

**The Psychology of Intersex: Research into the Experiences  
of Individuals/Parents who have Experienced Androgen  
Insensitivity Syndrome or Congenital Adrenal Hyperplasia  
within the UK**

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## **Chapter One**

### **"Normal Abnormalities"**

#### **Intersex and the Psychology of a two-sex system.**

#### **"Perhaps Adults just don't take childhood seriously"**

### **Abstract**

This is a study involving intersex individuals and their parents. It asks them to talk about how they experienced intersexuality. It investigated their views on the medical treatment and management of Congenital Adrenal Hyperplasia (CAH) or Androgen Insensitivity (AIS) Syndrome and the psychological affects of the medicalisation of intersexuality. This study involves 32 interviews with adults/parents from the AIS/CAH support groups around England and Wales. For an interdisciplinary audience, this paper aims to highlight briefly, some of the impact theories of intersexuality have had on a variety of theories of sex and gender. It also unveils how society responds to intersexuality. Intersexuality is a concept that transgresses our socio-cultural meanings around boundaries of gender and in doing this, it disrupts our binary logic of the sexes. These intersexuals do not conform to society's fundamental assumption that there are two sexes and only two types of normal bodies. My interest in this study is not just giving a voice to intersex people and discovering what their individual perceptions are, but highlighting what the theoretical concept of intersexuality can illuminate about the everyday social construction of sex and gender for everyone. From a transdisciplinary<sup>1</sup> approach to intersexuals views, personal perspectives and from both theorists and support group activists, this paper will highlight contemporary issues both in theory and practice for the

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<sup>1</sup> The definitive use here of both interdisciplinary and transdisciplinary is borrowed from Celia Kitzinger, (1997:207). Where she replaces the emphasis of 'inter' meaning, with 'trans'. "I do not want an interdisciplinary perspective to which each discipline offers its particular perspective on the human condition, with the psychologist contributing what we purportedly know about the interior workings of the human psyche, while sociologists offer their knowledge of 'society', and anthropologists offer a 'cross-cultural' perspective, and so on. This approach assumes that there are distinct entities (psyche, society, culture, etc.) which can be studied separately and then 'combined' for a fully rounded picture (Celia Kitzinger, 1998:207 in Journal of Gender Studies, Vol.7, No.2, 1998)

psychology of intersexuality. This study also shows our society's reaction when a child is born intersexed.

## Introduction

*Just as our ability to breathe, so we rarely question the habit of dividing human beings into two categories: females and males. At the birth of a child we ask almost automatically 'Is it a boy or a girl? The question carries important messages about both biological and cultural differences; the two categories seem natural and the differences between them obvious.*

(Janet M. Bing and Victoria L. Bergvall 1996, p.23).

Over the past decade there has been a rise in interdisciplinary literature around issues concerning intersexuality. This marks a shift from medical and bio-psychological literature on intersexuality to writings within a variety of interdisciplinary contexts<sup>2</sup>. Most recently, within a psychological setting a whole issue was dedicated to the topic of intersexuality (Psychologist, August, 2004, Vol. 217 No. 8). Intersexuality in very simple terms refers to a number of conditions such as Androgen Insensitivity Syndrome and Congenital Adrenal Hyperplasia, "that lead to bodies having a mixture of male and female parts" (Fausto Sterling, 2000, p.257)<sup>3</sup>.

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2 Within US psychology literature: Suzanne Kessler (1998) 'Lessons from the Intersexed' Rutgers University Press, New Jersey. From a North American Sociological perspective Preves, S. E. 2000. From historical and Ethics approach: Alice Dreger (1998) "Hermaphrodites and the medical invention of Sex' also Intersex in the age of Ethics (2000). From a feminist biological perspective Anne Fausto-Sterling, (1995). From a feminist perspective Bernice Hausman (1995) 'Changing Sex: Transsexualism, Technology and the Idea of gender', Duke University Press, Virginia. From personal stories perspective: Cheryl Chase Archives of Sexual behaviour, 1995, 1998a, 1998b; Chase, C. Feminism & Psychology, 1999; Chase, C. (1998c) Journal of Clinical Ethics, 9(4): p.385-392; Chase, C. (1999) 'Rethinking Treatment for Ambiguous Genitalia': Paediatric Nursing 25(4): p. 451-455. Chase, C. & Coventry, M. (eds.) (1997-8) 'Special Issue: Intersex Awakening', Chrystalis. The Journal of Transgressive Gender Identities 2 (5): 1-56. From a bio-psychological perspective, Milton Diamond, 1982, 1993, 1995, 1996a, 1996b, 1997, 1999, Diamond and Sigmundson, 1997a, 1998b. From a cognitive perspective: Hines, M. 1998, 1999. Literature from Holland: M. Van den Wijngaard (1991a) 'The acceptance of scientific theories and images of masculinity and femininity', Journal of the History of Biology Vol. 24. (1) p.19-49. Also (1991b) Reinventing the sexes: Feminism and the biomedical construction of femininity and masculinity 1959-1958. Amsterdam: University of Amsterdam, 187. From the UK and a feminist psychological perspective Kitzinger, 1999a, 1999b, 2000. From a sociological perspective Hird, M. 2000, Hird, M., and Germon, 2001. From a Feminist Sociological perspective Jackson, 2000.

3 According to Susan Kessler the term 'intersexuality' was first used by a biomedical researcher in 1917 when it appeared in an article by Richard Goldschmidt called "Intersexuality and the Endocrine Aspect of Sex" Endocrinology Vol. 1 P. 433-456 (Philadelphia) and the term intersexual gained popularity in the medical profession. Previously, the term was associated with homosexuality and sexual inverts and was used in conjunction with this. Goldschmidt proposed the terms "intersexe, intersexual, intersexuality" to enable the understanding in all scientific languages. Intersex was previously described as sex integrades.

Chapter one outlines the medicalisation of intersexuality through different theorist's concerns and critically reviews some of the literature on intersexuality. When I began this research I arranged several focus groups in order to extrapolate societal understandings of intersexuality. These focus groups involved a group of 6-8 persons from a setting, i.e. undergraduate students and friends of the researcher. They involved watching a 20minute video of a prime time US television chat show on intersexuality. Most of the participants seemed to view intersexuals as the victims of misfortunate bodies and consequently as the victims of medical mismanagement. What they all accepted within their views was that intersexed individuals are presented as abnormal bodies in need of 'fixing' or 'healing'. This acceptance may be due to the over-emphasis of the medicalisation of intersexuality, which in the past constructed views of intersexed bodies as victims. Most focus group participants sympathised with these intersexed individuals but very few of them empathised with their experiences. In other words within each group there seemed to be a basic agreement that if surgery failed to take place their lives would be very difficult. Within this paper and in opposition to these views and the medicalisation of intersexuality, these individuals are studied in order that their perceptions, feelings and thoughts are valued, not as victims, but as part of their life experiences.

Within the medicalisation perspective there seems to be little room for valuing the bodies of these individuals as something positive, however, this can be done through the social constructionism. The social construction of intersexuality has received scant attention throughout the medical literature, however, the social and political importance of this topic has begun to be acknowledged within social and psychological theories of intersexuality and gender (Kessler, 1999; Kitzinger, 1999; 2000; Hird, 1999). This is despite certain criticisms that the medicalisation of intersexuality doesn't take into consideration sex and *gender as social constructs* (Fausto-Sterling, 1994).

Acknowledging the political nature of these bodies doesn't change current negative thinking and practice around intersexed bodies, but rather, it is a step in the right

direction. Due to the rise in interest within this arena alternative views on the medical management of intersex are slowly emerging. Theoretically, one perspective is viewing biological sex as a social construct and challenging the medical model through the lens of social constructionism. This study recognises it is helpful to begin to view the current management from an intersexed individual's and parent's perspective and less from a medical, paternalistic approach. ([www.medhelp.org/www/ais/](http://www.medhelp.org/www/ais/)).

To recap, Chapter one mostly works through the different theories of intersexuality and changing views of this subject. Importantly, the first chapter is very much viewing intersex as a theoretical subject. Chapter two brings to the fore intersexed peoples' experiences and compares these particular ideologies and theorist's concerns from chapter one. Some questions will hopefully be answered: How easy is the psychosocial approach to maintain? What does this maintenance depend upon? Does surgically reconstructed genitalia help or hinder this?

It is important to note here, that within this study not all of the participants acknowledged or identified themselves as intersexed, in fact very few of them did. The participants' perceptions of themselves were explained more in terms of; 'women with medical conditions' and in one case, identification was made as 'a male with CAH and another identification was made as a 'male'. Despite this, it is important to remember that intersexuality has an important place not just in the perceptions of intersexuals, but as a theoretical concept. As a theoretical concept, intersexuality has implications in terms of all biological sexes and genders. My interest in terms of what intersexuality can illuminate about the everyday social construction or performativity (Butler, 1990) of sex and gender by all persons. Viewing it from this space intersexuality is seen as a “*site of flexibility*” available to all. However, I do not wish in anyway to de-politicise intersex support group work and lived experience in this area<sup>4</sup>, as there is a significant difference between *theorising* and *living* as intersexed person.

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<sup>4</sup> Keeping in line with and by no means discarding intersex academics and support group members' work here is referring mainly to such people as; Stephen Whittle, “We elucidate in stark black and white (or should that be shades of gray) the discursive processes involved in the subjugation of all outlaws whether

### **...The beginnings of the medical management of Intersexuality**

In 1937, the urologist Hugh Young of the Johns Hopkins University published a Volume of genital abnormalities. This book was seen as somehow different to contemporary studies because of its remarkable open-mindedness and scientific insight. Young drew from a wealth of documented case histories to demonstrate the study of "accidents of birth". Young did not overtly judge the individuals he studied and referred to individuals who had had sexual experiences with men and women as "practising hermaphrodites". He described one participant Emma as feeling "quite content and even happy".

The extract below is very interesting. It highlighted how Emma viewed her body not only as female but additionally, she recognised her female body was an economic asset. This illuminated the hidden or invisible sexuality of hermaphrodites.

"Would you have to remove that vagina? I don't know about that because that's my meal ticket. If you did that I would have to quit my husband and go to work, so I think I'll keep it and stay as I am. My husband supports me, and even though I don't have sexual pleasure with him, I do with my girlfriends."

This extract shows that Emma is well aware of her 'wants' and 'needs', but recognises that her economic need surpasses her psychological, physical perhaps, emotional 'wants' or desires.

The potential danger of this comfortable perspective on sexuality became apparent and the research that followed began the suppression of intersexuality (Fausto-Sterling, 1994, p.20-24)<sup>5</sup>. In 1966, The New York Academy of Medicine argued regardless of the potentially changeable outward genital appearance, that the chromosomal sex should indicate and predict the sex definition (Fausto-Sterling, p.224). In 1969, the medical consensus was not quite universal. This can be gleaned from the tone of Dewhurst &

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non-white, non-male, non-able or non-anything else that leads to a position of disempowerment." (1998:pp269) 'The Journal of Gender Studies, Vol. 7, No. 3.

<sup>5</sup> Fausto-Sterling retraces institutionalised interest in hermaphrodites back further to the 1600's. In the 1600s a Scottish hermaphrodite living as a woman was buried alive after impregnating his/her master's daughter.

Gordon's book, which contrasts with the open-minded approach or the calm reasoning of Young's work. As Fausto-Sterling noted Dewhurst & Gordon give a "hysterical" (Fausto-Sterling, 1994, p.224) description of a new-born intersexed infant below:

"One can only attempt to imagine the anguish of the parents. That a new born should have a deformity ...[affecting] so fundamental an issue as the very sex of the child ...is a tragic event which immediately conjures up visions of a hopeless psychological misfit doomed to live always as a sexual freak in loneliness and frustration." (Dewhurst & Gordon: Cited in Fausto-Sterling, 1994, p.224)

Dewhurst & Gordon predicted that a miserable fate would fall on a child if they were improperly managed. This is despite being in existence very few studies to support this hypothesis, in fact some research is contradictory to this. For example, both Emma and another patient of Young's, Francis Benton felt happy with their bodies:

"...he/she had not worried over his/her condition and did not wish to be changed and was enjoying life".

Thus, Dewhurst & Gordon's approach attempted to rid intersex individuals of what these researchers interpreted and assumed as psychological pain. This was despite the results of previous research (like Young's study), which suggested a more positive and more strategic interpretation that pointed in the opposite direction. The modern day medicalisation and treatment protocols for intersexed individuals have mostly followed Dewhurst & Gordon approach. For example, it was this liberation of psychological pain that John Money built upon within his research and this idea directed how he shaped the medicalisation of intersexuality. Money well known for his work on gender identity has published much work on the psychological aspects of patients with 'abnormal' sex morphology. The medicalisation of intersex is usually cited to John Money because he focussed upon surgical procedures to re-align the physical sex characteristics of intersexuals to their gender.

His research examined how surgical procedures combined with gender identity socialisation could construct and maintain a 'normal' life and more importantly a 'normal' sexual identity. The medicalisation of intersex it seems has built a better understanding of surgical procedures in order to reshape 'abnormal' bodies into a recognised 'normal' body. However, it has added very little to understanding the wider socio-historical,

economic and cultural implications of how the medicalisation of intersexuality has institutionalised intersexuals. Unfortunately, this medical focus has hindered our understanding of the personal or emotional wants, needs or desires of people with these bodies.

This is what Foucault called the management of the "perverse bodies of the hermaphrodite and the homo", which is seen as part of a much larger social, medical, psychological project in the management of people and their bodies in general (Liao & Boyle, 2004, p.446). Liao & Boyle have commented in a recent issue of the *Psychologist* that the medicalisation of intersexuality was seen as necessary in order to protect against any psychological, social or economic threat. As they argued; "the focus on these perverse bodies reflected their potential to disrupt a social order built on gender separation and hierarchy (Liao & Boyle, 2004, p.446). This protection however, did not involve any safety for the intersexed individual, but rather, for the wider society.

When an intersexed infant presents itself as ambiguous at birth, (i.e. violating medical normative assumptions of sex) a Doctor begins a series of tests to determine the underlying condition. A team of medical practitioners can potentially become involved, such as; a physician, a paediatric endocrinologist, a paediatric urologist, a geneticist, a psycho-endocrinologist, a psychiatrist or a psychologist (Migeon, 2001). This multidisciplinary disciplinary team seek to identify the persons' "true gender". They then choose a gender assignment and a gender of rearing both in line with a two-sex model. This method is an example of what Foucault has described as "biopower" (Foucault, 1980). Knowledge that has been developed within medical discourse has "enabled physicians to control the very sex of the body" (Fausto-Sterling, 1994, p.20-24). Also, in line with this Fausto-Sterling has noted:

"Medical management of intersexuality certainly developed as part of an attempt to free people from perceived psychological pain (though whether the pain was the patient's, the parents' or the physician's is unclear)."  
(Fausto-Sterling, 1994, p.20-24).

There are certain generic standards of practice that are always adhered to: For example; "[g]enetic females should always be raised as females, preserving reproductive potential, regardless of how severely the patients are virilized. In the genetic male, however, the gender assignment is based on the infant's autonomy, predominantly the size of the phallus" (Donahoe et. al., 1991; also Riley & Wodehouse, 1989, p.569-571; Money, 1975, p.610; Oberfield et al., 1989, p.453-154; Fausto- Sterling, 2000; Dreger, 1998, 2000). Some scholars have argued that studies seem to concentrate more on anatomical appearance and function, than with investigating the relationship between certain conditions and psychosocial adjustment (Teifer, 1994, p.343-377; also Reilly & Woodhouse, 1989).

Of paramount importance within the present management of intersexuals is the initial communication between physicians and parents after the birthing process, whereby, physicians direct the parents not to assign a gendered name to their child. The parents are coached into how to avoid gender pronouns and to use phrases such as "our baby" and "our child", etc. (Dreger, 1999). Neutral terms such as baby, gonad and phallus are also used instead of penis, clitoris, testes and ovaries (Migeon, 2001). It is only after a "true sex" has been chosen and the parents are told of the result, that it is recommended to name their child. Some writers have commented this is a deliberate attempt to keep the infant's body unmarked with a social identity. This also insures the infant's scripted gender assignment is not undermined (Dreger, 1999; Fausto-Sterling, 2000)<sup>6</sup>.

Congruence and consistency of this message are at the fore of any follow up consultations with the intersex individual and parents (Peris, 1960, p.156-166; Slijper et al., 1994, p. 110-11, 14; Lee and Mazur, 1980, p. 156-163). Disclosing the truth about the individual's identity as intersex was seen as something that could threaten its success (Natarajan, 1996). This was because truth telling would involve informing the patient that their gender was questionable<sup>7</sup>.

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<sup>6</sup> The unmarking of the gender at this stage is premised on Money's original theory of gender neutrality at birth.

<sup>7</sup> Fausto-Sterling suggested that the research between 1930s to 1960s, (before surgical intervention became the norm) describes children who grew up knowing they were intersexed (though they kept it hidden) they

Thus, communication of diagnosis is based on the premise of non-disclosure of any ambiguous gender. This commitment is maintained after the Doctor cannot read the external sex characteristics clearly. A commitment that is based on an institutionalised (19<sup>th</sup> Century) binary system of differentiated gender marking. The ethos is that the medical practitioner will help the sex differentiation along in order to match an already existing gender identity. Success of this approach is based on continuous socialised gender symbols.

This method is ironic since the premise of this argument is based on surgical intervention before any arise within the child's mind. However, "for some intersexuals this creates rather than erases their intersexuality" (Dreger, 1999, p.86). Their intersex identity does not necessarily emerge for political reasons, but as a consequence of surgical experiences.

### **....How does the identification of intersex conditions take place?**

Medical practitioners communicate their recognition of intersexuality through phrases such as; "ambiguous" genitalia, "appears small", not within the "normal range" and "enlarged" clitoris. They judge the "correct" size from scales that have been developed (Riley & Rosenbloom, 1980; Oberfield et al., 1989; Sane & Pescovitz, 1992). Intersex diagnosis is made through a variety of medical procedures that determine the chromosomal sex and the syndrome that produced the genital ambiguity. How ambiguous do genitalia have to be that they are labelled intersexed? The standards permitted genital maleness are deemed to be no smaller than two and half cm's (about one inch) (Kessler, 1998, p.42-43).

The understanding is that if a male infant's genitalia fall's below this measurement they will not be accepted as male. What counts as a "definitive" gender marker varies with context and that these variations "are typically permitted to pass with little acknowledgement of gender's constructed nature" (Kessler, 1998, p. 42).

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adjusted well to their unusual status. She also stated that there was not one suicide or psychotic in any of the cases.

How big must a clitoris be before a surgeon will consider surgery? The "normal" clitoral size is deemed to be anything up to 0.9 cm. A "clitoris" is what a girl has, even if it is enlarged and accompanied fused "labia". "A clitoris is what a "girl" has, even if it is enlarged and accompanied fused "labia" (Kessler, 1998, p. 42). Kessler suggested that physicians are more likely to refer to clitoral size in terms of food, such as a pea or a small bean. The only reason for the precise measurement of the clitoris is not a medical one it a social reason so that it shouldn't mimic the penis (Kessler, 1998). If a child's phallus is deemed too small to be boy, the child becomes a girl whose fused labia and phallus are inappropriately sized/formed, who is then "fixed" so that she can later be allowed to procreate. A hypospadiac boy, on the other hand, must undergo surgery so that he can later stand to urinate. Intersexuality it seems is more a social issue than a medical one. What gender you assign the child determines how you will view the child's ambiguity and how you proceed with the necessary corrections (Kessler, 1998; Fausto-Sterling, 2000).

### **...Medicalisation of gender identity**

*"The difference between male and female is something that everybody knows and nobody knows". Money, (1987, p.13).*

It seems that almost everyone has a definite opinion about what a male or a female means. Moreover, people have views about whether males or females do or don't differ. Yet few people outside of academia are aware of how much research on intersexuality has impacted on our notions of what 'normal' sex is, and how it has been studied. An assumption that underpins all multi-disciplinary perspectives is that there are two biological sexes and each sex is understood through the lens of 'one gendered behaviour'. Multi-disciplinary scholars share other ideas such as, some believe that gender is predetermined before birth through pre-natal hormones (Diamond, 1965; Diamond et. al., 1996; Diamond & Sigmundson, 1997). Other scientific researchers suggested that gender is malleable at birth and thus not affected by hormones at all, that human beings can be socially constructed and conditioned into male or female (Money & Enhardt, 1972).

Proposing that even, if the sex is ambiguous at birth a human being can still be shaped into one gender or another.

It is impossible to approach the study of intersex from within a single discipline. So how do we gain a better understanding of intersexuality? Well, I will begin by retracing some of the ideas from the literature on intersex, although this approach is problematic and somewhat limited, as each study has been written for and from within a particular field of study. Moreover, each study has been recanted and examined by scholars and for their own particular theoretical purpose. For example, until relatively recently, intersexuality was only heard of within mostly medical and psychological circles, specifically from within textbooks that both explained and described how medical studies on intersex individuals was a good will gesture and a form of liberation for the mixed bodies. Most of these studies have had the primary function to outline anomalies within the body. They also advocate psychological success.

What is society's reaction when a child is born with ambiguous genitals? How do we respond to the knowledge that a determination of 'girl' or 'boy' can't be made? These intersexed individuals are viewed by our society as having abnormal sex morphology. Some scholars have suggested this fundamental presumptions about what 'normal' anatomical sex is can be retraced to the emergence of biological theories of sexuality in the seventeenth century (Foucault, 1980). Thus, not knowing how to respond has possibly stemmed from the emergence of biological theories of sexuality. These theories combined with legal conceptions of the individual led to rejecting the notion of any mixture of sexes within a single body (Foucault, 1980, p. viii). As Foucault suggested: "...this meant that when confronted with a hermaphrodite, the doctor was no longer concerned with recognising the presence of two sexes, juxtaposed, or intermingled. ...[B]ut rather with deciphering the true sex that was hidden beneath ambiguous appearances." (Michel Foucault, 1980, p.viii).

Alice Dreger noted that over the last 100 years the medical profession looked to the bodies of the then hermaphrodites (to the now termed intersexuals) to determine and understand the underlying causes of these 'conditions' or 'abnormalities' (Dreger, 1999).

Reassessing the binary logic of the sex system could solve the perceived problem with hermaphroditic bodies (Fausto-Sterling, 2000a). A fresh look to sex determination may present biological sex as something more complex, than previously accepted. Therefore, it may be beneficial to re-evaluate how we classify our sexed. A reaction to the knowledge that intersexed bodies are problematic might be to enact a corporeal ethic upon the bodies of those who do not display appropriate marking and behaviours. (Some research that can be criticised for utilising this approach are: Money et al., 1955; Money & Ehrhardt, 1972). This is similar to what certain theorists have suggested about the enforcement of gender categories (Butler, 1990; 1993) because intersex bodies are under question.

The rationale here is that a body without a clearly definable and determinable sex must have one made for it. This happens through surgery, hormones and psychosocial identification. If this does not happen the body is viewed as 'ill', 'diseased' or 'lacking' in some way and therefore cannot be socially accepted as 'normal'. This promoted a strong commitment to medical discourse that in order to become socially accepted and achieve an easy classification these bodies have to be 'healed' with medical treatment.

There is also a strong medical attention to 'curing' intersexed individuals both across the United States and within the UK. This focus is in order to provide them with the tools and skills to function well within our binary sexed social system (Rosenfield, Lucky & Allen, 1980; Glassberg, 1980). However, the medical interventions, that are performed to 'heal' intersexed people are extensive and may require some psychological work in order to help repair this transformation.

Some scholars studying intersexuality have responded critically to the dominant medical protocol of treatment for intersexuals (Beh & Diamond, 2000; Kipnis & Diamond, 1998). Some intersexed patients and parents have agreed with this and have criticised the medical management of intersexuality. Some personal story accounts have gone so far as to disagree with the whole medical "healing" and "surgically" process (Dreger, 1999; [www.isna.org](http://www.isna.org); )

These recent criticisms have been focussed on whether surgery is the best (Fausto-Sterling, 2000b; Alizai et al., 1982; Creighton, Minto & Steele, 1998). Many have pointed out the lack of long term follow up-studies (Chase, 1996; Kipnis & Diamond, 1998; Creighton & Minto, 2001). Other responses have been analysing whether intersex patients or parents fully understood all of the options before they consented to the medical management approach (Migeon et al. 2002). Thus, can ever be said that they gave there full consent (Ford, 2001).

What seems to be a growing concern to medical practitioners are particular criticisms with relation to gender neutrality. More specifically, critiques around the existence of psychosexual neutrality at birth and a general questioning of underlying presumptions guiding current medical management (Diamond and Sigmundson, 1997; contrast, however, Bradley et. al., 1998; more generally see Diamond et. al., 1996; Diamond, 1965; Reiner, 1996; Holmse et al., 1992). The psychosexual neutrality, which was first proposed by Money and is used at The Psychosocial Research Unit of Johns Hopkins Medical Centre has come under heavy criticism. This has been since the publication of David Reimer, the John/Joan patient whose case study provided proof that Money's theory of psychosexual neutrality actually had been successful. This case study guided thousands of medical interventions into the medicalisation of intersexuals (Colapinto, 1997; 2001).

### **...Money's research**

Money and his colleagues recognised the study of intersexuality could, “provide invaluable material for the comparative study of bodily form and physiology, rearing and psychosexual orientation” (Money, 1952, p. 8).

As mentioned previously, the medicalisation of intersexuality began with research work carried out by medical psychologist John Money and his colleagues between the 1950's

and early 1970's<sup>8</sup>. Although, research on hermaphroditism can be retraced earlier than the 1950's, this work represented the first series of publications concerning human hermaphrodites that combined psychological theories of gender identity with sex-reassignment treatment. Driven by the psychological healing of hermaphrodites, this work is of prime importance because John Money and Anke Ehrhardt (1972) published a research paper, which outlined a generic medical protocol for the treatment of infants who displayed sexual ambiguity. A general protocol that some surgeons still adhere to. Concern about this particular protocol is that this recommended process of care could have hindered intersexuals from developing psychologically healthy identities. Following this initial work many recommendations and inferences were established within the medical profession.

### **...Description and underlying assumptions of Money's protocol**

Here are some underlying assumptions of Money's argument, which Kessler has outlined. She questions why Money's theory has been the only theory that was communicated to parents of intersex infants. She goes on to critique gender theorists by arguing that they "were blinded to a number of unexamined and deeply conservative assumptions embedded in Money's argument." (Kessler, p.7) She underlines some of these assumptions:

- "1. Genitals are naturally dimorphic; there is nothing socially constructed about the two categories.
2. Those genitals that blur the dimorphism belonging to the occasional intersexed person can be and should be successfully altered by surgery.
3. Gender is necessarily dichotomous (even if socially constructed) because genitals are naturally dimorphic.
4. Dimorphic genitals are the essential markers of dichotomous gender.
5. Physicians and psychologists have legitimate authority to define the relationship between gender and genitals." (Kessler, 1998, p.7).

Number (6) would be that Money's theory advocates in order for an intersexed individual to develop a psychologically healthy identity, they must be assigned male or female sex within their first 18 months of infancy.

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<sup>8</sup> (Money, 1952, 1955, 1956, 1961, 1968, 1970, Money and Hampson, 1955; Money and Hampson et al.,

In order to analyse some of these basic assumptions, around the correlation between genitals and gender, Kessler proposed five questions:

- "1. How dimorphic are genitals?
2. How successful are genital surgeries?
3. Is gender necessarily dichotomous; could it be socially constructed to be trichotomous at --least?
4. Must genitals be the essential mark of gender?
5. How must the medical profession use its authority to manage a particular version of gender?" (Kessler, 1998. P.7-8).

(In Chapter two some of these questions will be used to disseminate the interview data).

With the emphasis on 'perfect' looking genitalia deemed to be achievable with little scar tissue if performed as quickly as possible it wasn't long before Money's protocol was widespread. Money's literature promoted the idea that intersex infants were to be treated as "a medical emergency" (Money & Ehrhardt, 1972). His treatment protocol also supported the rationale that there was a need for an infant's gender identity to be fixed as either male or female very early within their life. Despite, Money supporting the idea that gender identity formation was malleable in early childhood he also believed that ambiguity later was pathological.

How then was an intersexed child to make a transformation of endless possibilities available at birth to a fixed gender identity deemed necessary for psychological health? Money suggested that it was just as important for the parents to believe in this transformation as much as the child, in order to validate their child's identity (Fausto-Sterling, 2000).

Money recommended that it was fundamentally important to sex-reassign early because infants gender schema developed early and when developing this should match an infant's body parts. He viewed intersexuality as something developing from an abnormal

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1955a; 1955b; 1956; 1957: Hampson, 1955: Hampson & Hampson, 1961: Erhardt & Money, 1967).

process and suggested that these individuals "ought to have become male or female" (Fausto-Sterling, 2000, p46). Fausto-Sterling follows to criticized the underlying assumptions based within the medicalisation of intersex treatment and the medicalisation of gender:

"Did they then conclude that the categories of male and female had no biological basis or necessity? Absolutely not. These scientists studied hermaphrodites to prove that nature mattered hardly at all. But they never questioned the fundamental assumption that there are only two sexes, because their goal in studying intersexuals was to find out more about "normal" development." (Fausto-Sterling, p46).

Although these particular criticisms stem from a modern scholar there seems to be little similar criticisms at the time. The recommendations for this protocol were gained from his now famous case study of Joan/John (Colapinto, 1997). Historically, this case study is well known for the part it played in the nature/nurture debate in the 1960's and 1970's. It is usually cited as an example of how nurture can overturn nature. John was a male child who had lost his penis at about seven months of age after a circumcision accident. Using his theory of intersexuality John Money suggested the child should be raised a female and surgically altered to fit this new status. The now renamed Joan had a twin brother that Money suggested would be a control for this study.

Money's hypothesis was that if Joan as a female and her twin as a male achieved their gender identification successfully, then his protocol for intersexuality could be deemed successful. He famously used a quote from the mother of these twins that Joan had grown up to love her femininity; "she just loves to have her hair set" (Money, 1972, p.144). This text was presented as evidence that Joan was happy as a girl and that 'nurture' can overcome 'nature'. This study began to be cited as an overwhelming success and this continued over the next few decades.

However, contrary to this evidence it transpired thirty years later that this was not the case. Joan/John himself made public his discontentment about the whole process of sex-reassignment. His mother made another statement confirming that Joan was unhappy as a girl by corroborating John's memories of ripping off his frilly dresses (Fausto-Sterling, 2000). This lent support that Money's hypothesis had failed as the success of his intersex

protocol was based upon the reliability of this case. Moreover, this failure highlighted the difficulty of third party interpretation in case studies.

At the time of Money's case study of Joan and John he was challenged by a Psychologist Milton Diamond who questioned the scientific validity of Money's findings. He problematised the study by highlighting that Money provided no follow-up research studies to validate his initial findings (Diamond, 1965). Diamond argued that the Joan/John case study only promoted the notion that people were sexually neutral at birth.

Interestingly, Diamond criticized this case study not because he believed that nurture would overtake nature, but because nature predicts nurture. Diamonds' own stance argued that prenatal hormone development within the brain decided sexual identity and implicit in this assumption is that it would predict gender identity. Diamond agreed that there existed the potential for hermaphroditic individuals to assume sex roles that were opposite to their anatomical sex. However, he disagreed with Money's general conclusion. Diamond noted; "to assume that a sexual role is exclusively or even mainly a very elaborate, culturally fostered deception ... and that it is not also reinforced by taboos and potent defense mechanisms superimposed on a biological prepotency...seems unjustified and from the present data unsubstantiated" (Diamond, 1965, p. 148).

Diamond's contention did not prevent Money's original protocol from being utilised by medical practitioners (Diamond, 1982, 1993, 1996, 1997a, 1997b). Other scholars such as psychiatrist Zuger "dared to challenge Money" (Fausto-Sterling, 2000, p.68). Zuger claimed to have found several clinical case studies in which adolescent or adult intersexuals rejected their sex of rearing and insisted on a sex change. He argued that, "[t]he data from hermaphrodites purporting to show that sex of rearing overrides contradictions of chromosomes, gonads, hormones, internal and external genitalia in gender role determination are found unsupportable on methodological and clinical grounds" (Zuger, 1970, p.471).

Despite these challenges Money's research received widespread acclaim for work that analysed "differentiation of gender identity with intersex subjects" (Creighton, 2001, p. 1264). In Money and Ehrhardt's 1972 publication, Money produced a rebuttal of Zuger and Diamond's criticisms by stating,

"it thus appears that the prejudices of physicians skew today's hermaphroditic sex reassignment statistics in favor of change from girl to boy, and in male rather than female hermaphrodites. It would not be necessary to labor this point except that some writers still do not understand it" (Money & Ehrhardt, 1972, p.154).

Milton Diamond continues to challenge Money's theories and intersex management (Diamond, 1972; 1975; 1979; 1982; 1997a; 1997b). What is interesting is what has not been analysed is the notion to make the natural more natural (Sedgwick, 1990).

Currently, the treatment of intersexuality is in the process of being revamped and restructured. However this is geographically dependent. Some standards of care are being outlined within multidisciplinary teams within hospitals. These changes are a consequence of new research over the past ten years into standards of care and management practices. The tendency for physicians' paternalistic care has been changing and more patients and parents are being given a fully disclosed account of the condition in concern (Kessler, 1998). Surgical standards are being addressed in terms of surgery being carried out not just for the aesthetic outcome. Some medical practitioners have advocated that surgeons should consider post-surgical complications, such as sexual response and functioning. Moreover, practitioners are even considering and acknowledging the importance of gender identity correction that is inline with sex-assignment.

The question about surgery remains the same should an intersex child be subjected to the 'healing' practices (and in some cases updated guidelines) of surgical intervention? Or is this need to intervene more a reflection of reshaping these bodies back into line with the binary sex paradigm? How much does the presumed pathology of these conditions affect the practices of intervention and follow-up? What takes place in the child's mind when they are forced to go through medical interventions from surgery to hormone treatment, from daily reinforcement of gender roles to counselling: in order to conform to the binary

sex paradigm? It is postulated that this 'healing' or the 'curing' that takes place to conform their bodies more in line with nature can never be reached for the intersexed individual. An intersexed person does not fit into society's duality of sex and gender model and is under a constant 'unnatural' surveillance and control. Fausto-Sterling noted:

"Imagine a world in which the same knowledge that has been enabled medicine to intervene in the management of intersexual patients has been placed at the service of multiple sexualities. Imagine that the sexes have multiplied beyond current imaginable limits. It would have to be a world of shared powers. Patient and physician, parent and child, male and female, heterosexual and homosexual--- all those oppositions and others would have to be dissolved as sources of division. A new ethic of medical treatment would arise, one that would permit ambiguity in culture that had overcome sexual division. ...Thus hermaphrodites would be concerned primarily not about whether they conform to society but about whether they might develop potentially life-threatening conditions---hernia, gonadal tumors, salt imbalance cause by adrenal malfunction---that sometimes accompany hermaphroditic development" (Fausto-Sterling, 1994, p. 1-44).

However, in opposition to this utopia, the medical profession since the 19<sup>th</sup> century has codified the idea of the existence of two sexes and has institutionally sought to regulate bodies according to this notion of "one body, one gender" (Kessler, 1998, p.79-109; Fausto-Sterling, 2000b, p.1-44). This commitment to a standardised binary of sex model that underlies any medical intervention is still in existence despite, recent studies suggesting there are as many as 1.7% of intersexed births (Blackless, et. al., 2000, p. 151-166).

### **...Gender Socialisation**

Sex categorisation and normalisation processes are key to shaping the "doing of gender" through the social world (West and Zimmerman, 1987). West and Zimmerman argued that our social life is specifically organised to allow the legitimisation of certain ways of behavior over others. Between men and women "the social order can be seen merely as an accommodation of the natural order" (West and Zimmerman 1987). Some feminists may suggest that the circularity of these hierarchical arrangements are deliberately perpetuated in order that men remain dominant and women sustain a lower status. Also, legislative power changes have the potential to impinge on sex-categorisation and in turn they maintain gender relations. Foucault observed that knowledge is power. He

suggested the individuals of modern democracies were less controlled by violence or the economic power of employers but rather by the pronouncements of expert discourse. He argued that this was organised in 'regimes of truth'. In other words sets of understandings that legitimate social practices and attitudes. Thus, programs of social scientific research on subjects such as 'sexual deviance' have contributed to 'regimes of truth' (Cameron et al. 1999).

Therefore, the doing of gender, is not simply a 'role' utilised by the individual, it encapsulates power. As Foucault suggests power is all around us.

“We should admit...that power and knowledge directly imply one another: that there is no power relation without the correlative constitution of a field of knowledge, nor any knowledge that does not presuppose at the same time power relations.” (Michel Foucault, 1977, p. 27).

In other words gender as cultural is constructed in particular ways, which suggests that it is flexible in its meaning and construction. Gender is not simply a pre-fix from biological sex, but in line with what Foucault suggested it plays a large part in shaping our lives as gendered subjects, and this process is relational. This argument can also be extended to how intersexed individuals who are positioned in comparison to "normal" males and females. If our gendered world is specifically organised to allow certain ways of being over others, then how do intersexuals fit into our gendered culture ? Is the medicalisation of intersexuality another regime of truth?

### **...The Social Construction of Gender**

The study of sex is usually covered from within a debate of nature/nurture, which examines the relationship between biology and the environment<sup>9</sup>. The premise of sex difference is evident within interactionist accounts of nature/nurture. Within this context sex is usually referred to as an anatomical description of a body and gender describes

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<sup>9</sup> 'Nature as a concept' dates back to at least Plato and is the broad term encapsulating various ideas such as; genetics, heredity, nativism, innateness, and instinct. It generally in its extreme form refers to the humans genetic inheritance. 'Nurture' in its extreme form refers to ideas of John Locke, who suggested that the human mind is a blank slate when we are born. The nurture perspective is usually written and discussed in terms of social cultural, learnt behaviour or environmental influences.

how this body interrelates with the environment. This sexed body is usually described in terms of functionality as being one of two, female or male. The subject of this sexed body has been written about throughout the former part of the twentieth century in terms of sex, sex difference and social sex latter half in terms of gender.

What has emerged from recent scholars work is the suggestion that sex research needs to be re-examined and re-framed. This is perhaps because as Louise Newman points out; "[s]ex refers to biological sex and anatomy but even biology is complex and subject to interpretation. In nature there may well be more than two sexes or at least a variability in sexual characteristics" (Newman, 1999, p.395).

The question of reconfiguring has come about because some feminist scholars have challenged scientific assumptions around expected behaviors of male and female sexes. They have argued that there are particular biases in favour of male over female sex, both in the language used for description of these 'two sexes' and the expectation of particular behaviors (Kirkup & Smith-Keller, 1998; Lowe Benston, 1998). Interest in 'gender' as something separate from 'sex' is broadly linked to Freud's *gender subjectivity* in his theories of sexuality in which he catalogued the achievement of *gender subjectivity* as something achieved in the *psyche* through appropriate behavior in line with ones sex<sup>10</sup>.

Feminists in the 1960's (such as Greer, 1970; Millett, 1977, Oakley, 1972) actively utilised Robert Stoller's (1968) re-reading of Freudian psychoanalysis in order to separate biology form culture<sup>11</sup>. During this time it was deemed a positive move to view sex and

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<sup>10</sup> According to Freud, central to the transition from pre-odepal stage of polymorphous perversity to heterosexual maturity is the constitution of the 'unconscious', that is a site where meanings and desires which do not conform to societies laws must be repressed. These repressed desires always threaten the coherence of the conscious subject and can lead to neurosis if not well managed. Both for boys and girls, their relationship to their mother is primarily important, however it develops in different directions. Girls must become aware of lack of penis making them redirect their love to the father. Ultimately they are forced to redirect their desire to other men. Boys relinquish their love for their mother y redirecting it to other women and they identify with their father. Girls change their gendered love object from mother to men and transfer sexual excitement from penis like clitoris to vagina.

<sup>11</sup> Robert Stoller a contemporary psychoanalyst, is an authoritative source for the recent prominence of writings, which focus on gender. In order to account the etiology of transsexuals and transvestites Stoller (1968) suggested that these were psychological anomalies and he developed a distinction between sex and gender. The explanation that he offered was that the biological sex of a person has a tendency to augment, though not determine sex and the appropriate gender identity for that sex (male -masculine).

gender as distinct. It seemed advantageous to feminist politics to view sex as biological and gender as socially constructed. Millet in 1977 wrote;

“[p]sychosexuality (e.g., in terms of masculine and feminine, and in contradistinction to male and female) there is no differentiation between the sexes at birth. Psychosexual personality is therefore postnatal and learned”(Millet, 1971).

Here, Millet cites Stoller as political and theoretical ‘proof’ or ‘support’ of sex inequality as something socially constructed (and therefore flexible) rather than (fixed) biological. So, throughout the 1970's, second wave feminist researchers began to use this conception of '*sex as biological and 'gender as a cultural construct'*'. These scholars were interested in directing the focus of sexual difference and politics, away from a biological comparative debate about male and female. However, some feminists didn't agree entirely with this separation. Kessler and McKenna, (1978) undermined feminism and scientific research by producing a new radical theory of sex and gender:

“What does it mean to say that the existence of two sexes is an ‘irreducible fact’? ... this ‘irreducible fact’ is a product of social interaction in everyday life and that gender in everyday life provides the basis for all scientific work on gender and sex”.  
(Kessler and McKenna, 1978:vii)

Kessler and McKenna are acknowledged as the first to reject the sex/gender distinction, as a point of departure from feminist utilisation of sex and gender. They critiqued the use of such a distinction because they argued it is used with biological definitions that only promoted two types of sexes and two types of genders. Therefore, in rejecting these definitions they suggested that “sex is as much a continuum as gender, and therefore need not be separated linguistically from it” (Diamond, 2000:51). They were first to question the *reality* of how gender is constructed

Later, other feminists began to question the sex/gender distinction. A more theoretical approach from feminist theorist Gatens (1983), also problematised the sex/gender distinction by referring to Lacanian concept of the symbolic imaginary with her notion of the “imaginary bodies”. She argued that feminist philosophy must begin with an analysis of our social and sexual imaginary; and it must address the issue of the symbolic

representation of women. Her essays explore the ways in which male philosophers have theorised the human body.

“Masculinity and femininity as forms of sex-appropriate behaviors are manifestations of a historically based, culturally shared phantasy about male and female ideologies, and as such sex and gender are not arbitrarily connected. The connection between the female body and dominant ways of imagining them. She claims that the orthodox account of the femininity is not arbitrary in the same way that the symptom is not arbitrary related to its etiology. Hence, to treat gender, the ‘symptom’ as the problem is to misread its genesis.” (Moirra Gatens 1983, p.56).

Using metaphors, symbols and ready made images of sexual difference that dominate our lives and our imaginations; Gatens suggested how women and men are formed through the gender/sex distinction claims that the social determinant of ‘personal identity’ operates at the level of ideas, the level of the ‘mind’. She suggested what this account fails to note is the obvious divergence between feminine behaviour and experience, or experience that is lived out by a female subject and feminine behaviour or experience that is lived out by a male subject. Consequently, this alternative approach is in line with Kessler and McKenna who are both advocated that sex and gender are culturally constructed ideas that can be interpreted and imagined differently.

Here Teifer (2000) paraphrases and abbreviates Garfinkel's (1967) text on gender:

- "1. There are only two genders, and everyone is/has one.
2. Gender is lifelong, invariant, and unchangeable.
3. Exceptions to two genders are jokes or abnormalities.
4. Genitals (penis and vagina are the essential sign of gender.
5. The categories are created by nature, and membership in a gender category is assigned by nature."

There are differing stories of what ‘gender’ is and where ‘gender’ is located. The search for ‘gender’ immediately assumes an enlightenment idea that we can uncover the "truth" of an essential essence. This has been a preoccupation of psychological investigations of logging certain feminine and masculine behaviors, which are assumed to be interrelated to biological sex. In opposition to this, a sociological perspective claims to make sense of ‘gender’ as a socially prescribed ‘action’ or ‘behavior’ (West and Zimmerman, 1987). A ‘behaviour’ or ‘role’ which is regulated by laws and maintained by media representations,

prescribing certain 'stereotyped roles' to occur under particular settings (e.g. heterosexual relations) and regulated through everyday interaction with others (Kessler and McKenna, 1978). Kessler and McKenna (1978) argued that gender is an accomplishment that is constructed through cultural interaction that creates and maintains two genders. It is not a "fixed essence" that exists within the person (Stainton Rodgers, et a., 1999), but rather it is expressed in how we behave and how others react to our behaviour.

Postmodern discourse of the 1990's usually attributes these ideas of gender performance or the notion of "doing gender" to (Butler, 1990), however, they arise earlier from within Kessler and McKenna's (1978) work. Within this research they drew from Garfinkel ethnomethodological approach (1967). They do not make a distinction between sex and gender but propose that any distinction is a technical one "applicable to scientists in the laboratory and some textbooks" (1978, p. 7.). They used the word 'gender' not just to describe sex, but to encapsulate and call in to questions all of the dichotomies that are grounded within biology: chromosomes, hormones and genitals (Golden, 2000). Thus female and male were as socially constructed as categories of man and woman. However, the conceptual distinction between sex as biological and gender as social was and is still used (Unger, 1979).

Kessler and McKenna's publication *Gender* requires the reader to question the natural relationship about sex/gender. Their book queries how exactly gender is created and attributed? They presented a chapter on transsexuals in order to investigate the process of gender construction and social attribution. They argue that although transsexuals can refute the unquestioned propositions about our gendered culture, genitals still remain are the essential markers of gender (Kessler and McKenna, 1978). Kessler and McKenna's work suggested that gender acquisition is a two way process, " with most of the work [being] done for the displayer by the perceiver" (1978, p.5).

Later in a retrospective response to their ideas around gender and genitals Kessler and McKenna (2000) comment on the suggestions that the transgender movement (Teifer, 2000) and intersex movement (ISNA, 1999) have positively impacted on the relationship

between clinicians and people who want to change their gender. However, they suggest that this positive communication is only achieved through the person acknowledging that they are one gender or another and that gender is a fixed category (Kessler and McKenna, 2000). Golden (2000) suggested that "the natural attitude would certainly be destabilized by knowing that there are woman with penises...but since genitals are not clearly visible, many people remain unaware of such diversities" (Golden, 2000, p.31). Kessler and McKenna respond to this by agreeing that it is important to unveil and criticize social pressures to alter the body either; surgically or hormonally. However, "when it comes to gender these are not just 'self determination' decisions- like getting a body piercing" (2000, p. 70). They argued that until the natural attitude changes within individuals about how we each live our own gender then we all would still perform our gendered role within the gender system.

"In our everyday lives we do not treat gender as problematic, do not treat biology as constructed, and sometimes even continue to believe in genitals as essential defining features. In other words the natural attitude has not changed." (Kessler and McKenna, 2000, p.70).

Kessler's approach to the study of intersexuality is based on her perspective developed with McKenna, (1978). Hausman has critiqued Kessler's analysis of the study of intersexuality (Kessler,1999). Hausman has problematised the use "gender" to describe a physician's original assignment of an infant's sex or a surgeon's construction of a vagina/ or genitals. She argued to do this ignores the fact that these professionals work with material signifiers. She suggested the significance of this has to do with the way gender has been articulated within medical discourse as; "one component in a panoply of sexual signifiers, although different form the rest in that it is a psychosocial category rather than a physiological or anatomical one" (Hausman, 1999, p. 75). The Doctors who work with intersexed individuals "understand themselves to be working with "sex" in a context that accepts the nature/culture distinction between sex and gender" (Hausman, 1999, p. 75.).

Hausman advocated that the maintenance of the sex/gender distinction does not relegate sex to the realm of scientific fact, but rather it provides an opportunity to critically analyse sex and gender from within that context. She proposed that prior to the use of the concept "gender" within the twentieth century as a social sex signifier, the category of sex itself was a signifier, which encoded both biological and social categories. As she notes;

"gender was no less operative in social relations but it went unmarked as a separate aspect of sex." (Hausman, 1999 p.75). Sex came only to refer to biology when the technology developed and had advanced to the point whereby, clinicians could intervene at the level of physical sex (and therefore change it).

### **...The Performance of Gender**

“Although the unproblematic unity of “women” is often invoked to construct a solidarity of identity, a split is introduced in the feminist subject by the distinction between sex and gender. Originally intended to dispute the biology-is-destiny formulation, the distinction between sex and gender serves the argument that whatever biological intractability sex appears to have, gender is culturally constructed: hence, gender is neither the causal result of sex nor as seemingly fixed as sex.” (Butler, 1990:82)

In 1990, the philosopher Judith Butler published an influential book called *Gender Trouble: Feminism and the Subversion of Identity*. This is a postmodernist re-conceptualization of gender. It makes use of a concept familiar to linguistics and discourse analysis from speech act theory performativity. This provided a new way of looking at gender, moving gender from being a fixed essence to a kind of performance. This extends to the traditional feminist account whereby gender is socially constructed rather than "natural", as Simone de Beauvoir suggested; "one is not born, but rather becomes a woman". Butler suggested that becoming a man or a woman is a constant repeated performance. Thus, this is a postmodern approach of deconstructing gender behaviour, locating it somewhere between structure and agency and this she terms “performativity” (Butler,1990, p82).

Therefore, for Butler gender is "the repeated stylization of the body, a set of repeated acts within a rigid regulatory frame which congeal over time to produce the appearance of substance, of a 'natural' kind of being" (Butler, 1990, p. 33).

Butler sees how the fundamentalism of gender and its practices are seen as the fictional and parodic repetition (performance) of the original that reveals the original to be nothing more than a myth. For Butler, the self and gender do not precede the performance: the role/performance is gender: defining it as it simultaneously produces it. Performance then does not exist in some transcendental realm, taken on and enacted by a "true self"; performance rather constitutes the gendered subject. Thus, Butler suggested we operate within a moral certainty of a world of two sexes, taking-it-for-granted that sex and sex categories are congruent. However, physical differences should not be understood as the forerunners to gender; rather they should be identified as a consequence of gender. Notions of femininity and masculinity should not be seen as referring to some putatively pure sense of anatomy but they could be taken as semantic equivocations.

Butler in her selection of Freudian theory suggested that gender may not be the identification of one sex, nor one object, or a fantasy, a set of internalised images and not a set of properties governed by the body and its organ formulation. But it can be viewed as a set of signs that are internalised. They are psychically imposed on the body and on one's psychic sense of identity, and thus not a primary category, but an attribute, a set of secondary narrative effects. Gender is thus a fantasy enacted by "corporeal styles that constitute bodily significations" (Butler, 1990, p.34). In other words, gender is an act, a performance, and a set of manipulated codes, costumes, rather than a core aspect of essential identity.

Thus, gender becomes intelligible through the "heterosexual matrix" which she defines as; "the grid of cultural intelligibility that assumes for bodies, and genders are naturalised" (Butler, 1990, p.34). This is characterised by

"a hegemonic discursive/ epistemic model of gender that assumes that for bodies to cohere and make sense there must be a stable sex expressed through a stable gender

...that is oppositionally and hierarchically defined through the compulsory practice of heterosexuality" (Butler, 1990, p.34)

Hausman (1995) has examined Butler's argument and suggested that both sides work to "demonstrate the problematic conceptual position of gender in the field of its operations" (Hausman, 1995, p.178). She follows on to state that:

"Butler might argue that since sex is mediated by gender, and gender is the foundational category that regulates sex as sexual difference in a binary opposition-- to re-deploy gender and proliferate its meanings would be to reconfigure the possibilities of sex" (Hausman, 1995, p.179).

Hausman takes Butler's argument further by suggesting it is possible to re-conceptualise the sex/gender debate past the nature/nurture tendencies in order to rethink the category of sex as representational of both the body and its culture. In other words not just in term of the concept of gender as foundational and analysed as something separate from sex/ (body).

" [W]hile cultural perceptions regulate the articulation of "sex" historically, influencing and producing particular representations of sex as the natural, original condition of the body in sexual difference, the specific conditions of gender have not-- until the latter half of the twentieth century. It is possible to rethink sex as a category of representation that refers to both body and culture." (Hausman, 1995, p.179).

Hausman suggested that it is more profitable not to critically (theoretically) attack sex because the discursive nature of science, usually include counter discursive tendencies. (Hausman, 1995, p. 179).

### **...What is the reality of sex?**

*"Do we truly need a true sex? With a persistence that borders on stubbornness, modern Western societies have answered in the affirmative. They have obstinately brought into play this question of a "true sex" in an order of things where one might have imagined that all that counted was the reality of the body and the intensity of its pleasures."*  
(Michel Foucault, 1980:vii)

To our society sex is defined as "the sum of characteristics which distinguish an animal as male or female; either of the divisions according to this, or its members collectively",

or to be sexless- “is of neither sex”<sup>12</sup>. This definitive description presents the idea that two sexes are truly in existence, because without either one would be sexless. Culturally, we place a great deal of importance to the existence of two true sexes. Why we have this preoccupation with the ideology of a true sex is not as clear-cut. Psychoanalysis has been one of the most dominating psychological theories of the twentieth century. The psychoanalytic perspective placed an important emphasis on the *penis* as the distinguisher of sex. Developing on from this stance with Lacanian theory provided more understanding as to why the penis defined two true sexes. It described the *phallus* as relating to cultural power.

Within the scientific community, *the reality of sex* has gone relatively unquestioned in the light of historical reviews and scientific evidence shows a variety of combinations of sexes<sup>13</sup>. In Western culture science defines biological sex, and sex defines gender “but the definition of sex is more complex than we may imagine at first glance”<sup>14</sup>.

Within many different disciplines sex is taken as true given, a biological reducible fact. In contrast, over the last 30 years gender has been seen as either a psychological phenomenon or socially shaped, or both. Some schools of feminism rest on the assumption, that men and women are radically different human beings<sup>15</sup>. As Pat Califia suggested:

“Sometimes this difference is talked about in ways that make it sound as if it is biologically based; sometimes it is attributed to social learning or conditioning that is so intense as to be ineradicable” (Califia, 1997, p. 44).

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<sup>12</sup> The Chambers dictionary definition of sex (1998).

<sup>13</sup> For historical reviews of the intersexed person in ancient Greece and Rome, see Leslie Fiedler, *Freaks: Myths and Images of the Second Self* (New York: Simon and Schuster, 1978); and Vern Bullough, *Sexual Variance in Society and History* (New York: John Wiley and Sons, 1976). For the Middle Ages and Renaissance, see Michel Foucault, *History of Sexuality* (New York: Pantheon Books, 1980). For the eighteenth and nineteenth centuries, see Michel Foucault, *Herculine Barbin* (New York: Pantheon Books, 1978); and Alice Dreger, *Hermaphrodites and the Medical Invention of Sex* (Cambridge: Harvard University Press, 1998). For the early twentieth century, see Havelock Ellis, *Studies in the Psychology of Sex* (New York: Random House, 1942)

<sup>14</sup> Gill Kirkup and Laurie Smith Keller (1998:p3) in “Inventing Women: Science, Technology and gender”.

<sup>15</sup> Liberal, Radical etc.

### ...Sex Difference Research

Sex difference research is always studied as if there were only two clear sex types with no variations. The idea that anatomical sex is not a simple task to describe is both new and old. For example, most people both inside/outside of academia have not heard of intersex as (in its simplest form) representing an example of sex variation. However, Freud in his (1905) paper outlined the idea that because anatomical sex was historically and culturally specific it was difficult to represent its definition correctly:

"[N]o healthy person, it appears, can fail to make some addition that might be called perverse to the normal sexual aim; and the universality of this finding is not itself enough to show how inappropriate it is to use the word perversion as a term of reproach. In the sphere of sexual life we are brought up against peculiar and, indeed, insoluble difficulties as soon as we try to draw a sharp line to distinguish mere variations within the range of what is physiological from pathological" (Freud, 1905, 26f).

Although, Freud is mostly studied for ideas about sexuality, the last sentence of this quote can be interpreted as representing Freud's knowledge of sexual anomalies. What can be inferred from this is acknowledgement that there is no 'natural' point where we can decide what is 'normal' and 'abnormal', that there are "mere variations within a range" of physical sex and sexual identity. He suggested that the cultural trend in which his theories are set construct an abnormal sexuality from a normal sex. Bringing this into the context of Fausto Sterling's critique of John Money's ideas about gender identity and intersexuality (Fausto-Sterling, p46). Even with theoretical base and biological evidence that anatomical sex is on somewhat of a continuum variation the cultural trend of not questioning the assumption of two sexes is still alive today.

"Our observations of the world suggest to us that there are two categories of human being - men and women. Social constructionism would bid us to question seriously whether even this category is simply a reflection of naturally occurring distinct types of human being" (Burr, 1995, p.3).

Intersexuality relies on a particular biological stance and it incorporates an example of a distinction between sex and gender. This view advocates a tight correspondence between sex and gender that there are two sexes and two genders. However, writers such as Laqueur (1990) have suggested that "sex is a shaky foundation" (Laqueur, 1990, p.135) and can be socially interpreted also not only be biologically definable. As Crouch

(1999) puts it, "with instabilities in sex can often come instabilities in gender" (Crouch, 1999, p.29).

### **“Coming out” and the Self-Disclosure experience.**

“One must decide ‘to display or not to display, to tell or not to tell, to let on or not to let on, to lie or not to lie, and in each case to whom, how, when, and where.’” (Goffman, 1963).

The existing body of literature on self-disclosure provides the basic theoretical framework within which the discovery of a child’s sexual orientation is generally viewed (Ben Ari 1985). The concept of self-disclosure became a focus of interest in the early 1960’s<sup>16</sup>. Since that time research into self-disclosure has taken different forms in terms of the topics emphasised or studied and the methods used to study the phenomenon. The process of self-disclosure has mostly been associated with sexual orientation, however this process is a generic concept and can be used inline with intersexuals and the disclosure of their identities. It is often argued to be a difficult and complex process for many adolescents and adults to disclose information around issues of sex, gender or sexuality. This is because our society works within a sex and gender system whereby, there are only two expected norms of either sex or gender.

Social Scientists have become increasingly aware of the relational tensions and difficulties faced by individuals who possess traits or attributes that are potentially stigmatising. Erving Goffman argued particular interactional problems encountered by people vary according to the visibility of the attributes that make them ‘different’ or ‘less desirable’. For some individuals, like those who are physically handicapped, the trait is evident to the onlooker.

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<sup>16</sup> Self-disclosure or coming out can be dated back to Freud 1920 in his vivid description of real-life contemporary of the fictional Idgie and Ruth, an adolescent coming out in middle-class Vienna 1920. Freud describes scenes and situations still common in families nearly eighty years later (Domenici and Lesser 1995).

Goffman referred to these persons as ‘discredited’ because the discredited persons cannot hide stigmatising attributes. Goffman offers a second classification ‘discreditable’. For the group discreditable, the issues related to interaction become more complex because a choice is involved. One can conceal it or make it known. If one chooses to continue concealment, then one must develop strategies for covering and dealing with the anxiety of keeping the secret. If one chooses to disclose, then one must face the possibility of rejection. Self disclosure has been singled out by many scholars as a central experience in the lives of those who possess discreditable characteristics. In these studies researchers identified strategies for concealment and strategies for attention reduction once the stigmatising attribute is revealed.

Ben Ari (1985) suggested that previous researchers may have treated too lightly or have overlooked the perceptions and reactions of the discloser. Moreover, situations in which the participants have different perceptions of the disclosed information, e.g. a discloser perceives the disclosure as positive (or at least not negative), while a discloser perceives it as negative, have not been studied. Gay individuals have often sought support in the disclosure to their friends before disclosing to family members. However, one of the pivotal moments in the lives of gay or lesbian individuals is the unveiling of their sexual orientation to their families. Troiden (1988) suggested that gay individuals do not perceive “being gay” as negative information. Yet, they have to deal with a disclosure that is more often than not known to be stigmatising and negative by the recipients of their disclosure.

### **Intersex Support Groups UK**

Consultant gynaecologist Sarah Creighton recently noted that intersex can be detected at any time during the life course. It may occur when an infant is born with ambiguous genitalia or it may appear later in childhood, or adolescents. Diagnosis may also be detected from an affected sibling (Creighton, 2001). The category of intersex covers a variety of medical conditions such as (AIS) androgen insensitivity syndrome (previously known as testicular feminisation condition), (CAH) Congenital Adrenal Hyperplasia,

Klinefelters Syndrome, Anorchidism, Turners Syndrome, Hypospadias<sup>17</sup>. Past definitions of intersex conditions were classified into three groups; female pseudo-hermaphrodite (this includes CAH women), male pseudo-hermaphrodite (which refers to XY females such as AIS) and true hermaphrodite. Sara Creighton advocated the use of the term intersex as both clinicians and patients have found these terms confusing and offensive and instead they now use the name of each condition.

The two conditions that are of relevance to this study are Androgen insensitivity syndrome (AIS) and Congenital Adrenal Hyperplasia (CAH). Generally, AIS refers to a person with XY chromosomes and who is insensitive to androgen (which prevents the testes to descend and the genital organs to develop as a penis). Two forms of AIS have been medically described as, Complete Androgen Insensitivity (CAIS) and Partial Androgen Insensitivity (PAIS). Individuals with (partial) PAIS have XY chromosomes just like (complete) CAIS people. However detection is mostly made at birth to PAIS individuals because they are born with ambiguous genitalia whereas, CAIS people are born with (typical) female genitalia. What is noticeable is that both PAIS and CAIS have bodily characteristics that are not 'typically' expected from (male) XY chromosomes.

CAIS is more often detected later than birth because the genitalia display a 'normal' appearance. Also, the term CAIS is a medical description given to a person who has (typically male) internal testicular gonadal tissue and has (typically female) external genitalia and a small vagina (or in some cases no vaginal opening and a non-typical urinary tract).

In some cases patients are diagnosed when menstruation does not occur, or when considering sexual relations or fertility. Other times it is later or never at all. For

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<sup>17</sup> The intersex support groups within the UK are: Androgen Insensitivity Syndrome support Group (AISSG), Adrenal Hyperplasia Network (AHN), Congenital Adrenal Hyperplasia Support Group (CAHSG), Anorchidism Support Group (ASG), Klinefelters Syndrome Association (KSA), K-S Link (another Klinefelters group), Turners Syndrome Society (TSS), Turners Syndrome Support Group (TSSG), Hypospadias Support Group (HSG). There are three that also cover other conditions: Genetic Interest Group (GIG), Child Growth Foundation (GGF) and Children Living with Inherited Metabolic Diseases (Climb).

example, one 36 years old woman was diagnosed when she was 19 years old. She told me that it was only when she was considering sexual relations that she noticed her body as different. Also, a 59 years old AIS woman said that she had recently learned about her AIS condition when she had visited her doctor for a check-up. The doctor described to her that she had lumps that may be carcinogenic and he advised her to have what he described as 'a hysterectomy'. She later believed this to have been the removal of testicular tissue. According to medical practitioners, diagnosis can also be gained through patients complaining of pain due to swellings in the groin area and are more often than not this is identified as testes ([www.medhelp.org/www/ais/](http://www.medhelp.org/www/ais/))<sup>18</sup>.

The second support group is the Congenital Adrenal Hyperplasia (CAH) support group that offers help to persons with CAH<sup>19</sup>. With CAH diagnosis can be detected at birth due to ambiguous genitalia and/or no vaginal opening, and/or no typical urinary tract. CAH refers to a person who has (typically female) XX chromosomes, ovaries and ambiguous genitalia. CAH is medically described as a consequence of the production of large amounts of androgens (by the adrenal glands of the foetus), which result in the genitals being "masculinised" ([www.climb.org.uk](http://www.climb.org.uk)). The prognosis for CAH people varies widely. At one extreme it can be diagnosed as a life threatening metabolic disease and this is medically explained, when aldosterone is completely lacking and the body loses salt. Medical practitioners have also noted that if the loss of salt in the urine is uncontrolled it can cause acute dehydration, very low blood pressure and/or vomiting.

It has been estimated that about 80% of CAH people are salt losers and 20% of persons with CAH the salt balance is considered 'normal'. It has been suggested that in stressful situations some non-salt losing CAH people may become salt losers, but there is no evidence to support this perspective ([www.climb.org.uk](http://www.climb.org.uk)). Moreover, most parents of CAH people question whether the categories of either 'salt-losing' or 'non-salt-losing' are the only options. CAH people (and parents) have outlined the difficulties of getting the

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<sup>18</sup> Support and help is offered to persons with CAIS and PAIS by the UK's Androgen Insensitivity Syndrome (AIS) Support Group (registered charity no.1073297).

salt balance right. Some have suggested that the categories may fall more along the lines of a continuum. Others question whether they or their children are ‘salt-losing’ at all. Also, they noted that medical practitioners may be over-prescribing salt tablets due to their lack of understanding of CAH.

Non-salt-losing CAH people who are brought up female are medically described as born with an enlarged clitoris with partially fused labia due to an *excess* of testosterone. Despite these people being already healthy the current medical guidance within Britain is to 'surgically repair' the enlarged clitoris. In non-salt-losing CAH people who are brought up as male, CAH produces no detectable signs at birth. The growth of the penis coincides with the onset of early puberty and diagnosis is made when the penis of the child begins to enlarge at an age earlier than (typically) expected. CAH is described as a ‘serious metabolic disease’ that can be 'life-threatening' due to 'salt-losing', which can result in ambiguous genitalia. However, 'ambiguous genitalia' are not in themselves a disease and do not necessarily need medical treatment (Kessler, 1998).

AIS and CAH are examples of two intersex conditions that are bodies that consist of male and female parts. These conditions come under the term intersex, with "inter" referring to "between" or "among". Intersex is usually associated with the naturalised language of a failing of the *natural* progression of the (typically male) XY chromosomes or the (typically female) XX chromosomes. AIS people are more often than not assigned female, due to the size of their small penis/enlarged clitoris. However, there are some AIS people (both identifying as either men or women) who are unhappy that their bodies have been medically constructed more towards a female body.

In the first chapter, I suggested that theories, which acknowledge *the medicalisation of intersexuality and gender and view gender or sex as a social construct* are not adequate accounts of the varying complexity of intersexed lives. Generally the term ‘gender’ is used to replace ‘sex’ and because of this reasoning there is *a gap in theorizing* between

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<sup>19</sup> CASSG is a sub-group of Climb (Children Living With Inherited Metabolic Diseases registered charity no. 283541).

the use of gender and its meanings and the use of and meaning of sex. Consequently, *the gap* produces and maintains gender behaviour and roles is already assumed to correspond to one's sex. As Kate Bornstein a gender theorist, talks about the problems with unquestionably connecting sex with gender. She writes here in the context of transgender theory and feminism.

“[r]ather than look at some underlying reasons for inequality, most people keep going on about differences between genders. *The differences are only what we decide they are.* By focusing on so-called “inherent differences” between men and women, we ignore and deny the existence of the gender system itself, and so we in fact hold it in place. But it's the gender system itself- the idea of genders itself-that need to be done away with. *The differences will then fall aside of their own accord*”. (Kate Bornstein, 1994, p.114).

As long as there are two and only two sexes (female/male) theorised within a medical discourse, then all gender will be seen as a reconstruction of those traits that are female/feminine and male/masculine. It is argued that intersexuals lives need to be examined in terms of how the medical management affects them psychologically. This is in order to re-conceptualise our sex/gender system. (This is analysed within chapter two). The next chapter on intersexed persons (from their personal experiences perceived) shows us how ideas around the fixity of gender have practical implications for mapping the future of children born outside the ‘normalised’ expectations of definitive sex. The continuing persistence of the observation of two chromosomally defined categories excludes the practical reality of a multitude of combinations, which make up sex<sup>20</sup>. Implications from this are that any other sex definition or gender behaviour is kept in the periphery to the orthodoxy of naturalness (Butler, 1990).

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<sup>20</sup> For example: “There is no standard legal or medical definition of sex” Julia Epstein (1990:104) quotes a medical textbook that says this. Biological sex results in variations of chromosome combinations (XX, XY, XO, XXX, XXY) internal gonad structure, hormonal dominance, secondary sexual characteristics, apparent sex, psychological sex, and sex or rearing.

## Chapter two

### Abstract

Dewhurst and Gordon predicted that a miserable fate would fall on a child if they were improperly managed. Money's research is based on this 'myth' of psychological pain.

Yet there are no studies to support this hypothesis.

This section tests out a variety of assumptions that were conjured up and given as a humane impetus to support the medical management of intersexuals. For example; there was little or no research evidence to support psychological suffering taking place in the minds of hermaphrodites prior to medicalisation or that they were lost in the world. Thus this section analyses whether the medical management of intersexuality has produced this psychological pain the very subject medicalisation was premised upon. Furthermore, whether it is useful to choose one gender over another and to focus on gender rather than biological sex.

Chapter one outlined the medicalisation of intersexuality through different theories of gender; psychosocial, biological social constructionist accounts. This section analyses how intersexed individuals' experience, correlates with these particular theories. How easy is the psychosocial approach to maintain? What does this maintenance depend upon? How does surgically re-constructed genitalia help or hinder this? How much does medical intervention help these individuals and their families? This section details a variety of emergent themes to determine how beneficial medical treatment has been for 16 adult intersexuals and 16 parents of intersexuals.

Individual interviews are with members of the Androgen Insensitivity Support Group (AISSG) and the Congenital Adrenal Hyperplasia support group (CAHSG). It brings together different themes such as; disclosure, surgical issues, growing up intersexed, intersex, transgender and gay identities, positive experiences, negative experiences.

## Introduction

## Methodology

*“Discourse analysts treat the variety of things that psychologists tell us they have ‘discovered’ inside us and among us as forms of discourse.... Traditional psychology is seen as consistently misleading us about the place of mental phenomena, which it invariably locates inside individual heads rather than between people, in language”.*

*Ian Parker (1997: 286)*

*“Telling the stories of our lives is so basic to our nature that we are largely unaware of its importance. We think in story form, speak in story form and bring meanings to our lives through stories”.*

*Robert Altkinson, (2002, p121)*

*"Everyday language and the construction of meaning are central topics in present social research. Nuclear concepts such as identity, society, person or power have been redefined using language and discourse as constitutive elements. "*

*Joan Pujoi, (1999; 87-88)*

In the previous chapter the medicalisation of intersexuality and gender have been explored. This paper presents an argument that the past medical literature on intersexuality and gender has not presented an effective way of dealing with intersexed conditions. It also suggests that the medicalisation of intersexuality "creates rather than erases their intersexuality" (Dreger, 1999, p.86). This section investigates intersexed peoples' (and their parent's) experiences and examines these through how they talk about their lives. Interest here is how their experiences correlate with some of the medical perceptions and theories that were reviewed within chapter one. For example: How well do physicians communicate an intersex diagnosis? Is the gender they are socially ascribed at birth easy to maintain? What does this maintenance depend upon? Does the surgical re-construction of their genitalia help or hinder people's experiences of living with intersexed conditions?

As Foucault (1972) suggested, identity and subjectivity are, in contrast, taken to be constituted through discourse and not discoverable through a transparent language or positivistic methodology that reflect reality (Burman and Parker, 1993; Potter and Wetherell, 1987; Henriques et al, 1984; Stainton Rogers et al, 1995). Thus, an alternative

method of investigation that focuses on the discursive production of subjectivity will be employed. In my analysis of the data I will utilise discourse analysis in order to unveil the social and political relevance to the support group members' experiences, and offer a better understanding of intersex.

"...a group of statements which provide a language for talking about a topic and a way of producing a particular kind of knowledge about a topic. Thus, the term refers both to the production of knowledge through language and representation and the way knowledge is institutionalized, shaping social practices and setting new practices into play.  
(du Gay, 1996, p. 43)

While approaches to discourse analysis differ, they also share some common characteristics. For example: the use of naturally occurring, unedited text or talk as data; focus on the significance and structuring effects of language; attention to the local and global context of discourse. Also, discourse as social practice, that is, how discourse users enact or resist social and political structures, an attention to the ways in which social members interpret, categories and construct their social experience and the use of interpretative and reflexive styles of analysis (van Dijk, 1997a; Burman and Parker, 1993).

Beyond these general similarities, discourse research differs in its focus and approach, between descriptive studies or critical studies (Philips and Ravasi; van Dijk, 1997a). Descriptive studies explore the discursive processes of social construction whereas critical studies focus explicitly on the reproduction of power relationships and how structures of inequality (Fairclough and Wodak, 1997) such as gender and sexuality are reproduced in discourse (Fairclough, 1995).

Within this context texts can be used as empirical data that articulate complex arguments about gender and sexuality in contemporary life (Denzin, 1994). Potentially what can be uncovered are various struggles of power, which underlie the creation and dissemination of such texts (Phillips and Hardy, 1997). Texts provide discursive cues to these power relationships and therefore through analysing texts, the power implications of various constructions of identity can be studied.

### **...The construction of social identity in discourse**

Burman and Parker suggested that identity is an ongoing process, which is accomplished through social interaction, particularly language and communication (Burman and Parker, 1993; see also du Gay, 1996; Phillips and Hardy, 2000). Therefore, social identity becomes internalised through social meanings. For example, discursive studies of sexuality and gender identity are not regarded as stable, fixed or inherent, but rather embodied and constructed in discourse. This constructivist view of social identity has implications for design and research. For example if social identities are seen as accomplished then they can only be interpreted through his accomplishment (West and Zimmerman, 1987; West and Festermaker, 1995). Discourse constructs social identity in society (Hardy, Lawrence and Grant, 1999; Mumby and Clair, 1997) and helps by defining different groups, interests and positions within this society (van Dijk, 1997b; Wodak, 1996). Thus, it is argued that social identity (in this case intersexual identity) within this setting offers an interpretative framework for social action (du Gay, 1996).

So, if language users engage in talk and text not just as individuals but as members of various social categories, then it is through analysing discourse that how these mechanisms function and relate can be viewed (van Dijk, 1997b). This is not to claim that this method could offer the only clear view in which to study a variety of intersex as a social identity. As it is sometimes difficult because there are an interplay of various social identities, which offer sometimes contradictory and complex discourse (Garsten and Grey, 1997; Hardy et al., 1999). What discourse analysis can offer is a setting to locate the fragmented subject through the constant reproduction of political, social and discursive processes (Hardy et al., 1999).

"Discourse about others is always connected with one's own identity, that is to say, with the question 'how do we view ourselves?' The construction of identity is a process of differentiation, a description of one's own group and simultaneously a separation from the 'others' ". (Wodak, 1996 p.126).

If discourse about others and is always connected with one's own identity it is because identity reproduced and sustains power relationships between different social groups. Intersexed identity has rarely been examined, the construction of gender and sexual identities have been the subject of critical discourse research for sometime. This is broadly referred to as the discourse of difference (Wodak, 1996). Gender studies research has explored how language use and behaviour constructs, reproduces and resists masculine and feminine identities, gender-based prejudice and inequalities (Gill, 1993a; 1993b; West, Lazar and Kramarae, 1997). Thus the current research project attempted to extend this existing 'discourses of difference' tradition to research another body-based system of social categorization intersex identity.

Undertaking discourse research presents inherent challenges because of the variety of different discourse analytic tools available (Burman and Parker, 1993). Burman and Parker warn against blurring approaches which subscribe to " specific and different philosophical frameworks" (1993, p. 3), van Dijk, (1997a) has advocated multi-method studies. It has been suggested that critical discourse may benefit from multi-dimensional approaches because they can contribute to "our insight into the role of discourse in society and the reproduction of inequality" (1997a, p.24).

Discourse analysis as a methodology can be seen as problematic as there are issues of "intention of the text" (Pujoi, 1999, p. 88). Language does not merely 'describe' the world but it 'acts' in the world thus, intentionality becomes a central concept (Harris, 1988). There is a potential problematic area within the relationship between the researcher and the text. This can be viewed as a problem of how to ground the researcher's access to the 'meanings' of the text. (Gadamer, 1960) argued that the author and the reader share a common language, an empathetic understanding. However this relies on the competence of the author to connect with the participants understanding of the "horizon of the text" (Pujoi, 1999, p. 89) and therefore interpretation becomes a fusion with the text than rather a process of revealing the text. Thus, interpretation is not about 'uncovering what is behind' but 'constructing it ' through the interaction between the text and the reader.

Therefore, discourse analysis as a ‘workable methodology’ (Potter and Wetherell, 1987:32), reflexively recognises versions of psychological phenomena as ‘public and collective realities’ (Burman and Parker, 1993:1). These realities are storied into being; created by and constituted within the language used to describe them. It is argued that selves, experiences, social and psychological properties and their significance are constructed through culturally available and mutually recognisable resources and practices (Widdicombe, 1993; Fairclough, 1989). Discourses are ‘systems of meaning’ which are both reflective and regulative of social and psychological phenomena.

This research uses this critical methodology as the means through which the ‘nature’ of subjective intersexed individuals and parents disclosees’ experiences are investigated as text. Turning to the text propels a transformation rather than a reproduction of previous psychological research (Burman and Parker, 1993) allowing the problems experienced by the recipient of self-disclosure to be analysed separately from the discloser. Additionally allowing, the re-conceptualisation of a ‘intersexuality’, sex and gender to be further understood through new terms. A terminology, which highlights a variety of discursive constructions and functions to reduce any problematisation of the self-disclosure any intersexual may experience.

According to Parker (1992) and Burr (1995) a distinction is made between what can be conceived as a top-down (radical) and bottom-up (less radical) approaches<sup>2</sup>. Foucauldian and feminist (poststructuralist) notion of discourse, power, ideology and social process are all drawn upon within the ‘top-down’ approach (e.g. Hollway, 1989; Billig 1991; Parker, 1992; Stenner, 1993; Malson, 1997a). *Discourse* is used here, instead of *repertoire* to describe discursive structures, practices, cultural narratives and the way people position themselves in and by discourse. Discourse, rather than reducible to just language and speech, is seen to be determined by underlying linguistic conventions that

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<sup>2</sup> The ‘bottom-up approach refers to discourse that provide a descriptive analysis of conversation; how people talk about phenomena. This approach is criticised as in restricting the analysis to a particular text, it evades issues of politics and power (e.g. Parker, 1997).

include different ideologies and serve social and political interests (e.g. Foucault, 1977); Fairclough, 1989). Malson (1997b) and Ussher (1997) prescribe a feminist understanding of this approach by concerning themselves with how discourse analysis engages with the extra-discursive of social reality and corpo-real bodies; that discourses have powerful and material effects on (discursively) embedded and embodied subjects (Malson, 1997b).

The ‘top-down’ approach to discourse analysis as a theoretical perspective is adopted here. The analysis will focus on various discourses (narratives, stories) used by the participants to construct and position themselves and their family member in particular ways. Furthermore, highlighting to what extent the discourses are derived from underlying social practices and conventions (particularly medical discourse); and providing an opportunity to analyse the construction of ‘intersexuality’ and ‘gender’. There are three primary (but not prioritised) questions: (1) How/To what extent can intersexuality be less problematised and re-conceptualised? (2) To what extent does this re-conceptualisation disrupt the medicalisation of intersexuality and (3) Will new terminology help with regard to intersex discourse.

## **Methodology**

### **Participants:**

Participants were recruited from two intersex support groups that the researcher and specifically targeted because they were intersexed or they were a parent of an intersexed individual. The sample represents a cross section of the current AIS and CAH support group community. This consisted of interviewing 32 participants, 16 parent members and 16 adult members from each group; 8 AIS parents, 8 AIS adults; 8 CAH parents and CAH adults. All participants are of ages between 31-65 years.

## Procedure and Analysis

This analysis is based on data (transcribed discussed)<sup>4</sup> collated from a series of four in depth structured interviews of mutual exchange. Thirty-four interviews were carried out and recorded with consent in the participants' homes. One interview was conducted in an outside location, (this participant did not want to conduct the interview at her home). Another interview was conducted at the participant's place of work. In contrast to a non-structured format of questions (Malson and Ussher, 1997<sup>5</sup>) a semi-structured format of questions was used. The researcher therefore was advantaged by presentation of a list of questions that directed information according to presupposed areas of significance. The questions given were set under a variety of headings; communication of diagnosis; surgery; childhood; living with intersex condition; medical management and disclosure. The interviews covered a wide range of issues and particular attention was paid to the medicalisation of intersexuality and how successful this process has been.

The theoretical framework has been specified, the analytic approach will apply three characteristics of discourse (analytic tools), which were first described by Foucault (1972) and later used by Potter and Wetherell (1987): *variability* (multiplicity and contradictions of meanings), *construction* (discursive utilisation of pre-existing cultural and linguistic resources) and *function* (what emerging discourses achieve particularly in relation to power and knowledge). This procedural approach to the analysis will allow particular issues raised in the first chapter to be re-addressed in the light of the data.

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<sup>4</sup> The transcription code is used in this analysis indicates speech features such as pauses and emphasis but is the readability of the text which is stressed. Detailed reproduction of speech features, such as length of pause (as in Potter and Wetherell, 1987), are therefore not transcribed. In the transcripts italics indicate emphasis of words; (...) indicates a pause greater than 4 seconds; = refers to an absence of a pause between two utterances; (inaud) means that part of the reading was inaudible and so omitted; .... indicates that part of the transcript has been omitted when used as extract in the analysis; [] are used to distinguish participant speech from points of clarification made by the interviewer. Interjections are transcribed as /MF;/ . All names and identifying references have been changed.

<sup>5</sup> This refers to criticism by Malson and Ussher 1997 maintaining that a non structured format of questions should be used in favour of conducting naturalistic conversations with participants thus maintaining the integrity of the social context.

## **Analysis and discussion**

In order to highlight the three underlying research aims referred to, the analysis will pay particular attention to five emergent themes of under the title of problematisation. It is hoped that this analysis is viewed not in a negative way but valued as a deconstructive tool. It is not intended the following interview data be viewed as a comprehensive indication that intersex individuals are mistreated within the UK today. But rather, it seeks to highlight a variety of emerging themes:

(1) Parent's description of one's own group identity and simultaneously a separation from others. (2) Knowledge is institutionalised (3) Reproduction or Resistance of Intersex identity. (4) Crisis of Definitions (5) Congruence of Communication (6) Fixed Misconceptions (7) Psychological Scars (8) Disclosure (9) Secrets and Lies (10) Recommendations (11) Apportioning Blame.

### **Parents views**

In this section I examined the participants text primarily in terms of patients and parent's perceptions of their/ (their child's) treatment. This was in order to decipher whether an intersexed person can and should be successfully altered by surgery. Whether intersex members believe that physicians and psychologists should have the legitimate authority to define the relationship between gender and genitals. This section examined some of the practical ideologies through which the problematisation and lack of acceptance of intersexuality is explained and justified. Moreover, the way in which the participants espoused a particular attitude, or advanced a specific explanation to account for the experience of diagnosis of intersexuality.

### **...Problematisation: Communication of Diagnosis**

The following extract illustrates how repertoires of 'physical difference' are overruled by assumptions of "normality". These are presented as typical responses, which do not appear to accord well with Money's typology for the treatment of intersexuals. Here a parent talks about her experience of hearing her child's diagnosis. Verity is in a state of shock after giving birth but remembers her uneasiness the way in which this diagnosis was communicated.

**Verity:** "The paediatric breezed in wearing a wholly T-shirt ...looking like a Nigel Kennedy of the medical world and said, ... I don't think it's outside the realms of normality and if it is something its something called congenital adrenal hyperplasia. ... Em (...) He said well if you're going to have a genetic illness this is the one to have ...and he breezed out."

The Doctors communication within the above text actively discursively utilises pre-existing, cultural linguistic medical interpretation of what a "normal body" should look like. This medical discourse of 'normal' and 'abnormal' is used in order to reassure a patient. However, in this instance it didn't have the desired effect of reassurance. What can also be inferred from this extract is that Verity felt that the communication was expressed in a flippant manner. Whilst, the communication by the doctor implied that the child may not be outside the "realms of abnormality", it simultaneously raises the worry that it might be. The Doctor's talk attempts to prepare the parent in order that she is ready to accept an "abnormal" infant. The hegemonic workings of the above medical diagnosis can be understood as already fixed and unchangeable. The way this is described to Verity is that her child may or may not be abnormal, but with no explanation at this stage of exactly what that might mean. Here Verity continues to talk about her dissatisfaction with the explanation offered about her child's condition. Particularly with regard to her child's "missing vagina".

**Verity:** " We weren't happy with the way they spoke to us about it and (...) it was very strange the thing is we couldn't get the medical world to take any interest in [her missing vagina]. They'd say yes her clitoris is slightly enlarged and we'd say yes [we know but] there's no vaginal opening. That's what distressed us. We could cope with an enlarged clitoris but we knew something was wrong with no vaginal opening (...) that phrase seemed to slip by them. They couldn't seem to take that in."

Here, the communication between the physician and the parents is characterised as flippant or uncommunicative. This text is an exemplar of what happens when an issue falls outside the realm of the physician's medical script. This repertoire also highlighted how medical discourse views children as non-sexual beings. An inference is that because it is not mentioned the infant's vagina appears not to be identified as an important thing. Perhaps this happened because the medical practitioners felt unable to provide

reassurance. In comparison to this is that the external genitalia is viewed and treated quickly (as in a medical emergency). The next extract gives an adult's account of her experience of finding the size of her vagina to measure about 1inch in length.

**Beryl:** "Well my GP was a surgeon and he performed the hernia operation himself. But (...) the vagina wasn't looked at (...) at all. I think because it was the 1960's it was thought inappropriate for them to look or think about a young girl's vagina. What makes me angry now is that all they were looking for was did I have a uterus or not, they weren't interested in me being able to have sex."

In the above text, Beryl is angry at the reason behind her medical treatment. A view that positions women/intersexuals as baby machines. This text characterises the trend of how sexual functionality does not appear to be high on the agenda. Thus, sexual arousal is ousted by reproductive potential.

Here Fairy talks of her experience of diagnosis. The emergent theme of her explanation is that the polarity of normal and abnormal is still concurrent. According to this story Fairy assumes a position of something different. This stance is so different that even she fails to recognise what meaning of the "white crib" signified. However, she does recognise this meaning when it is contrasted to what it is not; i.e., a boy or a girl and thus she understands it as something in between.

**Fairy:** "They just said ambiguous genitals and it's quite common. I said, well I've never heard of it. I assumed what it was ...and it wasn't until they hang a white tag on your crib (...) that you think well everyone else has a pink or blue one and mine is white. The physician came round and explained that they weren't quite clear if it was a boy or a girl. If she was a boy then the penis was not fully developed and if it was a girl then her labia lips had fused."

The above extract describes a confidently communicated message to a parent, which is enacting and incorporating the medicalisation of intersexuality. It is an example of how size of genitals are diagnosed within the medical literature. The unquestionable nature of this statement is an example of the well-documented interest in what a normal clitoris should look like, even to the exactly cm range. The inference here is her son's penis may not have reached its 'normal' potential also the labia had fused so he was reared female. His genital structure was taken as an indication of abnormality. What is interesting is that

within the literature scant attention is paid to how 'normal' labia or scrotum should look, the main focus is on "fused" labia and "not fully developed" penis (Kessler, 1998).

Here Fairy talks about the conflicting advice given to her by a physician and she relinquishes any responsibility from the Doctor by blaming herself and her partner for "pushing" the Doctor into deciding.

**Fairy:** "So they did a chromosome test and we stupidly pushed him to say which it was more likely to be. He said it was most likely a boy, but I should give the baby a girl and boys name until test results came back. The tests came back and she was a girl and then said that was the best option of the two."

The above text is communication between the medical practitioner and a parent. The Doctor suggests that the infant had successfully achieved the best sex outcome "the best option of the two". The kind of communication that this parent received is common within research on intersexuality, to preference the rearing towards females and not males is viewed as the "best option". This is because it is deemed easier to surgically reduce the phallus, rather than increase its size. However, it is also based upon the premise that it would create a psychologically negative experience for a boy if his penis were 'too small'.

Asking the physician to make a decision as to whether it was a boy or a girl seems to be a common need. These texts below validate that the physicians are under a certain amount of pressure to estimate correctly what sex the infant is. Here Kirstin's text highlight's the sense of impatience from the parent to want to know what sex there child is. Kirstin's extract unveils the assumption that parents make about medical practitioners that they already know the status of the infant's biological sex. All the Doctors have to do is to confirm male or female.

**Kirstin:** " Er, I just wanted to know. I mean it's not like they don't have some idea about which one they think it is (...) do they? I just wanted it over and done with you know. I mean having a baby's bad enough without dealing without waiting for the Doctors taking ages and then telling you what sex it is. (...) I could have done without that."

**Flora:** " (Em) (...) I remember waiting in anticipation for the Doctor to decide which sex she was. It was really odd (...) I felt like I couldn't begin thinking about it as a real person until we knew that she was either one or the other."

According to Flora text she is anxious and didn't expect to have to wait to find out about her child's status. One of the issues these stories unveil is that parent's come to the birthing process with their own expectations and assumptions. Flora mentioned that she couldn't think of her child as a 'real person' until she knew what sex it was. This highlights the lack of language and unacceptability about not being overtly male or female.

### **...Problematization:Treatment**

Here Deidre talks about her lack of communication between herself and the medical practitioners. It also highlights the frustration, dis-empowerment and lack of knowledge that she felt. Here Deidre felt she was unable to ask anything. The diagnosing process was unfolding and she it was out of her control. This may be a generic experience in dealing with infants with medical conditions. Despite this it is clear that Deidre wanted to know and understand more about the whole diagnosing process but was kept in the dark.

**Deidre:** "Nobody would talk to us=In fact the radiographer just sat taking notes and said oh I think that's an ovary- oh they were expecting this. They obviously did know something perhaps the doctor had written suspected CAH, but we didn't have the nerve to say or ask who said that about the ovary?"

**Verity:** "We were absolutely lost at sea. Nobody was communicating or making any diagnosis. Dealing with a young child having a scan who is uncooperative actually takes up all of your parental energy. To then try and ask the Doctor [questions] whilst trying to get a nappy on [renders] you incapacitated and not able to function=We would then of course go home away from the hospital (...) and think of things to ask when your functioning as an independent adult and not as an adjunct to its happening."

The above extracts highlight the power dynamic at play, with the lack of communication within the medical setting and the patient or in these cases the parents. Here Verity described feeling "absolutely lost at sea" This perhaps illuminates the participant's lack of pre-existing cultural linguistic resources that may enable her to understand what was 'wrong' with her child. The text; "nobody was communicating" infers impatience on the

part of the parent who is desperate to know one way or the other. But, also it is a direct criticism to the way the medical practitioners were handling this process. It can also be assumed that she experienced the whole process of her finding out her child's condition, as dis-empowering, (at least within the hospital environment). This was highlighted by the fact that she felt unable to function "as an independent adult" within the hospital setting. Any opportunity she had of finding out more information was avoided by her having to be compliant and attend to her child. To just go along with what "was happening". Verity's description outlines how uncomfortable she felt in being compliant within the medical management

### **...Problematisation: Hindsight**

The following extracts of parent's talk appear to be in opposition to the success of Money and Erhardt's (1972) intersex treatment protocol. The different texts below highlight some afterthoughts on the whole experience and in particular the diagnostic reasoning. This text highlights a reflective account of what they should have perhaps asked or done differently.

**Flora:** " (Er=they emphasised functioning rather than cosmetic but in hindsight it was cosmetic as she was functioning fine. ...She just didn't look the same. (...) I suppose because you want your child to look as normal as possible and you assume [that] the Doctors know best. Although, in hindsight, I know it's done her a lot of psychological damage ...in terms of sensation=I don't know as she refuses to speak about it."

**Penelope:** "(...)You know I look back and wonder they didn't even mention it (...) I don't know why we didn't make more action, why we didn't make more waves (...) Em=I mean we were really lost at sea."

Here Penelope ponders about why she "didn't make more waves". She is referring here to the lack of understanding that she felt toward the medical communication of the diagnosis and toward the impetus for urgent genital surgery. The metaphor Penelope uses above is given as an exemplar of the invisibility and non-acceptance of 'intersexuality'. Furthermore, this metaphor is used to relinquish responsibility from the Penelope to practitioners. This use of metaphor as a rhetorical device is similarly common in psychology with its "metaphorical framing" of theory and knowledge (Leary, 1990). "Metaphors can encapsulate and put forward proposals for another

way of looking at things. Through metaphor we can have an increased awareness of alternative possible worlds” (Sarup, 1993, p. 50). However, Nietzsche described truth as ‘a mobile army of metaphors that camouflage the illusory nature of truth’ (in Levy, 1964). In the above text, the use of metaphor can be seen as disguising and camouflaging any acceptance of having an intersexed infant and displacing the responsibility to the practitioners.

In these texts parents are reflecting their passivity when it came to receiving any medical communication about what options they were given. In Flora's case she provides her justification for agreeing to her child's surgery by assuming that the "Doctor's know best", at the expense of her child suffering psychologically. She acknowledges that the surgery her child experienced was psychologically damaging but what is interesting is that she separates the psychological from physical in terms of "sensation". It is as if any physical lack of sensation or outward aesthetic would not be connected at some psychological level.

However, this may just outline the awkwardness that she has experienced as a parent in; a) having to make this decision, and b) feeling too uncomfortable to communicate with her child. She also takes responsibility for this assertion by claiming that she (like any other) parent wants their child to look as "normal as possible". Flora's perspective assumes a fundamental essentialist truth current within medical practice that surgery is essential and with it, it can create 'normality'. What is at the fore here is aesthetic normality over psychological harm. (These issues arise again within the next section on treatment).

In the following text parents talk about some regrets they have about consenting to their children's treatment.

**Bee:** "I'm not sure I would have made the same decisions now. Em I was just in shock I couldn't really cope and the Doctors (...) I suppose just seemed to smooth over any [of the] difficulties. I mean although I'm not sure [now] that was a good thing."

**Milly:** "I mean (er) (...) now I don't think I would have put her through that. But you don't know that then. You think your doing what's best. I mean you do believe that the

Doctor's know best (..) and they are truly doing there best for you and your child. But I think now that it wasn't about Clare it was more about reassuring me."

Both Milly and Bee's texts denotes the repertoire of 'regret' about the decisions they made about their child's surgery and treatment. Bee's extract thinks retrospectively about what was the best treatment for her child. In explaining this Bee's text refers to being in "shock" and not being able to "cope" and how the Doctor's communication was reassuring in that it "smoothed over the difficulties".

Sarah Creighton and Cathy Minto have conducted one of the few long-term follow-up studies of intersexed women. They compared the outcome of a small group of women who had escaped surgery with others whose genitalia had been feminised. It was found that most adult women did not have surgery did not have any overwhelming problems because their genitals looked different, "She says some of the best adjusted women I've seen are in the group that didn't have surgery"(Melton, 2001). Creighton commented: "Both groups had sexual dysfunction, but those who had surgery had worse problems. The main difference is that of those whose clitoris was operated on, one in four could not reach orgasm" (See Melton 2001, p. 12).

These findings suggested that genital surgery is not helpful, that it is painful and can lead to a loss or lack of sexual arousal. Therefore, it may be more appropriate not to operate on a child with an enlarged clitoris until the child is old enough to decide what they want. There is no functional reason for clitoral surgical procedures apart from to make the genitals look more female. The research above emphasises the feeling of women who didn't have surgery, the following extracts asks parents what they think about genital and vaginal surgical procedures.

### **...Medical emergency**

The following extracts culminate stories of "surgery as the best option". They denote exemplars of lack of choice around the medical management. Polly presents her subject position within this text, which describes how she was feeling about surgery.

**Polly:** "I wasn't happy about surgery. I only remember it seemed very important that it take place immediately or as soon as. I don't know why but we just went with that."

**Flora:** "They then said surgery was the best option for her. They said she needed this done as soon as possible like there was no choice. You don't argue when you know nothing else. Hindsight is a wonderful tool. She had genital reduction and labia reconstruction she's had three so much for it being one. She was supposed to have another one but she put her foot down. She had a vaginoplasty just to check it was functioning."

**Bee:** "They told us surgery was the best option that it could fix the Em (...) you know her abnormalities down there. "

Here both Flora and Bee talk about surgery described to them as the "best option". Bee's description draws from the medical discourse around "healing" and "fixing" the abnormal body. Flora talks about not having any other options apart from surgery for her intersexed child. Her text unveils feelings of dis-empowerment, "you don't argue when you know nothing else". This is concurrent with most of the parents that were interviewed. These texts present little or no other options as an alternative. For example the following text explains how Deidre felt:

**Deidre:** "You aren't given any choice you either go with what the Doctor's were saying or god knows what would happen if you went against them."

By using the words "God Knows" Deidre's text unveiled the intimidation she felt by the medical practitioners. It can also be inferred that she positioned her medical practitioners in a position of authority and subsequently she felt unable to talk freely to these perceived powerful individuals.

### **...Surgery as a social emergency**

The following texts described a mother's decision to have surgery performed on her daughter. Reference is being made to the moralistic, scientifically constructed, cultural and historical specificity of what a 'proper mother', normal female' is and a 'good parent' should be. The essentialist tradition with reference to "proper parenting" is continued here (Burman, 1996).

**Flo:** “As a working mother or a mother with a social life if somebody else was going to change her nappy I'm sorry I wanted her to look as normal as anybody else. When she stood up I didn't want her to have a protrusion of her clitoris. Any good parent could see that was important. If she was going to the swimming baths I didn't want anyone to notice her it was for her as well. Not that people stand and look at your genitalia. I didn't want her to be labelled different by other people.”

Here Flo described her fears of potential interactional problems that she or her child may encounter if her child doesn't receive surgery. She is concerned that if her child's attribute is visible then it might make them feel ‘different’ or ‘less desirable’. This text is in line with Goffman's theory of self- disclosure: “One must decide ‘to display or not to display, to tell or not to tell, to let on or not to let on, to lie or not to lie, and in each case to whom, how, when, and where’” (Goffman, 1963). Flo then apologised for her opinion “I'm sorry I wanted her to look as normal as anyone else”, pre-empting any attempt to engage in 'rational' debate about the consequences of surgery, physically or psychologically. She immediately positions her attitudes around the subject of intersexuality as fixed and unchanging. Thus limiting the characterisation of non-genital surgery as normal.

### **...Surgery as the child's choice**

Here Harry talks about his knowledge about AIS and how he implemented it to his daughter's treatment.

**Harry:** “I see no reason for operations to remove testes unless there has been a biopsy. I had read the research and the follow up research on the instances of cancer—I didn't see any relevance other than that. I also feel very strongly that it is morally objectionable to operate on a healthy person. I consider it unnecessary the attitude that this person is ill or has a condition or whatever to be fairly ridiculous to operate on someone because their gender doesn't comply with social concepts. I am aware at developing cancer in the future are quite high (...) I'm aware that if they wish to have penetrative sex how developed their vagina is important. I feel it is up to them at a later date to decide if they want surgery—but certainly not in childhood.”

Here is an example of a parent being involved in the decision making of their child's treatment. It is also quite an unusual perspective at least within this research, but it does present a position that certainly couldn't be described as dis-empowering or lacking in knowledge. It is perhaps the future of decision making process, whereby the parent takes

on board more responsibility in this process to shape how their children are treated. It is also more representative of a fairer process in terms of consent and choice.

This perspective by Harry is compared with an intersexed adult's account of the implications of surgery. It seems that they share the common ideals in terms of consent and choice.

**Molly:** "I think that cosmetic genital surgery should only be done if the individual wants to have it and is fully informed of all the pros and cons. Surgery must be with fully informed consent of the individual, unless it's for life-threatening or serious health problem. Ambiguous genitalia isn't a medical or psychological emergency it's a social emergency for the medics and parents and as such they should stand back and think deeply of the consequences to their child's sexual future."

The above text is very powerful as this perspective is from an adult who had received surgery and unfortunately was left with problems with painful orgasms and terrible scarring. Of course not all surgery practice is experienced negatively, however what is inferred both in Harry's talk and in Molly's is that it should be an informed choice made by the child when they are old enough. Reference is made in both texts that genital surgery is not a medical emergency and should be recognised as a social emergency. This social emergency affects the medics and the parents.

### **...Institutionalised Intersexuality**

Medicine deals with the production of medical knowledge and provides the justification for medical processes, which are based on the premise of health production and 'illness' eradication. Definitions of the body and its cures are historically contingent (Prayer, 1990). These definitions construct metaphors with a similar method of reality to the 'sickness' or 'illness' itself (Sontag, 1977, 1989). We interpret these definitions and understand them as "[I]llness --any illness -- is meaningful as "illness" only to the extent that it has particular implications for us as people and not just as biological organisms" (Stainton-Rogers, 1991, p. 31). Assisted technologies illustrate the process of specialisation of the medical institution, in which a person as a whole is lost and intervention is directed towards the surgical production. Production, that enables the fragmented body to return back to the realms of a recognisable reality.

In the following extract Verity's text describes her self as a 'layperson' and alludes to her non-medical knowledge. This acknowledgement simultaneously positions her as a non-professional person against the construction of the medical establishment who are so-called 'experts'.

However, what is apparent here is that Verity foregrounds medical knowledge as somehow more important than her general knowledge. She is attempting to communicate to her medical practitioner and she describes it from "layperson's" stance.

**Verity:** "Well we had just agreed we'd ask for a scan because that's all we knew in a non-medical way. (...) As lay persons at that time we [thought] hermaphroditism that's all we could muster from our general knowledge. I remember saying could it be hermaphroditism? (...) She then asked me what did I do? I said I'm at home with the children, she then asked what Berty did. I said he teaches. So she said neither of you are in the medical profession? I said no so she then said well how do you know about that? [I said] general knowledge. She was very abrupt. It was as though knowledge is pure. Like nothing exists outside the medical world and that you cannot or shouldn't have general knowledge. (Em) (...) Like you shouldn't own it it's not yours. I mean you've only got to know Greek Mythology to work it out. (...) Yes, it's the privatisation of knowledge."

Here Verity talks about the ownership of knowledge. Although she doesn't expand on this what we can decipher from this text that she feels medical knowledge is privatised. Her description of the "privatisation of knowledge" denotes that she feels critical of medical knowledge and feels that this type of knowledge is not easily shared or communicated. In other words she felt that this knowledge was set apart and divorced from the public and entry into this realm of knowledge can and should only be achieved through a medical qualification. In another interview Flora has the opportunity to combine her knowledge of hermaphroditism against medical interpretation.

**Flora:** "Er, the doctors didn't mention it [hermaphrodites] at all. It was the health visitor (inaud) was very good, she gave us lots of information about female hermaphrodites and we were comfortable with that."

Flora talks openly about hermaphroditism. Flora's text denotes her surprise that it wasn't mentioned when her daughter was diagnosed. Her talk suggested that she expected the

doctors to talk about hermaphroditism and felt comfortable when she received information about it. Instead they described her daughter in terms of a medical condition. Here is an example of a parent that didn't mention any sort of challenge or questioning of the medical practitioners.

### **...Perceived Mismanagement**

The extracts below outline some parent's views of medical practitioners who treated their children. It explains what they felt was inappropriate treatment of their children.

**Flo:** "When she progressed from a paediatric to an adult patient she went in for her first check-up. (...) she was [examined] by the consultant and a room full of students. He didn't ask her permission. She 17 was lying there, legs spread naked and he kept being interrupted going in and out of the room. (Em) (...) He started by saying 'look at this obese young woman with all this stray'. I just said can we stop now, (...) she doesn't need this shit and I'd like you to leave so she can get dressed."

In the text above Flo describes how she felt her daughter was inappropriately treated.

This overt insensitivity is a common theme throughout this research, for example in the following text Harry, Flora and Verity described how they felt about the attending doctors.

**Harry:** "Well, the Paediatrician =I would have gladly torn apart. I found him brutal, (...) callous and extremely unpleasant. I didn't like the way he was talking about her or handling her".

**Flora:** "Well you don't give a new born baby tablets".

**Verity:** "We left very confused and I went to a six weeks check at my local health clinic. The Paediatrician took me into a room and said now why are you here? (...) I said because I'm concerned about my child's genitalia. She said well, (...) this is very abnormal you usually do this with your GP. Your GP won't be very pleased with you=who was you health visitor? Oh if it was Silvia then this wouldn't have happened. So I started getting all sorts of politics (laugh). (Sarcastic laugh) (...) She then examined my child (huh) and stopped all her slurry and said=I'll speak to a consultant who is more specialised that me in this area and we will probably take blood tests".

The above extracts are examples of lack of continuity within the medical management of intersex conditions. Harry's text obviously displays his anger at the way the Paediatrician's was touching and referring to his daughter. Flora's text talks more practically about methods of administering treatment and how little thought had gone into treating an infant. This displays the lack of understanding of how best to treat an infant

regardless, of the medical condition. Here Verity's text shows the lack of attention paid to her or her daughter. It also highlights how a patient within the medical world is positioned fixed practices and procedures that limit any outside input or individual thought.

### **...Different Bodies**

This next extract displays an exemplar of the medical language embodied by the parents in the description of intersex and what "causes" these "abnormal" conditions.

**Deidre:** "No, we had no idea an endocrine disorder could cause an abnormality like that, so we had been floundering in our lack of knowledge."

**Penelope:** "Well I just noticed there was something different down there at about seven years old. Although I'd noticed it the [Doctors] brought it to my attention at the hospital and told me it was an abnormality. So I how asked what was the best way forward. So she had surgery which fixed it. I felt it was best for her to experience a normal life."

**Harry:** "I preferred not to ask the Doctors unless there was a medical problem. (...) I think that should probably come from the child and not from me. We knew more about it than the doctor did—he wanted to take a chunk of her labia to make sure that she was female. (...) If a child has to regularly see the Doctor for regular check ups in order to remain healthy at least maintain the appearance of healthy strikes me as wrong. (...) If your child has to be given something because they're not producing it then it's an illness but at the moment she is not ill she is functioning normally. Well I just feel that until they've got an emotional development, its they're choice."

Here Deidre text utilised the medical terms of "cause" and "abnormality" to comprehend intersexuality. Deidre's story highlighted how she has partly made sense of and accepted this diagnosis through the medical information given to her. This text suggested this parent's potential need to know where this condition came from. There is an acceptance that the cause of the abnormality came from within the body. Rather, than from societal constructions of normal and abnormal bodies. In the text, Penelope had noticed that there was something different. Penelope said; "I felt it was best for her to experience a normal life". There is an overt assumption within this text that the individual will not be able to experience a heterosexual lifestyle.

Harry's story picks up on the social construction of femaleness and maleness within the context of intersexuality (Hird, 1999). The impression from Harry's text is that his views are simple and logical. For example; there is male or female and anything in between is "inter".

**Harry:** "Society seems to need male or female, (..) [but] reality is not like that we all have degrees of masculinity and femininity. I feel that male and female are extremes and anything else in between is 'inter'. (...) This could include anything from enlarged clitoris to micro penis. I feel that treatment is based on two sex categories, two ways of behaving and that were supposed to be heterosexual for that matter".

Harry's text describes how he comprehends definitions of male and female. His dialogue is in opposition to the previous texts above as it assumed what can be described as a social constructionist approach to gender and sex. His text is very interesting because it incorporates what Butler (1990) describes as the "heterosexual matrix". Theorists such as Butler question the truth of the ontology of gender by proposing that sex, gender and sexuality are social constructions. Other theorist's suggested that the assumed 'natural' relationship between the three constructions: sex; gender; and sexuality are maintained and perpetuated by compulsory "hetero-patriarchal hierarchy" (Butler 1990: Kitzinger, 1987).

### **...Parental Disclosure**

Most of the parents that were interviewed didn't talk or disclose their child's status to anyone either within the family or to close friends. They either felt embarrassed or ashamed or they were doing something wrong.

**Bee:** "My husband and I didn't talk about it to anybody. We were strongly advised [by medical practitioners] that would be best not to talk about it with [our child]. To be quite honest we were embarrassed about it."

**Fairy:** "But of course we had to tell people we'd told it was a boy to (...) that she was a girl (...) and that was quite traumatic. After that they didn't really say anything—we were embarrassed but we had a lot to deal with."

**Polly:** "I think we were probably ashamed you know ashamed to have a baby that was different I mean nobody wants to stand out."

Bee, Fairy and Polly's use the "ashamed", "embarrassed" stories to recant how they felt about their infant's different bodies. These texts are contrasted to another parent who felt more positively about his child's sex and felt the need to talk and disclose to as many people as possible.

**Harry:** "Mavenwyi understands it as 'inter' (...) that there are a whole range of sexes, men at one end and women at the other (...) and then there is a whole group, which are in between. And you are 'inter' and it's no big deal. She understands that she is a boy inside and a girl outside."

By including Mavenwyi in the discussion of the how her condition is perceived. Harry evokes Mavenwyi's collusion in the discussion and consequently gives her a voice. Even if Mavenwyi wasn't present at the interview to respond verbally, reference has successfully been made (by Harry) to the fact that he felt she has a voice.

### ...Sexuality

Reference is made in the texts that some surgeons expected their intersex patients to have "normal" relationships and these "normal relationships" are achieved with men. No mention is made here that women can achieve sexual arousal with other women or without a vagina. The stereotypical "normal relationship" usually denotes penetrative sex between a woman and a man involving a penis and a vagina. However, Flo's text illuminates the lack of knowledge the surgeon displayed about sexuality.

**Flo:** "The surgeon said that she wouldn't need much surgery=to have a normal relationship with a man that she could just use dilators. But the funny thing is she's a lesbian. They didn't know how to communicate about that. (...) Before we thought the only thing that might be negative is that=because she had too many male hormones and it might make her gay. (...) Our main aim throughout our life is that whatever she is as long as happy (...) it doesn't matter what she is. I remember her telling me she was gay and I said well so long as you've explored and thought about this and its not just fear because of your physical differences. If it's because you're scared of penetrative sex and you're going to a woman because it's easier then that's something we have to deal with."

Here Flo disclosed her discomfort about her daughter being gay. Her discourse draws from essentialist traditional discourse and provides her justification for thinking her daughter may become gay. For example, having too many male hormones and a connection to lesbianism. Flo's abstract also draws on another traditional discourse of a "failed normal female". There is an underlying assumption in her text that her daughter's turn to gayness is indeed her failure at heterosexuality. Her text displays an understanding to her daughter about her failure to become heterosexual. Flo actively

discursively utilises pre-existing cultural and linguistic resources for her acceptance about her daughter's gayness. She then states that she will accept this on the conditions that it is not based on her "fear because of your physical differences" and "going to a woman because it's easier". Flo's process of accepting her daughter's gayness has come about only after she dismisses her heterosexual assumptions of lesbianism. For example, the assumed connection around the biological basis to homosexuality, women are more understanding about physical differences than men, most lesbians are gay because they are scared or fearful of men and that lesbian relationships are easier than heterosexual relationships.

### **...Psychological issues**

The following extract a parent describes her child's psychological pain. Here Beryl empathised with her daughter and acknowledged the rationale for feelings of depression and eventually her nervous breakdown. She described her daughter's psychological conflict as not having anything to identify with i.e., male or female. She talks about this in terms of lack, "neither one or the other". By avoiding to acknowledge intersex as a viable sexuality this extract illuminates the importance of positive representation of intersexuality as an identity.

**Beryl:** "It was like a storm beginning to break she began to have a breakdown. It's like they give the child the pills or whatever but it's the reaction to it all. I can understand how she felt she was neither boy nor girl but something in between. I can understand feeling that way because you're neither one or the other. ...I mean what do you identify with?"

Reference is made in Marigold's text to her daughter's nervous breakdown when she was 21 and Marigold's attempt to help her by visiting the family GP. The mother's text critiques the GP for their lack of understanding and their lack of knowledge about the connection between depression and CAH. The parent also talks in terms of fixing physical differences but fails to heal any psychological damage. She uses a metaphor of a whirlpool to describe the negative psychological affect that this has had on her.

**Marigold:** "I remember when she was 21 and she just snapped. I did go to my family Doctor—who was always very good (...) but not on the psychological side. It was

although that had nothing to do with it CAH. (...) You know physical things they can put right but the emotional side=it's like a whirlpool the ripples just go out. You have to move on and you have to let it go=I have been through horrendous things."

**Bee:** "Without a doubt it been awful for her I don't know how she's manage. Of course I haven't really talked to her much about it (..) I mean I have tried but we both just get fractious, but I do no it's been really stressful and difficult for her in her mind."

**Meryl:** "I mean I could talk about the negative impact its all had on me but to be honest I can deal with that its not me I'm worried about its [my daughter]."

The extracts above are characteristic of all of the parents talk, for example; when asked "how has it affected you?" They answered I terms of how it has affected their child psychologically and not themselves. If they do mention psychological negativity about themselves they displace this by positioning the affects of the medicalisation of intersexuality as seriously affecting their children.

One of the strongest messages from people with intersex or parents of intersex children is that the conspiracy of silence that surrounds the whole issue (Kitzinger, 2000). That this silence seemed to cause far more anguish and distress than does intersex itself. That it re-inscribes and reinforces intersex identity rather than rendering intersex invisible (Kessler, 1999)<sup>21</sup>.

Reference is made here by Lee that she was happy to perform the non-disclosure and uncommunicative secrecy. This method seemed to work for her and she believed it was working for her daughter. Inference can be made from this text there is a hidden sadness and psychological pain that intersex individuals withhold from their parents. Perhaps it is they do not want their parents to feel guilty for making a decision for them.

**Lee:** "I didn't feel it necessary to go in depth in to the condition I found that I was dealing with it quite well. Well at least that's what I felt, she wasn't I didn't know how bad she felt until she tried to kill herself."

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<sup>21</sup> The foremost researchers in this area now emphasise that "full and honest disclosure is best" (Diamond & Sigmundson, 1997), and that even very young children can gradually be given accurate information (Goodall, 1991).

**Verity:** "It has taken me until now to come to terms with all of it. But I'm not sure how well she will take it when she's older. You just don't know. Although, (..) Em I feel that I did my best for her (..) I'm just left feeling incredibly uncomfortable with the knowledge that all this treatment and surgery has damaged her psychologically. I suppose the fear is that when she's older she'll ask me why I agreed to the surgery."

Verity's extract highlights her worry and guilt about the decision she made about the treatment of her intersexed child. She makes a connection between psychological damage and her daughter's treatment and mentions feeling uncomfortable about this. Here Verity acknowledges that there is a reasonable possibility that although she as a parent felt that she did her best that her daughter will disagree or confront her. This text is interesting, as Verity seems to be able to manage her own psychological aspects of consenting to treatment. However, when it comes to her daughter she is nervous, unsure, scared and fearful.

## **Adult views**

### **...Diagnosis**

Reference is made in the following texts about non-communication between patients and physicians, which seems to suggest a negative view of the medicalisation of intersexuality. Lou describes how she found out about her diagnosis as intersex.

**Lou:** "Em at nineteen I was in my GP surgery asking about IVF treatment and I noticed that lots of my medical notes were highlighted and they read XY chromosomes and I wasn't to know. The Doctor just said well that's what you've got (...) you're taking hormones otherwise you'll turn into a man. There was no way on earth I looked like a man and no way I would turn into a man".

Here Lou talks of the clumsiness of GPs and the lack of responsibility taken about this kind of disclosure. This maybe due to lack of knowledge on the GPs part or it maybe because he didn't know how to interrelate about the subject of intersexuality. Lou's text displays the GPs insensitivity "you're taking hormones otherwise you'll turn into a man". Thus, the consequence of this clumsy disclosure didn't only confirm to Lou that she had a hormone condition, but that she was actually a man. This is an exemplar of the "blundering paternalism of medical practitioners" that cause "a great deal of unnecessary suffering" (Kitzinger, 2001, p.104).

**Betty:** "I started wondering what was wrong with me and began to explore my body I discovered that my vagina was only about 1 cm long. So that made me think its some sort of structural problem its not hormonal disorder.

The specialist told me that I had complete AIS and that the vagina was very short and I had XY chromosomes and testes and if I wanted to get married I should come back and he'd see if he could doing anything about the vagina. That was it lasted ten minutes."

**Vera:** "The Doctor began describing to students in front of me of were they went wrong [with my surgery] he said they did this and they did that, if they'd done this, they cut too much of the clitoris off so I have got none. They stitched up too much there and this wouldn't have allowed for a normal birth anyway bla bla. I was very uncomfortable. I remember another time I went to be catheterised and I was on the bed no knickers on legs up sort of thing. The Doctor that came to do it and just kept looking at me and said I don't even no were to put it because I've never seen anything like this before. That cut and I said I'm sorry I got up and left. She said why what's the matter I said I'm sorry you've done it completely you've absolutely floored me."

In the above extract Vera talks of her discomfort with the way Doctors examined her. The next text is of a woman of 30 talks about finding out about her diagnosis as AIS and intersex and how she began not coping. When she asked for help from her GP she was told to pull herself together.

Another participant who describes himself as male with CAH talks about his diagnosis process.

**Sam:** "I was diagnosed 3 weeks after birth. I thought this lovely nurse was my mum. When I was five they sent me home. They were keeping me in and observing and giving me loads of injections loads of sitting on the drip and loads of Doctors prodding me left right and centre. I used to have what felt like 20 per day. My mum said when I was about four I had a lot of body pain. They told my dad that I was dying when I was born and then they were told that I might live to one year, then when I got to a year I might live to nine and it caused my mum and dad a lot of stress. The Doctors said that I might be mentally challenged or, unable to walk."

Here Sam recounts his childhood experiences and of spending so much time in hospital he believed a nurse was his mother. He talked of the communication, which was given to his parents and his father's impression that Doctors weren't doing enough. His memories of this time are of feeling confused as to why he was receiving lots of "painful injections" and constantly being prodded. There is a reference within the following in the texts to "non-urgency" in disclosing to the participant's what their diagnosis was. Betty and Lilly both talk about the lack of communication around their conditions.

**Betty:** " My parents told me at 11 that I might not menstruate or have children. There didn't seem to be any urgency expressed in terms of diagnosing anything it was just left."

**Lilly:** " I was born at home and the GPs made a mistake I wasn't christened Catherine it was Robert or something like that. My condition was diagnosed to my parents when I was young. They were in no hurry to explain to me what I had".

Here Betty talks about being told that she can't have children and that it wasn't open for discussion. This is a similar story to Molly as her parents didn't talk to her about her condition. She gleaned her knowledge and understanding about her diagnosis from her own research.

**Molly:** "Three weeks of age as I looked ambiguous and slightly more male until chromosome and X-Ray tests were performed confirming XX female with classic salt wasting Congenital Adrenal Hyperplasia. I was kept in intensive care for three months at hospital. I actually found out about the surgery and what it was when I was about eighteen. My parents didn't know much and the doctors refused to talk about it, which really annoyed me that there wasn't much information. My parents did have the impression that the surgery was urgent."

Other problems arise with participants finding out about their intersex diagnosis. Reference is made within the following text of ambiguity about the treatment she received.

**Bee:** "(Er) (...) [Diagnosis] It wasn't really expressed to me at all. I went to get my gonads removed but it was never really mentioned in words what I was going in for like a hysterectomy [or something] it was all very vague. (...) Even when I was in hospital on the ward everybody skirted around the issue. I suppose I just shut it out of my mind because obviously it wasn't something that was going to be talked about. What I didn't like was going for check ups and having armies of students around in white coats. I agreed but I didn't feel I had any say in the matter. I'd just been brought up in an era where you didn't question Doctor's."

Bee's text highlights her lack of understanding about her condition. What is interesting here is that even though there is a strong notion of secrecy and invisibility in terms of "it was something that was going to be talked about". This is in opposition to the visibility and interest shown by the Doctors of other medical students. Bee's text highlights

common assumptions that most patients make, which is that the Doctor knows best or where; “you didn’t question the Doctor’s”. This raises ethical issues as Bee felt she was going to have a particular procedure performed on her and realised later it was something different. How far should non-disclosure and secrecy go when it is levelled against consent? ”

### **Problematism of the Body ...Medical treatment and Surgery**

William Reiner of the Johns Hopkins Children's Centre in Baltimore famously stated: "You can do anything you want surgically to a newborn; it isn't going to change who they are" ([www.med.jhu.edu](http://www.med.jhu.edu)).

Despite this confident medical view, the following texts highlighted some negative psychological consequences of surgery. The following extracts may be classed as an example of bad practice or simply miscommunication. In Lou's text she describes what seems to be common practice the genderless description of gonadal operations. This text highlights ethical issues of what patients actually consent to in terms of surgery.

**Lou:** "Er, they said I had cysts on my ovaries. ..I didn't realise I didn't have ovaries at the time. I went back two months later to have what I thought was my ovaries and fallopian tubes removed ...that’s what I consented to. I've since found out that I had no ovaries to be removed that it was gonadal tissue and I still have fallopian tubes they didn't remove them."

Molly's text talks about her "appalling" experience of surgery and of non-communication. She has been left with psychological damage in the form of flashbacks and nightmares.

**Molly:** "I had an appalling experience of surgery not least waking up on the operating table. This experience has given me flashbacks and nightmares ever since. At 4 years of age I had a clitorrectomy, then at ages 11, 12 and 13 several vaginoplasties were performed. I was never told anything other than “the doctors have fixed something

down there it's not important". I remember having an enlarged clitoris as a child, which didn't bother me and I've always felt female, albeit a "failed female", in that society and the medical profession wouldn't allow me to choose or know what surgery I could have."

Here Molly talks about feeling like a "failed female". This was the consequence of having several surgical procedures performed on her. What can be inferred here is that femaleness is something that is achieved, something to be worked at (Hird, 2000). She described her experience as appalling and she still suffers from the psychological pain to the present day. She talks of how nobody would speak to her about it and she was told it wasn't important enough to know about. She recalls remembering what her body felt like untouched and comments that it wasn't a difference that bothered her. Her text highlights the importance of choice and consent. Molly is angry about her experience and expressed this anger toward society and the medical profession as removing the choice away from her. Here Meredith comments on how she feels about the surgery performed on her that it "messed her up". She relays a comment by a friend that physicians had butchered her.

**Meredith:** "My surgery has messed me up down there it's a mess. My girlfriend said what they've done to you is they've butchered you. ...I'm not happy with the treatment and I can't orgasm. ...[it's] not painful, [but now] I'm not really interested in sex, but I can have sex with a man if you know what I mean."

Meredith is not happy about losing her sexual response due to surgery. However, she mentioned that she can have sex with a man indicating to the researcher that she has a vagina. Her text draws from medical discourse that despite having no clitoral sexual response it is an achievement that she has a vagina and can procreate. Meredith understands that she has a surgically constructed vagina for the purpose of her having sex with men. However, the inference here is that this is both unfortunate and unnecessary as she identifies as gay and doesn't have sexual intercourse with men.

The description of butchery is concurrent within Molly's text. Here Molly describes how an ex-boyfriend talked about her genitalia.

**Molly:** "Surgery with visible scarring, stenosis, 95% lack of sensation, excruciating pain on arousal and sexual intercourse and the inability to achieve orgasm has had a devastating effect on my relationships. To be told by an ex-boyfriend that "your genitalia

looks worse than a piece of raw meat on a butchers slab and a piece of meat is less scarred and more appetising” certainly doesn’t help, my body image or sexual confidence.”

Molly's text illuminates her unhappiness about the treatment she received and links this to her poor body image and struggle with her levels of confidence. Nell 's story of treatment is described as a kind of "abuse". The feelings of abuse that Nell expresses stems from constant photographs taken of her naked body, long stays at hospital on her own, and standing up against height charts and being measured. She recanted the experience of bed wetting because of the surgery she had received and being chastised about it by the nurses. Most Medical Doctors and psychologists would have seen pictures within textbooks of people like Nell. These pictures are explained as examples of sex morphology gone wrong. What is interesting after reading Nell’s account is that within these pictures hold a different story. The next extract highlights feelings of fear, torment and abuse.

**Nell:** "(Em) I wasn't ever told I had CAH. I obviously had it as a child. I can recall some of my visits to the children's hospital and they were horrid. I've tried counselling and all sorts because I feel that I was abused as a child because I was taken photographs of in those days your mum and dad didn't come with you that was it. I had a lot of genital corrective surgery. I was in hospital a long time on my own. (...) You were quite an exhibit to whip the cloths back and have a look. It was a very hard system that I went through. I can remember having schooling in hospital. I remember hating it and screaming. I have horrendous memories of going in and lying on that trolley I can see it now. I had to take my son into the same ward and that ward just haunts me. The smell, the wall tiles, I remember being in a big metal cot with high sides and you just didn't get out. You were in and I could remember getting into terrible trouble for wet sheets and it was because of my surgery, it was awful. (...) They had height charts basically I was stripped off under the height chart then they'd do that clothes were on the other side of the room and then they'd take photo's of various parts of you. I hated it I do think it was abuse. I can picture the room, the drab curtains and they'd be six Doctors on that side, his desk on the other and you'd just wait there for the consultant. You just lay there."

Nell' s text highlighted negative memories of her treatment and in particular her visits to hospital she described as "horrid". Her text described how she perceived the whole process of her childhood intersex management as abuse. In particular having to stand at height charts and getting pictures taken of her when she was naked. She used a metaphor of feeling like an exhibit. Her extract depicted humiliation and she remembered "hating

it and screaming". Her negative experience resonates strongly within her memory. She described having horrendous memories of the hospital and getting into trouble for wetting the bed. The following extract is a contrast to this in that Lilly's experience was mostly positive in terms of aftercare.

**Lilly:** "They tucked it away when I was twelve. They began it when I was an infant but I'm not clear what they did. They didn't desensitise it or anything. The Doctors were marvellous about surgery they were very kind and very gentle. I can't remember them saying when you wake up that won't be there, which would have been nice."

Lilly described her experience in a positive way and praised her Doctors for being successful and sensitive. However, she timidly mentioned that she would have appreciated being told that her enlarged clitoris was going to be taken away.

Maud's extract illuminated the difficulty she faced due to the lack of communication with her peers as she wasn't given the opportunity to "share other children's worlds". This resulted in her not fitting in and in terms of her own personal identity not knowing whether she was male or female. She goes on to talk about how she dealt with these negative emotions.

**Maud:** "I remember telling my parents throughout my childhood that I felt lonely and unhappy. But, perhaps adults just don't take childhood seriously. I suppose I grew up in a radio four, proper books and none of this popular culture business as I didn't share other children's worlds at all. I wasn't quite sure whether I was supposed to be a boy or a girl and I really wanted more to be a boy. ...I worked very hard at school and [sport]. I tried my best at everything. If I did let go I was criticised for being too rough. People talk so much crap about just be yourself. Well I'm not allowed to be myself. I wanted to be a little boy playing football."

Maud's extract raised issues of failed communication between herself and her parents. She seemed disappointed that her parents didn't take more or any responsibility for her unhappiness and loneliness. She then follows to excuse her parents and takes the responsibility away from them by saying;

"[p]erhaps adults just don't take childhood seriously". Maud developed strategies such as studying more than usual and doing well at school and having a natural ability and flair for sport. Adding, to her experience of failed communication, humiliation and

unhappiness, she felt patronised whenever she was told to just be herself. As she felt she wasn't allowed to be herself, "I wanted to be a boy playing football".

Here Polly's text is concurrent with Maud's in that she experienced certain restrictions as in not being allowed to be 'herself' in school and by her parents.

**Polly:** "I felt restricted mentally and physically the whole thing. In school, by the Doctors even by my mum and dad. My childhood consisted of restrictions."

In the following extract Meredith compared her life to her sisters and described her experience through emotions such as "loneliness" and "feelings of isolation". The emotions she experienced had an impact on her behaviour as they made her not wish to display her body at the gym.

**Meredith:** "Well compared to my sister's life I felt isolated, kept myself to myself and had nobody to talk to. Nobody told me about any of it and I just didn't speak much. I remember I didn't like the gym much."

Meredith's text is an example of how her negative experience affected her behaviour in a negative way.

### **...Secrecy and disclosure**

The following texts described different issues concerning talking openly about intersexuality. Betty's text unveiled her feelings of distress on hearing that she wouldn't be able to have sex or children. Maud's text described how difficult it is to talk about these issues particularly when it is viewed as abusive. The experiences in this section incorporate a variety of issues, such as; loneliness, bullying, humiliation, abuse, secrecy and both voluntary and involuntary disclosure. The following texts describe different issues concerned with intersex individuals need to disclose or talk more freely about their lives.

**Betty:** "Em, I remember crying in the car in the way home and my mother saying there's more to life than sex. (...)That's the only time my mother has ever mentioned it or it was talked about in the family."

**Maud:** "Er (...) I could talk to my mum and my dad but it's something I didn't feel I could talk about.=You didn't have to talk about CAH for very long to feel uncomfortable the fact that you have little boys who look like little girls it was a very sensitive subject to

me. I was a tomboy I didn't like being called a boy, but I became used to it as a term of abuse and a form of humiliation. (...) I didn't want to say when I was born I was a little boy and had it chopped off. I'd worked out for myself I didn't want that sort of attention from other people. Mm there were a lot of things I was guarded about. My friends were my mum and dad."

**Meredith:** "I don't usually talk about it or anybody".

**Lou:** "Of course there was a student there and I've worked with her since and it was really embarrassing. Em what makes it even worse is that I work with these people in the hospital so it had a massive impact. When I went for a hepatitis B jab at work there was a nurse reading my notes of whom I worked with. It was horrific and traumatic and I felt panic. (...) Even my friend who I work with in the hospital when I told her she didn't seem surprised, retrospectively she probably knew but couldn't say."

Lou's extract above raises issues of involuntary disclosure whereby, Lou realised just how many people already knew about her, both friends and colleagues before she found out. Her experience is talked about in terms of "horror" and "panic". This raises issues of disclosure as going beyond the control of the intersexed person. Lou's text highlights the problems (in terms of disclosure) of having intersexed conditions and working within the medical profession. Reference is made in the following text about negative consequences of voluntary disclosure. Cameron's text described the inner conflict that he experienced with the decision he made to disclose that he was "mixed gender".

**Cameron:** "When they're going to say to me why haven't you got any children I don't have to want to lie. Why do I have to lie? It's a bit like coming out and having to go back into the closet again. The whole difficulty about disclosure to people you know, I as I say I went for an interview for a job with my local authority and I got the job and about a year into the job I disclosed that I was kind of mixed gender. They said you should have told us this at the interview. And I asked why? (...) They said because you were asked, if you had any medical conditions on your application form and you didn't put it down. Well I just said that I didn't put it down because I didn't feel it that it affected my job. Which is doesn't. They said, well that's for us to decide in fact what your saying is that your contract is now null and void. I said well what would have happened if I'd disclosed at the interview? Er, they said well, we wouldn't have given you the job. So I was damned if I had disclosed and damned if I didn't (...) And then they tried to get rid of me they said were going to fail you on your probationary period and I said fine have you got any evidence that I am not fulfilling my job description."

Cameron's text highlights the negative consequences choosing to just be himself and disclose his status. This extract is the only one where the participant talks about choosing to disclose their intersex identity within the work place. What this raises is the legal consequences of characterising intersex as a medical condition and not as a healthy intersex identity. Characterising intersex conditions as medical fails to support not just Cameron's own personal identity but more practically his legal status. In the next extract, Clare's text raises other issues of responsibility and highlights the fact that Clare is taking responsibility for her mum's "guilt" or regret. Clare attempts to talk to her GP about the difficulty she had been experiencing, but this was unsuccessful.

**Clare:** "I didn't want to talk to my mum about it because of her guilt, didn't want to talk to friends about it. I finally plucked up the courage to go and see my GP. I said look I've found out about this diagnosis and I'm just not coping with it. I'm breaking down in tears you know I just can't cope. I've ended relationships I just can't do relationships. She said go away and just pull yourself together. So I said I can't just pull myself together you know coming down here is quite hard. She said, all right you need counselling. So we'll sent you to Relate. She was alright, but knew nothing about the condition. I went back to my consultant and got the information about the support group who previously had advised me not to associate with them as they may not be."

Clare's text described how she had to demand psychological help and when she didn't find it satisfactory. As it was assumed that she would want help in order to gain a sexual relationship. There is no acknowledgement or understanding from this GP about the possibility that Clare may be suffering any psychological pain.

### **...Psychological distress**

Reference is made in the following extracts to experiences of psychological pain, in terms of nervous breakdown, not able to cope or communicate and feelings suicide with nobody to talk to, confusion about sexuality and been forced to take time out.

**Maud:** "Er (..) When I began to study for my [exams] I began to crack up ...and well basically I thought I'll get through my A' level's, I'll do my degree and then I'll kill myself. ...The reason I cracked up was without my parents I didn't have any friends and I didn't know how to cope around my peers. I was very frightened that I was gay and I didn't know what to do. I ended up being in hospital for eleven months and my life fractured from top to bottom."

**Clare:** "I suddenly realised the implications of what I had. I think I'd realised it before but I'd shut it away and thought I was coping with it and I really wasn't coping with it. (...) I just completely fell apart."

**Polly:** "I just had to take time out wasn't coping."

**Lee:** "It was very traumatic (...) em it was mental anguish and I just felt very different. I can't really remember anything different except from this horrible mental thing. The bad dreams and the attraction [same sex] I kept it all bottled up. I had this feeling of being very different. It was like not male or female but something in the middle. Er I began to feel I couldn't cope."

Maud, Clare, Polly and Lee's extracts exude negative feelings of psychological pain they perceived from their experience of medical treatment. The lack of psychological support impacted on their lives in a very dramatic way. Lee and Polly's texts describe feeling very unable to cope with their confusion of how to fit in to a two gendered society.

In the extract below Maud described her negative experience of her medical treatment.

She talks about how she still recalls and relives certain negative feelings from her treatment like having her arms stretched out. Maud talked about sexual fantasies that she found troubling. She talked about how she sexualised her memories from her painful medical experiences.

**Maud:** "Apparently I used to suffer from night terrors after two operations and I was very upset by the two toys I had with me in hospital. I was running around in a state of terror. Weird things. You're on a crucifix shape so that you obviously don't move around too much and even now I have a phobia of having my arms out. From a very young age my memories are of medical sexual fantasies, for want of a better description, not very nice to admit. Goodness knows what you can attribute that to. I think I was in quite a lot of discomfort in that area. It became something And it was the only time I paid attention to it was when I had urinary tract infections. I think children of quite a young age are able to enjoy themselves in a sexual way. I think it's something I probably wouldn't have done. I had a bad relationship with myself. The sensation were mixed up it was pleasure with pain. God I hate this subject I've just realised."

The extract above described Maud experience as being difficult and confusing. She felt that her desires were difficult to communicate or admit to her perceived sexualisation of pain. She also talked openly with regard to feeling sexualised from a young age. She experienced her sexual feelings and desires as being mixed up with pleasure and pain because of her medical treatment.

### **...Psychiatric help**

Meredith and Polly's extracts highlight their negative experiences with Psychiatrists. Polly's text highlighted sense of feeling lost in her sexual identity and wanting somebody to talk to. She described seeking help from her GP and visiting a Psychiatrist, however this left her feeling more confused.

**Polly:** "I went back to my Doctor and asked to speak to a psychologist. I'd been asking for almost ten years just to talk to someone, but my consultant told me it wasn't necessary. I said I feel like a homosexual, but it's not quite like that I don't want to be a man. It's a weird thing and very difficult to describe. Er, he said I know the chap you need to see he's at Charing X. (...) He was awful, so direct and frightening. He was saying you just need to decide to have a sex change or you don't. (...) I felt he was pushing me to have this stuff done. I just thought my Doctor doesn't understand and has send me to someone that I don't need and he's making it worse. I thought that maybe I'm just not expressing myself in the right way."

**Meredith:** "Er, I thought if you had CAH or whatever then you were expected to be gay or at least that's the impression I got from the psychiatrist. I was sent to the Maudsley Psychiatric hospital in London at about 15 or 16 to talk about my feeling about girls until I refused to go anymore (...) it was a terrible experience."

Reference is made in the text above to the disappointing psychiatric treatment given to individuals with intersex. Meredith describes attending the psychiatric hospital and experiencing it negatively.

In the next extract Maud talks here about the fragmentation of disciplines within the treatment of intersex individuals. Maud (sarcastically) talks about the unhelpful psychiatric treatment that she received. Her text explains that to her it seems logical to provide medical and psychological support to intersexed individuals. However, she

found it shocking that it was not more obvious that she should be feeling depressed after experiencing living with CAH. Her text epitomises the problem of an intersex adult's medical management. Maud is very unhappy about the fragmentation of different disciplines that deal with her intersex management. This text compared what she had experienced with her own research and disagreed with the assumptions underpinning the medical treatment she received. For example, children who experience sex-reassignment surgery, or who are diagnosed as having CAH should not suffer from depression.

**Maud:** "Well I was a shaking depressed wreck who has a condition that is described as mostly harmless and what's the connection, there's no connection. There's nothing in the textbooks that say there's any connection we don't know anything about gender identity problems and she doesn't even have the vocabulary to tell you what's wrong. I was so frightened of using words like the sexuality, or gender identity I couldn't even tell them what was wrong. I mean they thought that I had a nervous breakdown for no reason. That's an endocrine problem so it's nothing to do with psychiatry. (...) Oh psychiatry has nothing to do with endocrinology and vice versa. The two things cannot be related even though they are occurring in the same person. There are lots of causes for depression there's no definitive cause for it. Er, there's no evidence that CAH has anything to do with it basically it was never mentioned. What a load of rubbish it's shocking! Well basically none of the endocrinologists know anything about the psychological side and none of the psychiatrists know about having any psychological implications. If it's not written in the textbooks then it doesn't exist. What those people who write those textbooks don't seem to understand that if it's not in a previous edition of a textbook nor a new edition it doesn't mean it's not occurring. But somewhere along the line new things come into being. If it's not on the hymn sheet then it doesn't exist."

Maud questions the way CAH has been and is medicalised. She viewed a direct correlation with secrecy, non-disclosure, physical pain and mixed gender with depression. She seems very angry and confused as to why these topics or relationships haven't materialised within the research on intersex. Her text highlighted the need to re-evaluate what emotional support and care intersex people should receive particularly in terms of aftercare growing up as adults. It also strongly suggested that a more psychological approach should be given to these children in order to counteract, prevent or respond to any depression that may arise through medical management. In the following extracts other negative emotions are highlighted. Such as, feeling like a freak or a guinea pig or feeling uncomfortable with Doctors looking and touching their genitals. These

experiences have arisen from the medicalisation of intersexuality and subsequent interest from medical students.

**Lilly:** "One of my memories was of lots of Doctors gathered around looking at my genitals, which didn't phase me as I was used to it but, as I got older it did. I do make very light of it now and close friends I do joke about it, but I just didn't like the physical discomfort and pain of it. I can't bear to go for a smear because of it."

**Beryl:** "I felt like a freak. We had communal showers at my school and I used to take my towel actually into the shower with me so that people couldn't see that I didn't have pubic hair."

**Polly:** "I felt like a complete freak, it was horrible I was a guinea pig. I can remember in London being at hospital with my legs spread and a room full of students. I mean they did ask me but it was horrible. I remember being naked and photographed and it did effect me really badly. Low self esteem and I had a bad body image I hate people looking at me for too long."

**Maud:** "I felt uncomfortable when people were looking at my private bits. Felt like some sort of freak."

The above texts display the negative emotions that Maud, Polly, Beryl and Lilly all experienced due to the lack of psychological knowledge or counselling psychological support. In the text below Milly talks about how she experienced her body and how that had a negative impact on her childhood. She described the fear she had of feeling transparent and possibly being found out as different.

**Milly:** "I perceived myself to be very fat. I was always told I was like a boy. Yes I think so. I didn't have a very elegant walk and I didn't hold myself or want to play with girls. In childhood I was terrified that people would find out about me and I was terrified of being persecuted for being different. I don't know why I was I was just worried about touching other people encase they could tell I was different. I was worried that people could see inside me. So you sort of crumple yourself like a piece of paper so that they can't see the writing on the inside."

Beryl's text displays a similar theme of transparency. She reports feeling negative emotions because of the secrecy and non-disclosure of her body design. She describes the pressure of keeping her "shameful" secret.

**Beryl:** “I always felt that people knew I felt really transparent. Because I was tall my imagination would [link] it to other people knowing. That I was wearing it on my sleeve because nobody was really talking about it I felt that they all knew something about it that I didn't because they weren't telling me about it that it was too awful or shameful. I was always petrified about talking to anyone about it. I felt different I just always felt that different avenues were not going to be open to be like relationships, fertility. The whole thing about fertility was just really low on my list of issues because I just felt I had more urgent things to consider like my vagina.”

Beryl's extract also highlighted the fact that fertility was very low on her agenda as she was dealing with the psychological implications of her medical management. She was more concerned about finding more out with regard to her vagina. The following extract described how the lack of psychological support created negative experiences for Betty.

**Betty:** “The whole psychological thing was completely ignored. There was no mention about talking to a counsellor about it or how I was going to cope with not having a vagina until sometime, as I wanted to get married. I mean I had to find someone to marry me and tell them about my vagina and then say okay here he is now can you do something about it. I know that not having a vagina is not the absolute be all and end all of sex, but I didn't know that then that wasn't explained to me. So I just feel very angry that the whole psychological dimension was not considered at all.”

**Polly:** “I was given the contraception pill, not for contraception but to enhance my breasts. I still felt I was trapped in this body. I just hated myself so much. I just felt unattractive and I didn't want anybody to be attracted to this.”

Betty mentioned that psychological support would have been advantageous to her. She seems to be slightly dismayed that the doctors wouldn't take seriously her concerns about her vagina. She felt that she was expected to produce a partner before her doctors would consider surgery on her.

### **...Positive Aspects**

The following texts highlighted some of the positive aspects surrounding intersex.

Cameron talks about his view on his sexuality and on relationships. It's a very mature well-balanced perspective. He seems comfortable with the knowledge that he can choose to have a relationship as either gender and with either sex.

**Cameron:** " With me is that I have had relationships with men and women you know sex with men and women. That was fine by me I didn't have a problem with either. I think

its been so long know that I have had to survive on my own now because my family couldn't cope with it the medical profession treated me badly and my friends very nervous around me. So you end up having to be very sufficient as a result of the condition and not many people can understand what your going through it's a very private kind of experience. So on that basis, you develop good coping mechanisms about how to cope emotionally, psychologically on your own and then I don't experience loneliness and I can cope on my own very well."

**Clare:** "It has made me a stronger person, (...) emotionally anyway."

**Lou:** "I suppose it's a positive in some way that I am part male and female, I could have the best qualities of both."

**Molly:** "I see intersex as a continuum of two bipolar male and female sexes. I'm certainly not ashamed to have an intersex condition and society shouldn't stigmatise or surgically try to normalise intersex genitalia, (...) nor should they frightened of intersex or hide us away. We are like anyone else, we are human beings and have feelings."

### **...Thoughts on sexuality and gender**

Clare described not knowing whether she should be attracted to males or females. This text is interesting as it supports the view that we are all socially constructed into one gender or the other. Clare talks about how she experienced her gender as stressful and confusing.

**Clare:** "You do begin to think should I be attracted to men should I be attracted to women. If I'm attracted to women then in reality terms being classified as a lesbian or I have relationships with men and am I homosexual in that respect? I mean it just plays havoc."

Vera's experience is similar to that of Clare's in that she wasn't sure how to view herself. She knew what gender she was comfortable with but she didn't know how to come to terms with her masculine side. Hilda's text highlight's how she felt she was masculine because she used to be attracted to females. The extract lends to the pressure of gendered social construction of sexuality. In that Hilda understands her masculinity in relation to her desire for women.

**Vera:** "Now I see myself as a woman and before as a woman but, there was a time in the middle that I wasn't sure and that was the time I was really struggling with the diagnosis

because it just plays havoc with your mind. I've always felt very feminine, I've always looked very feminine and people have always told me I was feminine and that has helped. But I am also quite assertive and can get aggressive, but I suppose everybody is like that."

**Hilda:** "I thought I was masculine. Even mentally I used to be attracted to the same sex. I used to have dreams and in them I always used to be I was a man with a woman. That was very problematic. But if it was accepted that I could be both genders it would make is a lot easier".

Hilda's text above explains that she would understand her sexuality better if she didn't have to choose one gender or the other. In Molly's extract we are made aware of how she feels that there is some kind of connection between homophobia and as she calls it intersex-phobia.

**Molly:** "People are more intersex-phobic than they are homophobic. Intersex seems to challenge and confront everyone's own sexuality be they male or female, because they can see bits of themselves in each sex coming together in the intersex individual."

### **...So What's Changing?**

Beryl's text suggests that the support groups are trying to promote more awareness of the child's future needs as well as care for the parents. She suggests that it is imperative that the child is allowed some form of communication about their condition order that they do not experience psychological damage.

**Beryl:** If [intersex] is discovered at infancy I think the parents need a lot of help at that stage because in that case I think that psychologists should be an integral part of the diagnosis and disclosure process. Be there to help parents and almost force the parents to talk about it and how to tell their child at the appropriate time about their condition. So that they don't have to be isolated. I think that a large part of coping with these conditions is to do with the psychological and social elements. Yes there are some medical issues and I think it has been over medicalised. I mean it certainly has in the case of genital surgery."

Maud's text is quite positive in that it is explaining the success of some new intersex management. Maud talked about her relief that she feels just having an open consultation about her sexual organs.

**Maud:** "I went to Cathy Minto for an examination and she said the surgeon did a remarkably good job and if you didn't know a great deal about it you wouldn't even know you'd had surgery, you're just slightly smaller than normal. The weight that had lifted off me... it was such a change I thought I was going crazy again. I went to see my counsellor and said I'm not going crackers am I, I can actually live now can't I? She said yes good luck have fun."

Molly talked about similar issues regarding open disclosure and experiencing being able to talk about their issues and hearing other people's stories and concerns.

**Molly:** "I went to a conference and met Sarah Creighton, Cathy Minto, Lei Mei and Gerald Conway and it was an adult meeting. It was so wonderful to talk to these people who although we didn't touch on the sexuality thing at the time. I mean we did you know the speakers but not individuals. It was just great finding out about other people and also hearing their experiences and there's me, I thought mine was peanuts compared to what they had experienced. This has all been within the last 3 years and I feel like a different person."

**Clare:** "I think there is a lot more support now, counselling support, endocrinology and the gynaecological support. I think of me growing up I would have a different image of myself growing up. When I went to get my medical records they were very open about it, however they still didn't advocate attending any support groups, which I'm quite angry about. If I'd been given that option I would have gone through a lot of the personal anxiety."

**Molly:** "Some intersex conditions such as CAH and CAIS look younger than they actually are and CAIS have excellent blemish free skin. Maybe intersex holds the key to youthful looks?"

Clare's text highlights her gratefulness on receiving more support, however she does mention that this may only be limited to location. She advocates the importance of attending the support groups and the difference she felt being there. Finally, Molly is joking about having intersex and experiencing looking young and having youthful skin.

### **...Conclusion and Discussion**

The first chapter highlighted the researchers who are specialising on intersex don't agree on whether some conditions should count as intersex. In other words, they don't really agree on what is necessary for femalehood or malehood. However, what is agreed is that intersexuals do not conform to society's fundamental assumption that there are two sexes and only two types of normal bodies. Most of the participants had an expectation that femaleness and maleness was something that could be explained precisely via their medical practitioner. Unfortunately, their comments and responses tell us that this is not the case.

A child is born with an obvious intersex condition at least once in every 1500 births. It is more like once in every 100 births if you count relatively simple variations like odd-looking clitorises and penises. Immediately there is the question about what gender to assign the child, which has implications for the child's name, clothes and pronouns used to describe the infant. It also has implications for the child's future sexual orientation, usually with the expectation from parents that the child will be heterosexual.

This uncertainty means that the parents' relationship to the child is questionable. Is my child a son or a daughter? Is that child perfect or flawed? Is this going to be a constant embarrassment for the parent and the child, or will reactions from others be positive? In total, this is a very anxious time for the parents. The literature contains repeated allusions to psychological harm and suicides of intersexed patients whose gender identities never solidified. What seems more accurate based on adult responses in this study, is that psychological pain stems from the fact that these individuals cannot be, live or act as themselves.

The traditional approach to intersex assumes it is a medical and psychosocial emergency, which must be dealt with by concealment. The goal of the concealment approach is a healthy patient with a stable gender identity, usually meaning heterosexual. There are both ethical and empirical problems with this concealment-centered approach. Firstly, it is questionable as to whether parents should ever be able to consent to medically unnecessary genital surgeries. Secondly, this approach violates patient autonomy without

just cause as they can experience physical harm because their genitals make others uncomfortable. Thirdly, it limits the child in terms of future choices in terms of gender, sexuality, identity and access to support.

Overall the parents' responses do not appear to accord well with Money's typology for the treatment of intersexual individuals. In the Parents section the general feeling is that of psychological pain, uncertainty, secrecy, unease, guilt, shame and lack of good communication between the medical profession and the parents. Some parent's texts camouflaged any acceptance of their child's intersexed bodies and thus, displaced the responsibility of this to the Doctors. The parents seemed to relinquish their responsibility for their lack of understanding of their child's condition and focussed on the medical practitioners guiding them and giving them answers. In some cases it seems that the practitioners who followed Money's protocol of treatment did not deal well with this responsibility.

Other trends are that most parents chose an aesthetic normality in terms of surgery instead of considering psychological harm or sexual functioning. The parents' texts also highlight that they as individuals come to the birthing process with their own agenda, values, assumptions and expectations. It is unfortunately in this environment that they have to make these serious decisions with little or no psychological support. Some of the parents who were interviewed thought about their children as only having an unfortunate medical condition. Whereby, other parents consciously thought about it as something else; hermaphroditism, intersex or inter. The consensus is that both sides seemed to be disappointed with how the whole subject or condition was talked about. The way that the treatment and management was administered only seemed to add to the stress and strain of their child's and their experiences.

Some parents have thoughts on their decision to consent to their child's surgery and feel they have made the correct decision for them at the time. Other parents have regretted or at least worry and feel guilty about their decision and this is apparent in the relationship between themselves and their adult children. Overall, it would be fair to summarise that

no parent was entirely happy with the communication from the medical practitioners, the treatment, the surgical options and after care. There was certainly no mention of psychological help or advice offered to the parents, if anything they were steered more into secrecy and just dealing and coping with it.

Overall the intersex adults' responses do not support Money's protocol for the treatment of intersexual individuals. In the adults section the general feelings that arise from the medical treatment are of negative emotions. An important distinction here is that most of the adults believe these feelings arose as a direct result of their medical management and not simply being different as in intersexed. Some of the feelings experienced were emotions such as; anger, feelings of abuse and butchery, low self-esteem, feelings of uncertainty and confusion and both physical and psychological pain and sadness.

Other trends are that most adults understand and respect the difficult choices their parents had to make and have come to terms with these decisions. However, other adults seem angry at the passivity that surrounded this process and perhaps feel that it may have been better to think more about the physical and psychological consequences for the child as a sexual adult. There is a general consensus that the medical management was poor, leaving some individuals feeling loss, or loneliness, in physical pain and mental torment. The lack of communication, non-disclosure and secrecy issues between the Doctors, parents and the child only caused the intersex adults to experience unnecessarily feelings of isolation and confusion. The adult's responses were mostly negative and the only positive reports were either as sarcastic remarks or concessions as in their experiences were viewed as something they just had to deal with. The adults talk sometimes reflected their necessary acquired optimism in order to cope with their bad experiences.

To summarise, all of the adults interviewed expressed concerns about how badly they were treated. They agreed to take part in this study in order that their experiences could be heard also that future intersex children would not experience similar negative treatment. None of the adult were happy with their treatment and most of them, had felt or feel victimised by their surgery and medical management. Other adults also feel that

they have not been able to experience what it feels like to be “truly themselves”. Surely this should be central before any treatment takes place. Both the adults and parents texts highlight the overwhelming need for psychological support to be included within the medical management of intersex individuals. Also consent issues need to be thought about in more detail, in terms of waiting until the intersex child is old enough to choose what they want to do with their body and how they want to live. There is no medical justification for surgically altering a child’s genitalia, nor allowing this whole process to unfold in secrecy and to sit back and expect these individuals to simply cope with this physical and mental pain. The medicalisation of intersexuality is a social phenomenon. Psychological harm and pain comes from the uncertainty and secrecy surrounding an infant born intersex. A more open inclusive approach needs to be developed. As peer support saves lives and families, and that public discussion about intersex and the uncertainty it causes leads to greater understanding and acceptance of it.

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## **Appendices:**