed in infancy, and has been on patches to counteract low oestrogen "for some years" (2004: 1).

After misdiagnosis of hypogonadism at age 21 Pat "resisted pressure to undergo testosterone therapy for the purpose of masculinizing me" (2003: 1-2). After warnings from medical specialists of impending secondary health problems Pat agreed to undergo testosterone therapy. The first couple of years Pat underwent "monthly injections, then added oral testosterone then switched to oral and implants for the final couple of years" (2003: 2). The results of which were "severe psychological and later physiological negative reactions. After six years on large doses of testosterone, developed near-fatal Deep Vein Thrombosis from site of implants" (2003: 2). Pat has since reduced hormone intake to minimum levels, however, the "outcome of therapy - permanent fatigue, body-pain, low-stress thresh-hold" (2003: 2).

8.2.3.2 Can you tell me a bit about how you feel about these surgical or hormonal treatments?

Intersex individuals have perceived surgical and hormonal treatments in a range of different ways, some positive some negative. While Jamie felt as though they had nothing to add to this question (2003: 2), Terry gives details of the *physical* reaction to treatment, "my voice dropped, my body hair increased" (2003: 3). When not adhering to treatment "I become irritable, scattered, poor memory, poor concentration, fatigued etc. I noticed this also and of course during my degree all these symptoms caused havoc with my learning and academic tasks" (2003: 3).

Chris feels "angry." Describing the procedures as "non-therapeutic ... performed without my informed consent [and] they are immoral, unethical and illegal" (2003:1). Kerry feels that the surgery was "necessary and I could not have done without it" (2003: 1) adding "I

am glad my parents made the decision for surgery” (2003: 1). However, Kerry also states that the penis did not look normal after the surgery (2003: 1), and acquiesces that “I can’t do anything about that” (2003: 1). Leigh similarly felt that the surgery was necessary, and expresses gratitude “I am one of the lucky ones, I’ve still got all my goodies” (2004: 1). Yet Leigh indicates that the hormone treatment was a waste of time, hardly working and having bad side effects that outweighed the minimal benefits (2004: 1).

While not regretting the therapy, Pat does regret persevering with it because it generated severe and permanent negative psychological and physiological side-effects (2003: 2). Further, Pat believes “that the therapies need to be applied with far more caution and supervision” (2003: 2), with assumptions about the therapies’ benefits being challenged (2003: 2). Pat does not believe “that all people with XXY (Klinefelters Syndrome) should be coerced into therapies simply in order to masculinize them. Choice [should be] left to [the] individual who is provided with all the options - not just the recommendations of the medical profession” (2003: 2).

Lou is “quite happy about it” (2004: 1).

8.2.3.3 Can you tell me a bit about how you feel about your life if you did not have these surgical or hormonal treatments?

While the intersex movement campaigns for the stopping of medical intervention procedures, there appears to be some ambivalence toward not undergoing surgery or hormonal treatments. If the intersex movement is successful in stopping these procedures I wondered what would be the effect on the lived experiences of intersex individuals. Chris describes this question as a “difficult” and a “very philosophical” one. Reflecting “I recognise I would not be the person I am today if I didn’t have these experiences so I will have to overlook that” (2003: 3). Chris does not feel that being raised as a girl was the problem, thinking it a sensible approach (2003: 3), but Chris highlights

Irreversible non-therapeutic surgery and hormone treatment was stupid, irresponsible, negligent, immoral, unethical, illegal and against my fundamental human rights. People with genetic conditions should have the same level of protection as those born without them. Why are the genitals of typical children protected but the genitals of those with intersex conditions treated so ambivalently? (2003: 3)

Kerry reflects that surgery would have to have happened. Kerry states that they had to sit to urinate and has memories of “how I hated to do that” (2003: 1), adding that it would have been devastating to grow up without surgery as a child (2003: 1). For Terry without HRT the major concerns would be the physical ramifications of low stamina and high predisposition for osteoporosis. Terry already has a lot of problems with joints and supportive structures (2003: 3). Similarly Lou felt that “my breasts would be smaller and my bone density would be worse” (2004: 1). For Leigh not having surgery would have meant that “I’d be stuck somewhere between male and female I don’t think I would be able to cope with that” (2004: 1). Similarly Pat initially describes not having surgery may have meant that they:

Would never be sure of who or what I was ... Probably would not have developed the self-knowledge and thus self-esteem and confidence, if I had not undertaken the journey (2003: 2)

Yet Pat considers that overall health would still be OK, “rather than suffering permanent debilitating effects of therapies” (2003: 2). Further, Pat was able to revert back to pre-therapy state, because had they begun therapy late in life, and is concerned that “children and adolescents don’t have this choice - so early intervention prevents ‘natural’ development of the self” (2003: 2).

8.2.3.4 Summary

Most participants indicated that they had had some surgical procedure and/or some hormonal treatment. A few felt negatively about the treatments, and a few felt positive about the procedures. Most reflected that life would have been more difficult without treatment, and further reflected that treatment has had a significant role in developing a sense of self.

8.2.4 Identity

8.2.4.1 How do you, personally, define your sex at birth (sex assignment)?

Participant	At-Birth Sex
Chris	Intersex
Jamie	Female
Kerry	Male
Mel	Perfectly Normal Androgyny
Terry	Heterosexual
Pat	Male-Variant
Lou	Female
Leigh	Male

Table 8.3 Participants' at-birth sex.

Identities have been witnessed as significant foci of intersex scholarship and the lived experiences of intersex individuals. Sex, gender and sexuality are pivotal identities under investigation in this present study and are its main aim. I wanted to investigate whether and how one's intersex status affected one's sex, gender and sexuality identities. Did intersex individuals invest in any self-analysis and self-reflective process? Did intersex individuals notice changes in their sex, gender and sexuality identities or the ways that these identities were presented to others?

To gauge whether these analyses and changes took place, I first considered what was the initial assignment of sex at birth. Chris's "sex at birth was in between that considered

typical male and typical female. I was born with a legitimate intersex condition (i.e. not transsexualism) and am therefore intersex by sex” (2003: 3). Two other participants described their at birth sex in terms other than “typical male” and “typical female.” Pat describes their at-birth sex as “male-variant” (2003: 2) and Mel describes their at-birth sex as “perfectly normal androgyny” (2003: 1).

Kerry and Leigh define their at-birth sex as “male” (Kerry, 2003: 1; Leigh, 2004: 2) and Jamie and Lou define theirs as “female” (2003: 2; Lou, 2004: 1). Lou expands this by saying “Always female. Didn’t know anything else” (2004: 1). Terry describes their at-birth sex as “heterosexual” (2003: 3).

8.2.4.2 I’d like to talk with you now about your gender. How do you define your gender?

Rather than offering individuals a pre-designed selection of identities, they were asked to express in their own terms how they defined their gender. Chris describes their gender as “more male than female,” exploring that “ultimately I don’t care that much about gender. I’m just me” (2003: 3). Pat describes their gender as “intersex male-variant” (2003: 2), and adds

Primarily male but recognition of aspects which extend beyond the classification of male. Don’t identify as female even though I recognise that I possess feelings, emotional reactions and thought patterns often associated with women (2003: 2-3)

Kerry, Leigh and Terry defined their gender as “male” (Kerry, 2003: 1; Leigh, 2004: 2; Terry, 2003: 3). Leigh adds that they are “100% prime time lean good looking healthy male” (2004: 2) and Terry says “remember with your study ‘gender’ is not biological but a social construct” (2003: 3). Lou and Jamie defined theirs as “female” (Lou, 2004: 1; Jamie, 2003: 2). Jamie adds

Androgen has no effect on me, I was obviously meant to be female. Nothing can change that. Give me a male hormone and it will not impact on my (body hair and so forth), give it to my best friend and her appearance will change. Aspects of 'normal' woman are changeable as they have no resistance to the hormones. I could never be male (2003: 2)

Mel defines their gender with the term "Androgyny" (2003: 1) and states that it "is defined in your myths and religions, look there for our definition" (2003: 1).

8.2.4.3 How do you express this gender identity to others?

Gender is perceived as an in-situ culturally mediated negotiation of one's sense of self, with an emphasis on behavioural characteristics. As such individuals were asked to reflect upon ways of expressing this gender identity to others. Chris lives "as a man in all aspects of my life, albeit with breasts and atypical genitalia" (2003: 3). Kerry feels "most of the time definitely" male (2003: 1). Kerry goes on to say

However, experiencing erectile dysfunction often makes me not feel as male as I should plus having a different penis which does not look normal impacts on my feelings of maleness. I look male and act male, I have stereotypical male behaviours but with a sensitive side (2003: 1)

Jamie states that this is something that "I generally do not discuss ... with people" (2003: 2). Jamie expands this by saying

At times I find it difficult and emotional to express myself. Unfortunately I have had a lot of negative conditioning in learning to accept and cope with who I am. At times it creeps back in and my emotional walls come back up again (2003: 2)

Terry says that

While male I'm not inclined toward strong masculine identities such as those who are into motor cars, I hate bucks nights and strip clubs and the denigration of women, I'm not 'handy' around the house and am not into building things ...I'd never have a garage workshop ... I guess I'm a New Age Sensitive type but have never felt any inclination toward homosexuality. I am fairly comfortable in the company of gay men but have found this comfort shifts completely in a gay bar scene where the 'gay gender' is being expressed explicitly (2003: 3)

Mel expresses their gender "by being what and who we are designed to be" (2003: 1). Leigh says "every way that I can?" (2004: 2). Lou describes their gender expression in terms of relationships with others: 'daughter/mother/sister/wife/aunt" (2004: 1). Pat doesn't feel the need to express the 'female' side in behaviour or appearance, appearing to the world as male (2003: 3). Nor does Pat feel the need to change self to suit the social expectations of a sex and gender variant person (2003: 3). Pat goes on to state that those with whom Pat has a close relationship with

Recognise that I possess characteristics of thought, action and reaction which is a blend of male and female (2003: 3)

8.2.4.4 I am also interested in issues of sexual orientation. How do you characterise your sexual orientation?

Sexuality's aetiology is not a recent phenomenon and debates about nature versus nature have reigned for over a century. In addition over the last decades of the twentieth century and the first few years of the twenty-first discourses, terminologies and identities surrounding contemporary sexuality has diversified.

Recent contributions by the intersex literature and intersex narratives have further called into question binaries of heterosexual/homosexual. As Table 8.4 suggests intersex individuals express their sexuality identities in a similar vein, that is, diversely.

Participant	Sexual Orientation
Chris	Preference for Women
Jamie	Heterosexual
Kerry	Gay
Mel	Normal Androgyne Orientation
Terry	Heterosexual
Pat	A-Sexual
Lou	Heterosexual
Leigh	Heterosexual

Table 8.4 Participants' Sexual Orientation

While Jamie, Leigh, Lou and Terry define their sexual orientation as “heterosexual” (Jamie, 2003: 2; Leigh, 2004: 2; 2004: 1; Terry, 2003: 3). Chris refers to being “attracted to nice people, with a preference for women” (2003: 3). Kerry describes their sexual orientation as “gay” (2003: 1). Mel refers to a “normal androgyne orientation” clarifying this point by stating that there is no other way to explain this orientation “to the mono-gendered mind because, ‘it just will not compute’” (2003: 1). Pat says

Do not possess a sexual orientation - don't have a sex drive, sexual awareness, nor have had much experience with sexual interaction. Attracted to males, but not sexually - not interested or inclined to express visual attraction via sexual contact. Able to establish non-sexual intimate relationships with males, more so than with females. Best described as being a-sexual (2003: 3)

8.2.4.5 What have been the most significant events that helped you to develop your sense of gender and sexual identity?

Gender and sexuality are personally negotiated, as they are culturally mediated identities. Therefore it is argued that significant events in one's life history influence one's gendered and sexuality identities. Chris insists that “it certainly wasn't the disgusting and

highly abusive treatment of medical professionals. I just grew up and became me. Gender isn't a significant issue in my life. Intersex is about a variation of sex chromosomes or sexual reproductive organs and not gender identity" (2003: 3). Kerry has always felt an attraction to people of the same sex "despite my hypospadias" (2003: 2). Kerry expands this

I do feel however, that I have always been interested in other male genitalia because mine was different, I was always interested in something I desperately wanted but was never going to have and that was normal genitalia (2003: 2)

For Mel a significant event was "awareness that 47xxY is a completely different breed of human to those of 46 xx or 46 xy variety and is now officially recognised in the Australian and International Commonwealth as a third gender and not a 'condition' at all" (2003: 1). "Nothing significant stands out" for Jamie (2003: 2) adding "I was raised female because to all appearances I was female" (2003: 2). Terry has "never had any issue ... its always been clear" (2003: 3). One significant event for Lou was "upbringing" stating that "mentally I'm female. One knows this early - 2 years old? It is in your *head* and not in physical sex characteristics that one knows this" (original emphasis, 2004: 1).

Pat identifies four significant events and their effects

Testosterone therapy and ceasing testosterone therapy - graphically demonstrated to me what I was not. Buddhist practice and theory - enable me to see beyond the binaries. Academic studies, especially the works of Foucault - taught me that binary classifications are only one means to order the world. Discovery of the ISNA on the web and meeting fellow XXY's and intersexed people via on-line discussion lists - proved to me that I was not alone (2003: 3)

8.2.4.6 Has your sexual identity changed over time? If so, tell me about this.

Contemporary queer theory scholarship argues that sexuality identities are fluid through time and space. That is, one's identity is capable of transitioning through one's life. Kerry, Leigh, Jamie, Lou and Terry each state that their sexual identity has not changed over time (Kerry, 2003: 2; Leigh, 2004: 2; Jamie, 2003: 2; Lou, 2004: 1; Terry, 2003: 4). Mel states that theirs has, but indicates they do not wish to 'tell us about this' because "we do not know you" (2003: 1). Chris states that "I've changed a lot over the years, but my sense of self has been fairly constant" (2003: 4). Pat informs us they were

Labelled as being homosexual in my late teens. Tried to accept this label, but was very unsuccessful as I did not receive satisfaction or enjoyment from sexual contact with males (or females for that matter). Experienced severe trauma when I realised that I was neither straight, gay, bi - did not have the knowledge or awareness at this time that there were alternatives. On discovering my intersex state and discussing sexual orientation/identity with other intersexed people discovered that a non-sexual identity was just as real and as valid as a sexual identity. So now I choose to identify as not having a sexual identity (2003: 3)

8.2.4.7 Has the way you see you gender identity, or the way you express your gender identity to others changed over time? If so, tell me about this.

Similarly one's gender identity has the capacity to change through one's life. Mel indicates that a change has taken place but indicates they do not wish to 'tell us about this' because "you are not known to us" (2003: 1). Chris explores the fact that their expression of gender has changed in particular in terms of clothing "because I reaffirmed my true self by trying to reverse what doctors did to me as a child and adolescent. I still feel and act the same way though" (2003: 4). While raised as male, Pat felt that they were more than a male, yet Pat never identified as female. As Pat states

However, did not have the awareness, language or knowledge to identify as anything else but a male. Never had any feelings of being a female. Discovering the existence of intersex, enabled me to adopt the identity of intersex – for both my sex and gender identity. However, in recent years modified this identity to accept my predominantly male sex and gender identities. Maybe later, if circumstances change - i.e. new knowledges and awareness's that identity may change again. Self-expression as remained the same - even with changing of self-identity, I don't feel the need to change my behaviours or presentations in order to fit into social expectations of sex and gender performance-identity (2003: 4)

Kerry (2003: 2), Leigh (2004: 2), Jamie (2003: 2), Lou (2004: 1) and Terry (2003: 4) indicate that they have not changed their gender identity, nor have they changed the expression of their gender identity. Kerry adds "I have always identified as male and that has never changed or been any different. I don't think the way I express my maleness has changed at least not consciously (2003: 2). Jamie elaborates

I have always considered myself female even at my darkest moments. My biggest issue has been interpersonal relationships. I would create a buffer/barrier between myself and people. Actually communicating my condition only made me feel even more isolated as I felt labelled. I have always considered myself to have an invisible disability. In many ways I have lost years from my life in my struggle to find acceptance and understanding from within myself and from others. I had a number of other issues to contend with, dysfunctional background, inadequate parental role models, coupled with isolation and anxiety. I was diagnosed with clinical depression and social phobia in my mid 20's. Drug therapy and cognitive psychotherapy counselling and the support of one very good friend helped me through the darkest parts of this life. Today I am married to a wonderful man who sees me not as a sum of body parts but the person that completes him. When he looks at me I know that I have acceptance and love, things I never thought would be achievable in my life and at times I still battle to accept all the good that I have

in my life. I look at my circumstances in a difference light these days. The veil is lifting (Jamie, 2003: 2)

Lou describes childhood behaviour as “a tomboy” (2004: 1), but “never thought I was male. Even though I had XY chromosomes I looked female (like Shirley Temple!) I am a married woman with CAIS. I do not regard myself as intersex. I don’t know what intersex means. Having always thought of myself as female. Have three adopted children and nine grandchildren. My sister was also CAIS, but was not so fortunate” (2004: 1). Terry answers “no” (2003: 4).

8.3 Intersex Voices - Revisited

Acquisition of social knowledge through interviews is a process whereby individuals are given the opportunity to share their lived experiences in a researcher-researched hierarchy. However, at times these narratives are imperfect representations of a life history. The methodology, memory or what the researched determine as relevant to the research or desired by the researcher may bias them. Minimising these biases was considered imperative to this study. Hence, individuals were asked to reflect on and make any relevant alterations to their original responses.

8.3.1 Jamie

Jamie was asked whether their spirituality had helped in having AIS. Jamie’s sharing of a belief system with others has led Jamie to finding a community of tolerance, something Jamie hitherto did not have “mainly due to self alienation” (2004: 1). Jamie talks of those who pray to either God or to the Goddess, or both and says, “In our Mothers arms we find solace and compassion, something that we sometimes lack in our physical circumstances” (2004: 1). Jamie’s faith in the Goddess extends to acceptance of Jamie’s situation: “To our Mother I am not male or female I am me and through her I feel true love that is there for everyone, if we so choose to accept her love” (2004: 2).

In Jamie's initial interview, Jamie noted that 'there was something different about me,' Jamie was subsequently asked to clarify what sorts of things were different. To which Jamie responded by describing how at age 11, during a period of discovery with a close female friend, that there were major differences between them, notably "I have a blind ending vagina" (2004: 1). Also Jamie notes that the fact that while others were menstruating Jamie was in denial. About why Jamie was not "looking for answers I heard that it was possible for girls to wait to 18 to start menstruation (evidently rare cases). The reality set-in in my early twenties" (2004: 1).

Indicating that Jamie found out about the AIS through a magazine article, Jamie was asked to explain more about the article. Unsure whether it was in Cleo or Cosmopolitan, either way they described the article as "partially fact and largely titillation for the masses" (2004: 2), with little medical information "that I could apply to myself" (2004: 2). Being "written for the average time a person takes to go to the bathroom" (2004:2) left Jamie feeling "Kinda sad" (2004: 2).

Jamie's mother found out about Jamie's intersex status when Jamie's sister, who also has AIS, was undergoing medical attention. Jamie believes they have found a common ground, as Jamie's mother has recently experienced ill health, and has had to come to terms with alcoholism, which according to Jamie has "toned down her a great deal" (2004: 2). More importantly it seems "She makes sure to let me know that she loves me with every conversation we have. Something that I didn't have growing up" (2004: 2). On the other hand, Jamie guesses that others in the family know, however, Jamie doesn't care either way: "at this point I am only interested in communicating with my mother and AIS sister" (2004: 2).

Jamie's 'AIS sister' apparently has a lot of issues surrounding abandonment and trust (2004: 3). As a result Jamie states that "We are still working on our relationship ... It is difficult at times, we seem to talk about the past a lot which is sometimes distressing for me. We will understand more about each other with time I believe" (2004: 3).

Jamie's husband appears to have been very accepting of Jamie's AIS, despite some initial fears of Jamie being a preop transsexual, their relationship "transcends physical" (2004: 3). Their relationship began through a chance conversation in an Internet chat room. And although they lived on opposite sides of the world "within nine days of knowing each other he proposed marriage as we were so set on each other" (2004: 3). Jamie explains that there were some initial differences to overcome, cultural and spiritual, but it was Jamie's AIS that took "a few hours to summon up the courage" to talk about on the telephone. As Jamie tells it

All I could really do was describe my physical attributes and explain that I did not know what that meant for us until we could be in the presence of each and expressing ourselves physically (2004: 3)

Despite Jamie's concerns "that it would all be too much for him" (2004: 3), Jamie's husband "took it all in stride and accepted that we would have to wait to see if we could work around my having AIS" (2004: 3). However, nothing appears to have been able to stand in their way, not distance, cultural or spiritual differences or Jamie's AIS "he wants me - AIS and all my moods and everything else. Do I ever question his love for me - never" (2004: 3).

Jamie remarked on an incident that indicates why fear stops Jamie from undergoing surgery. In the process of preparing for Jamie's immigration medical, Jamie was told of the need to have a pregnancy test

I tried to explain that I had AIS and it was a medical impossibility for me to conceive. The doctor said 'oh sometimes people don't realize they are pregnant' - the stupidity of her response is still lost on her. I walked out on her. Giving me a pregnancy test right now is so cruel (2004: 3)

The experience left Jamie in tears and insulted and reflective of "able-bodied people have no idea what it is to walk in the same space as them and just feel like a spectator in life"

(2004: 3). Ultimately the experience has led to a comment on Jamie's ultimate dream to have a child "I never expected to find a fella that I loved implicitly who would return that love and be able to accept my AIS. That has changed and it makes me wonder if other things are possible like having a menstrual cycle and (gasp) having our child (my ultimate dream - impossible but still a dream)" (2004: 3). In regards to any future surgery, Jamie would like a gonadal check up and perhaps a lengthening of the vaginal cavity (2004: 3).

While Jamie's husband has been "good for me - gives me a kick up the backside when I most need it" (2004: 3), Jamie describes growing up with mistrust, self-reliance and "too much silence and non communication" (2004: 3). Jamie's childhood friendships were fragmented because the family moved about. A situation that was further disrupted in Jamie's mid-20s, sharing with trusted friends "went painfully wrong" (2004: 3). Jamie reflects on sharing feelings with others with some anguish

The intense burden that I felt made it so difficult to explain to people, I felt such deep pain within myself that I was certain that sharing my condition would only lead them to feel the same intense pain (2004: 3)

Anguish that appears to be aggravated by Jamie's family situation

My mother was more intent in her life and ensured that her children grew up fast as possible to alleviate her burdens. Each of us coped with many things on our own. There was no loyalty in our family, we were never truly bonded. This just amplified all the negatives I was feeling within myself about AIS. The big truth is that my family just didn't know how to respond to my AIS and probably were hoping it would just go away (2004: 3)

Jamie concedes that "I would really love for AIS to not be in my life" (2004: 3), and states that "the pain of AIS has been so great and so difficult to cope with that sometimes I am amazed that I have made it this far" (Jamie, 2004: 3).

8.3.2 Mel

When asked to give an example of how Mel expresses the gender identity of ‘perfectly normal androgyne’ to others, Mel attached a newspaper clipping (Appendix G).

Mel was queried to explain what was meant by Mel’s answer to the initial question regarding Mel’s sexual orientation. In response Mel provided a diagram (Figure 8.1.) and subsequent explanation.

Unlike conventional xx or xy gender identity's, androgyne identity as this diagram illustrates, is as diverse as it is complex to explain to those who do not have the necessary DNA to fully comprehend these subtle differences. (If you do not have the 'hardware,' i.e. DNA, you cannot download, much less, file the 'software' necessary to complete these tasks) (Mel, 2004: 2)

In addition Mel believes that since “the number 47 is greater in numerical value than 46 and, xxy is more sophisticated in genetic material (DNA) than xx or xy, it is my view that XXY is one of the missing identity links for which academic humanity is searching” (2004: 2).

47 XXY ANDROGYNE

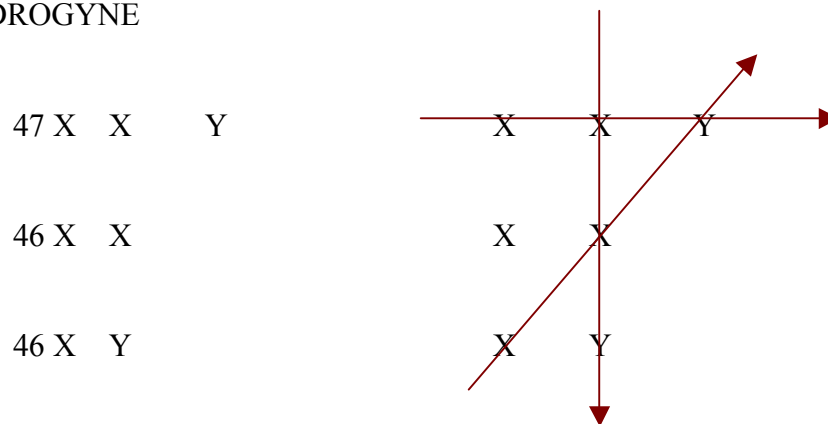


Figure 8.1. Self-description of Mel’s Sexual Orientation of 47XXY Androgyne.

Mel was asked how they became aware of being 47XXY, and Mel answered by saying “Brutally, after a 'punch biopsy,' the discovery was made whilst I was recovering in hospital from the [xy male] incurred injuries” (2004: 2). However, Mel states that as a consequence “there is no love lost between xy's and myself” (2004: 2).

8.3.3 Pat

Pat was asked to clarify an indication that Klinefelters was not the initial diagnosis. At 21 Pat was diagnosed with hyperparathyroidism, which was caused by a tumour in Pat's parathyroid gland. Tests showed that Pat's testosterone production was similar to that of a prepubescent child. According to Pat's endocrinologist, Pat had only gone through a partial puberty, and was diagnosed with hypogonadism. While Pat was recommended to undergo testosterone therapy, Pat was concerned with effects on the body and mind, as a result Pat did not undergo the treatment (Pat, 2004: 1).

After eight years, Pat succumbed to the endocrinologists' and a psychotherapists' “disempowering and negative” (2004: 1) insistence that not undertaking testosterone therapy “I could not live as a ‘normal’ man” (Pat, 2004: 1). The expectation that Pat would become ‘normal’ after the therapy was not met.

Rather the testosterone generated several severe psychological and physical negative side effects. I experienced a nervous breakdown as a consequence of the testosterone within the first year of commencement of the program. By the third year I began to present the first symptoms of chronic fatigue, partial androgen insensitivity syndrome and muscle spasms (Pat, 2004: 1)

According to Pat these side-effects were not adequately investigated by the endocrinologist, and Pat was prescribed an increased dosage of testosterone, the high dosages of testosterone “led to the development of a deep vein thrombosis, which required emergency hospitalisation and two weeks in intensive care” (2004: 1). This experience forced Pat to end the relationship with this endocrinologist, a few months later

Pat was introduced to a General Practitioner who “specialised in non-heterosexual identifying people” (2004: 1). Working with this GP, Pat was diagnosed with Klinefelters Syndrome within the first few visits, and they negotiated a dosage of testosterone to maintain Pat’s bone strength, without the physical and psychological side-effects (2004: 1). Pat is concerned that while Klinefelters was never mentioned with the previous endocrinologist

I fear that possibly the diagnosis was made but, for whatever reason, the endocrinologist decided not to tell me of this diagnosis - or he was simply incompetent, having not made a correct diagnosis (2004: 1)

Pat reflects on how both their sisters reacted well to the diagnosis, and are very supportive, despite some concern over whether Klinefelters was hereditary, since both sisters had male children. Pat says that they were relieved by an explanation for Pat’s physical and psychological problems during childhood and adolescence (2004: 2). Pat does indicate however, that they are embarrassed by Pat’s promotion of intersex issues in public (2004.2).

Pat’s father died when Pat was eight, years before Pat was aware of the symptoms of hypogonadism or Klinefelters. The diagnosis of hypogonadism however, caused tension between Pat and Pat’s mother. This is because the endocrinologist claimed that Klinefelters Syndrome could have been treated in Pat’s early teens, treatment the endocrinologist led Pat to believe would have let Pat grow up ‘normal,’ something that would later turn out to be untrue. However, at the time Pat’s mother felt Pat’s anger “because my lack of maturation was ignored by my mother” (2004: 2). However, Pat now understands more about their mother’s feelings

I came from a Catholic household where sex was never mentioned - so in this environment, my lack of sexual maturation was not discussed. My mother felt very guilty about the claims the endocrinologist made, and blamed herself. Fortunately, through a third party, the rift and silence between my mother and

myself was healed as I realised that my mother never did anything intentionally to harm me - as she was just as uninformed of these issues as anyone else (2004: 2)

In regards to the endocrinologists' incorrect claims Pat is glad that an early diagnosis wasn't made "as I would have commenced the therapy, which would have resulted in my adolescent physical and psychological development being dependant on a drug" (2004: 2). Pat expresses sadness that Pat's mother had died before Pat knew that Pat's mother's actions "actually served to save me from far greater negative consequences later in life" (2004: 2).

Pat identifies behavioural problems associated with having an extra X chromosome, such as introversion and learning difficulties, "which caused problems with my relationship to my sisters, and caused my mother significant grief" (2004: 2). Further, "my sisters considered me strange and my behaviours often incomprehensible, to such an extent they often isolated me from their social lives" (2004: 2).

Pat believes that while it was never discussed, Pat's family thought that Pat was gay, even though Pat was never "sexually active for much of this time, and was never sexually attracted to anyone" (2004: 2). Yet, Pat did assume the identity of a homosexual only because Pat did not have access to the relevant concepts and language. In regard to Pat's fluid gender identity, Pat explains "I never articulated my issues with fluid gender identity, simply because I did not comprehend my difference in that manner during my adolescence" (2004: 2).

Pat articulates how non-sexual relationships are more easily established and maintained with men rather than with women. Pat believes that they are able to talk about feelings, vulnerabilities and problems because they do not have to put on "macho competitive behaviours" (2004: 3). Pat admits to being "attracted to the physical strength of males, probably as they represent aspects which I lack in myself-and so, like the old saying, 'opposites attract'" (2004: 3). In regards to Pat's relationships with women, Pat reflects on the idea that "ironically ... the straight females I have known have perceived any

closeness as a precursor to a physical intimate relationship” (2004: 3). As a result Pat has established barriers with women not only to reinforce the platonic nature of the relationship, but because Pat thinks “my emotional/feeling self is too female-like to establish an intimate connection with females” (2004: 3).

Buddhism offers Pat a number of ways of thinking and being that counter the Western conceptualisations. This appeals to Pat’s outlook and gender and intersex identity history. Pat identifies with Buddhism’s eastern influence of ordering the world in “multiplicities, rather than binary systems” (2004: 3). As a result “applying it to myself, I see that I represent the world as it is, and not the rigid system the West has constructed, which after all is a man-made illusion” (2004: 3). In regards to Pat’s identity history, Buddhism equipped Pat to accept changes in identity

I lived as a homosexual man for many years until I realised that this life-style and identity was not appropriate for me. I then discovered the intersex identity, assumed the label ‘Intersex’ and spent a few years exploring this identity. However, in recent times I have recognised the limitations of this identity and realised that it’s not entirely applicable to my situation, so I dropped that identity, and now identify as being a variant a-sexual male. Later, if circumstances change, or I accumulate more knowledges about myself, I will again adopt another identity and explore that. I accept that, biologically, I am an intersexed person, but my identity is something which will change over time (2004: 3)

8.3.4 Kerry

Kerry explains that at age 5 they were told the reason they were admitted to hospital. Also at this time Kerry was aware that other boys did not have to sit to pee. Kerry describes the explanations as “basic” ones (Kerry, 2004: 1). In regards to Kerry’s intersex status, Kerry’s mother dominated the familial relationships.

Mum did the telling. It's not something I remember my Dad discussing although he always visited me in hospital (Kerry, 2004: 1-2)

In discussing parental decision to agree to surgery, Kerry made a statement that was unclear to the researcher "I am glad my parents made the decision for surgery and not to wait for me to decide at a later stage" (Kerry, 2003: 2). Kerry was asked to clarify this point. In response Kerry writes

My condition is distressing enough as it is for me now. I can't imagine what my self-esteem would have been like if I had been left unrepaired and then having to decide as a teen whether or not to have my penis operated on. I can honestly say that at age 41 now I don't know what I would have decided if the decision had been mine (Kerry, 2004: 2)

Kerry's penis is described as "normal," and Kerry expresses a strong sense of self as "male." Kerry was asked to reflect upon these two aspects.

So much emphasis on being male revolves around the penis, its size and ability. Having a penis different to the norm and one that does not work properly makes you feel inadequate and less male, its very isolating especially through the teen years. I feel inadequate most of the time and then being gay as well doesn't help (Kerry, 2004: 3)

Conclusion

The diversity of the lived experiences of intersex Australians avoids sufficient similarity to provide an all-encompassing congruent conclusion. Yet, I do argue that these stories are comparable to those articulated in other intersex narratives, as will be explored in the following chapters. However, at this point in time I fall short of arguing that there is a universal intersex experience. This is because intersex Australians have flagged concern regarding the influence International intersex movements have had on Australia. In

particular they argue that there is assumption that the medical, legal and social situation in the United States of America is reproduced here, what one intersex Australian coined a 'U.S style intersex.' Therefore any claim of a Universal intersex experience could lead to an appropriation by an U.S. style intersex experience. Regardless of the reluctance of these stories to coalesce into a coherent all-encompassing statement, I argue that this incongruence is a trend of intersex narratives elsewhere. The issues presented here are echoes of those expressed in other forums within which intersex voices are heard. Therefore as an addition to these voices I offer a set of thematic threads (Appendix H) that have been identified from intersex Australian voices.

Summarising these voices into thematic threads is an important yet problematic analytical process. The thematic threads while useful, are counter to the fundamental assumptions of this project, namely, I wanted to give intersex Australians a voice. Hence I have left this chapter relatively 'interpretation-free.' The next chapters allow analyses of these intersex voices through an academic lens. I will explore the socio-political and theoretical ramifications of these intersex voices and thematic threads on intersex individuals, the intersex movement, intersex medical intervention, queer and gender theory and the future of Western conceptualisations of intersex.

CHAPTER 9: THEMES

Introduction

- 9.1 Feelings of Shame, Stigmatisation and Secrecy
- 9.2 Questioning and Disruption of Sex/Gender Identities
- 9.3 'Passing,' Self Monitoring and 'Doing' Gendered Behaviour
- 9.4 Reactions to Clinical Procedures
- 9.5 Relationships with Parents and Family Members
- 9.6 Acceptance of Difference, Political Empowerment and Mobilisation
- 9.7 Spirituality
- 9.8 Sexual Orientation
- 9.9 "You Can Always Adopt"
- 9.10 Analogies of Sexual Abuse

Conclusion

Introduction

I have given primacy to intersex individuals and their voice(s). I have not neglected to undertake a level of analysis in the process of investigating their lived experiences. What follows therefore is an attempt to reel in some of the theoretical threads introduced in the previous chapters. Further, I want to take this opportunity to employ the voices heard in my interviews with intersex Australians and compare and contrast them to voices heard in other forums. Specifically I will weigh them up against Preves' study (2003) that utilises approaches and themes that inspired and informed this study.

I have argued that intersex narratives (Chapter 6) revolve around central issues of 'discovery,' 'reaction by others,' and 'reflections.' Moreover I have identified that located within each of these discourses are significant themes of finding out about one's intersex status, what others did and said to them, and how one's intersex status has led to a reflection on self-identities. Issues and themes include, but are not limited to, surgical complications, hormone side-effects, relationships with doctors, parents and partners, psycho-emotional trauma, fertility, 'coming out,' deception, sexual function, intimacy and orientation, loneliness, empowerment, spirituality and gendered identities.

In Chapter 6 I introduced Sharon Preves' *Intersex and Identity* (2003) and remarked that an analysis of this text shall be postponed. Further, in Chapters 7 and 8 I once again referred to Preves, yet merely referred to methodologies and how I have adopted similar, if not the same, approaches. Presently I shall combine Preves' contributions to our understandings of the lived experiences and issues of intersex individuals. In particular I shall compare the lived experiences and issues of intersex Americans to intersex Australians I interviewed. Considering the similarities between intersex Australians and those in the United States I can appreciate the view of one of my key informants, who suggests that Australians experience a "US style intersex," however, I reserve making a similar conclusion until I have also fully explored the differences.

Preves (2003) employs a multistage coming out model (61) to illustrate how intersex Americans undergo a process of “embracing one’s identity” (61). These coming out stages included 1) recognition of one’s nonconformity; 2) acknowledgement of one’s difference to self and others; 3) seeking and socialising with others; 4) pride in one’s marginal identity; and 5) integration of one’s identity within a prevailing sociocultural context (61). The goal of this chapter is to tie up those theoretical threads that weave throughout this thesis. Therefore I want to tie in Preves’ work and my own respondents interviews with these hitherto discussed threads, giving a comparative analysis. Thus while I concur with Preves’ employment of a ‘coming out’ model it does not coincide with my present project.

Instead I cite a number of key social issues pertinent to this present project. Some of these are supported by narrative in Preves’ work; others are not. The social issues herein analysed include: 1) feelings of shame, stigmatisation, and secrecy; 2) questioning and disruption of sex/gender identities; 3) ‘passing,’ self-monitoring and ‘doing’ gendered behaviour; 4) failure and complications of and alternatives to clinical procedures; 5) relationships with parents and family members; and 6) acceptance of difference, political empowerment and mobilisation. I shall set up these social issues and draw parallels between Preves’ findings and my own. In addition I choose to isolate a number of issues in more detail, namely spirituality, sexual orientation, in/fertility and analogies of sexual abuse. I shall postpone a thorough analysis of gender identities until Chapter 10.

9.1 Feelings of shame, stigmatisation, and secrecy

Feelings of shame, stigma and secrecy are born from the interaction intersex individuals have with doctors and family members, usually parents. In particular intersex individuals have these feelings because doctors/parents react negatively to or actively ignore their patients/child’s intersex status. Arguably it is this issue that is most evident within intersex narratives and the intersex literature.

The actions that medical practitioners undertake have drawn considerable attention in regards to individuals' negative experiences. Preves indicates that constant exposure to medical examinations; in particular exposure of one's genitals has led to feelings of shame (2003: 66). Greta, for example, describes having naked pictures taken

I remember going down to the bowels of the hospital and having some photographer take photos. And, you know this is the thing that was just unbelievable, is that I have such a hard time these days still, not so much anymore, setting boundaries. It's because my mother was condoning this ... These were naked pictures. It was just ridiculous. It's unbelievable actually. I remember being on [an] examination table, and having medical students parade in and out, you know, and I was by myself. My mother was not in the room (Greta, cited in Preves, 2003: 66-67)

In my study Jamie has expressed concern over feelings of isolation and loss

My biggest issue has been interpersonal relationships. I would create a buffer/barrier between myself and people. Actually communicating my condition only made me feel even more isolated as I felt labelled ... In many ways I have lost years from my life in my struggle to find acceptance and understanding from within myself and from others (Jamie, 2003: 2)

The flash point to these emotions has been widely cited in intersex narratives as the ubiquitous assumption in the medical profession that telling intersex individuals the truth about their own intersex status would not only risk the success of any gender assignment, but would also traumatise the individual. Therefore an almost universal experience among intersex individuals is the deception regarding their intersex status.

They wouldn't tell me anything. I knew that there was more to it than all this. I knew that I wasn't being told the truth but there was no way anybody was gonna tell me the truth. It was such a mess. There was so much lying and symboling

going on that there's a wonder I ever figured it out (Sarah, cited in Preves, 2003: 73)

Individuals in my study, such as Chris, describe long histories of lies "From the time I was 11 to the time I was 30 I was lied to by my doctors about my condition" (Chris, 2003: 2). Lou discovered their intersex status at the age of 65 years stating that "This was due to being kept in ignorance, also the silence that pervaded the condition" (2004: 1). Kerry indicates that while they were told the basics, this was a painful experience, further "my hypospadias was never really discussed from an early age" (Kerry, 2003: 1). While Kerry's parents are aware of their condition, they never discussed it (2003: 1). Jamie's experiences are explicitly described

It was never discussed within my family. My mother never took me for treatment. I lived in shame enclosed in a wall of alienation. I still don't know why my mother was afraid to help me (Jamie, 2003: 1)

Terry also expresses how they internalised negative emotions

I had issues with my body ... lack of strength and coordination ... I avoided sport and experienced internal trauma that lasted until my late twenties. I hid my body away ... filled with fear that someone would see me naked I refused to go into change rooms, to swim at baths, to have relationships, to be seen by my family or friends naked (Terry, 2003: 1)

The internal wellbeing of intersex individuals is central to much of the intersex literature and narrative. Lies, alienation and trauma are not only ways that intersex individuals express their experiences. There also are direct responses to the medicalisation of their intersex status, these negative feelings add weight to the intersex movement's criticism of the current medical management.

9.2 Questioning and disruption of sex/gender identities

The assignment of sex and gender through medical management is predicated on John Money's gender role theory, that is, the assumption that one can successfully be raised as a male or a female only when one's assignment is not delineated from one's genital configuration. However, there is evidence to suggest that discovery of one's intersex status either disrupts one's sex/gender identity or reinforces a previously held doubt about one's sex/gender identity. For Sherri this knowledge drew attention to gendered aspects of themselves

When I figured out that I had XY chromosomes and had testes, I did at some point look myself over from head to toe and say 'Okay, what about me is male? Where is that male part of me hiding, waiting to come out at night? Where is it? What's visible to other people? What's visible to the world? What is it?' And I went through my body, pretty much head-to-toe (Sherri, cited in Preves, 2003: 82)

In my study Pat's self identity currently is located as "intersex male variant" (2003: 2) yet adds that while "primarily male" Pat recognises "aspects which extend beyond the classification of male. Don't identify as female even though I recognise that I possess feelings, emotional reactions and thought patterns often associated with women" (2003: 2). Chris underwent a sex change at the age of thirty, despite reluctance of their doctors, and while Chris downplays the significance of gender, they describe themselves "more male than female" (2003: 3). Chris goes on to indicate that their gender and physical configuration, while at odds are not an issue for their sense of self

I live as a man in all aspects of my life, albeit with breasts and atypical genitalia (Chris, 2003: 3)

When I asked Jamie about their gender identity they responded with reluctance and expressed an obvious negative reaction to this part of their life

I generally do not discuss this with people. At times I find it difficult and emotional to express myself. Unfortunately I have had a lot of negative conditioning in learning to accept and cope with who I am. At times it creeps back in and my emotional walls come back up again (Jamie, 2003: 2)

In contrast, Kerry indicates that while they feel definitely male most of the time, “experiencing erectile dysfunction ... plus having a different penis which does not look normal impacts on my feelings of maleness” (Kerry, 2003: 2). Although the intersex movement cites statistics to suggest that gender issues are not a universal concern, it does not negate the fact that intersex individuals are articulating uncertainties, transitions and difficulties in their sex/gender identities.

9.3 ‘Passing,’ self-monitoring and ‘doing’ gendered behaviour

For some intersex individuals in Preves’ and my own study, issues concerning one’s gender behaviour only arose after acquiring knowledge of their intersex status. They engaged in an active project of ‘passing,’ self-monitoring and ‘doing’ gendered behaviours. Martha indicates this by stating that “I think you [are] constantly monitoring yourself. Is this the way women act? Is this what women think? Is this how women are? It’s maybe not something that you do consciously, but it’s a constant kind of trying to fit in” (Martha, cited in Preves, 2003: 82). Some ways intersex individuals deliberately gendered themselves is explored by Preves, such as pretending to have periods, becoming promiscuous, nude modelling, and participating in such gendered rituals as marriage (2003: 84-85). Some even expressed their gendered behaviours in terms of ‘doing drag.’

I kid myself. I sometimes say all I do is drag. And in this society, all I really do is drag. I do execu-dyke drag, I do girl drag, I do boy drag. This is girl drag, what I’m wearing today (Gaby, cited in Preves, 2003: 86)

In my study gender was described in emphasised terms

100% Prime time lean good looking healthy MALE! (Leigh, 2004: 2)

And as being a ‘natural’ expression of their sense of self

Mentally I’m female. One knows this early on - 2 years old? It is in your *head* and not in physical sex characteristics that one knows this (original emphasis, Lou, 2004: 1)

Or if they saw their gendered behaviour as outside of the norm, they did not see this as counter to or as a barrier to their identity

I was a tomboy as a child, but never thought I was male. Even though I had XY chromosomes (Lou, 2004: 1)

Terry and Kerry were able to reconcile their gendered behaviour in terms of contemporary fluid notions of masculinity

While male I’m not inclined toward strong masculinity identities such as those who are into motor cars, I hate bucks nights and strip clubs and the denigration of women, I’m not ‘handy’ around the house and am not into building things ... I’d never have a garage workshop ... I guess I’m a New Age Sensitive type (Terry, 2003: 4)

I look male and act male, I have stereotypical male behaviours but with a sensitive side (Kerry, 2003: 2)

This engagement with a social constructionist paradigm enables the reader to see that intersex individuals do not place considerable weight on the biology equals destiny credo that appears to reinforce medical practises. Indeed intersex individuals are aware that their own gendered behaviour requires monitoring, doing and an (over)emphasising via established naturalising discourses.

9.4 Reactions to clinical procedures

Intersex individuals raised their concern over procedures being recommended by doctors to ‘treat’ their intersex status. While some within my study saw medical invention as “necessary” (Kerry, 2003: 2; Leigh, 2004: 1) and others “didn’t regret” (Pat, 2003: 2) or are “happy” (Lou, 2004: 1) about having had treatment, there is a larger proportion of individuals who do not feel this way. As Preves reports “iatrogenic complications ... were common among” interviewees (2003: 81). Chris is “angry” (2003:1) and describes the surgery as “immoral, unethical and illegal” (2003: 1). While not regretting hormone treatment, Pat does regret persevering with the treatment, having generated severe and permanent negative psychological and physiological side-effects (2003: 2). In Pat’s view “all people with XXY (Klinefelter Syndrome) should not be coerced into therapies simply in order to masculinize them” (2003: 2). The non-universality of these responses seems counter to the large amount of narrative cited in previous chapters, however, I don’t believe this diminishes the primacy given to those stories that criticise the current medical management. In reference to Leigh’s positive experiences and being the youngest of my participants (aged 20) it could be argued that there has been some changes to the way that the medical profession react to intersex.

9.5 Relationships with parents and family members

What appears to be a significant contrast between this and Preves’ study is that Preves appears not to have placed emphasis on intersex individuals and their relationship with parents and family members. While in this study there was no universal point of view, some talked of these relationships in negative terms. Chris’ relationship with their mother appears to have been “irreparably damaged” (2003: 2) by the events surrounding their intersex status. Jamie was estranged from their family for seven years, a separation that appears to have been recently ended

One of my sisters has been diagnosed with AIS and we have been talking more openly with each other over recent years. My sister and I were living in separate

parts of Melbourne during our teens and had no opportunity to support each other. I'm stepping into unexplored territory (Jamie, 2003: 1)

Kerry suggests that their mother “feels guilt” over the fact that Kerry was born that way, a feeling that has prevented them from discussing Kerry’s intersex status (2003: 1).

Contrary to this view some intersex individuals appeared to have an open, rewarding and successful relationship with their parents, family members and sexual partners. Leigh has had a life-long history of being informed and supported by parents

My mother was very open and told me from the start everything she could. [My family] have all known since I was a baby, as have friends of the family, and they are all supportive and open about it (Leigh, 2004: 1)

Chris (2003: 2) and Pat (2003: 1) have siblings who are understanding and supportive of their intersex status

Siblings relieved as I, because diagnosis has enabled physical and psychological history to be explained. Family far more accepting of my personal idiosyncrasies - especially in relation to my fluid sex and gender identity (Pat, 2003: 1)

Some have open and supportive relationships with their partners

[My partner] is extremely supportive, and amazingly understanding. She is open and curious about it, and very accepting. Things are going very well, and we’ve been together for approximately six months so far (Leigh, 2004: 1)

Yet there is evidence that the information shared in these relationships may not be the ‘whole truth’

[My husband] was aware that I had *a medical condition* before we considered our intimate relationship. We were both apprehensive about our physical relationship. We have had no difficulties, I am obviously one of the fortunate ones (emphasis added, Jamie, 2003: 1)

My husband married me knowing I had *a gynaecological condition* and that we would only be able to adopt (emphasis added, Lou, 2004: 1)

Although Preves study does not cite participants' relationships with family and partners, the intersex literature does give some insights. Once again there is evidence to suggest that intersex individuals' experiences are not uniform. According to the literature and this study's participants their relationships with family and partners range from open and informative to closed and painful.

9.6 Acceptance of difference, political empowerment and mobilisation

Some intersex individuals resist the notion that they are different, preferring to reinforce 'normalcy' via adoption of naturalised identities and intersex status as medical condition epistemologies. Illustrated by Lou's statement "I am a married woman with CAIS. I do not regard myself as intersex. I don't know what intersex means having always thought of myself as female" and as cited above, "I never thought I was male, even though I had XY chromosomes I looked female" (Lou, 2004: 1). This finding was first encountered in the methodology phase of this project, whereby support groups refused to assist in recruitment unless terms such as 'intersex' were removed from all advertising material.

However, as Preves suggests (2003: 132), there is an identifiable period through which intersex individuals pass, a period that enables them to move beyond feelings of stigmatisation and shame and enabling them self-empowerment and political mobilisation, being proud of 'difference' rather than shying away from it.

I feel special. My AIS has made me feel special and it finally makes me understand why I am the way I am. It has made a big difference because I feel complete. I have found a part of myself that was lost (Chimera, cited in Preves, 2003: 117)

Pat's experiences include a reluctance to alter gendered behaviours

Don't feel the need to change myself to suit social expectations of a sex and gender variant person. People close to me recognise that I possess characteristics of thought, action and reaction which is a blend of male and female (Pat, 2003: 3)

For Chris accepting intersex, while difficult, was necessary

'Coming out' as a person with an intersex condition and then reaffirming my true self by changing to live as a male made life difficult in areas of work, political life and social activities, but it was a challenge I took on and feel I have been fairly successful (Chris, 2003: 2)

Aligning one's self with one's intersex status enables individuals to move beyond hitherto experienced negative feelings. While this negotiation may not be easily achieved, it offers an individual a source of inspiration, which is witnessed in the broader narrative and discourse of the intersex movement.

The narratives of Australian intersex individuals are not always easily aligned with equivalent life stories from the intersex literature or Preves' interviewees. There are some striking differences, such as a few in my study who have positive responses to surgical intervention. Further, I was able to explore participants' relationships with parents and other family members, some of whom had negative and some positive experiences. However, my analysis does not end here. In addition to these lived experiences I have identified other issues that have significant social ramifications (some of which do not appear in Preves' study), that is, spirituality, sexual orientation, in/fertility and analogies

of sexual abuse. To do justice to the complexity, depth and significance of these issues I do not limit myself to a comparison between Preves' and my own study, but draw threads from the wider intersex literature.

9.7 Spirituality

It is arguable that the recent trend of modernisation in western cultures is also a trend in secularisation. Further, it could be argued that the separation of 'church' and 'state' is also an indication of a reduced importance of spiritual self in a modern world. While the term 'spirituality' is not uncontested, it could be said that it is a personal journey of attempting to find meaning and connection between one's self, the natural and (for some) the supernatural. A journey that may or may not take place in a relationship between an individual and an organised religion, philosophy or system of belief. In Australia there is a move away from Christianity that would appear to support this trend, yet the number of Australians being attracted to other systems of belief like Buddhism is increasing (ABS, 2004). This shift counters the argument that there is a positive correlation between modernisation and secularisation.

The importance of spirituality for intersex individuals has not gone unnoticed (Gross, 2003; Preves, 2003; ISGI, 2004). However, any sufficiently in-depth analysis is virtually absent from the intersex literature. This is perhaps another indication of the perceived secularisation of the west. Yet, there is evidence to suggest that one's spiritual journey enables methods of coping and engenders a sense of hope in intersex individuals. The Intersex Support Group International (ISGI) founded in 1998 (Preves, 2003: 93) has made spirituality a central focus, they have "gathered together trustworthy and competent individuals to direct us in our service to intersexuals in the love and understanding of God who made us" (ISGI, 2004). Establishing an international network of counsellors and collectively praying for intersex individuals.

This move to actively support intersex individuals and their spiritual journey has taken place as a direct reaction to the ISGI's perception of the negativity within religious

organisations, Christianity in particular. This attitude, they argue, mirrors the medical management

Errant treatment of intersexuals is not exclusive to medical protocols. The response by the [Christian] Church at large to these specific individuals has alienated intersexuals and has also served to drive real people away from a personal relationship with God. That consequence is not God's will (ISGI, 2004)

Gross (2003) supports this view that fundamentalist Christians

Should feel threatened by the phenomenon of intersexuality and should seek to find religious arguments against it. It is not uncommon for Christian fundamentalists ... to adduce scriptural grounds for the condemnation of avowed intersexuality, at least, as 'unnatural' and as something which is at odds with the will of God as expressed in the order of creation (Gross, 2003)

I argue that the lack of attention being paid to spirituality in the intersex literature is remarkable because there is evidence that a spiritual journey is important to many intersex individuals. In Preves' study (2003), for example, 76% of participants had some spiritual or religious affiliation. Of my own participants six out of the eight indicated that they had some affiliation to an organised religion or a spiritual belief (Table 8.1 page 262). In Preves' study Julian infers that having a sense of spirituality is able to help intersex individuals

All the people [polled on an intersex chat site who had] 'come to terms with [their intersex status]' ... had one thing in common and that was their spirituality ... [it] seems to be what saved us; what saved our lives (Julian, cited in Preves, 2003: 100)

For Pat, Buddhist practise and theory has enabled a means of negotiating gender/sex identities that extend beyond traditional binaries (Pat, 2003: 3). Jamie's faith not only

supports and makes up for a lack in the physical but also sees faith as accepting regardless of one's form.

In our Mothers arms we find solace and compassion, something that we sometimes lack in our physical circumstances ... To our Mother I am not male or female I am me and through her I feel true love that is there for everyone, if we so choose to accept her love (2004: 1- 2)

I argue that not only has intersex spirituality been ignored in scholarship, but also its contribution to the lived experience, coping mechanisms and general wellbeing of intersex individuals has been greatly underestimated. I suggest therefore that future studies on intersex individuals, and their experiences with medical management, should endeavour to explore intersex individuals' spirituality.

9.8 Sexual orientation

Intersex individuals may circumvent traditional notions of heterosexuality but at the same time may not necessarily adopt a queer identity. A significant portion of participants in my study identified as 'heterosexual' and some did not see themselves as sexual. It has been suggested that a motivating force behind the medical management is to prevent the creation of queers (Fausto-Sterling, 2000: 72; Dreger, 1998: 76). Further, there is an active practise of distancing intersex from queer discourses, identities and communities. There is evidence in the intersex literature that indicates that adopting a queer identity is common among intersex individuals (Bucar, 1999). In the next chapter I will explore the ramifications these experiences have on our theorisation of sexuality, my present project is to offer up the myriad of ways that intersex individuals engage with queer discourse(s).

For some intersex individuals a queer identity or use of queer rhetoric has been the result of acquiring knowledge of one's intersex status. For others a queer identity or use of queer rhetoric is reinforced by doubts about one's sexual orientation that existed prior to acquisition of knowledge pertaining to intersex status. Also intersex individuals see their

intersex status as contributing to already held queer identity. In regards to a concrete sexuality identity some intersex individuals were confused between desire and assigned sex

I like men. I've never felt gay until the seed was planted. Then I searched. I searched. I wondered if perhaps I'd been deluding myself. I was told I was male. So that to me, if I'm male, I would be attracted to women. And I thought, 'No, that's bizarre. I'm not.' So what is going on? (Melody, cited in Preves, 2003: 112)

Expectations by others also featured

Because my family was so against homosexuality, I always tried to deny my lesbianism, I hoped to marry, adopt children as the counselors at Buffalo Children's [Hospital] suggest. But I was never really attracted to men, and then I would see a girl, and feel this intense attraction (Walcutt, 1999: 200)

Others employed phrases attempting to move away from hitherto traditional and thereby inhibitive language

I personally feel like 'a straight woman trapped in a gay man's body' (Cameron, 1995: 9)

I also had to come to terms with my sexual preference. I call myself pansexual because bisexual implies that there are only two genders (Kaldera, 1998: 228)

In my study Pat navigated through several identities before settling on a non-traditional version, although Pat also acknowledges that the process may not yet be over

I lived as a homosexual man for many years until I realised that this life-style and identity was not appropriate for me. I then discovered the intersex identity, assumed the label 'Intersex' and spent a few years exploring this identity.

However, in recent times I have recognised the limitations of this identity and realised that it's not entirely applicable to my situation, so I dropped that identity, and now identify as being a variant a-sexual male. Later, if circumstances change, or I accumulate more knowledges about myself, I will again adopt another identity and explore that. I accept that, biologically, I am an intersexed person, but my identity is something which will change over time (2004: 3)

Accepting one's intersex status was only possible after first negotiating with and accepting a queer identity

Embracing my love for women not only makes me happy, it is the thing that I had been waiting for to give me the courage to look at my body, and at who and way I truly was, without turning away. I could never have found my intersexual self until I had found and loved my sexual self (Coventry, 1999: 75)

Australian Chris Somers indicates that it was behaviour and its direct relationship to one's intersex status that drew attention to issues of language and identity

There are some of us who perceive ourselves to be bisexual, there are a number who see us as heterosexual, male to female relationships. Others who see themselves as I like I do, if I'm making up to a women, gosh, I keep on checking myself as to whether I'm actually a lesbian. It's a dilemma, because the language doesn't allow for a difference in understanding as to who we are (Somers quoted in Swan and Fry, 2003)

Sexuality is not easily quantifiable, especially queer identities within intersex individuals' lived experiences. I argue firstly that this is not an exhaustive provision of the diverse ways that queer intersex individuals identify or behave. Secondly, I argue that this is merely a glimpse to highlight the positive ramifications queer sexualities have on the lived experiences of intersex individuals. Thirdly, these lived experiences counter the innate queerphobia of medical management.

9.9 “You can always adopt”

Intersex narrative suggests that the (in)ability to have children plays a role in the discovery of one’s intersex status. Some individuals report that the details of their infertility are disclosed to them. Information that is buried under misnamed gonadal tissue. Disclosure of infertility information is frequently followed by statements from doctors and parents regarding adoption. Intersex individuals interpret these statements as their doctors/parents’ misplaced intentions to alleviate distress. As Hastings states

My mother, trying to make me feel better immediately told me ‘*you can always adopt.*’ Hearing that didn’t help me at all, it was not a comfort. That was such a small Band-Aid to put on such a huge wound (original emphasis, Hastings, 2003)

For Lou there was some comfort in the notion of adoption

My husband married me knowing I had an unknown gynaecological condition and that we would only be able to adopt. Since knowing the truth it hasn’t made any difference (2004: 1)

For others being fertile plays an important role in the assertion of one’s sex/gender.

I was a grown woman when I started to ask questions again about my body ... I had never been sure of my sexual identity and was still afraid that what the surgeon cut off was a penis. I spoke with my father again, asked for my medical records, and listened to my gynecologist read me the summary the hospital sent. My father and my doctor had the same sensible responses when I asked what sex I really was: ‘You had children, isn’t that proof enough?’ No, as a matter of fact it wasn’t (Coventry, 1999: 72)

Martha Coventry’s experience indicates that despite the fact that medical professionals are partially motivated by a desire to maintain an individuals’ fertility potential, at times

this fertility potential does not correspond to that individuals' sense of sex/gender identity. While intersex individuals practice adoption, as a 'consolation' it does not alleviate the stress associated with coping with one's infertility, nor with the misinformation surrounding this infertility.

9.10 Analogies of sexual abuse

In this era of media and community concern with abuse of children (especially within the Catholic Church) it is concerning and politically explosive that many intersex individuals draw haunting similarities between their experiences at the hands of the medical profession and narratives of sexual abuse. In Chapter 10 I will discuss the power of medical professionals and their medical management. However, I will firstly explore why intersex individuals have turned to a sexual abuse discourse in their descriptions of exposure to medical procedures. While no participants in my study explicitly articulated this view Preves claims that

Many participants I spoke with viewed their medical exams and treatments as instances of sexual abuse ... 95 percent of the sample encountered some form of medicalization, ranging from repeated genital exams to genital surgeries performed without their consent. Most of these procedures were carried out during the formative years of infancy and early childhood (Preves, 2003: 72)

Intersex activist Emi Koyama concurs with this view

Our experience is that intersex genital mutilation and other medical management of intersexed children result in post-traumatic responses similar to other forms of childhood sexual abuse (Koyama, cited in Mason, 2002)

As a partner of an intersex individual, Tamara Alexander, in their article *The Medical Management of Intersexes Children: An Analogue for Childhood Sexual Abuse* (1997) analyses in detail exactly how these surgical procedures and the subsequent psycho-social

trauma that arises in intersex individuals coincides with definitions of sexual abuse. According to Alexander the comparative aspects of sexual abuse and intersex abuse are: repeated genital traumas kept secret within family and in surrounding society; individuals are frightened, shamed, misinformed and injured; and they view their parents as having betrayed them and colluded with the medical professionals. In addition they both exhibit a range of psychological factors such as, depression, suicidal attempts, failure to form intimate bonds, sexual dysfunction, body image disturbance and dissociative patterns (Alexander, 1997). It is these basic comparative aspects that are the focus of my present analysis.

It is the details of the telling of stories that is most provocative in intersex narratives. Intersex individuals explicitly describe their experiences with medical examinations, visits and procedures as well as, literally, their exposure to the gaze of medical practitioners. Some of the more striking stories include the asking and exposing of pre-adolescent individuals to inappropriate topics and material as a means of determining sexual orientation and thereby assigning sex/gender.

[My GP] referred me to a gynaecologist who examined me thoroughly and quizzed me about my sex life - a traumatic experience for a naïve and sheltered virgin (Author Unknown, 1994: 542)

The medical literature has made use of photographic evidence in their publications on intersex. These photographs have had the eyes of the individuals omitted by black squares, reportedly to protect the identity of the individual. However, as the intersex literature indicates these photographs have been central to many individuals' stories of abuse

In reality though these rooms always had people in them, doctors, someone to take the photographs, sometimes a nurse to help the poor child take their clothes off and place them on the chair, always on a chair (Andie, 2002)

I was an interesting lab rat. I call myself a lab rat because that is how intersexed kids are treated. Tested, photographed, tested again, photographed some more (Triea, 1997, cited in Holmes, 2002: 169)

Then of course the many horrible, tense visits to the pediatric endocrinologists to have my genitals gawked, fondled and stared at by hordes of what I perceived to be nasty, despicable men (Anger, 1997 cited in Holmes, 2002: 169-170)

For the first seven years of my life, I was passed from doctor to doctor, and I remember that they all wanted to do the same thing: look up my crotch (Holmes, 1994: 5)

My clinic visits were very humiliating as I remember, I would have to strip below the waist and have doctors poke and prod at me, all done with the consent of my mother, and what I now see as childhood sex abuse (Graham, 2002)

Being paraded in front of others, notably medical practitioners, is reported as a traumatic experience for many intersex individuals

They would make me sit in frog-legged position, and invite teams of earnest interns to come in and look at me while I was naked on the cold metal examination table ... peering at me as if I were a bug under a microscope (Hawbecker, 1999: 112)

One thing I hated, occasionally the school doctor and nurse would visit and class by class they would line the boys up and check for head lice and God knows what else. Part of this examination was to check that the boy's testicles had descended ... Along comes this doctor (supposedly) and plunges his hand down my underpants in order to have a look ... I felt that I had been completely humiliated ... in today's climate I feel that the practice was tantamount to child abuse (Tony, 2000)

The fact that narratives of sexual abuse are being cited in the intersex literature (Fausto-Sterling, 2000; Alexander, 1997) indicates that not only are these concerns being taken seriously, but also it offers significant weight to the intersex movements' demands. I have discussed in Chapter 2 how intersex has been compared to illness, disabilities and female genital mutilation discourses, therefore there are benefits in describing the psychosocial trauma caused by medical management in terms of sexual abuse. I submit that intersex medical management does contribute to intersex individuals negative experiences and thereby this researcher and the research supports this through drawing analogies to established sexual abuse discourses and arguing that these procedures are forms of sexual abuse.

Conclusion

Intersex individuals have a lot to say. Their lives have been full with experiences, some unique most universal. Here I have drawn attention to those issues that are prevalent in the literature, Preves' study and my study, and some issues that appear to have been overlooked by several forums. This mirroring of issues renders Australian intersex narratives comparable to those elsewhere. From feelings of shame to reactions to medical management there are glaringly obvious similarities across the western world in regards to the conceptualisation of contemporary intersex. While there is a propensity for describing quite traumatic lived experiences there is evidence that some intersex individuals do not feel the same way, especially in regards to surgical intervention, disclosure of information and familial relationships.

Setting aside these there are other issues that are becoming more prevalent in intersex literature and intersex narratives, namely spirituality, sexual orientation, infertility and sexual abuse. More attention needs to be given to these issues so that a more robust understanding of intersex lived experiences can be garnered. What is possible is a contention that intersex individuals are engaging with discourses to not only help them cope with their experiences but also to find ways to articulate and gather support and

understanding of their lived experiences. What is striking is the absence of consideration of spirituality; thus I urge that this be pivotal in any further research.

I must now turn attention to the fact that I have centralised intersex individuals' sex, gender and sexuality identities and behaviours. While above I have offered some insights into these lived experiences, the final chapter will further elucidate these aspects of humanity, their significance for intersex and the ramifications intersex has on them. In addition I shall analyse the matrix of power and theory that surrounds, influences and is embedded in contemporary conceptualisations of intersex.

CHAPTER 10: CONCLUSION

Introduction

10.1 The Didactics of Power

10.2 Theorising Sex, Gender and Sexuality

Conclusion

Introduction

This thesis has drawn attention to contestation of the least contested question in contemporary society: is it a boy or a girl? I have peered into a controversial corner of the world that has only recently been exposed to public scrutiny. Some, especially within the medical profession, may have preferred that this corner be left undisturbed. Intersex is a dynamic location of heated and contested discourse, it cannot be conceptualised by a simplistic monothematic pedagogy, and it inhabits a complex matrix of lived experience, power and theory. Throughout this thesis I have argued that intersex has been conceptualised in a myriad of ways and further how we see intersex is only as clear as the lens through which we look.

Intersex has been a catalyst for social theory, identity politics and contemporary social change movements, whereby it has intrigued gender theorists and embodied many of queer theory's arguments (Chapter 2). From historical and cross-cultural perspectives the conceptualisation of intersex ranges from including them as part of a world-view, to demonisation (Chapter 3). In Chapter 4 I presented the contemporary western medicalisation of intersex, whereby intersex is now compartmentalised into a range of variations and treated via surgical and hormonal treatments. Since the early 1990's intersex individuals have coalesced into a socio-political movement demanding not only an end to their medicalisation (Chapter 5), but also narrating their own lived experiences (Chapter 6). Whether theoretical, historical, anthropological, medical, socio-political or personal narrative the conceptualisation of intersex is biased by its context. It is hoped by presenting the lived experiences of intersex individuals with these contexts in mind, we have a better chance of understanding - of hearing - intersex voices.

I have through a careful introductory note on my own influences in this research, enabled the reader to determine for themselves, where my words end and those of intersex individuals begin. I hope that this thesis has allowed the reader to adequately and succinctly hear the voices of intersex individuals. However, while I argue for a postmodern prioritisation of the lived experiences of intersex individuals, preferring to

see them as ‘experts’ in the field, it would be remiss of me to imply that that is all this thesis holds.

I argue that there needs to be an exploration of the contradictory dimensions of contemporary intersex. The central issue of this chapter therefore is to ask what are the broader political and theoretical ramifications of intersex. To achieve this goal I need to ask what are the didactics that contribute to contemporary conceptualisations of intersex? What are the interrelationships between the epistemologies located in the preceding chapters? Where do the layers of lived experience and power and theory collide and coincide?

10.1 The Didactics of Power

Throughout the preceding chapters I have delivered an analysis of the interrelationships between intersex individuals and others, namely doctors and parents. It is these who have had immediate and arguably the most influential affect on intersex individuals. What is striking about these relationships is that they have been articulated by intersex individuals as loci of feelings of mistrust, betrayal and abuse. It is doctors and parents who therefore traditionally hold power over intersex individuals, and thereby occupy the dominant position in a doctor-parent-intersex individual triad.

Steven Seidman’s (1997) view of postmodernity implies that one may never be free of domination. Intersex individuals may never be free from being dominated by doctors and parents. Conceivable though this future is, I would rather take a leaf out of the book written by the disabilities rights movement. Albeit not wholly successful, yet the discourses surrounding the Deaf community indicates a map to freedom. The compatibility between the intersex and the disabilities discourses has not gone unnoticed by intersex individuals

The long-term impact of sex assignment surgeries on the gender identities of intersexed children is not dissimilar to the impact of cochlear implant surgery on the identities of prelingually deaf children (Crouch, 1999: 42)

While it could be argued that adopting other discursive fields might lend a level of credibility to the intersex movement, those who do not see the similarities often meet intersex with disinterest or outward hostility. Such as attempts to align intersex with the female genital mutilation movement (Kessler, 1998: 80).

Although the disabilities rights movement has fostered visible and public support and lobbyist groups, intersex individuals themselves clearly state one significant difference between themselves and other people with a disability: the sense of isolation and lack of communication among intersex individuals. In my study Jamie describes themselves as such, “I have always considered myself to have an invisible disability” (Jamie, 2003: 2). Individuals in my study and the intersex literature see their intersex status as something that they cannot talk about, an aspect of themselves, their lived experiences, that is policed by a taboo. Graham makes an explicit distinction between their lived experiences and those in wheelchairs

If we had been born to life in a wheelchair or something similar, then we would have been allowed to communicate with each other, but as we were born with ambiguous genitalia then it was a taboo subject (Graham, 2002)

Behind this invisibility, taboo and isolation works another power that manoeuvres outside the doctor-parent-intersex individual triad. The ebb and flow of this tidal force influences the motivation of doctors and/or parents to intervene on their patient/child’s behalf. Suzanne Kessler’s analysis (1998) tells us that doctors justify intervening in cases of ambiguous genitals, because *the genitals demand* it. However, as Kessler points out, it is not *the genitals* that demand. The demand is discursive; its aetiology is societal. The power is felt in the genitals. Perhaps then certainly intersex is unlike other disabilities. One’s genitals appear to hold disproportionately more power than other parts of one’s

body. As Triea says “[my genitals] were different from normal genitals, they must be more powerful” (Triea, 1999: 143).

Like an invisible puppet master manipulating the opinions, behaviours and language of medical professionals, the power of the genitals dismisses intersex individuals’ concerns as “only anecdotal” (Kessler, 1998: 120), intersex activists are “radical zealots” (Preves, 2001: 546) and Cheryl Chase in particular as a “kook and a fanatic” (Torassa, 2002). Medical professionals appear to have an unshakable faith in not only the procedures they perform, but in the argument that by surgically altering these people they are providing them a better quality of life. It has already been revealed that there are no conclusive studies to support this. Subsequently medical power is wavering, the intersex movement cites doctors who concur with the intersex movement and are arguing against their colleagues’ insistent faith.

The parents are located as another axis of this power triad. Familial relationships especially in regards to ‘illness’ may mute the agency of the intersex individual. Medical management is performed to prevent an intersex individual from having to deal with some very complex and potentially traumatic issues, namely their own sex, gender and sexuality ambiguity. While parents are sometimes left out of the at-birth decision making processes in regards to their child’s treatment and sex/gender assignment, they are called upon to police any subsequent and life-long gendered behaviour.

I have already introduced contemporary thinking in regards to illness and the family where considerable emphasis is placed on the reflexivity between a family and a person’s illness. As Roger says “the flow of influence from family members to a particularly ill member can have significant consequences for the prognosis of an illness” (1996: 13). This influence translates, in intersex families, to control over information, access to health care and ultimately physical and psychosocial wellbeing. A parent’s power in the ‘prognosis of an illness’ cannot be limited to just the physical. Such that many intersex individuals cite their parents as active participants in their negative attitudes toward self, in the collapse of their familial relationships and in their failure to cope with aspects of

life (for example fertility, sexuality and interpersonal relationships). Having said this several participants in my study do have positive relationships with their parents. A position that which may in part be due to the relatively young age of these participants and therefore recent changes to medical managements' view of the parental role.

While medical language and parental gender-policing are a compass to intersex individuals' pain it is difficult for intersex individuals to articulate exactly what it is that has caused their trauma. While physical scars are a visible testimony it is harder to quantify life histories. Narrative is biased by an intersex individual's memory of medical conversations, visits and examinations. Yet, it is not my intent to argue that intersex individuals have no power. In terms of Foucauldian analysis of power the doctor-parent-intersex individual triad is complex.

This thesis has spent considerable time describing how their power is located in several locations. I for one have given them the role of 'experts' and 'co-researchers.' Over the past fifteen years, especially as an 'intersex movement,' intersex individuals have wielded weapons of solidarity, autonomy, and even legal rights in order to be heard. As I have presented here intersex individuals have power in changing medical management, they insist that they are not used simply as 'real life' illustrations in counter gender dichotomy discourses and they occupy a 'gatekeeper' role. They reclaim a power that is denied them in a 'culture of silence.' It could be argued that the intersex movement's policing of the ways in which they can be viewed, researched and talked about is a policing of knowledge and is removing 'outsiders' from any legitimate role in contributing to an 'intersex pedagogy.' I prefer to work on a platform of respect, as trans activist Leslie Feinberg says

Where I come from being 'politically correct' means using a language that respects other people's oppressions and wounds. This chosen language needs to be defended (1996: ix)

I argue that I, like my colleagues, have been able to work as an ‘outsider’ to defend intersex autonomy *and* through a social science framework contribute to an ‘intersex pedagogy.’

The didactics of power are located in the self, the body and socio-political discourses. Yet its manifestation in political action, story telling and community building is only the tip of the iceberg. For example, although Preves’ work (2003) is considerable in regards to an intersex individuals’ self-identity I predict that there is a lot more yet to be unearthed, especially in regards to spirituality. Power will play a pivotal role in the telling of that story also.

10.2 Theorising Sex, Gender and Sexuality

The Cartesian ‘other’ informs the theorisation of sex, gender and sexuality. Individuals whose identities, relationships and behaviours do not conform to traditional notions of sex, gender and sexuality, that is the ‘other’ assist in defining sex, gender and sexuality for the rest of ‘us.’ Thus, as ‘other’ intersex individuals have had considerable impact upon analysis of sex, gender and sexuality. Academics, social commentators and gender/queer activists have not only explored the lived experiences of intersex individuals, but also analysed these in terms of sex, gender and sexuality theory. It could be argued that they have appropriated intersex as ‘real life’ illustrations adding depth to theorising. As I introduced in Chapter 7 Intersex activist Koyama (2002) warns against inappropriate use of intersex

Do not write about intersex existence or the concept of intersexuality without talking about the lives and experiences of intersex people as well as issues they face. Do not use intersex people merely to illustrate the social construction of binary sexes (Koyama, 2002)

I argue that most writers, activists and scholars heed this warning and are all too aware of the social, moral and political responsibilities that come with employing intersex in their

theoretical considerations. I have witnessed in my analysis the capacity of writers, activists and scholars to engender sympathy and respect for the lived experiences of intersex individuals, and more importantly their political autonomy. Many have become strong supporters and active members of the intersex movement.

Previously I have offered an analysis of forums in which intersex voices are heard to draw attention to the biases within specific contexts. What I identified then was how certain texts, certain authors, brought to the work their own influences, drew conclusions taking into consideration their own motivations, backgrounds and expectations. With these thoughts in mind I turn my attention to theoretical perceptions and ramifications of intersex. That is, how does intersex contribute to a (re)conceptualisation of sex, gender and sexuality.

10.2.1 Sex

One's sex and subsequently one's sex identity is often determined by the physical characteristics that come to distinguish us as either male or female. Usually these physical characteristics are limited to one's genital configuration. Despite this seemingly simple equation, our genitals are at the centre of much controversy and contradiction. Our sex identity is predicated on a decision that is made about our genitals in the first few moments of our life. Yet there are relatively few times when they reappear to reinforce this identity. We literally cover up our genitals - to the point of criminalising their exposure in public - and rely almost exclusively on sexed behaviour and external signs (such as clothes) to 'tell' others our sex identity or 'category' (West and Zimmerman, 1987). Despite this 'denial' of our genitals, they are major influences throughout our lives, identities and behaviours. Intersex it seems is an unwitting central player in this contradiction. Medical professionals declare that genital surgeries are performed because of the 'inadequate' appearance of a person's genitals, making somewhat vague references to 'the locker room' (Kessler, 1998). As discussed above this highlights the power of one's genital configuration to rescind other priorities.

Aside from the way that our genitals influence our identities the existence of genital variation counters the argument that there are two and only two naturally occurring and mutually exclusive sexes. The western conceptualisation of sex, contrary to popular belief, has been in a constant state of flux. The Ancient Greeks saw sex in terms of a one-sex model, whereby the female was merely a 'failed' male. Contemporary views propose a two-sex model. It could be argued that this development is a retrograde move, whereby the former at least considered the possibility of genital variations. The latter is predicated on the fact that one's sex must conform to an either/or model. The demarcation of sex in the late nineteenth century - 'age of the gonads' - was determined by what gonadal tissue one possessed (Dreger, 1998). With the advent of surgical techniques during the twentieth century, sex was guided by genitals. The insertion of John Money's gender role theory into intersex medical management once again shows that sex is a shifting variable. Sex was no longer solely based on the way genitals looked, but rather whether one could successfully raise a child as a boy or a girl, a fact predicated on the notion that one's genital configuration must look normal.

Contemporary attempts to rethink sex have been a controversial project. Twelve years ago Fausto-Sterling (1993), biologist and long-time supporter of the intersex movement, proposed that there are five sexes: males, females, merms (male pseudohermaphrodites), ferns (female pseudohermaphrodites) and herms (true hermaphrodites). While provocative Fausto-Sterling concedes that this demarcation was intended to be sardonic (Fausto-Sterling, 2000: 78). However, it was not received as such and it caused an outcry from the religious right, seemingly fearful of an 'insane' conspiracy to install other sex categories (Fausto-Sterling, 2000: 78, Kessler, 1998: 121). Fausto-Sterling's pivotal proposal may not have garnered support or longevity, it seems to have been the impetus for a plethora of theories that focus on what constitutes the sexes, and just how many sexes there may be (2000: 79).

Do we need perfectly formed and socially sanctioned genitals to live, to have successful identities, relationships or behaviours? In colloquial discourses there is a prioritisation of particular genital configurations: big penises for men and tight vaginas for women.

However, one is able to have genitals that do not necessarily conform to an ‘ideal,’ neither to a general standard nor to one’s external signs.

The intersex literature invests time in incorporating trans experiences, identities and behaviours (Fausto-Sterling, 2000; Kessler, 1998). This interest in trans theory is perhaps because trans is no longer about the transition from one sex to the other. Further, trans do not necessarily coincide with the assumption that all trans people are merely reproducers of traditional gender dichotomies. Rather they are living lives, adopting identities and behaving in ways that counter this assumption. A negotiation of the body-identity inconsistency has largely taken place within trans discourses, notably the F2M community. For trans people the body is no longer the final frontier to conquer and colonise, rather they successfully reconcile contradictions brought about by the body-identity inconsistency. That is, they determine for themselves how they wish to live, identify and behave, regardless of the body or the social expectation that is associated with that body. Devor (1997) explores how some transmen in their study, while conceding that they wished they had been born with penises, were capable of living successfully as men without them.

The existence of intersex individuals who share similar lived experiences with trans people reinforces the role that intersex plays in reconceptualising sex. Sex is no longer a priori, it no longer defines one’s gender, nor does it determine any subsequent lived experience, identity or behaviour. In my study Chris identified and lived as man although certain physical features may dispute this. Sex is not ‘natural’ or immutable. It follows that the argument that sex is as much a product of socially constructed mechanisms not dissimilar to what is described in constructionist theories of gender. As Fausto-Sterling suggests

Choosing which criteria to use in determining sex, and choosing to make the determination at all, are social decisions for which scientists can offer no absolute guidelines (2000: 5)

Kessler also ponders how genital variation could be seen “as an expansion of what is meant by female and male” (131). The shifting notion of ‘sex’ and its social meanings is illustrated by Alex MacFarlane’s landmark achievement in having a third sex option on their passport (Butler, 2003) and the condoning by intersex movement of raising children one gender while their bodies are incommensurate with this assignment. Therefore illustrating the ability to delineate the meanings of and thereby reconceptualise sex. Also it signifies a space in mainstream society to acknowledge the possibility that some members of our society are pursuing choices beyond two sexes.

10.2.2 Gender

Almost two decades ago Grimm speculated that we were on the verge of a Kuhnian revolution of gender (1987: 84). Any casual observation of our contemporary society would suggest that this revolution appears not to have transpired. Despite a move toward greater social equality, any time traveller from the 1980’s would perhaps not be out of place amongst the gendered behaviours of 2005. However, it could be argued that Grimm’s revolution is being championed by contemporary intersex discourses. While there is evidence to suggest that the intersex movement shies away from gender issues; the ramifications for intersex have not gone unnoticed. A few years after the initiation of the intersex movement in the United States, Kessler came to suggest in 1998 that “the future of intersex is in some sense the future of gender” (Kessler, 1998: 131).

Kessler’s landmark text *Lessons from the Intersexed* (1998) is arguably the most significant contribution to the intersex literature. Not only because it was one of the first academically motivated texts to collate intersex issues for an academic audience, but also because Kessler introduces to the reader intersex and its attraction to gender theorists

Gender theorists are intrigued by intersexuality ... an idea symbolizing complexity and fluidity (Kessler, 1998: 5)

Yet the bridge between gender theorists and intersex is not traversed by one-way traffic. Kessler suggests intersex individuals

Have turned to gender theorists not because we have tremendous influence on the medical profession but for an articulation of the grounds of gender's authority Gender theorists are in the position of being able to demonstrate that intersex need not be constructed at all, and this is one pathway toward arguing that gender need not be (1998: 120)

Gender has attracted the attention of academics, social commentators and activists over the past four decades as a site of social injustice. Central to these discourses has been the view that the hegemonic gender system in western societies places women in a subordinate position. While four decades of feminist and other discourses have achieved the gradual decriminalisation and destigmatisation of certain gendered behaviours, there has been little in the way of removing gender as a primary demarcation of humanity and a primary organising principle of social systems.

While some within intersex communities are concerned that they may be mistaken for transgendered people, and others are wary that there is a trend to conflate intersex and trans issues, the collision of trans and intersex leads to a potential shattering of traditional gender concepts. In recent decades trans discourses acknowledge the diversity of lived experiences that come under the umbrella term "transgender." As discussed above these narratives include the revelations that some trans people do not see the necessity to align one's physical configuration to one's gender identity. One's gendered self is indeed delineated from one's body. Trans people are expressing concern over the expectation that their gender identity may not in fact coincide with their gendered behaviour. For example trans people have become 'gender outlaws' (Bornstein, 1994) who 'gender fuck' (Whittle, 2002) the expectation to reproduce recognisably stereotypical characteristics attributed to one gender or the other.

In addition these ramifications on gender are not only mirrored in the intersex discourses, but also intersex individuals are adopting identities and behaviours that contradict the assigned gender. In particular 'intersex' has been adopted as a 'third' gender identity. As noted above with Alex MacFarlane's success in having a third category awarded to them on their passport, the aligning of intersex individuals to a call for more gender identities to choose from disrupts not only the binary gender system, but also gender itself.

If men behave in different ways to each other and so too do women, if women are able to transition and thereby identify as men and vice versa men as women, what is stopping any one of us from having behaviours that are not recognisably 'our own'? Even while gender is a vastly dominant demarcation in our societies it is not static; its borders shift. While men may not be able to wear dresses and skirts in public without ridicule, the rise of the Metrosexual certainly has done a lot (especially in the public sphere) to deconstruct what it means to be a 'man.' If gender identity is best aligned with one's gendered behaviours, and these gendered behaviours are themselves vastly diverse Rothblatt (cited in Ramet, 1996) has speculated then there are as many gender identities as there are people in the world. If there are no longer two, or three genders but billions surely intersex individuals need not undergo considerable psychosocial trauma in the name of 'gender.' The fact that the intersex movement condones one's decision to change gender places intersex at a central nexus of our reconceptualisation of gender.

10.2.3 Sexuality

One's sexual life is predicated on a matrix of visceral and psychosocial knowledge and praxis. Attribution of an identity to this matrix depends on the corresponding (self and external) assigning of appropriate markers. Traditionally one's physical configurations, desires and sense of self determine one's heterosexuality, homosexuality, or bisexuality. However, the demarcation is problematic. Feminism, queer theory and queer have spent several decades deconstructing this linear way of thinking about ourselves, choice of partners and sexual acts. The lived experiences of queer and trans individuals in

particular have been a central location for challenging such conceptualisations of sexuality, we can safely add intersex as another site of sexuality's contestation.

When one's visceral experience does not coincide with this simple formula how can one successfully, accurately and justifiably assign a sexuality to one's self? The fact that intersex individuals do, and do not find the delineation between physical configurations and identity as problematic infers that sexuality is not an immutable concept. Most of the participants in my study aligned themselves with hitherto traditional sexuality identities (Table 8.4 page 275), with an indication that these identities were 'natural,' uncontested and incontestable. However, others in the intersex literature express sexualities that extend beyond these epistemologies. Intersex individuals acknowledge that their intersex status does disrupt their ability to assign an appropriate term to one's sexuality. But are they queer?

An individual's lived experience is able to coincide with a queer project without requiring that person to endorse self-identification as queer. Therefore the appropriation of intersex into queer is unavoidable. The conflation of queer and intersex movements is not just a sharing of epistemologies, praxis and socio-political power. Queer offers intersex not only a way out of the quagmire of psychosocial trauma generated by the medicalisation of their intersex status, but also it allows intersex individuals - not unlike other queers - a means to express dissatisfaction with social expectations placed on one's body, identity and behaviour. Further, 'pride' in an intersex status and an intersex identity allows one to not only step out of the closet generated by a 'culture of silence,' but also offers a means of articulating difference.

When one talks about visceral experiences and desires it is striking that one dimension of this discourse rarely appears in the intersex literature, that is, desire for intersex bodies. As Kessler writes the "ISNA occasionally gets letters from people interested in meeting hermaphrodites" (Kessler, 1998: 124). While the desires of 'others' for intersex individuals and their bodies is outside the scope of this study, its presence should at least be included within a contemplation of queer and intersex. Kinsey et al (1948) mention "a

number” of men who dream of women with male genitalia, yet it could be argued that this is more in line with what contemporaries would call “chicks with dicks.” Kinsey et al also go on to describe them as “heterosexual” and attributes these dreams to the lack of knowledge these men have of female genitalia (1948: 526). Who writes these letters to ISNA? Could sexual attraction for intersex bodies be considered a fetish? Are these individuals and their contemporaries the ultimate queers? Is it not *they* who disturb the “homo-,” “hetero-” and “bi-” prefixes?

Some intersex individuals are not delineated from the expected socially sanctioned sexual orientations and some intersex individuals identified as ‘gay,’ ‘bisexual,’ or ‘lesbian.’ However, others do not utilise recognisable terms such as ‘heterosexual,’ ‘gay,’ ‘bisexual,’ or ‘lesbian’ to describe their sexuality. Intersex narratives give a glimpse into how the intersex medical management not only fails to prevent queerness, but also contributes to it. Intersex individuals invest in terms and phrases such as ‘asexual,’ ‘pansexual,’ or even ‘a straight woman trapped in a gay man’s body’ to better describe their lived experiences, identities and behaviours, especially in the context of their intersex status. While intersex individuals are not universally aligning themselves with queer epistemologies and praxis the sexual diversity embedded within the communities is unavoidable.

Conclusion

I met Lee Brown, an intersex activist based in Sydney, a few years ago when I first embarked on this project. I recently learned in an Australian transgender publication called *Polare* that Lee died of cancer at the end of 2004. In this edition of *Polare* an article Lee had written regarding intersex was reprinted. Lee stated that to infer that throughout history cultures conceptualise intersex differently is a cliché. Rather than dismissing this view I choose to embrace it as a reminder that the key to any research into intersex should not ignore the necessity to understand the contemporary view of intersex. Indeed romanticising the past neither furthers knowledge nor helps contemporary intersex individuals, as Triea (1999) says “I go blank when people tell me that ‘in other cultures,

intersexed people are respected as Shamans.’ This knowledge was of absolutely no value to me at all when I was 14 faced with either hormonal mutation and surgery” (142-143).

The conceptualisation of intersex has been neither universal nor static, even within the same culture intersex bodies have sparked a range of reactions from others. Yet react they have. While several societies have demonised intersex and others revere it they all have included intersex in one way or another as part of their world-view. Intersex has become a central theme and subject of art and literature, religion and cosmology, biology of the body, legal citizenship and what it means to be human. It cannot be ignored that intersex is integral to understanding the humanity. The existence of intersex has influenced the way we think about the universe and ourselves. Conversely the way we see the world influences the way that intersex is conceptualised. Therefore it is logical to suggest that as our view of contemporary intersex is changed by contemporary intersex voices a subsequent change to our current view of the world will also emerge. Yet, as the negative reactions to Fausto-Sterling’s ‘five sexes’ (1993) indicates this change may not be swift.

Grimm’s proposal in 1987 that western society was on the verge of a Kuhnian revolution in gender may not necessarily be observable. Yet a paradigm shift is taking place in the intersex discourses now raging across the western world. What would it take for us to be aware of such a paradigm shift? At which point could intersex individuals take to the streets in celebration? Kuhn insisted that revolutions are not necessarily instantaneous. Indeed, Seidman (1997) suggests that the end-goal of social movements - that is social change - is unachievable. Joshua Gamson (1996) goes as far as to ask whether social movements are destined for self-destruction. If nothing else has been gathered from the proceeding chapters then let us accept two facts. Firstly, the intersex movement is a coalescence of individuals who share a universally traumatic experience and offer each other support in coping with that experience, and secondly, at the very least these individuals have themselves made the conceptual shift away from a ‘culture of silence’ and a ‘paradigm of deceit.’

I would like to indulge two interdisciplinary approaches briefly; one from quantum physics the other philosophy. As an amateur astronomer and cosmologist I have always been wooed by the machinations of galaxies, solar systems and interstellar phenomena. However, I have never really been able to merge this with my interest in gender and queer theories beyond an analysis of women in science. That is until I was introduced to the Heisenberg Uncertainty Principle. In short this principle of quantum physics postulates that the more one knows about one particular aspect of a particle (speed) the less one knows about another (location). This means knowing a particle's entirety is not possible. Moreover it is the process of measuring and observation of one aspect that disturbs our ability to know the other. It has always struck me as somewhat heretical that a science, especially one of the 'hard' sciences, would actively support such a theory, but at the same time it is reassuring that the human mind has the ability to reconcile and concede contradiction.

Setting aside the findings of this study, albeit briefly, what was striking was the reaction to the study itself. Notable is the way Mel posed questions to the researcher and some intersex organisations became 'gatekeepers.' Therefore, any research being conducted on intersex individuals, communities and populations is bound to receive scepticism, reluctance and out-right avoidance from its sample. It seems that the Heisenberg Uncertainty Principle also governs the social sciences. It is the measuring that interferes with knowing. Therefore, let us accept that what we know about intersex is by no means exhaustive and I hope that this project enables a 'knowing' of many aspects of intersex. Let us also accept as scholars, gender theorists and individuals that there are some aspects of intersex that may not be 'knowable.' Just like the particles bound by Heisenberg's theorem these aspects of intersex are kept secret to observers, to those who would measure it.

The second interdisciplinary approach I would like to touch on is philosophy; moreover existential angst. The meaning of life and what it means to be human have played central roles in human thought. While no consensus has been reached as to what constitutes and who therefore belongs to the category 'human,' the use of the term is broadly adopted.

The United Nations insists that humans possess certain 'Human Rights,' albeit rights that are predicated on an individual's citizenship of a recognised country. Does gender contribute to this project? Shouldn't we ask what gender says about our understanding of humanity? As I end this journey literally ten days prior to submission I had the privilege of hearing a public talk by gender theorist Judith Butler (2005). An experience that reaffirmed a previously held thought that I should find the time to read Butler's *Undoing Gender* (2004). Both draw attention to what it is to be human. Specifically in *Undoing Gender* transgender and intersex movements, what Butler refers to as "New Gender Politics," are central to determining who does and who doesn't belong to the category 'human'

The norms that govern idealized human anatomy thus work to produce a differential sense of who is human and who is not, which lives are livable, and which are not (2004: 4)

As noted earlier trans discourses are not content with arguments of a third sex or gender, rather a third space outside of gender. Is not this 'third space outside gender' merely humanist? Whereby one's gendered actions should not be 'judged' masculine or feminine, nor assessed as of value or not. This is not to argue for a removal of gender; rather it's disarming.

Intersex individuals and the intersex movement insist that they do not condone the raising of gender neutral children. Indeed it is said that the majority of intersex individuals do not have an issue with their gender. However, even for these people, not unlike everyone else, gender plays a central role in their lived experiences, their social behaviours, relationships and identities. In addition even those individuals who negotiate around traditional genders and 'do' a third gender, gender neutrality, androgyny or trans at the very least acknowledge and give weight to gender. Whether transitioning between or 'fucking' traditional gendered positions in its current form gender is ubiquitous. We cannot escape it. In light of the psychosocial trauma and physical side effects caused by medical management, and its proclamation of genders and if gender is a human issue this

medical management is not only “Gendercide” (Shorona, 2000), but is also a “crime against humanity.”

Our knowledge of intersex is not and may never be complete. The way we conceptualise intersex has changed and is changing. Listening to the voices of intersex individuals will lead us to a new way of thinking about intersex and humanity. By listening to alternative proposals of the intersex movement - that is allowing individuals to grow up with genitals that are delineated from one’s sex/gender assignment and condoning sex/gender changes - offers a glimpse into not only a new real world for intersex individuals, but also a new theoretical one. As Kessler speculated the future of intersex is the future of gender. Today post-birth questions as “is it a boy or a girl?” may seem incontestable. This thesis renders sexes, genders and sexualities potently contested, and infinitely contestable.

REFERENCES

- Abramsky, Lenore, Hall, Sue, Levitan, Judith, and Marteau, Theresa M. (2001) "What Parents are Told after Prenatal Diagnosis of a Sex Chromosome Abnormality: Interview and Questionnaire Study" *British Medical Journal* v. 322 24 February, 2001 pp. 463-466
- Adam, Barry D. (1987) *The Rise of a Gay and Lesbian Movement* Twayne Publishers, Boston.
- AISSG (2001) "Intersex Information Booklet" *Androgen Insensitivity Syndrome Support Group Australia* <http://home.vicnet.net.au/~aissg>, Date Accessed 3rd December 2003.
- AISSG (2002b) "Comparison Between Those with Intersex Conditions and Transsexualism" *Androgen Insensitivity Syndrome Support Group Australia* <http://home.vicnet.net.au/~aissg> Date Accessed 12th July 2003.
- AISSG (2003) "Transgender & Intersex?" *Androgen Insensitivity Syndrome Support Group Australia* http://home.vicnet.net.au/~aissg/transgender_and_intersex.htm Updated June 13th, 2003 Date accessed 12th July 2003.
- Alexander, Tamara (1997) "The Medical Management of Intersexed Children: An Analogue for Childhood Sexual Abuse"
- American Academy of Pediatrics (2000) "Evaluation of the Newborn With Developmental Anomalies of the External Genitalia" *Pediatrics*, Vol. 106 No. 01 July 2000, pp. 138-142.
- Andie (2002) "Andie" <http://home.vicnet.net.au/~aissg/Andie.htm> Last Modified 13th October, 2002. Date Accessed 1st May 2003.
- Author Unknown (1994) "Once a Dark Secret" *British Medical Journal* v. 308 n. 6927 pp. 542 February 1994.
- Author Unknown (1996) "Why the Olympic sex test is outmoded, unnecessary and even harmful" *Journal of the American Medical Association*, July 17, 1996, vol. 276, no. 3, pp. 177-178
- Author Unknown (2001) "Our Website Recognised as Being of 'Lasting Cultural Value'" *dAISy* March, 2001. AIS Support Group Australia <http://www.vicnet.net.au/~aissg>

- Author Unknown (2003) "Sex Chromosome Variations: About 47XXY" <http://www.genetic.org/ks/scvs/47xxy.htm> Date Accessed 2nd March 2003.
- Bem, Sandra Lipsitz (1974) "The Measurement of Psychological Androgyny" *Journal of Consulting and Clinical Psychology* Vol. 42 pp 155-162
- Benney, Mark and Hughes, Everett C. (1977) "Of Sociology and the Interview" in Bulmer, Martin (Ed.) *Sociological Research Methods. An Introduction* The Macmillan Press, Houndsmill.
- Berenice B. Mendonca, Inacio, Marlene, Costa, Elaine M.F., Arnhold, Ivo J.P., Silva, Frederico A.Q., Nicolau, Wilian, Bloise, Walkter, Russel, David W., and Wislon, Jean D. (1996) "male Pseudohermaphroditism due to steroid 5-alpha-reductase 2 deficiency: diagnosis, psychological evaluation, and management" *Medicine* Vol. 75 no. 2 pp 64-77 March 1996.
- Berry, Chris and Jagose, Annamarie (1996) "Australia Queer" *Meanjin* Vol. 55 no. 1 1996 pp. 5-11.
- Betsy (2003) "Betsy's Story" <http://www.cahourstories.net/Bestsy.html> Date accessed 1st May 2003.
- Billings, Dwight B. and Urban, Thomas (1996) "The Socio-Medical Construction of Transsexualism. An Interpretation and Critique" in Ekins, Richard and King, Dave (Ed.s) *Blending Genders. Social Aspects of Cross-Dressing and Sex Changing*, Routledge, London
- Blackless, Melanie, Charuvastra, Anthony, Derryck, Amanda, Fausto-Sterling, Anne, Lauzanne, Karl and Lee, Ellen (2000) "How Sexually Dimorphic are we? Review and Synthesis" *American Journal of Human Biology* v.12 pp. 151-166.
- Bleier, Ruth (1991) "Science and Gender" in Gunew, Sneja (Ed.) *A Reader in Feminist Knowledge* Routledge, London.
- Blizzard, Robert (2002) "Intersex Issues: A Series of Continuing Conundrums" *Pediatrics* 1103(3): 616-21.
- Bloom, Amy (2002) *Normal. Transsexual CEOs, Crossdressing Cops, and Hermaphrodites with Attitude*, Bloomsbury Publishing, London.
- Blundell, Sue (1995) *Women in Ancient Greece*. British Museum Press, London.

- Boddy, Janice (1998) "Violence Embodied? Circumcision, Gender Politics, and Cultural Aesthetics" in Dobash, R. Emerson and Dobash Russell P. (Ed.s) *Rethinking Violence Against Women* Sage Publications, Thousand Oaks.
- Brandt, Paul (1974) *Sexual Life In Ancient Greece* AMS Press, New York
- Briffa, Anthony (2003a) "Discrimination Against People Affected by Intersex Conditions" *Submission to NSW Anti-Discrimination Board and NSW Law Reform Commission* 22nd January, 2003.
- Briffa, Anthony (2003b) "Discrimination Against People Affected by Intersex Conditions" *Submission to ACT Chief Minister and Department of Justice and Community Safety* 15th February, 2003.
- Briffa, Anthony (2003c) "Removing Legislative Discrimination Against People with Intersex Conditions" *South Australian Attorney General, South Australian Minister for Health and South Australian Commissioner for Equal Opportunity* 22nd January, 2003.
- Briffa, Tony (2002) "Sorry for What We Did. Can We Do Anything to Help?" *dAISy* March, 2002. AIS Support Group Australia <http://www.vicnet.net.au/~aissg>
- Brown, Kathleen (1995) "'Changed ... Into the Fashion of a Man': The Politics of Sexual Difference in a Seventeenth-Century Anglo-American Settlement" *Journal of the History of Sexuality* 6, 2, pp. 171-193.
- Bucar, Bill (1999) "Survey Report on Klinefelter's Syndrome" November 6th 1999, <http://www.ifas.org.au/IFAsKlinefelters.html> Date Accessed 26th August 2003.
- Bullough, Vern L. (1976) *Sexual Variance in Society and History*, John Wiley and Sons, New York.
- Bullough, Vern L. (1994) "The Development of Sexology in the USA in the Early Twentieth Century" In *Sexual Knowledge, Sexual Science. The History of Attitudes to Sexuality* Porter, Roy and Teich, Mikuláš (Ed.s) Cambridge University Press, Cambridge
- Burshatin, Israel (1996) "Elena Alias Eleno. Genders, Sexualities, and 'Race' in the Mirror of Natural History in Sixteenth-century Spain" in Ramet, Sabrina Petra (Ed.) *Gender Reversals and Gender Cultures. Anthropological and Historical Perspectives*, Routledge London and New York

- Butler, Judith (1990) *Gender Trouble. Feminism and the Subversion of Identity* Routledge, New York
- Butler, Julie (2003) "X Marks the Spot for Intersex Alex" *Polare* v.50 February-March 2003.
- Bynum, Caroline Walker (1992) *Fragmentation and Redemption. Essays on Gender and the Human Body in Medieval Religion* Zone Books, New York.
- Cadden, Joan (1993) *Meanings of Sex Difference in the Middle Ages*, Cambridge University Press, Cambridge
- Califa, Pat (1997) *Sex Changes. The Politics of Transgenderism* Cleis Press, San Francisco
- Callender, Charles and Kochems, Lee M. (1983) "The North American Berdache" *Current Anthropology*, 24, 4 August-October, pp. 443- 470
- Cameron (1995) "Klinefelter (XXY) and gender" *Hermaphrodites with Attitude* Summer 1995 pp. 9
- Cameron, D. (1999) "Caught Between: An Essay on Intersexuality" in Dreger, Alice Domurat (Ed.) *Intersex in the Age of Ethics* University Publishing Group, Hagerstown
- Campbell, Jane and Oliver, Mark (1996) *Disability Politics* Routledge, London.
- Carden, Jane (1995) "Learning to Speak at 36" *Hermaphrodites with Attitude* Spring 1995 pp. 2-3
- Charles/Cathy (1995) "Klinefelter and 'Normalcy'" *Hermaphrodites with Attitude* Summer 1995 pp. 9
- Chase, Cheryl (1998a) "Hermaphrodites with Attitude. Mapping the Emergence of Intersex Political Activism" *GLQ* v.4 n. 2 pp.189-211
- Chase, Cheryl (1998b) "Affronting Reason" in Atkins, Dawn (Ed.) *Looking Queer. Body Image and Identity in Lesbian, Bisexual, Gay and Transgender Communities* Harrington Park Press, New York.
- Chase, Cheryl (1999) "Surgical Progress Is Not the Answer to Intersexuality" in Dreger, Alice Domurat (Ed.) *Intersex in the Age of Ethics* University Publishing Group, Hagerstown

- Chodorow, Nancy (1974) "Family Structure and Feminine Personality" in Rosaldo, Michelle Zimbalist and Lamphere, Louise (Ed.s) *Women, Culture and Society* Stanford University Press, Stanford.
- Cohen, Andrew (2000) *The Boy Who Was Turned Into a Girl* BBC.
- Colapinto, John (1997) "The True Story of John – Joan" *The Rolling Stone*, December 11, 1997 pp. 54-97
- Colapinto, John (2000) *As Nature Made Him. The Boy Who Was Raised as a Girl* Harper Collins, Sydney.
- Conway, G. S. (1999) *Adrenal Hyperplasia Network* <http://www.mlcull.demon.co.uk/> Updated 30th November 2003, Accessed 3rd December 2003.
- Corker, Mairian (1999) "New Disability Discourse, the Principle of Optimization and Social Change" in *Disability Discourse* Corker, Mairian and French, Sally (Ed.'s), Open University Press, Buckingham, Philadelphia.
- Coventry, Martha (1999) "Finding the Words" in Dreger, Alice Domurat (Ed.) *Intersex in the Age of Ethics* University Publishing Group, Hagerstown
- Cranny-Francis, Anne, Waring, Wendy, Stavropoulos, Pan and Kirkby, Joan (2003) *Gender Studies. Terms and Debates* Palgrave Macmillan, Houndsmill.
- Creighton, Sarah and Minto, Catherine (2001) "Managing Intersex. Most Vaginal Surgery in Childhood Should be Deferred" *BMJ* v.323 1st December 2001, pp.1264-5
- Creighton, Sarah and Minto, Catherine (2002) "Clitoral Surgery"
- Creighton, Sarah M., Minto, Catherine L., and Steele, Stuart J. (2001) "Objective Cosmetic and Anatomical Outcomes in Adolescence of Feminising Surgery for Ambiguous Genitalia Done in Childhood" *Lancet*, July 14, 2001. v.358 i9276 p124-125
- Crouch, Robert A. (1999) "Betwixt and Between: The Past and Future of Intersexuality" in Dreger, Alice Domurat (Ed.) *Intersex in the Age of Ethics* University Publishing Group, Hagerstown
- Cummings, Katherine (1993) *Katherine's Diary. The Story of a Transsexual Mandarin*, Port Melbourne

- Danette (2003) "Danette's Story" <http://www.cahourstories.net/danette.html> Date accessed 1st May 2003.
- David (1994) "I am Not Alone!" *Hermaphrodites with Attitude* v. 1 n. 1 Winter 1994 pp. 4-5
- David (1995) "Talking About It" *Hermaphrodites with Attitude* Summer 1995 pp. 4
- David (1999) "David (Western Australia)" in O'Keefe, Tracie *Sex, Gender and Sexuality. 21st Century Transformations* Extraordinary People Press, London.
- David (2002) "Letters" *dAISy* March, 2002. AIS Support Group Australia <http://www.vicnet.net.au/~aissg>
- Davis, Lennard J. (1995) *Enforcing Normalcy. Disability, Deafness and the Body* Verso, London and New York
- de Beauvoir, Simone (1949/1983) *The Second Sex* Penguin Books, Harmondsworth.
- Delcourt, Marie (1961) *Hermaphrodite Myths and Rites of the Bisexual Figure in Classical Antiquity*, Translated by Jennifer Nicholson, Studio Books, London.
- Denzin, Norman K. (1994) "Postmodernism and Deconstructionism" in Dickens, David R. and Fontana, Andrea (Ed.'s) *Postmodernism and Social Inquiry* Guilford Press, New York
- Devor, Holly (1997) *FTM Female-to-Male Transsexuals in Society* Indiana University Press, Bloomington
- Devore, Howard (1999) "Growing Up in the Surgical Maelstrom" in Dreger, Alice Domurat (Ed.) *Intersex in the Age of Ethics* University Publishing Group, Hagerstown
- Diamond, Milton and Sigmundson, H. Keith (1997a) "Sex Reassignment at Birth: Long-term Review and Clinical Implications" *Archives of Pediatrics and Adolescent Medicine* March. 1997 Vol. 151 No. 3 p.298(7)
- Diamond, Milton and Sigmundson, H. Keith (1997b) "Management of Intersexuality: Guidelines for Dealing with Persons with Ambiguous Genitalia" *Archives of Pediatrics and Adolescent Medicine* Oct. 1997 Vol. 151 No. 10 p.1046(5)
- Dowden, Ken (1995) "Approaching Women Through Myth: Vital Tool or Seld-Delusion?" in Hawley, Richard and Levick, Barbara (Ed.s) *Women in Antiquity. New Assessments*, Routledge London and New York.

- Dreger, Alice Domurat (1998) *Hermaphrodites and the Medical Intervention of Sex*, Harvard University Press, Cambridge.
- Dreger, Alice Domurat (1999) *Intersex in the Age of Ethics* University Publishing Group, Hagerstown
- Dreger, Alice Domurat (2000) "Jarring Bodies: Thoughts on the Display of Unusual Anatomies" *Perspective in Biology and Medicine* v.43 n. 2 Winter 2000.
- Dreger, Alice Domurat (2004) "Shifting the Paradigm of Intersex Treatment" www.isna.org
- DRK (2000) "A Native American Perspective on the Theory of gender Continuum" Healthy Place, http://www.healthypace.com/communities...ntersexuals/article_native_american.Htm Viewed 29th May 2002.
- Du Bois, Cora (1944) *The People of Alor. A Social-Psychological Study of an East Indian Island*, Harvard University Press, Cambridge.
- Edgerton, Robert B. (1964) "Pokot Intersexuality: An East African Example of the Resolution of Sexual Incongruity" *American Anthropologist*, 66, pp. 1288- 1299.
- Epstein, Julia (1990) "Either/Or – Neither/Both: Sexual Ambiguity and the ideology of Gender" *Genders*, 7, Spring, pp. 99- 142
- Epstein, Steven (1996) "A Queer Encounter: Sociology and the Study of Sexuality" in Seidman, Steven (Ed.) *Queer Theory/Sociology* Blackwell Publishers, Cambridge
- ERC (2001) "What is Turner's Syndrome?"
- Family Law Council (1994) *Female Genital Mutilation* Discussion Paper, 31 January 1994, Family Law Council, Barton, ACT, Australia.
- Fausto-Sterling, Anne (1993) "The Five Sexes: Why Male and Female are not Enough" *The Sciences* Vol. 33 n. 2 pp20-26.
- Fausto-Sterling, Anne (2000) *Sexing the Body. Gender Politics and the Construction of Sexuality*. Basic Books, New York.
- Feinberg, Leslie (1996) *Transgender Warriors. Making History From Joan or Arc to Dennis Rodman*, Beacon Press Boston.
- Fletcher, Anthony (1995) *Gender, Sex and Subordination in England 1500-1800* Yale University Press, New Haven

- Foley, Sallie and Morley, George W. (1992) "Care and Counseling of the Patient with Vaginal Agenesis" *The Female Patient* v. 17 (October) pp.73-80.
- Fontana, Andrea and Frey, James H. (2000) "The Interview. From Structured Questions to Negotiated Text" in Denzin, Norman K., and Lincoln, Yvonna S. (Ed.s) *Handbook of Qualitative Research, Second Edition* Sage Publications, Thousand Oaks.
- Foucault, Michel (1972) *Archaeology of Knowledge* Trans. Smith, A.M. Sheridan Tavistock Publications, London.
- Foucault, Michel (1979) "Truth and Power: Interview with Alessandro Fontano and Pasquale Pasquino" in *Michel Foucault: Power, Truth, Strategy* trans. Patton, Paul and Morris, Meaghan, Feral Publications, Sydney.
- Foucault, Michel (1980) "Introduction" *Herculine Barbin. Being the Recently Discovered Memoirs of a Nineteenth-Century French Hermaphrodite* Trans. McDougall, Richard Pantheon Books, New York
- Foucault, Michel (1990) *The History of Sexuality. Volume I: An Introduction*. Translated by Robert Hurley, Vintage Books, New York.
- Foxhall, Lin and Salmon, John (1998) *Thinking Men. Masculinity and its Self-Representation in the Classical Tradition*. Routledge, London and New York.
- Fran (2002) "Personal Stories" *dAISy* March, 2002. AIS Support Group Australia <http://www.vicnet.net.au/~aissg>
- Frank, Arthur W. (1995) *The Wounded Storyteller. Body, Illness and Ethics* The University of Chicago Press, Chicago and London.
- Fraschetti, Augusto (2001) "Introduction" in Frascchetti, Augusto (Ed.) *Roman Women*, Translated by Lappin, Linda, University of Chicago Press, Chicago.
- Frequency (2002) "Frequency: How Common Are Intersex People?"
- Friedli, Lynne (1988) "'Passing Women' – A Study of Gender Boundaries in the Eighteenth Century" in Rousseau, G.S. and Porter, Roy (Ed.s) *Sexual Underworlds of the Enlightenment* University of North Carolina Press, Chapel Hill.
- Furth, Charlotte (1993) "Androgynous Male and Deficient Females: Biology and Gender Boundaries in Sixteenth- and Seventeenth-Century China" in Ablove, Henry,

- Barale, Michele Aina and Halperin, David M. (Ed.s) *The Lesbian and Gay Studies Reader*, Routledge New York.
- Gad, Y.Z., Nasr, H., Mazen, I., Salahm N., and El-Ridi, R. (1997) "5 α -Reductase Deficiency in Patients with Micropenis" *Journal of Inherited Metabolic Diseases* 20 (1): 95-101 March 1997
- Gamson, Joshua (1996) "Must identity Movements Self-Destruct? A Queer Dilemma" in Seidman, Steven (Ed.) *Queer Theory/Sociology* Blackwell, Oxford.
- Gamson, Joshua (2000) "Sexualities, Queer Theory, and Qualitative Research" in Denzin, Norman K., and Lincoln, Yvonna S. (Ed.s) *Handbook of Qualitative Research, Second Edition* Sage Publications, Thousand Oaks.
- Garber, Marjorie (1992) *Vested Interests. Cross-dressing and Cultural Anxiety*. Routledge, New York.
- Garfinkel, Harold (1967) *Studies in Ethnomethodology*, Prentice-Hall Inc., New Jersey
- Gilbert, Emma (1997) *Female Genital Mutilation. Information for Australian Health Professionals* The Royal Australian College of Obstetricians and Gynaecologists, East Melbourne
- GLBTQ (2001) "Gender Instability: Hermaphroditism, Transvestism, Androgyny" *GLBTQ An Encyclopedia of Gay, Lesbian, Bisexual, Transgender and Queer Culture* <http://gltq.com/brochure/classicalp2.html> Date Accessed 16/8/02.
- Gleason, Maud W. (1995) *Making Men. Sophists and Self-Presentation in Ancient Rome*, Princeton University Press, Princeton.
- Gossar, Jack (2003) "Jack's Story" *dAISy* March, 2003. AIS Support Group Australia <http://www.vicnet.net.au/~aissg>
- Graham (2002) "My Story" <http://home.vicnet.net.au/~aissg/Graham.htm> Last Modified 6th May 2002. Date Accessed 1st May 2003.
- Grimm, David E. (1987) "Toward a Theory of Gender. Transsexualism, Gender, Sexuality and Sexuality, and Relationships" *American Behavioral Scientist*, vol. 31. no. 1 September/October 66-85
- Gross, Sally (2003) "Intersexuality and Scripture" <http://www.bfpubs.co.uk/sally.htm> date accessed 18th July 2003.

- Groveman, Sherri A. (1999) "The Hanukkah Bush: Ethical Implications on the Clinical Management of Intersex" in Dreger, Alice Domurat (Ed.) *Intersex in the Age of Ethics* University Publishing Group, Hagerstown.
- Häberle, Peter (2003) "Peter's Story" in O'Keefe, Tracie and Fox, Katrina (eds) *Finding the Real Me. True Tales of Sex and Gender Diversity* Jossey-Bass, San Francisco
- Hall, Donald, E (2003) *Queer Theories* Palgrave Macmillan, Houndsmill.
- Hanley, S. Asher (2000) "Different: My Experiences as an Intersexed Gay Boy" in Sonnie, Amy (Ed.) *Revolutionary Voices. A Multicultural Queer Youth Anthology*, Alyson Books, Los Angeles.
- Harlow, Mary (1998) "In the Name of the Father: Procreation, Paternity and Patriarchy" in Foxhall, Lin and Salmon, John (Ed.s) *Thinking Men. Masculinity and its Self-Representation in the Classical Tradition*. Routledge, London and New York.
- Harris, Lynn Edward (1995) "Legal Sex Change, No Surgery" *Hermaphrodites with Attitude* Spring 1995 pp. 5
- Hastings, Jeanne (2003) "You Can Always Adopt" *dAISy* March, 2003. AIS Support Group Australia <http://www.vicnet.net.au/~aissg>
- Hausman, Bernice L. (1995) *Changing Sex. Transsexualism, Technology, and the Idea of Gender* Duke University Press, Durham and London.
- Hawbecker, Hale (1999) "'Who Did This to You?'" in Dreger, Alice Domurat (Ed.) *Intersex in the Age of Ethics* University Publishing Group, Hagerstown
- Haynes, Felicity (2001) "Introduction" in Haynes, Felicity and McKenna, Tarquam (Ed.s) *Unseen Genders. Beyond the Binaries* Peter Lang, New York.
- Haynes, Felicity and McKenna, Tarquam (2001) *Unseen Genders. Beyond the Binaries* Peter Lang, New York.
- HealthyPlace (2000a) "Specific Syndromes of Sex Differentiation"
- HealthyPlace (2000b) "Endocrine Treatment"
- Hekma, Gert (2000) "Queering Anthropology" in Sandfort, Theo, Schuyf, Judith, Duyvendak, Jan Willem and Weeks, Jeffrey (Ed.s) *Lesbian and Gay Studies. An Introductory, Interdisciplinary Approach*, Sage Publications, London.
- Herd, Gilbert (1987) *The Sambia. Ritual and Gender in New Guinea* Harcourt Brace Jovanovich College Publisher, Fort Worth.

- Herd, Gilbert (1990) "Mistaken Gender: 5-Alpha Reductase Hermaphroditism and Biological Reductionism in Sexual Identity Reconsidered" *American Anthropologist*, 92, pp.433-446
- Herd, Gilbert (1993a) "Introduction: Third Sexes and Third Genders" in Herd, Gilbert (Ed.) *Third Sex, Third Gender. Beyond Sexual Dimorphism in Culture and History*. Zone Books, New York.
- Herd, Gilbert (1993b) "Mistaken Sex: Culture, Biology and the Third Sex in New Guinea" in Herd, Gilbert (Ed.) *Third Sex, Third Gender. Beyond Sexual Dimorphism in Culture and History*. Zone Books, New York.
- Herd, Gilbert and Davidson, Julian (1988) "The Sambia 'Turnim-Man': Sociocultural and Clinical Aspects of Gender Formation in Male Pseudohermaphrodites with 5-Alpha-Reductase Deficiency in Papua New Guinea" *Archives of Sexual Behavior*, 17, 1, pp. 33-56
- Hider, Andie (2004) "Does *Re: Kevin* Re-define the Meaning of Intersex to Include Transsexualism?" AIS Support Group Australia <http://www.vicnet.net.au/~aissg>
- Hines, Melissa, Ahmed, S. Faisal, and Hughes, Ieuan A. (2003) "Psychological Outcomes and Gender-Related Development in Complete Androgen Insensitivity Syndrome" *Archives of Sexual Behavior*, Vol. 32, No. 2 April 2003 pp. 93-100
- Hird, Myra J, and Germon, Jenz (2001) "The Intersexual Body and the Medical Regulation of Gender" in Backett-Milburn, Kathryn and McKie, Linda (Ed.s) *Constructing Gendered Bodies*, Palgrave, Houndsmill.
- Holmes, Morgan (1994) "I'm Still Intersexual" *Hermaphrodites with Attitude* v. 1 n. 1 Winter 1994 pp. 5-6
- Holmes, Morgan (1996) Biography Entry in Feinberg, Leslie *Transgender Warriors. From Joan of Arc to Dennis Rodman*, Beacon Press, Boston.
- Holmes, Morgan (1998) "In(to)Visibility: Intersexuality in the Field of Queer" in Atkins, Dawn (Ed.) *Looking Queer. Body Image and Identity in Lesbian, Bisexual, Gay and Transgender Communities* Harrington Park Press, New York.
- Holmes, Morgan (2002) "Rethinking the Meaning and Management of Intersexuality" *Sexualities* v.5 n.2 pp.159-180, 2002.

- <http://47xxy.org/> (2003) "What is XXY?" <http://47xxy.org/> Date Accessed 3rd December 2003.
- Humm, Maggie (1992) "History of Feminism in Britain and America" in *Modern Feminisms* Columbia University Press, New York.
- Hutchins, Loraine and Kaahumanu, Lani (1991) *Bi Any Other Name. Bisexual People Speak Out* Alyson Publications Inc., Boston.
- INNSW (2002a) "The Intersex Network" *Polare* n.45 April-May 2002, pp. 9
- INNSW (2002b) "The Intersex Network" *Polare* n.46 June-July 2002, pp. 10
- ISGI (2004) "ISGI Manifesto" *International Support Group International* <http://www.xyxo.org/isgi.Manifesto.html> Date accessed 5th May 2004
- ISNA (2002) <http://www.isna.org>
- Jacquart, Danielle and Thomasset, Claude (1985) *Sexuality and Medicine in the Middle Ages* (Adamson, Matthew, *Trans*) Polity Press, Cambridge
- Jagose, Annamarie (1996) *Queer Theory* Melbourne University Press, Carlton South
- Jeff (1995) "If You Have Had Bad Surgery ..." *Hermaphrodites with Attitude* Spring 1995 pp. 5
- Jones, Ann Rosalind and Stallybrass, Peter (1991) "Fetishizing Gender: Constructing the Hermaphrodite in Renaissance Europe" in Epstein, Julia and Straub, Kristina (Ed.s) *Body Guards. The Cultural Politics of Gender Ambiguity* Routledge London.
- Kaldera, Raven (1998) "Agdistis' Children: Living Bi-Gendered in a Single-Gendered World" in Atkins, Dawn (Ed.) *Looking Queer. Body Image and Identity in Lesbian, Bisexual, Gay and Transgender Communities* Harrington Park Press, New York.
- Katz, Marilyn A. (1995) "Ideology and 'the Status of Women' in Ancient Greece" in Hawley, Richard and Levick, Barbara (Ed.s) *Women in Antiquity. New Assessments*, Routledge London and New York.
- Kessler, Suzanne J. (1998) *Lessons from the Intersexed*, Rutgers University Press, New Brunswick.
- Kim (1999) "As Is" in Dreger, Alice Domurat (Ed.) *Intersex in the Age of Ethics* University Publishing Group, Hagerstown

- Kirsch, Max H. (2000) *Queer Theory and Social Change* Routledge, London.
- Koyama, Emi (2002) "Suggested Guidelines for Non-Intersex Individuals Writing about Intersexuality and Intersex People" www.transfeminism.org date accessed 15th January 2002.
- Kuhn, Thomas (1962) *The Structure of Scientific Revolutions* University of Chicago Press, Chicago.
- Kylie (2000) "Kylie's Story" *dAISy* September, 2000. AIS Support Group Australia <http://www.vicnet.net.au/~aissg>
- Laqueur, Thomas (1995) *Making Sex. Body and Gender From The Greeks to Freud*, Harvard University Press, Cambridge
- Lee (1995) "Hermaphrodite and Damn Proud!" *Hermaphrodites with Attitude* Spring 1995 pp. 10
- Lehrman, Sally (1999) "Sex Police" *Health and Body* April 5, 1999
- Longino, Helen E. (1990) *Science as Social Knowledge* Princeton University Press, Princeton.
- Lowe, Marian and Lowe Benston, Margaret (1991) "The Uneasy Alliance Of Feminism and Academia" in Gunew, Sneja (Ed.) *A Reader in Feminist Knowledge* Routledge, London.
- MacDonald, Mairi (2000) "Intersex and Gender Identity" *The UK Intersex Association*, http://www.ukia.co.uk/voices/is_gi.htm , Date Accessed 26th May 2003.
- Marks, Deborah (1999) *Disability. Controversial Debates and Psychosocial Perspectives* Routledge, London and New York.
- Mason, Katherine A. (2002) "The Unkindest Cut. Intersexuals Launch a Movement to Stop Doctors From 'Assigning' Sex with a Scalpel" *New Haven Advocate* <http://www.hewwhavenadvocate.com/articles/unkindestcut.html> Date Accessed 15th January, 2003.
- McFarlane, Delphine (2001) "Unseen Genders: Looking for the Orlando Effect" in Haynes, Felicity and McKenna, Tarquam (Ed.s) *Unseen Genders. Beyond the Binaries* Peter Lang, New York.
- Medical Questions (2002) "Medical Questions about Intersexuality"

- Migeon, Claude, J., Wisniewski, Amy B., Brown, Terry R., Rock, John A., Meyer-Bahlburg, Heino F.L., Money, John, and Berkovitz, Gary D (2002b) "46,XY Intersex Individuals" Phenotype and Etiology Classification, Knowledge of Condition, and Satisfaction with Knowledge in Adulthood" *Pediatrics* v. 110 n.3 September, 2002. <http://www.pediatrics.org/cgi/content/full/110/3/e32> Date accessed Tuesday 4th March 2003.
- Miles, Rosalind (1990) *The Woman's History of the World*, Paladin Grafton Books, London.
- Mills, Sara (2003) *Michel Foucault* Routledge, London
- Minto, Catherine L., Liao, Lih-Mei, Woodhouse, Christopher, R.J., Ransley, Phillip G., and Creighton, Sarah M. (2003) "The Effect of Clitoral Surgery on Sexual Outcomes in Individuals who have Intersex Conditions with Ambiguous Genitalia: a Cross-sectional Study" *The Lancet* Vol. 361 no. 9365 12th April 2003.
- Money, John (1995) *Gendermaps. Social Constructionism, Feminism, and Sexosophical History* Continuum, New York.
- Money, John and Ehrhardt, Anke A. (1972) *Man and Woman. Boy and Girl. The Differentiation and Dimorphism of Gender Identity from Conception to Maturity* Johns Hopkins University Press, Baltimore.
- Moreno, Angela (1999) "In Amerika They Call Us Hermaphrodites" in Dreger, Alice Domurat (Ed.) *Intersex in the Age of Ethics* University Publishing Group, Hagerstown
- Mortimer, Roz (2002) "Gender Trouble" *Wonderdog Productions*.
- Murray, Stephen O. (2000) *Homosexualities* The University of Chicago Press, Chicago
- Nanda, Serena (1990) *Neither Man Nor Woman. The Hijras of India*. Wadsworth Publishing Company, Belmont.
- Nanda, Serena (1993) "Hijras: An Alternative Sex and Gender Role in India" in Herdt, Gilbert (Ed.) *Third Sex, Third Gender. Beyond Sexual Dimorphism in Culture and History*. Zone Books, New York.
- Natarajan, Anita (1996a) "In Reply: Sex Lies and Androgen Insensitivity Syndrome: The Author Replies" *Canadian Medical Association Journal*, Vol. 154, no. 12 pp. 1833.

- Natarajan, Anita (1996b) "Medical ethics and Truth Telling in the Case of Androgen Insensitivity Syndrome" *Canadian Medical Association Journal*, Vol. 154, no. 4 pp. 568-70.
- Nederman, Cary J. and True, Jacqui (1996) "The Third Sex: The Idea of the Hermaphrodite in Twelfth-Century Europe" *Journal of the History of Sexuality*, 6, 4, pp. 497-517.
- Nicholson, Sven (1999) "Take Charge! A Guide to Home Auto-Catheterization" in Dreger, Alice Domurat (Ed.) *Intersex in the Age of Ethics* University Publishing Group, Hagerstown
- Noble, Michael (2002) "I am Me and I am O.K." *The UK Intersex Association* <http://www.ukia.co.uk/voices/mnoble/htm> Date Accessed 24th February 2003, Presented as the "Feast 2002" Gay and Lesbian Festival Adelaide, South Australia
- Nussbaum, Emily (2000) "A Question of Gender" *Discover* January, 2000.
- O'Keefe, Tracie (1999) *Sex, Gender and Sexuality. 21st Century Transformations*, Extraordinary People Press, London.
- O'Keefe, Tracie and Fox, Katrina (2003) *Finding the Real Me. True Tales of Sex and Gender Diversity* Jossey-Bass, San Francisco
- Olesen, Virginia (1998) "Feminisms and Models of Qualitative Research" in Denzin, Norman K. and Lincoln, Yvonna S. (Ed.s) *The Landscape of Qualitative Research. Theories and Issues* Sage Publications, Thousand Oaks.
- Perkins, Roberta, Griffin, Aidy and Jacobsen, Jeddah (1994) *Transgender Lifestyles and HIV/AIDS Risk*, Australian Government Publishing Service
- Philips, Helen (2001) "The Gender Police" *New Scientist*, Vol 170 No 2290 12th May 2001.
- Plato (1951/1981) *The Symposium* Trans by Hamilton, W. Penguin, Harmondsworth.
- Poole, Fitz John Porter (1981) "Transforming 'natural' woman: Female Ritual Leaders and Gender Ideology Among Bimin-Kuskusmin" in Ortner, Sherry B. and Whitehead, Harriet (ed.s) *Sexual Meanings. The Cultural Construction of Gender and Sexuality* Cambridge University Press, Cambridge
- Poole, Fitz John Porter (1996) "The Procreative and Ritual Constitution of Female, Male and Other. Androgynous Beings in the Cultural Imagination of the Bimin-

- Kuskusmin of Papua New Guinea” in Ramet, Sabrina Petra (Ed.) *Gender Reversals and Gender Cultures. Anthropological and Historical Perspectives*, Routledge London and New York
- Preves, Sharon E. (2001) “Sexing the Intersexed: An Analysis of Sociocultural Responses to Intersexuality” *Signs: Journal of Women in Culture and Society* v.27 n. 2 pp. 523-556
- Preves, Sharon E. (2003) *Intersex and Identity. The Contested Self* Rutgers University Press, Piscataway.
- Ramazanoğlu, Caroline and Holland, Janet (2002) *Feminist Methodology. Challenges and Choices* Sage Publications, London.
- Ramet, Sabrina Petra (1996) “Gender Reversals and Gender Cultures. An Introduction” in Ramet, Sabrina Petra (Ed.) *Gender Reversals and Gender Cultures. Anthropological and Historical Perspectives* Routledge London.
- Randy (1995) “What I Wish My Parents Had Been Told About Hypospadias” *Hermaphrodites with Attitude* Spring 1995 pp. 11
- Rangecroft, L., Brain, C., Creighton, S., Di Ceglie, D., Ogilvey-Stuart, A., Malone, P., and Turnock, R. (2001) “Statement of the British Association of Paediatric Surgeons Working Party on the Surgical Management of Children Born with Ambiguous Genitalia”
- Raven (2003) “Raven’s Story” <http://www.cahourstories.net/raven.html> Date accessed 1st May 2003.
- Reinharz, Shulamit (1992) *Feminist Methods in Social Research* Oxford University Press, New York
- Renee (2000) “Renee” <http://home.vicnet.net.au/~aissg/renee.htm> Last Modified 26th September, 2000. Date Accessed 1st May 2003.
- Reynolds, Robert (2002) *From camp to Queer* Melbourne University Press, Carlton South.
- Rigby, S.H. (1995) *English Society in the Later Middle Ages. Class, Status and Gender*. St. Martin’s Press, New York
- Rodger, John J. (1996) *Family Life and Social Control* Macmillan, Houndsmill

- Roscoe, Will (1991) *The Zuni Man-Woman* University of New Mexico Press, Albuquerque
- Roscoe, Will (1998) *Changing Ones. Third and Fourth Genders in Native North America*, St. Martin's Press, New York
- Rosenthal, Allison (2001) "Allison" *Patient's Story* http://xyxo/xyxo_files/allison.htm
Last Modified 6th January 2001. Date Accessed 1st May 2003.
- Sarndra (2001) "Infertility " *dAISy* March, 2001. AIS Support Group Australia
<http://www.vicnet.net.au/~aissg>
- Schuyf, Judith (2000) "Hidden from History? Homosexuality and the Historical Sciences" in Sandfort, Theo, Schuyf, Judith, Duyvendak, Jan Willem and Weeks, Jeffrey (Ed.s) *Lesbian and Gay Studies. An Introductory, Interdisciplinary Approach*, Sage Publications, London.
- Seidman, Steven (1994) "Introduction" in Seidman, Steven (Ed.) *The Postmodern Turn. New Perspectives on Social Theory* Cambridge University Press, Cambridge
- Seidman, Steven (1996) "Introduction" in Seidman, Steven (Ed.) *Queer Theory/Sociology* Blackwell Publishers, Cambridge
- Seidman, Steven (1997) *Difference Troubles. Queering Social Theory and Sexual Politics* Cambridge University Press, Cambridge.
- Shorona (2000) "Gendercide" *dAISy* September, 2000. AIS Support Group Australia
<http://www.vicnet.net.au/~aissg>
- Shorona (2003) "Remembering my Queer Body ..."
- Slijper, Froukje M.E., Drop, Stenvert L.S., Molenaar, Jan C., and de Muinck Keizer-Schrama, Sabine M.P.F. (1998) "Long-term Psychological Evaluation of Intersex Children" *Archives of Sexual behaviour* Vol. 27 no.2 pp 125-145 April May 1998.
- Slocum, Virginia (1995) "Dear Suzanne" *Hermaphrodites with Attitude* Summer 1995 pp. 6-7
- Somers, Chris and Haynes, Felicity (2001) "Intersex: Beyond the Hidden A-Genders" in Haynes, Felicity and McKenna, Tarquam (Ed.s) *Unseen Genders. Beyond the Binaries* Peter Lang, New York.

- Sonnie, Amy (2000) "Speaking for Ourselves: A Note From the Editor" in Sonnie, Amy (Ed.) *Revolutionary Voices. A Multicultural Queer Youth Anthology*, Alyson Books, Los Angeles.
- Stein, Arlene and Plummer, Ken (1996) "'I Can't Even Think Straight': 'Queer' Theory and the Missing Sexual Revolution in Sociology" in Seidman, Steven (Ed.) *Queer Theory/Sociology* Blackwell Publishers, Cambridge
- Strozier, A. Melton (1996) "Families with Chronic Illness and Disability" in Harway, Michele (Ed.) *Treating the Changing Family. Handling Normative and Unusual Events* John Wiley and Sons Inc. New York
- Sue (2002) "Personal Stories" *dAISy* March, 2002. AIS Support Group Australia <http://www.vicnet.net.au/~aissg>
- Swan, Norman and Fry, Rae (2003) "Boy or Girl?" *The Health Report* Radio National. ABC FM, Broadcast Monday 6th January, 2003.
- Tarnas, Richard (1996) *The Passion of the Western Mind. Understanding the Ideas that Have Shaped Our World View*, Pimlico, London.
- Thomas, Carol (2002) "Disability Theory: Key ideas, Issues and Thinkers" in Barnes, Colin, Oliver, Mike and Barton, Len (Ed.s) *Disability Studies Today* Polity Pres, Cambridge
- Tong, Rosemarie (1989) *Feminist Thought*, Routledge, London.
- Tony (2000) "Tony" <http://home.vicnet.net.au/~aissg/Tony.htm> Lat Modified 16th September 2000. Date accessed 1st May 2003.
- Toomey, Christine (2001) "Hidden Genders" *The Weekend Australian Magazine* December 8-9, 2001.
- Torassa, Ulysses (2002) "Profile: Cheryl Chase, Medical Activist Boy or Girl? Advocate for Intersex Children with Influences Attitudes" *San Francisco Chronicle* Sunday, August 2, 2002. Date Accessed 3rd March 2003.
- Triea, Kiira (1994) "The Awakening" *Hermaphrodites with Attitude* v. 1 n. 1 Winter 1994 pp. 1/6
- Triea, Kiira (1999) "Power, Orgasm, and the Psychohormonal Research Unit" in Dreger, Alice Domurat (Ed.) *Intersex in the Age of Ethics* University Publishing Group, Hagerstown

- Trumbach, Randolph (1993) "London's Sapphists: From Three Sexes to Four Genders in the Making of Modern Culture" in Herdt, Gilbert (Ed.) *Third Sex, Third Gender. Beyond Sexual Dimorphism in Culture and History*. Zone Books, New York.
- Turner, Stephanie, S. (1999) "Intersex identities. Locating New Intersections of Sex and Gender" *Gender and Society* v. 13 n. 4 August 199 pp. 457-479
- Valentine, David and Wilchins, Riki Anne (1997) "One Percent on the Burn Chart. Gender, Genitals, and Hermaphrodites With Attitude" *Social Text* v.15 n.'s 3 and 4 pp. 215-222.
- Victorian Turner's Syndrome Association Inc. (2001)
- Virginia (2001) "My Journey With AIS" *dAISy* March, 2001. AIS Support Group Australia <http://www.vicnet.net.au/~aissg>
- Wafer, James (1996) "Out of the Closet and into Print: Sexual Identity in the Textual Field" In Lewin, Ellen and Leap, William L. (Ed.s) *Out in the Field. Reflections of Lesbian and Gay Anthropologists* University of Illinois Press, Urbana and Chicago.
- Walcutt, Heidi (1995-1996) "Healing Begins ..." *Hermaphrodites with Attitude* Fall/Winter 1995-1996 pp. 12
- Walcutt, Heidi (1999) "Time for a Change" in Dreger, Alice Domurat (Ed.) *Intersex in the Age of Ethics* University Publishing Group, Hagerstown
- Warne, G.L. (1989) *Your Child With Congenital Adrenal Hyperplasia* G.L. Warne, Melbourne.
- Watson, Linda Ann (2000) "My Experience as a Person With AIS Working With Milton Diamond" *dAISy* September, 2000. AIS Support Group Australia <http://www.vicnet.net.au/~aissg>
- West, Candace and Zimmerman Don H. (1987) "Doing Gender" *Gender and Society* Vol. 1 No. 2 June 125-151.
- Whittle, Stephen (2002) *Respect and Equality. Transsexual and Transgender Rights* Cavendish Publishing Ltd., London.
- Wilchins, Riki (2004) *Queer Theory Gender Theory* Alyson Publications, Los Angeles.
- Willett, Graham (2000a) *Living Out Loud. A History of Gay and Lesbian Activism in Australia* Allen and Unwin, St Leonards

- Willett, Graham (2000b) "The Origins of Homosexual Politics in Australia" in *Australia's Homosexual Histories* Phillips, David L. and Willett, Graham (Ed.s) Australian Centre for Lesbian and Gay Research, Sydney.
- Williams, Walter L. (1992) *The Spirit and the Flesh. Sexual Diversity in American Indian Culture*, Beacon Press Boston.
- Wilson, Bruce E. and Reiner, William G. (1999) "Management of Intersex: A Shifting Paradigm" in Dreger, Alice Domurat (Ed.) *Intersex in the Age of Ethics* University Publishing Group, Hagerstown
- Wilson, Dudley (1993) *Signs and Portents. Monstrous Births From the Middle Ages to the Enlightenment* Routledge, London.
- Wilson, E. O. (1975) *Sociobiology: A New Synthesis* Harvard University Press, Cambridge.
- W-o-m-a-n (2004) "Transsexualism - An Intersex Condition" Australian W-o-m-a-n Network <http://www.w-o-m-a-n.net> Date accessed 16th March 2004.
- www.genetic.org (2003) "Sex Chromosome Variations: About 47XXY"
- www.transfeminism.org (2002) "Introduction to Intersexuality and Intersex Activism"
- Young, Ian (1995) *The Stonewall Experiment. A Gay Psychohistory* Cassell, London.
- Yronwode, Althaea (2000) "Intersex Individuals Dispute Wisdom of Surgery on Infants" <http://www.luckymojo.com/tkintersex.html> Date Accessed 15th January 2003.

APPENDIX A: Phase I Questions

“A Study of the Social Lives of Intersex Australians”

I have included here a list of the questions that I would like you to consider. Feel free not to answer any of the questions that you do not wish to answer. If you could please email your responses, that would be greatly appreciated.

Identity

I see issues related to identity as significant for this present study. The following refer specifically to issues related to identity.

1. For the majority of people with an intersex condition gender identity is not an issue, how do you feel about this statement?
2. For people who question or change their gender identity, what do you see as the major issues surrounding this questioning or change?

The Australian Situation

Another aim of this study is to compare issues relevant to people with intersex conditions in Australia to those overseas. This next set of questions relates to how you view issues pertinent to Australian people with intersex conditions.

1. Are there any issues that directly related to the lives of *Australian* people with intersex conditions?
2. In recent years more and more support groups and service providers have become available in Australia, what do you see as the main aims of these support groups and service providers?
3. In what directions do you think these organisations will go in the next 5-10 years, that they aren't presently?
4. What do you see as the future hopes/aspirations for people with intersex conditions in Australia?

This Study

Another aim of this study is to include input from others to push the study in directions that better reflect the needs of people with intersex conditions. This section will ask you to provide feedback on this study and offer your own opinions on what this study should be asking people with intersex conditions.

1. As I have stated above the two aims of this study are to investigate issues related to identity and a comparison of Australia and overseas issues. What are your views on these two aspects of the study?
2. If any, what are some of the other issues that you would like to see explored in this study?
3. What would you suggest as the most efficient method to recruit people for the interview stages?
4. If any, what problems would you foresee for this present study? Are there any measures that you can recommend to prevent them?
5. Please feel free to make any further comments.

Thanks for your time.

Sincerely,

Stephen Kerry
School of Social Sciences
University of Newcastle
stephen.kerry@studentmail.newcastle.edu.au

APPENDIX B: Phase II Letter/Advert Information

Hi [insert name]

Thanks for your continual and invaluable support of my PhD project titled “A Study of the Social Lives of People With Intersex Conditions.” Following your previous assistance I am currently in the process of compiling Phase Two Interviews.

Presently, however, I am writing to you regarding assistance in recruitment of phase two participants. Because of the unique problems associated with accessing people with intersex conditions I am using the method of word of mouth to recruit potential interviewees. Therefore I write to ask if you would be willing to pass on an invitation to persons who you feel may be interested in participating in the study.

If you know of anyone who may be interested, but does not have access to email, could you please ask them to contact my principal supervisor.

Dr. Kevin Markwell

School of Social Sciences
University of Newcastle
University Drive,
Callaghan NSW 2308.
[02] 4921 6573

I have attached a copy of a letter introducing myself, the study and providing potential interviewees with information pertaining to becoming participants in the study.

Thanks again for your continual support

Regards

Stephen Kerry

Information Letter

A Study of the Social Lives of Intersex Australians

Interviews with Intersex Australians

You are invited to take part in the research project identified above which is being conducted by PhD candidate Stephen Kerry from the School of Social Sciences at the University of Newcastle. The research supervisors are Dr Kevin Markwell and Dr. Bethne Hart.

The purpose of this project is to explore the social lives, identities and relationships of people with intersex conditions in Australia. I invite you to participate in two interviews three months apart that will ask you questions about your social life, identity, and relationships.

The two interviews will be conducted late in 2003. Each interview will ask open-ended questions about your social lives, identities and relationships. The second interview will also allow you to reflect upon earlier responses. Participants can choose to participate through one of the three following processes:

- 1) Interview (in person or by phone);
 - Interviews, either in person or by telephone, will be arranged at a time and place that is mutually agreed upon. The interviews will be audiotaped with your consent. The audiotapes will be erased after their transcription.
 - Participants have the right to review, edit or erase their contributions to the interview, up until the data collection is completed (December 2003)
- 2) Recording responses to interview questions on cassette tape;
 - Participants will be sent an audiocassette tape and the open-ended questions referring to social life, identity, and relationships.
 - Responses to these questions are then recorded onto this audiocassette tape, returned to the researcher in the reply-paid envelope provided. The audiotapes will be erased after their transcription.
 - Participants have the right to review, edit or erase their contributions to the interview, up until the data collection is completed (December 2003).
- 3) Writing responses to interview questions (written, typed or email);
 - Participants will be sent the open-ended questions referring to social life, identity, and relationships (by email or post).

- Responses to these questions maybe hand-written or typed, and returned to the researcher by email or in the reply-paid envelope provided.
- Participants have the right to review, edit or erase their contributions to the interview, up until data collection is completed (December 2003).
- Please note that due to the insecure privacy of email communication, confidentiality cannot be completely assured. Thus it is advised that participants set up a separate email account that removes identifying markers.

Participation is voluntary.

All identifying characteristics will be removed when interview responses are transcribed. Participants will not be identifiable through the transcriptions or any reports of the study. They will be asked not to identify others in their responses.

During the study and after its completion all data will be stored securely at the University of Newcastle for a period of five years. Throughout this period only my supervisors and myself will have access to data collected.

Participants will be contacted within two weeks of receipt of the Consent Form to arrange the interview, depending on the selected process.

Please indicate your consent to participate by completing the Consent Form and return it to:

Stephen Kerry
C/- Dr Kevin Markwell
School of Social Sciences
University of Newcastle
University Drive,
Callaghan NSW 2308.

Thank you for considering this invitation,

Stephen Kerry

Dr Kevin Markwell
[02] 4921 6573

Bethne Hart
[02] 4921 6761

Email:

stephen.kerry@studentmail.newcastle.edu.au
kevin.markwell@newcastle.edu.au
bethne.hart@newcastle.edu.au

Complaints about this research

This project has been approved by the University's Human Research Ethics Committee Approval No. H- [H-520-0203].

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, University Drive, Callaghan NSW 2308, telephone (02 49216333, email Human-Ethics@newcastle.edu.au.

APPENDIX C: Phase II Interview Schedule

“A Study of the Social Lives of Intersex Australians”

The purpose of this project is to explore the social lives, identities and relationships of people with intersex conditions in Australia. You are asked to consider these questions about your social life, identity, and relationships.

Please feel free not to answer any question that you do not feel comfortable answering.

These questions are divided into three sections: 1) **Introductory Questions**, where you will be asked some demographic information 2) **Intersex Conditions**, which will ask you specific questions about your intersex condition; 3) **Surgical or Hormonal Treatments**, which will ask about any surgical or hormonal treatments you may or may not have had; and 4) **Identity**, which will ask you to reflect on your identity.

For the purpose of this study ‘intersex’ refers to people who were born with ambiguous genitals, gonads or chromosomes or who may or may not have Turners Syndrome, Klinefelters Syndrome, Androgen Insensitivity Syndrome and Congenital Adrenal Hyperplasia or Hypospadias. Therefore, this does not include people with gender dysphoria, transsexuals or cross dressers.

If you have any further questions please do not hesitate to contact my principal supervisor or myself.

Stephen Kerry.

stephen.kerry@studentmail.newcastle.edu.au

Dr Bethne Hart

02 4348 4333

Bethne.Hart@newcastle.edu.au

Introductory Questions

1. How old are you?
2. What is the highest level of education you completed?
3. What kind of work do you do?
4. What is your current romantic relationship status?
5. What is your religious or spiritual identification?
6. What is your racial or ethnic identification?

Intersex Condition

1. At what age did you find out about the intersex condition?
2. Can you tell me a bit about how you found out about the intersex condition?
3. If your parents/family know about your intersex condition, can you tell me a bit about how they reacted?
4. Can you tell me about your relationship with your partner/parents/family since you found out about your intersex condition?

Surgical or Hormonal Treatments

1. Can you tell me a bit about any surgical or hormonal treatment you may have had as a direct result of your intersex condition?
2. Can you tell me a bit about how you feel about these surgical or hormonal treatments?
3. Can you tell me a bit about how you would feel about your life if you did not have these surgical or hormonal treatments?

Identity

1. How do you, personally, define your *sex at birth* (sex assignment)?
2. I'd like to talk with you now about your gender. How do you define your gender?
3. How do you express this gender identity to others?
4. I am also interested in issues of sexual orientation. How do you characterize your sexual orientation?
5. What have been the most significant events that helped you to develop your sense of gender and sexual identity?
6. Has your sexual identity changed over time? If so, tell me about this.
7. Has the way you see your gender identity, or the way you express your gender identity to others changed over time? If so, tell me about this.

APPENDIX D: Phase III Introductory Letter

Dear participant,

Firstly we would like to express our appreciation in your continuing participation in the project titled “A Study of the Social Lives of Intersex Australians.” As per the previous contact with you we are sending you the information pertaining to the follow up interviews.

Firstly, we have included the answers you provided to the initial set of interview questions. The reason for this is for you to reflect on your answers, and for you to consider making any additions, omissions or revisions to your answers. This is done on the understanding that some participants may wish to add something that may have thought of since this initial interview.

Secondly, we will also include some further questions that we would like to ask you. These questions have been compiled as a result of consideration of your initial answers. You are reminded, as with the first interview questions, that you should feel free to answer as many or as few of the additional questions as you like.

Thirdly, we will include a copy of the main themes identified from all the participants to date.

Please note that this information is confidential to participants of the project and is not for publication or citation.

If you choose not to continue any further participation in the project you may elect to not respond to this invitation and the follow-up interview.

Thank you again for your consideration,

Sincerely,

Stephen

Supervisor
Dr. Bethne Hart
School of Humanities
Faculty of Education and Arts
University of Newcastle
[02] 4348 4054
Bethne.Hart@newcastle.edu.au

APPENDIX E: Phase II Themes

Demographic Characteristics

The demographic profile of participants ranged in age from 20's to 70's, obtained High School or University education, identified as being straight, gay or a-sexual, ethnically they have a European background, are currently employed in the professional or service industry, or studying, and participants expressed that they were either not religious, had some spiritual belief or identified with a specific religion (Anglican, Buddhism, Catholicism).

Intersex Conditions

Participants have identified Androgen Insensitivity Syndrome (partial and complete), Klinefelters Syndrome, or Hypospadias. For most participants disclosure of intersex condition in childhood was vague or absent and method of disclosure (at any age) was through participants' own investigation or incompletely from parents/doctors.

For most participants their parents either did not know of or reacted negatively to condition. Some participants indicated that they have a good relationship with partner, while other participants have indicated difficulties in relationships related to their condition. A small number of the participants indicated having a good relationship with family members.

Surgical and Hormonal Treatment

Most participants indicated some surgical procedure and/or some hormonal treatment. There were both negative and positive perceptions and evaluations from participants about the treatments. Most reflected that life would have been more difficult without treatment. A couple reflected that treatment has had a significant role in developing a sense of self.

Identity

Most participants identify as either male or female. Some of the participants saw their sex or gender as something other than male or female. Gender identity was perceived/experienced by participants as made difficult by their intersex condition. Most of the participants describe themselves as heterosexual. There were also indication that sexual orientation had changed throughout their lives. Some participants have undergone a change of sex or gender through their lives.

Overview:

Diversity

Fluidity of gender and sexuality

Pain-distress/trauma throughout lives

Struggles in identity

APPENDIX F: Phase III Questions

Mel

Identity / Question 3

Can you give me some examples of this?

Identity / Question 4

Can you give some more details to a 'normal androgyne orientation'?

Jamie

Introductory Questions / Question 5

Can you tell me in what ways, if any, your spirituality has helped you in having AIS?

Intersex Questions / Question 1

When you say you realised something was different can you tell me what sorts of things were different?

Intersex Questions / Question 2

Can you tell me more about the article and what it talked about that led you to find out about having AIS?

Intersex Questions / Question 3

You indicate that your mother knows of you have AIS but has been unwillingly to help. How did she find out you have AIS? Do any other family members (other than your sister) know?

Intersex Questions / Question 4

How has your relationship with your family developed in the year since you reopened communications?

Has your sister experienced similar issues as you have with regards to the rest of the family?

You mention that your husband was aware that you had a medical condition, and that you were both apprehensive. Can you expand on how you were approached the subject with your husband?

Surgical/Hormonal Treatments / Question 1

Does you fear stop you from having surgery? If so what surgery would you have done?

Identity/ Question 3

I can appreciate that this is a difficult issue. Could you tell me more about the negative conditioning in learning to accept and cope with who you are?

Pat

Intersex Conditions / Question 2

Can you tell me more about the initial diagnosis?

Intersex Conditions / Question 3

Can you tell me more about your siblings initial reaction to diagnosis with KS?

Did your parents know about the initial diagnosis of hypogonadism? If so can you tell me about how they reacted to that?

Intersex Conditions / Question 4

Has there been any incidence with your family that has been directly related to you having KS and your fluid sex and gender identity?

Identity / Question 4

Why do you think you are better able to establish non-sexual relationships with males than females?

Identity / Question 5

Can you tell me more about how your Buddhism has helped your understandings of yourself, your KS and your gender identity?

Kerry

Intersex Conditions / Question 1

When you say you had some understanding at age 5, can you be more specific?

Intersex Conditions / Question 2

Can you tell me more about what basics you were told and by whom?

Surgical/Hormonal Treatments / Question 2

Can you explain what you mean by “wait for me to decide at a later age”?

Identity / Question 3

Can you tell me more about the ways having a penis that does not look normal impacts on your feelings of maleness?

Chris

Introductory Questions / Question 5

Can you tell me in what ways, if any, your spirituality has helped you in having AIS?

Identity / Question 3

Does having breasts and atypical genitalia ever interfere with you living as a man? If so would you like to tell me about those times?

APPENDIX G: Mel's Newspaper Clipping

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copyright reasons

The full thesis is available in the
University of Newcastle Library

APPENDIX H: Thematic Threads From Interviewees

Interview Section	Summary
Demographic	<p>All participants are of European Descent and employed/studying. There is a universal response from participants in regards to their ethnic background and employment, where all participants who answered this question indicated that they were of European descent and in some form of employment (including studying).</p> <p>Participants are a Diverse Group. Other demographic responses indicate that people who answered these questions are a rather diverse group of people. With a propensity for: 1) being over 30, 2) higher education, 3) single, 4) straight, 5) not having changed their sex or gender, 6) conforming to a one or the other traditionally presented gender identities (i.e. male/female), and 7) belonging to some traditionally recognised established religion or spirituality.</p>
Intersex Conditions	<p>(4) Androgen Insensitivity (3) Klinefelters (1)Hypospadias</p> <p>Disclosure of condition in childhood vague or absent (7) Full disclosure of their condition in childhood (1)</p> <p>Discovery through own investigation or half-truths from</p>

	<p>parents/doctors (7)</p> <p>Full disclosure by parents. (1)</p> <p>Parents who did not know or reacted negatively (7)</p> <p>Full support from parents (1)</p> <p>Good relationship with partner (4)</p> <p>No relationships because of their condition (2)</p> <p>No answer given (2)</p> <p>Good relationship with family members (2)</p> <p>No answer given (6)</p>
Surgical/Hormonal Treatment	<p>Some surgical procedures (4)</p> <p>Some hormonal treatment (4)</p> <p>No surgery or hormone treatment (1)</p> <p>Negative feelings about treatments (3)</p> <p>Positive feelings about the procedures (3)</p> <p>Feeling good about surgery and bad about hormone (1)</p> <p>Feelings of indifferent (2)</p> <p>Feeling life would be more difficult without treatment (4)</p> <p>Treatment significant in developing a sense of self (2)</p>
Identity	<p>Conformity to traditional sex/gender identities (6)</p> <p>Sex/gender other than 'male' or 'female' (2)</p> <p>Difficulty in gender identity (4)</p>

	<p>No difficulty in gender identity (4)</p> <p>Heterosexual (6)</p> <p>Gay (1)</p> <p>Asexual (1)</p> <p>‘Normal androgyne orientation’ (1)</p> <p>Change of sexual orientation (3)</p> <p>Sex or gender change through their lives (3)</p> <p>Female to male (1)</p> <p>Adopting an intersex identity (1)</p> <p>No details (1)</p>
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