Intersexuality and its Intersections with Disability:

A Biopolitical Perspective

By

Arpita Das

Submitted to

Central European University

Department of Gender Studies

In partial fulfilment of the requirements for the Degree of Master of Arts in Gender Studies

First Supervisor	**Second Supervisor**
Prof. Eszter Timar	**Prof. Grazyna Zygadlo**

Budapest, Hungary

2011

Abstract

Recent developments to include intersex people within discourses of disability are indicative of the porous nature of these boundaries between identities. I explore the intersections between intersex people and disability within the realm of biopolitics that works towards classifying and hierarchizing people around the 'norm'. I argue that there is a collision between discourses of intersex people with discourses of disability which is reflected through the language of law and medicine. Because of this collision, both people with disabilities and intersex people are influenced in similar ways by processes of normalization and deemed 'the abnormals'. As people who do not fit within the logic of normalization, they are therefore not treated with rights at par with other citizens and lack equal rights including the right to consent and the right to bodily integrity and are therefore vulnerable to extreme marginalization and discrimination within society including abuse. As partial or non-citizens, they are subject to corrective surgeries and other alterations to fit them to the idea of the normal. These corrective procedures are not restricted to people who are already born, but within the era of molecular biopolitics, where normalization procedures are directed at the level of genes and chromosomes, it also takes shape through processes of genetic engineering. Through my thesis, I aim to question these normalization procedures and their impact on intersex people and people with disabilities.

Acknowledgements

Time for acknowledgements! First and foremost, I would like to thank my first supervisor Dr. Eszter Timar, for her endless patience and support for my vision and work. I am extremely grateful to her for going through several drafts of my work and giving extensive feedback. I would also like to thank Dr. Grazyna Zygadlo, my second supervisor, for her constant encouragement during my study at the University of Lodz, and for her feedback on the first draft of my thesis.

This work would not have been possible without the support of Dr. Linda Fisher and Dr. Judit Sandor who helped inform my initial ideas and thoughts. I am also thankful to Dr. Hadley Renkin and Dr. Anna Loutfi who provided valuable comments and feedback during the thesis writing workshops and the presentation of my study proposal. I would also like to thank Dr. Lena Eckert and Dr. Katherin Thiele for looking at my work and offering feedback during the NOISE Summer School in The Netherlands.

I am grateful to everyone at the Department of Gender Studies, Central European University for their help and support in several different ways and for making my time in Hungary academically fulfilling.

I would like to thank my friends, especially Manoela, Svitlana, and Tiina for their help and emotional support. I thank my family for being a constant support in my life and believing in me always. Last, but not the least, my greatest gratitude to Alankaar – you mean the world to me.

Table of Contents

Introduction

Intersexuality and disability although quite different from each other share certain similarities. Both these groups - intersex people and people with physical disabilities are subjected to processes of medicalization, medical classifications, as well as being subjected to silence and shame (Colligan, 2004); a number of studies would contend that these processes of medicalization often lead to their categorizations as ‘intersex’ or ‘disabled’ in the first place.

Both people with physical disabilities and intersex people do not fit in the standards that society sets for the ‘normative’ body. As such, they are both considered anomalies of nature. For example, intersex people are considered neither male nor female[1] and have often had to undergo multiple surgeries many a times without their consent to conform to being ‘proper’ males or females. People with physical disabilities[2] also make tangible their differences in terms of body size, shape, and ability. Both intersexuality and disability are medicalized as ‘conditions’ in need of treatment and cure and therefore to be ‘fixed’. In addition, there are also a number of assumptions with regard to sexuality for both these groups. People with disabilities often face being labelled as either asexual or being ‘hypersexual’ (TARSHI, 2010). Intersex people in turn are also subjected to negative images and stereotypes about their sexuality (Colligan, 2004). Both these groups “titillate the projected, often repressed fantasies of outsiders” (Colligan, 2004, p.45). In her study, Kafer (2004) highlights the presence of people as well as communities who worship amputees and have fantasies about them. The study marks how people in these groups actively stalk and

---

[1] I have used the terms male and female and not men and women very consciously throughout the thesis as I intended to bring attention to their sex and not their gender. I have used the terms men and women wherever I wanted to have a discussion about their gender.

[2] Politically, I align myself with the term people/persons with disability and not ‘disabled people’ as the latter accords more importance to the disability rather than the people themselves.

desire close contact and even sexual relationships with amputees specifically because of their disability.

Many intersex people may not have any other problems except that their external or internal genitalia, chromosomal level and/or hormonal levels may not be perfectly aligned to suggest being strictly male or strictly female. The usage of terms such as 'disorders' not just by the medical community but also by some international intersex organisations suggests clearly to a disability which needs to be corrected. Discourses therefore use the terminology of disability when referring to intersex identities.

I am interested in exploring the intersections between intersex people and disability within the realm of biopolitics and processes of governmentality that works towards classifying and hierarchizing people around the 'norm'. I argue that there is a collision between discourses of intersex people with discourses of disability which is reflected through the language of law and medicine. I contend that both people with disabilities and intersex people (because their discourses intersect with discourses of disability) are influenced in similar ways by processes of normalization and deemed 'the abnormals'. As people who do not fit within the logic of normalization, they are therefore not treated with rights at par with other citizens and lack equal rights including the right to consent and the right to bodily integrity. Because they lack equal rights as other citizens, they are therefore vulnerable to extreme marginalization and discrimination within society including abuse. As partial or non-citizens, they are therefore subject to corrective surgeries and other alterations to fit them to the idea of the normal. These corrective procedures are not restricted to people who are already born, but within the era of molecular biopolitics where normalization procedures are directed at the level of genes, chromosomes, cells and tissues, it is also directed to unborn foetuses through processes of genetic engineering. Through my thesis, I aim to question these normalization procedures and their impact on intersex people and people with disabilities.

Although there is a vast amount of literature already available exclusively on intersex people as well as on people with disabilities, due to constraints of time and space it would not be possible for me to touch upon all of them. It would be interesting and even pertinent to look at people who may be intersex as well as suffer from a physical disability (other than their intersex condition) at the same time. However, due to the same constraints, I will specifically be looking at discourses which label intersex people as disabled, especially the specific discourses of law and medicine. Also, it would be fascinating and perhaps relevant to explore the legal and medical discourses in different countries; however, for the purposes of this thesis, I will be focussing on the global scenario drawing examples from different regional contexts to substantiate my arguments wherever necessary. I will also be drawing examples from India where I think a lot of these concerns are current and shaping laws and policies. The impetus for my thesis also comes from a recent development when a committee constituted in India to suggest amendments to the national law on disability had proposed to include people with sex development disorder within the purview of the law. According to this proposal, intersex people would be included within the ambit of the national law on disability. Although this inclusion has been opposed by disability and sexuality activists and may not be formalised as a law, I think it is imperative to understand the argumentation behind such logic. I will therefore be using a few examples from the Indian context to substantiate some of my arguments.

In the theoretical account in chapter one, I will be discussing Foucault's (2003) idea of the biopolitical state wherein the government regulates populations through the execution of power on all aspects of human life and therefore the health of the population becomes a significant factor in regulating and classifying populations into neat categories for smooth and efficient operations. However, it is these processes of regulation and normalisation that lead people who do not fit in within these neat categories to be termed as 'the abnormals'. I will be exploring how these normalisation procedures impact intersex people as well as people with disabilities. I will also be looking at Agamben's (1995) idea of the bare life within biopolitics as well as Rose's (2007) idea of molecular biopolitics. The idea of the normal population is also led by questions of (re)production and here I will be using Ruth Miller's (2007) idea of the womb as a paradigmatic space of biopolitics. I argue that it is important to understand the machinations of the biopolitical state and its logic of normalization to understand the impact it has on people such as intersex people and people with disabilities, who are deemed as 'the abnormals'.

There is no consensus on the terms used for intersex people. Different terminology such as hermaphrodites, intersex, intersexed, intersexuals, are used to talk about intersex people. In chapter two, I provide a summary of the debates concerning the usage of these terms and also present a brief outline of some of the studies and work around intersex people. Intersex people and their issues are often confused with transgender issues not just in popular discourses but also within advocacy and activism. Although they may share commonalities, I contend that there are significant differences between the two. Although some of the arguments could be used for transgender people as well, I will be focussing on specific issues of intersex people. Since intersexuality often gets construed as a disability within the popular imaginary, I will also be discussing how intersex people are treated as 'the abnormal' within the biopolitical paradigm.

In chapter three, I will be doing a brief review of some of the literature on disability. What are the discourses and debates around disability? What counts as a disability? What are the parameters used in coming to a conclusion about one's disability? Are they universal? These are some of the questions I will be focussing on in this chapter. Suffice to say that disability is broad subject area including both physical and intellectual disabilities but for the purposes of this thesis I will be focussing on physical disabilities. Social constructions of disability also present them as a burden, sapping the resources of the family and the state. People with disabilities are often not considered a part of the productive population within the realm of biopolitics. I will be expanding on some of these constructions and how they may impact people with disabilities.

In chapter four, I look specifically at discourses of law and medicine at the global level. In particular, I explore the points of intersections between intersexuality and disability that occur in these discourses of law and medicine. Some of the questions I wish to explore through this study are: what is the language used for intersex people; when and how intersex people are considered disabled; do emerging discourses on disability include intersex people; how do organizations working on intersex issues define intersex people; does the language of the discourses for intersex people collide with the discourses of disability? In particular, I am interested in exploring whether international laws on disability include intersex issues. What is the language used in these laws? I will also be looking at the World Health Organisation (WHO) as a representative international organisation and explore how they define intersex people. I will explore if the definitions they use for intersex people are or can be used to pathologize, medicalize and disable them. I will also look at a few international organisations working on intersex issues and the definitions they use to refer to intersex people.

In chapter five, I will discuss some of the intersections between intersexuality and disability. I will discuss how biopolitics works through procedures of normalization to deem some people as abnormal. Both people with disabilities and intersex people are often impacted through such classification systems thus making them vulnerable to procedures such as corrective surgeries, genetic engineering as well as eugenics. I also discuss how within the biopolitical paradigm, people with disabilities as well as intersex people are often devoid of rights including their rights to bodily integrity thus finding themselves as less than normal. This situation however gets reversed in certain situations such as sports where certain people with disabilities and intersex people have been regarded as more than normal and seen as threats to the order of normalcy. Within this paradigm, people with disabilities and intersex people continue to be treated either as less than or more than the normal but never at par.

To my knowledge, I am not an intersex person. I write this not to create a moment of drama but to position myself within this work. Also, I would like to state that this work is tentative and I tread very cautiously in making any claims through my work. I am primarily a social scientist who has been profoundly interested in issues of gender, sexuality and gender-based violence. I have not actively engaged with intersex issues prior to this work. My work on disability has been mostly focussed on looking at issues of gender and sexuality for people with disabilities. I acknowledge that this study is more a process for me to understand and learn the issues specific to intersex people and people with disabilities. I am grappling with the nuances not just in the experiences of people who are intersex and/or disabled but also in the intricacies of the language and discourses used for both these communities. This study is a work in progress and not conclusive in any manner.

I have also been fascinated with the bio-political state and its machinery and how it works and affects different people as a part of my studies in Gender Studies. I feel it is important to look at the biopolitical state to understand the ways in which people are governed and made into neat categories for more efficient means of governing populations and examine its impact on intersex people and people with disabilities. Again, I acknowledge that this work is primarily a process for me to understand the machinations of the state and how it works on intersex people and people with disabilities.

I acknowledge the multiplicities and complexities in the meanings of terms, definitions and discourses. I do not profess to comprehend all of them. This work is tentative and hopefully a smaller part of a work-in-progress.

Chapter 1: The ‘Abnormals’ within Biopolitics

Foucault (1997) has discussed the intersex person as the figure of the ‘abnormal’ where he argues how the figure of the ‘hermaphrodite’ was one of the many representations of the ‘human monster’ which disrupted not only the idea of perfect human bodies but also destabilised juridical regularities such as destabilising laws related to marriage, inheritance etc. The juridical law also gives way to the medico-legal law in the case of the intersex person.

Intersex people who may either have variant external genitals or internal reproductive organs, different hormonal levels or a different chromosomal make-up or a combination of a few or all of these, do not fit in within stereotypical conceptions of being a ‘normal’ male or a female. They are often subjected to a plethora of medical procedures in order to be ‘fixed’ within the binary of male-female. The rule often followed is of raising genetic females as females so as to preserve their reproductive potential whereas for genetic males it would depend on the size of the penis (Fausto-Sterling, 2000). From this narrative, it can be inferred that the intersex person is construed as an ‘abnormal’ if the person fails to conform to societal norms of being a man or a woman.

Procedures and apparatuses which function in terms of labelling certain people as normal and therefore worthy while rendering others of little value can be understood from a biopolitical framework which has been espoused by Foucault (1993, 2003) and further developed by Agamben (1995) and Rose (2007). In this chapter I will be talking about Foucault’s ideas on governmentality and how the rights of the sovereign functioned within that framework. I will further be discussing Agamben’s ideas of life which was not considered worth living. Further, I find Rose’s ideas about the advent of medicine from the molar level to the molecular level fascinating in terms of discussing which bodies are considered worthy and which are left out in the process. The idea of 'worth' of human beings can also be understood from the lens of productivity and reproductivity. I will be discussing Irving's ideas of productivity as well as Miller's idea about the womb being the space of the biopolitical framework. Understanding the biopolitical state and the processes of governmentality which function through categorising populations into the 'normal' and those who are not, can enhance our ideas about how these procedures impact people such as intersex people and people with disabilities among others who often do not fit into these narrow compartments.

In his lectures entitled 'Society must be defended', Foucault (2003) discusses the power of the sovereign to decide whether the subject has the right to be alive or dead. He argues that a transition took place in the 19th century from the right of the sovereign to "take life and make live" to "make live and let die" (Foucault, 2003, p.240). The difference between the two could be located in the sovereign actively taking lives of its citizens in the first case to actively not playing a role in protecting the lives of its citizens in the second one. In the latter, although the sovereign could not be held responsible for taking people's lives, it was still responsible for not protecting them. The people who remained unprotected such as intersex people as well as people with disabilities were those whose lives were not valued enough by the state and the sovereign as they did not fit the parameters of a normal and healthy population.

According to Foucault, during the 17th and particularly the 18th century the right of the sovereign to take lives of people began to be debated. If the sovereign had been constituted to protect the lives of its citizens, how then could he have the right to take life? Foucault describes this transformation in the techniques of power during the two time-periods from the focus on the individual body to the focus on man-as-species. Disciplinary forms of power such as surveillance, inspections began to change to a regulatory power and applied not to man-as-body but man-as-species. In his words,

> “discipline tries to rule a multiplicity of men to the extent that their multiplicity can and must be dissolved into individual bodies that can be kept under surveillance, trained, used, and, if need be, punished. And that the new technology that is being established is addressed to a multiplicity of men, not to the extent that they are nothing more than their individual bodies, but to the extent that they form, on the contrary, a global mass that is affected by overall processes characteristic of birth, death, production, illness, and so on” (Foucault, 2003, p.242).

Therefore, even if individual bodies were still accounted for in the regulatory forms of power, it was to the extent of catering to a whole population and therefore newer devices and strategies were necessary for purposes of surveillance of an entire population. However, this transition from the disciplinary to the regulatory form of power was not a case of clean replacement. This new form of regulatory power included elements of disciplinary power as well. These forms of power were not mutually exclusive and influenced each other. Sexuality was at the intersection of both these forms of power and had effects at two different levels if it was not under both disciplinary as well as regulatory power. For example, the undisciplined masturbating body of the child would bring upon sexual depravity leading the child to be invalid and this would in turn have consequences at the level of the population by affecting many generations through genetics. It was during this time of transition that there emerged new methods of surveillance through statistics on birth-rate, longevity mortality etc. Statistics formed a major part of Foucault’s idea on ‘governmentality’.

> “Government as an activity could concern the relation between self and self, private interpersonal relations involving some form of control or guidance, relations within social institutions and communities and, finally relations concerned with the exercise of political sovereignty” (The Foucault Effect, Colin Gordon, pp.2-3).

The government was therefore part of complex relations between different individuals, institutions and communities. It derived a lot of its power from its control of the population through various statistical procedures such as the accounting for the fertility of women, the life expectancy of the children, their health status etc. Within the biopolitical framework, the sovereign focussed on governing an entire population through biopower or in other words, through governing all aspects of people's lives. The focus of the state was not just on the present population but also on what would count as the future population. The population was further looked at from the lens of healthy or not healthy, productive or not. It was important for the state to have a healthy and productive population and therefore to make do without the ones who proved a burden on the state. The state started dealing with not just issues of fertility but also that of morbidity. It started dealing with not just epidemics but also endemics. Endemics were different from epidemics in that they did not result in frequent deaths but created lasting conditions which would result in state expenditure. These illnesses would sap the energy of the population and result in decelerating the productivity of the nation.

This in turn resulted in the development of medicine and public hygiene and led to the medicalization of the population. Issues such as reproduction, birth rate and mortality began to be included in these surveillance programs. There were attempts not just to control the events within the population but also to predict the probability of events and further to either prevent or modify them. Biopolitics included not just old age and infirmity but also accidents and other anomalies. Agamben (1995) developed Foucault's idea of biopolitics by discussing the transition when biological life becomes important to the extent of being "politically decisive". Agamben says:

> the root of modern democracy's secret biopolitical calling lies here: he who will appear later as the bearer of rights and, (...), as the new sovereign subject (...) can only be constituted as such through the repetition of the sovereign exception and the isolation of the corpus, bare life, in himself. It is true that law needs a body in order to be in force, and if one can speak, in this sense, of "law's desire to have a body,"

> democracy responds to this desire by compelling law to assume the care of this body (Agamben, 1995, p.124-125).

Thus, for democracy to work, it had to be located on individual bodies, i.e., bare anonymous life of people. Within this framework, individual bodies within the population had to be cared for. This care came about through the body both being subjected to the law as well as being isolated. This subjection of the body was not limited to juridical law alone but extended to the medico-juridical domain as well. Agamben thus discusses the ‘corpus’ or the body as the new subject of politics and discussed the “*corpus as a two-faced being, the bearer both of subjection to sovereign power and of individual liberties*” (Agamben, 1995, p. 125) [italics in original]. He instantiates the significance on the body within this framework with the institution of *habeas corpus* which required individual bodies to be presented in the courts for the law to be executed.

Nicholas Rose in his book on *The Politics of Life Itself* (2007) argued that although the medical attention was still spatialized on individual bodies, the gaze in the last quarter of the twentieth century had changed in comparison to the nineteenth century from the molar level (i.e., the domain of limbs, organs and tissues) to the molecular level (i.e.., at the level of molecules through X Rays, ultrasounds, fetal images, EEG of the brain etc). This transition in the medical gaze thus exposes the body not just to technical innovation and experimentation but also to capitalistic exploitation. Further, this offers opportunities of creating new forms of molecular life and therefore life itself (Rose, 2007). Thus,

> “(...) Molecular biopolitics” now concerns all the ways in which such molecular elements of life may be mobilized, controlled, and accorded properties and combined with processes that previously did not exist. At this molecular level, that is to say, life itself has become open to politics. (Rose, 2007, p.15)

In this new era of molecular biopolitics, doctors gain in prominence and are found to be encroaching not just in matters of the body and medicine but also on morality and politics which were earlier not considered their domain. They are therefore considered the new arbiters of justice deciding on which lives are worth living and which are not, or rather which lives are worth protecting and which are not. The claims made by medicine which were based on the evidence of genes and chromosomes gave it an added impetus. The technology used comprised not just of equipment and techniques, but also included "hybrid assemblages of knowledges, instruments, persons, systems of judgment, buildings and spaces, underpinned at the programmatic level by certain presuppositions about human beings" *(sic)* (Rose, 2007, p. 16-17). Whereas, in earlier times, medicine was known to work towards arresting abnormalities in bodies and helping people to adhere to the normative body, in the age of molecular biopolitics, the function of medicine has been compounded to include alterations and corrections as well. Further, abnormalities could be traced not just at the level of organs but also at the level of chromosomes and genes etc. Therefore, it was now considered plausible to correct and alter bodies as the boundaries between treatment, correction as well as enhancement seemed to blur.

Through this biopolitical framework we can thus see the trajectory of how the state diverted its attention from individual bodies to that of the population. However, in order to have a control over this population the gaze of the state had to be still fixed on individual bodies. Individual bodies were thus subjected to processes of normalisation in which bare life was evaluated in terms of its value or worth. The bodies of individuals were therefore considered the spaces where the politics of the state was located. Thus individuals ceased to be natural bodies alone but came to be considered as bodies of the state and the government. While bodies which adhered to notions of normality were integrated within the state, the ones which did not needed to be altered and corrected.

The 'abnormal' can also be evaluated from the lens of productivity and reproductivity within the biopolitical framework. (Re)production therefore is an important ingredient in deciding the worth of human beings in the processes of governmentality. In his article, Dan Irving (2008) discusses the notion of productivity with respect to transsexual people. He suggests that capitalist modes of production often influence the construction of transsexual subjects as viable members of society (or not) and reinforce exploitative relations. To be recognised as a productive being, the transsexual body must constitute a working body capable of taking part in capitalist modes of production. Discourses of productivity make distinctions between bodies that are healthy, able, (re)productive and those that are not and reinforces heteronormative categories of sex, gender race and sexuality. Certain bodies are considered more productive and therefore are prioritised within these modes of production, e.g. male bodies over female bodies, healthy over unhealthy, able-bodied over disabled, white bodies over people of colour, heterosexual over homosexual, and reproductive over those which are not.

The politics of reproduction also plays a major role in discussions of citizenship and rights. Miller (2007) develops the ideas of Foucault and Agamben and argues for the womb as the paradigmatic space for biopolitics. Mindful of the debates on the foetus, she clarifies that in discussing the womb, she is not arguing for the foetus as a rights bearing entity (Miller, 2007). In addition, Miller draws attention not to the person who is the owner of the womb, but to the space itself. Therefore, the womb in question must be a functioning one, leading to procreation and therefore the expansion of the ‘population’. Drawing from her argument, it would be easy to surmise that this logic of reproduction hierarchizes certain women who first of all may have a functioning womb and must also be willing to reproduce, over others who cannot or are not willing to reproduce. In certain cultures the womb is also more valued if it belongs to a woman who is in a heterosexual monogamous marriage. A functioning womb of a single woman or a homosexual woman may actually be taboo in certain cultural contexts. States often decide which wombs to revere and which not to.

Therefore, wombs of certain communities are valued more than the others. This hierarchization and valuation of wombs differs across different countries, cultures, races and communities. The womb thus becomes the bearer of one's ethnicity and nationality. It is not just responsible in reproducing one's family but an entire population. Miller draws the linkage between the womb and the health of the population and within this framework the "women are the political actors" (Miller, 2007, p.152). The people in possession of these wombs therefore gain power through their ability to procreate.

Miller further argues that to the extent sexual and reproductive legislation are put in the centre with the biopolitical shift in ideology as "make live and let die", women become significant players in this system as they possess the wombs. They become the carriers of not just their own family but also the entire species. Within this framework, men have to conform to a secondary status. They gain in power only when they are in possession of a woman with a legitimate functioning womb. Thus, it is through the women's consent that men acquire "artificial wombs" (Miller, 2007, p.149) and are granted citizenship status.

I would now like to draw our attention to where does this leave intersex people and people with disabilities? In the modern biopolitical state whose main purpose is to produce and reproduce normal and healthy populations, and women appear to have acquired a more empowered status based on the possession of a legitimate functioning womb, where does the intersex body (which may either not have the reproductive potential or may be considered incapable of giving birth to and rearing babies, even if that may not be the case) fit? Does the intersex body then get counted as an abnormal? How do we position the body of a woman with a physical disability? Is she equally empowered as an able-bodied woman even if she possesses a functioning womb? Further, how does this position wombs that reproduce babies which are either intersex and /or with a disability? Are these wombs revered as much as others just with the power of reproduction? Does the reproduction of babies which are intersex and/or with a disability put these wombs under the scanner? Does this discourage any further reproduction by women with these wombs? These are significant questions that need to be answered.

Within the biopolitical framework certain bodies are therefore considered normal if they fit into parameters of being healthy, able-bodied, and fit in the male/female binary. The people who do not fit into these parameters of normalcy are thus subjected to processes of marginalization and discrimination and considered as the lesser citizens who therefore do not enjoy equal rights of other citizens.

Miller (2007) discusses rights and citizenship as “instruments of cutting, splicing and stitching as tools in the construction of the physical, flesh-bound citizen, rather than in the construction of the abstract, law-bound citizen (Miller, 2007, p.2). Within this shift from politics to biopolitics where the focus is more on the life or the health of the population, reproductive and sexual health of the population plays a significant role. She argues that consent and bodily integrity work as the twin pillars of appropriate sexual, reproductive, and political structures (Miller, 2007, p.6). She is interested in looking at the ways in which a citizen’s political status as a consenting individual collides with a citizen’s biological status as a being possessed of bodily integrity (Miller, 2007, p.6). She elaborates by distinguishing citizens who are capable of full consent from partial citizens or non-citizens who because of their levels of maturity and age are considered incapable of consent. However, Miller uses the example of a refugee to complicate the logic and bring to people’s attention that it is not simply children who are considered incapable of consent but also others including refugees (who may be adults) who are not considered as equal beholders of rights as other citizens. Miller argues that ideas of consent and bodily integrity become meaningful only in the context of citizenship. In my thesis, I would like to extend Miller’s ideas about citizenship to intersex people as well as people with disabilities who like the refugees, are not considered at par with other citizens as they do not fit the parameters of the normal and healthy population. I will elaborate on this in chapter five of my study.

It is significant at this juncture to also acknowledge that the biopolitical framework leans heavily on the presence of the abnormal. The presence of the abnormal helps to affirm that which is normal and therefore within this framework which operates through regulation and normalisation procedures, the abnormal exists to give an idea about the normal. Here I would like to rely on Butler's (1993) ideas of oppression that works not just through direct acts of prohibition but also through the constitution of "unviable un(subjects)" who do not exist in law either in name or in terms of actual prohibition. She focuses on lesbianism. Her argument in this text focuses on the analysis of the concept of the copy. She talks about gender as an imitation and a set of iterative strategies to produce the notion of the original. She debates the notion of compulsory heterosexuality[3] posited as the original and homosexuality as the copy. She complicates the position of the original as prior to copy by arguing that the original claims its position only in opposition to its derivatives, thus heterosexuality is the original only so far as it presupposes homosexuality as its copy. The copy (homosexuality) therefore precedes the original (heterosexuality) and in turn becomes the original thus destabilising the notion of which precedes the other.

I think this argument could be extended to include intersex people as well as people with disabilities who are excluded from the realm of discourse. In her argument, Butler discusses that the copy precedes the original and it is in the presence of the copy that the idea of the original is formed. By the same logic, it could be held that it is in the presence of intersex people (with variant genitals) that the idea of 'perfect' genitals is formed and reiterated in society. Intersex people are in the continuous process of rendering themselves as

---

[3] The concept of compulsory heterosexuality was introduced by Adrienne Rich in her essay *Compulsory Heterosexuality and Lesbian Existence* (1980) in which she argues that the institution of heterosexuality allows for men to have right on women physically, economically and emotionally. To counter this, she urges women to direct their energies towards other women.

either male or female identities. Therefore, if it were not for the existence of intersex as copy, there would be no existence of male/female as the original. Similarly, it is the presence of the people with physical disabilities that helps to formulate the idea of the 'normal' able-bodied person. Thus, it is the presence of the normal as well as the abnormal that lends to the logic of normalization. This idea of normalization also works through a binary logic with the two ends being the normal and the abnormal.

Biopolitics thus forms an important framework to understand how regulatory power is executed on whole populations to classify and hierarchize various bodies, deeming some as normal while relegating all others as abnormal subjecting them to corrections and alterations. In the next chapter, I give a brief overview about intersex people and bring attention to some of the debates surrounding them. In addition, I also discuss how intersex people may fit in within or may be impacted by the biopolitical framework.

Chapter 2: Intersex people within biopolitics

2.1 Positioning intersex people within the sex/gender paradigm

Gender norms necessitate people to fit in neat boundaries of being either male or female. When a person is born with genitals that do not fit in as either male or female, it troubles the sex binary and therefore necessitates medical management to make them adhere to being either a male or a female. However, what constitutes a biological male or a female? Is it the presence of male genitals such as penis, testes for males and female genitals such as vagina, clitoris for females?

In her book, *Sexing the Body*, Fausto-Sterling (2000) talks about determining sex as a complex process and that gendering the body as a social decision. Although there is an assumed linear relation between sex and gendered performances (Colligan, 2004), over the last few decades, sex and gender have been understood as different concepts. Whereas sex has been understood as the biological or anatomical attributes of a person, gender has been largely understood as the sociological and psychological process of being a man or a woman. Whereas sex was considered to be fixed, gender could be learned and therefore also unlearned. Sexologists in the 1970s as well as feminists emphasized this difference between sex and gender; whereas sexologists popularized the difference between the two categories, feminists stressed that although male and female reproductive functions were different, gender behaviour could be learned and therefore gender differences between men and women could also be unlearned (Fausto-Sterling, 2000).

Sex and gender are often considered in a linear relationship for people almost pre-supposing that the presence of the ‘correct’ genitalia should be followed by ‘appropriate’ gender behaviour and roles. Awareness about the difference between sex and gender brought about an analysis of how sex could not be changed, whereas gender could. This is probably one of the reasons that influenced doctors and sexologists such as John Money to carry out experiments on infants. In a much publicised case in 1972, Money conducted a surgery to reassign female gender on a biologically born male whose penis was cut off during a surgery. The premise of the case was that the boy would not be able to develop a normal male gender identity in the absence of his penis (Kessler, 1998). Kessler (1998) discusses that this case was considered particularly interesting as the infant was an identical twin and therefore would help to shed light on whether identical twins could develop different gender roles and behaviour and to explore the influence of biology and the socialization process. In this case, Money believed that even if the child was born a boy, a change in his gender could be effected through a change in the way he was reared. He advised the child’s parents also to rear him as a girl as well as undertook multiple corrective surgeries on the child. The case was considered a blow by social constructionism model of gender to the biological determinism model as Money reported that the infant was able to develop the gender behaviour of a girl and was quite different than her twin brother. However, another sex researcher, Milton Diamond found the girl years later, who was then living as a boy and reported that he had never accepted the female gender identity and had requested that he be converted to the male sex at the age of 14 years (Kessler, 1998). After hormonal treatment and surgery, this person was reassigned as a male. Diamond used this case to prove that the biological sex of a person influenced a person’s gender and not the socialisation process. This example instantiates some of the debates between biological determinism and the social construction model. While the model of biological determinism asserts that biology is a key determinant of human behaviour, the social construction model argues that society plays a key role in impacting human behaviour.

This case in question presents a number of interesting points to ponder about. While Money believed that gender behaviour may be independent of the sex one is born with and can be shaped by the socialization process, he nevertheless found it important that the child possess the penis to perform his gender behaviour. Diamond, on the other hand, allowed more primacy on the biology of the person and its determination of the person's gender. Whether or not one's sex leads to the determination of the person's gender, it can be argued that sex and gender are in a complex relationship with each other, whether it is sex that leads to the construction of gender or whether it is gender that constructs sex. This complexity is further enhanced in the case of intersex people.

2.2 Intersex people: The politics of naming

Intersex people have always been part of the population. Although medical experts mention one in every fifteen hundred or two thousand births as intersex, it is contended that there are a far greater number of people who have subtler forms of anatomical variations (ISNA, 2011). The prerequisites of being a male or a female have evolved with time. This can further be evidenced with the transition in biopolitics from the domain of the molar to the molecular, i.e., from the level of the external organs to the hormonal and chromosomal levels of the person. One of the contexts in which this evolution becomes apparent is in the field of sports. For example, in the Olympics until 1968 the competitors had to parade naked in front of the committee for the determination of their sex. This has changed over the last few decades and they now have to undergo chromosomal tests to qualify as male or female (Fausto-Sterling, 2000). Whereas it was considered okay to check the external genitalia of a person to determine the sex, gender identification today is dependent on a plethora of tests on these individuals. It is increasingly difficult to give clear-cut definitions of what constitutes the male and/or the female. Examples of several athletes and sports-persons, such as Santhi Soundarajan (Saner, 2008) from India or Maria Patino (Fausto-Sterling, 2000, pp.1-2) from Spain, being tested as male when all their lives they had perceived themselves as being females bring out the confusion and the overlaps between the oft-perceived neat categories of male and female.

With the advent of hospitals and clinics and interventions to fix intersex children at birth, reproductive abilities are often an important consideration to determine whether the child is male or female. Doctors and sexologists have often considered a person as female depending on the person’s ability to give birth when older; similarly they would consider a person as male if the person had the requisite penis size or the potential to grow to the requisite size of being able to penetrate (Fausto-Sterling, 2000; Kessler, 1998). People who fall in between the categories of being male or female are considered as intersex.

Intersexuality has also been termed as hermaphroditism (Kessler, 1998). However, many intersex groups including Intersex Society of North America (ISNA), an organisation in the USA which has been involved in several advocacy initiatives around intersex issues, contend that the term ‘hermaphrodite’ is not a factual description for them. The term ‘hermaphrodite’ signifies the simultaneous presence of both male and female characteristics which is not the case for a large number of intersex people (ISNA, 2011). Organisations such as ISNA and Accord Alliance in the USA choose to address intersex people as people with ‘disorders of sex development’ (DSD) as they believe that in doing that the focus is on the disorder itself and not on the people. They believe that in shifting the focus to the disorder itself, the marginalisation and stigmatisation that intersex people are often subjected to, would be reduced. However, Organisation Intersex International (OII-Australia), an organisation in Australia chooses to use the terminology of ‘intersex’. I will be discussing more about the terminology used by intersex organisations in the chapter on the legal and medical discourses. However, irrespective of the terminology used, organisations working with intersex people and associations of intersex people are coming together to assert their rights in the international arena. Although for many intersex people, their sexual variance may have been corrected or altered to fix them as either male or female, they have mobilised together as an identity group of intersex people to protest against medical (mis)management through infant surgeries (Kessler, 1998). The medical community however continues to look at intersexuality as “correctable” (Kessler, 1998, p.5) to fit these individuals into the sex binary.

Some definitions of intersex people define them as people with ambiguous genitals. For the purpose of this thesis I will be using Kessler’s (1998, p.8) terminology of ‘variability’ instead of ‘ambiguity’. The term ‘ambiguity’ which means vagueness or confusion again contains value judgments made by theorists whether consciously or unconsciously and affirms the bipolarity of the binary sex system. The usage of such terminology perpetuates the marginalisation and discrimination that intersex people face.

Intersex as a category is difficult to define. At the molar level, or the level of organs, it may consist of people who may not be born with external genitalia that may not fit the stereotypes of being a male or a female. There may also be others who may be born with perfect external genitalia of a male or a female but have internal reproductive organs that do not match the sex of the external genitalia. There are biological girls who may be born with a large clitoris and boys who may be born with a tiny penis. The notions of the perfect length of a clitoris or a penis differ across time, contexts, countries as well as doctors from different disciplines. The use of a phallometer by doctors to determine the sex of an infant has been documented by many (Fausto-Sterling, 2000, Kessler, 1998, Karkazis, 2008). There are girls who may be born without a vaginal opening and boys whose scrotum maybe divided like that of labia (ISNA, 2011). At the molecular level, people may be categorised as intersex depending on their hormonal levels or their chromosomal make-up. There may be individuals born with mosaic genetics so that some of their chromosomes are XX and the rest as XY (ISNA, 2011). Some of them may have been exposed to an unusual mix of hormones while in the womb. It is possible that many intersex people live through their lives without being aware of their intersex state till they seek medical help for their infertility etc. Therefore, it is difficult if not impossible to come to a decision regarding a definition for intersex people and it may not even be advisable.

Although the process of determining sex and gender on infants may have changed over the years, the decision of assigning sex to a child rested and still rests on medical professionals who thus acquire the status of arbiters of justice. However, decisions regarding sex and gender also differ across medical doctors within the same discipline or across disciplines. This instability in coming across a common definition for intersex also indicates that being male or female is not a category predetermined by nature. Whereas biology may govern what kinds of organs, hormones or chromosomes people are born with, the status of being a male, female or intersex is socially determined. "Intersex is a socially constructed category that reflects real biological variation" (ISNA, 2011). Within this complex relationship between sex and gender, sex like gender is also socially determined.

For the purposes of my study, I consider intersex people as those who are either born with genitals that conform to neither being strictly male nor female or have a chromosomal and/ or hormonal make-up that does not adhere to being strictly male or female thereby challenging our ways of thinking in simplistic sex binaries.

2.2 The decision making process

As discussed above, intersex people are those who either due to their gonadal, genetic, chromosomal or hormonal levels do not adhere to being either strictly male or strictly female. Those born with external genitalia that do not appear as 'normal' males or females are usually detected at birth. Further, there are other tests conducted to find out the alignments in the chromosomal, hormonal and gonadal make-up of the person in order to make conclusive decisions about the gender of the person involved. These test results may take a while to arrive and till then most parents and other caregivers experience immense pressure to make a decision about the gender of the person. There is usually a team of doctors to decide the gender assignment of the baby consisting of endocrinologists, paediatrics, urologists, psychologists etc and they come to a decision about the gender going by the results of the tests.

Although the appearance of the external genitalia of a person is an important factor in the determination of the sexual identity, the medical community increasingly acknowledges the importance of the chromosomal level and the hormonal level of the person. While the medical community realizes the importance of a 'normal' hormonal environment in the uterus of the woman it is still not clear how much androgen exposure is enough for an adequate male or a female (Karkazis, 2008). Some intersex people may not be aware of their intersex status for a long time until they are tested. Being intersex in most cases does not interfere with other activities as a person and may therefore not require any medical intervention. A recent study in India on ten adults with ambiguous genitals who had had genital surgeries in their late childhood or adolescent years unequivocally mentioned that they would have liked the surgeries earlier in their lives so they would have minimum recollections of the experience (Warne & Bhatia, 2006). Many international intersex organisations such as ISNA, Accord Alliance as well as OII-Australia openly advocate for no surgical interventions without the consent of the person involved except those that may be deemed necessary. They recommend that surgical interventions, if any, be postponed when the person can make an informed consent about their sex and gender.

The intentions behind interventions and corrective surgeries on intersex people make for an interesting study. Intersex people may have functioning bodies as most other individuals. However, most corrective surgeries are conducted on intersex infants with aesthetics in mind and fixing the bodies within the binaries of male and female. It is therefore not considered sufficient to have a functioning body but that body has to fit into the parameters of so-called 'normal' bodies or suffer the possibilities of being left out of processes of governmentality. Decisions could also be guided by the idea of whether the person can reproduce as a woman. If the person had the reproductive organs of a female and is able to procreate, efforts are made to get the person to conform to the feminine gender. For men however, the important parameter is whether they have the right size of the penis and is erectable to be able to participate in hetero-normative penile-vaginal penetrative sexual activity. It is interesting to note that John Money, one of the first few medical experts working on intersex issues stressed on retaining the reproductive potential of the intersex individual, if the latter has the capacity for the same. After the reproductive potential of the individuals is taken into consideration, it was important that the external genitalia matched the gender in which these individuals were being raised.

It was also vital that the size and the measurements of the external genitalia of the individuals were close to what was considered the right measurements for a male or a female. Thus, for a male, it had to have the right size for the penis accompanied by testes. For females, the clitoris had to adhere to the right size accompanied by the vagina. In the attainment of aesthetics for the perfect male or female it was not important to see if the individuals retained their sexual responsiveness. In a cross-sectional study conducted to analyse the effect of clitoral surgery on the sexual outcome of individuals, of the 39 respondents enrolled, 28 of them were sexually active and all of them had sexual difficulties (Minto et al., 2003). It was also observed that the 18 respondents who had had clitoral surgery had higher rates on non-sensuality and inability to achieve orgasms than the 10 respondents who did not undergo clitoral surgery (Minto et al., 2003). In another study, a number of the respondents reported a lower level of sexual responsiveness as a result of the ‘cosmetic’ surgeries undertaken when they did not have an opportunity to participate in the decision-making process (Frader et al., 2004). It is evident from these studies that very little attention is paid towards the sexual responsiveness of the intersex people after these surgeries are conducted.

The parameters for determination and assignment of sex are often very complex and change across different times, geographical contexts, as well as diverse socio-cultural and economic contexts. For example, in countries such as India where there is a preference for sons within the society, sex determination as well as assignment could be guided by these factors as well. In addition, because these processes of sex determination and assignment can also be quite expensive, it could also be influenced by the socio-economic condition of the family and the affordability of medical interventions.

2.3 Intersections within discourses of transgender people and intersex people

Intersex people also share commonalities with transgender people in how they are treated by nation states, and in certain societies they may be clustered in the same group as well, as people who are desirous of, have undergone or are going to undergo genital surgery/ies and procedures of sex assignment. However, an important point of distinction between the two groups is that of consent. Whereas transgender people may opt to have a genital surgery among other interventions, intersex people often do not enjoy the right to choose genital surgery. Many of them undergo genital surgeries at birth and have multiple surgeries through their lives without being informed about them. Treatment protocols however, differ across countries and have also evolved with time. There are also cases where parents have opted not to get their intersex child operated until the person can make an informed choice on one’s own.

Also, although transgender people are usually born in typically male or female bodies and consider their sex identity in conflict with their gender identity, most intersex people do not have doubts about their gender identity. Most intersex people come to the notice of doctors because there something unusual has been found about their bodies (ISNA, 2011).

Although they share commonalities as both being anomalies of nature, and are marginalised within societies, I will limit the focus of my thesis to intersex people and their intersections with disability within a biopolitical framework.

2.4 Intersex people within the biopolitical framework

As an organized discipline by the late nineteenth century, biology began to gain the authority not just to decide about ailments and treatments but also to decide which bodies were abnormal and therefore in need of correction (Fausto-Sterling, 2000). Infants born with "either/or - neither/both" disappear as they are surgically corrected as soon as they are born (Fausto-Sterling, 2000). Intersex people thus began to be medicalized and 'fixed' at birth. Whereas a large majority of intersex people do not need any kind of surgery, doctors and surgeons began to intervene to make them conform to being stereotypical males or females. Their gender behaviour is also made to fit the gender stereotypes of their genitals. While there is much emphasis on fixing individual bodies through disciplinary power, regulatory power also works towards eliminating chances of reproducing more intersex people through processes of genetic engineering as well as eugenics which I will be discussing in detail in chapter five.

Along with the medical community, families of intersex people as well as the society in general look at ways of getting the intersex bodies to conform to male/female norms and thereby adhere to norms of their specific gender. Efforts are made to make functional bodies that perform the gender imperative without causing any disruption or destabilising societal norms. Some may eventually fit into the sex and the gender categories allotted to them whereas the others may not. Irving (2008) suggests that these systems of normalisation create and strengthen hegemonic and binary systems which privilege some people while marginalising others.

However, within biopolitics with its emphasis on normalisation, attempts are constantly being made to fix intersex people at birth to make them conform to being either productive males or (re)productive females. Biopower is an indispensable component of the capitalist society where on the one hand individual bodies are constantly being used for production and on the other the population is geared towards economic processes (Foucault, 1990, p.141). This productivity is ensured by both disciplinary as well as regulatory mechanisms by "distributing the living in the domain of value and utility" (Foucault, 1990, p.144). People are thus assessed, classified and hierarchized according to their worth, their productivity and their contribution to the society and the state. Thus, people's productivity formed an important parameter around which the normalisation procedures were instituted.

Another important component in determining people's productivity would be through the lens of reproduction. Intersex people, who are often considered 'not complete', are by that logic disable-ed. While they may be perfectly functioning bodies in most ways, some of them may lack the function of being able to procreate. While some of them may be born with the ability to reproduce, many others may not. Of those who may be born with the reproductive organs and are fertile, there are many who have been operated on (once or several times during their lifetime) for the removal of some of these reproductive organs to make them into neat stereotypical males or females. Doctors often consider it their moral imperative to convert an intersex infant into a male or a female body so as to make them into (re)productive beings. The person is converted into a female if she is able to fulfil her worth as a woman by being reproductive. For men it would be significant to perform the role of being the penetrator in a sexual relationship. The presence of ovaries even if they exist alongside a number of masculine characteristics would get the person considered a female and similarly the presence of testes along with female characteristics would make the person male (Fausto-Sterling, 2000). However, whether or not they are biologically able to reproduce, there is an implicit assumption that they lack reproductive abilities. They may therefore be considered as bereft of a ‘womb’ and therefore the possibility to reproduce. Thus, in not owning a womb and a perfectly functioning one at that, they lack the power of holding one.

Miller discusses the most significant player in a liberal sovereign relationship as the “normative neutral citizen” who incidentally is also male. She argues that to the extent that women have acquired a political identity, they have to conform to masculine stereotypes. In a footnote to this argument she expands ‘women’ to include “transsexuals – or anyone defined as not-male” (2007, p.149). This could be inferred to include intersex people as well as they are not considered males, at least not fully so. Not only may they lack masculine power in not being born as ‘perfect’ males, they may also not be able to claim the secondary power of some women in owning a functioning womb and be the carriers of an entire population. Within this framework of patriarchy where men enjoy a superior status and women’s status is dependent on men and their own ability to reproduce healthy babies, intersex bodies could be considered as disabled and thus disempowered.

In the next chapter, I will be briefly looking at some of the discourses on disability, the perceptions around the disabled bodies as ‘monsters’ ‘the abnormals’ or ‘freak bodies’ as well as look at the disabled body within the biopolitical framework.

Chapter 3: Disability

3.1 Disability – A brief Overview

People with disabilities are not a homogenous group and must not be treated as such (Silverberg, 2006). There are many kinds of disabilities – physical and intellectual. Some people may be born with a certain disability whereas many others acquire disabilities during their lifetime. Whereas some may acquire a disability through their genetic composition or through aging, many others may acquire disabilities due to accidents or fighting in wars. For example after the World War II, there was a considerable increase in the number of people with disabilities. Still others acquire disabilities due to natural disasters, as well as environmental hazards such as the Chernobyl disaster in Ukraine in 1986 or the Bhopal gas tragedy in India in 1984. Shildrick (2002) refutes the image of the body as static instead positing it as a dynamic process and phantasmatic in some ways. Definitions of disability vary across time as well as region. Whereas certain conditions may be considered a disability in certain regions, they may not be considered so in others. For example, whether HIV/AIDS or diabetes can be considered a disability is debated across different countries and contexts. The experience of disability is unique to every individual. Also, the experience of disabilities varies across gender, race, caste, class, age, geographical location, sexuality and the presence of one or more disability.

People with certain disabilities face more stigma and discrimination than others. People with intellectual disabilities are often under-researched and face considerable social exclusion. However, in this thesis, I will be focussing on people with physical disabilities as I am interested in locating the debates and discussions on the ‘normal’ and ‘able’ body.

Disability is also a matter of identity. Whereas one may identify as a person with disability, many others may not. While identifying as a person with disability may help in acquiring certain benefits from the state, should the state identify the particular condition as a disability, this identification process may also subject people to stigma and discrimination in society. Many people also do not identify as being disabled but 'differently able' than others. This view acknowledges diversity amongst people and their abilities and recognises uniqueness of individuals. Further, it expands unilinear notions of ability. For reasons such as these some people do not want to be identified as one with disability.

The stigma and discrimination that people with disabilities face within society sometimes accentuate their disabling conditions. Some disability activists contend that it is not the impairment or the handicap itself that causes the disability, but the systemic and structural problems that create the disabling conditions in society. For example, many feel it is not the act of using a wheelchair that is disabling but having limited or no access to buildings which have either no elevators or do not accommodate the varied needs of people with disabilities. Similarly a person with hearing impairment may feel disabled if not accompanied with a sign interpreter in the hearing world although they may feel completely at home amongst other people who are hearing impaired. In fact, a person who can hear well can equally feel disabled within the world of the hearing-impaired. According to this world view, it is not the physical or the bodily impairment itself that causes the disability but the social exclusion and marginalisation they face because of limited access and participation.

There are thus two separate domains that discuss the sociology of disability. Whereas one talks about social inequities and oppression, the other domain talks about the physical illness and the bodily impairment that entails suffering as well as some social inequality; the distinction between the two is indicative of the presence of multiple sociologies of disability instead of a singular one (Thomas, 2004, p.570). The Union of the Physically Impaired Against Segregation (UPIAS), an important organisation working on the disability rights movement in the United Kingdom since 1972, was instrumental in positioning disability within the social model. According to the UPIAS, while impairment could be defined as “lacking part or all of a limb or having a defective limb, organ or mechanism of the body (including psychological mechanisms)”, disability was defined as “the disadvantage or restriction of activity caused by a contemporary social organization which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities” thus leading to the coinage of the phrase ‘social model of disability’ by Mike Oliver (Inahara, 2009, p. 51).

The emphasis on social ramifications of disability while denying the effects of physical impairment has been heavily critiqued by disability experts such as Shakespeare and Watson who argue that the bodily impairments and disability also impact people with disabilities (Thomas, 2004, p.573). The medical model of disability believes that in according importance to the social inequities and exclusion, the physicality of the impairment or disability is often ignored, if not negated. Critics of the social model of disability thus call for a theory of disability that gives due importance to bodily impairment as well as the socio-cultural factors that impact people with disabilities. To address an adequate theory of disability, it would be important to deal with multiple bio-psycho-social factors (Thomas, 2004).

Whether a certain condition qualifies as a disability or not also depends upon how the laws and policies of a state define it. For example, homosexuality was earlier considered a mental disorder by the American Psychological Association under the Diagnostic and Statistical Manual of Mental Disorders (DSM) and resultantly by the mental health associations in many countries including India. However, homosexuality is no longer considered a mental health disorder. Thus, definitions of disability and their translations into laws and policies keep changing with time and contexts. Framing disability in national and international laws and policies helps acquire benefits and welfare from the state. Therefore, recognition of disabilities in laws and policies forms a significant element of advocacy.

Advocacy initiatives to include certain conditions as disabilities would be higher in states that recognise disability as one of the parameters for distributing welfare benefits and other incentives such as discounts on public transportation, and affirmative action in education and employment. Initiatives to include a certain condition as a disability would perhaps be considerably lower in countries which offer no subsidies or additional benefits for people with disabilities.

Apart from the national level laws and policies, the needs of people with disabilities were recognised internationally through the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) which was adopted by the United Nations General Assembly in December 2006 recognising the need for a separate convention for people with disabilities. This convention is unique as it was framed by people with disabilities keeping in mind their own needs and requirements. The definition of disability within the convention recognises that it is an ‘evolving concept’ and therefore not a ‘fixed’ one (United Nations, n.d). Around 148 countries in total are signatories to the convention and around 100 countries have ratified it so far. “Operational measures of disability vary according to the purpose and application of the data, the conception of disability, the aspects of disability examined – impairments, activity limitations, participation restrictions, related health conditions, environmental factors – the definitions, question design, reporting sources, data collection methods, and expectations of functioning” (WHO & the World Bank, 2011, p.21).

3.2 Monsters and Freaks

In the socio-politico-cultural context the disabled body is often positioned in relation to the ‘able-bodied’ and is found lacking within this binary categorical system of ability vs. disability. In this kind of a binary culture, as much as the presence of ‘normal’ bodies gives meaning to the idea of disability, it is also the presence of the disabled bodies which shapes the society’s ideas about normality and ability. In ways that female sexuality has been conceptualized on the basis of masculine parameters, disability has also been conceptualized on the basis of able-bodied parameters (Inahara, 2009). Just as Irigaray debates the notion of female sexuality as a lack[4] with regards to masculinist and patriarchal cultures, Inahara (2009) in her article argues that disability is often looked at from the lens of the able-bodied world and therefore seen as weak and lacking. This idea of the lack can be seen only within the context of the whole body and thus normalizes certain bodies over the others. It also promotes the idea of a singular image of a whole body and therefore relegates all other bodies which do not fit this image, to the periphery.

Disabled bodies have also been looked at from the lens of the 'monstrous' and the 'deviant'. Bodies which look different have been called as monsters and more recently as 'freaks' as they "defy the ordinary and mock the predictable, exciting both anxiety and speculation" (Garland-Thomson, 1996, p.1). Shildrick (2002, p.1) discusses the concept of the monstrous from the earliest narratives to the more contemporary representations of the cyborg[5] as a "deeply disruptive force".

Shildrick (2002) describes the freak shows held in earlier times wherein people who did not fit in the ideas of normalcy were often exhibited in freak shows. Onlookers would come to visit these shows often not only because these bodies aroused their curiosity but it would also help the onlookers believe and find solace in the normalcy of their own bodies. These extraordinary bodies have included a variety of people including people with disabilities. They have included conjoined twins, tall people, short people who are also referred to as 'midgets', fat people, hirsute people, hermaphrodites, people without limbs,

---

[4] This idea has been borrowed from Luce Irigaray's (1977) seminal work on 'the sex which is not one' in which she discusses how female sexuality has always been conceptualized in relation to male sexuality and has been found lacking on those parameters.

[5] This is in reference to Donna Haraway's article on 'A Cyborg Manifesto: Science, Technology and Socialist-Feminism in the Late Twentieth Century', published in 1991. In this article, Haraway discusses how everyone could be viewed as a cyborg when navigating the spaces between science and the human world, thus challenging notions of what it is to be human.

people who are lion-faced etc. The extraordinary or the exceptional bodies, by their very presence "compel explanation, inspire representation, and incite regulation" (Garland-Thomson, 1996, p.1). These exceptional bodies are therefore not categorised on any uni-linear definition of appearance or ability but in terms of how they may differ from the so-called normalised body. People from various ethnic backgrounds have also been subjected to the white colonial gaze and been turned into the body of a freak and thus exhibited in freak shows as well as museums. The body of Saartje Baartman who was considered to have 'abnormal' genitalia in addition to being a person of colour was thus exhibited as one such monstrous or freak body.

> "By constituting the freak as an icon of generalized embodied deviance, the exhibitions also simultaneously reinscribed gender, race, sexual aberrance, ethnicity, and disability as inextricable yet particular exclusionary systems legitimated by bodily variation – all represented by the single multivalent figure of the freak. Thus, what we assume to be a freak of nature was instead a freak of culture" (Garland-Thomson, 1996, p.10).

Thus the body was an important location where politics of normalcy were played. The ideas of normalcy differed across context and time. Sometimes the freak body could be located in the woman as opposed to the man, sometimes it was race that played a vital role as a parameter of the normal body. Thus, "all bodies are discursively constructed rather than given" (Shildrick, 2002, p.4). People with disabilities were often considered as the freak bodies judging through the parameters of able-bodiedness. It was not the body in itself that was considered freak but its freakishness was derived from what it was not, in comparison to other so-called 'normal' bodies. Shildrick (2002) discusses the concept of the monstrous as a notion which is projected on the other. The idea of the monster does not therefore stand on its own right but acquires its meaning in relation to the reactions of others. Because it finds projection in the presence of others it would be safe to state that the monstrous is not a 'natural' concept but more of a cultural one, acquiring its meanings from what is considered normal and what is not. These abnormal bodies have also been associated with criminal behaviours often linking their ‘monstrous bodies’ with monster behaviours’. For example, people of colour have often been associated with higher participation in criminal activities than the white population. The presence of people with disabilities playing characters of villains and vamps in literature, theatre and films also provide evidence to how abnormal bodies have also been associated with criminal behaviour.

While these bodies were shrouded in mystery earlier, with the rise in the scientific discourse in the modern age these bodies began to be pathologized and relocated from freak shows to the medical theatre (Garland-Thomson, 1996, p.2) moving from the “discourse of the marvellous to the discourse of the deviant” (Garland-Thomson, 1996, p.3). Thus, while these bodies were viewed from the lens of the mysterious and therefore even as spectacular, they gradually began to be viewed as unusual and aberrant. Pathologization and medicalization were often considered the methods to fix these bodies and make them comply with the society’s notions of the normal. Thus ‘wonder becomes error” (Garland-Thomson, 1996, p.3) which meant that this error could then be corrected and therefore needed to be fixed and normalised.

3.3 Disability and Biopolitical framework

People with disabilities have always been part of the population. At present, there are more than a billion people in the world who face some form of disability or the other (WHO & the World Bank, 2011). People with disabilities all over the world face social exclusion and marginalisation. Disability may however disadvantage people differently. No two people with the same disability have the same experiences with their disability. Women have been considered more at a disadvantage than men in terms of their gendered experiences. Different physical disabilities also affect and impact people differently. Experiences may also differ with regards to the visibility of a particular disability. For example, the experiences of a person with hearing impairment may be considerably different from a person who uses a wheel chair. If physical disability is viewed as abnormal "it is because *to be seen* is the mode of normalization of norm" (Inahara, 2009, p.53) [italics in original]. The visibility of wholeness therefore is an important criterion in order to be normalized. Further, this visibility of wholeness is valued on the market and gives the impression of the likelihood of its possession (Inahara, 2009). This likelihood gives the impression that this whole and able body is achievable and can therefore be possessed and guides normalization procedures undertaken to correct and fix disabled bodies at birth.

The idea of disciplinary normalization discussed by Foucault has been used by feminist disability studies to question ideas of normalization within patriarchy, racism, classism, compulsory heterosexuality[6] as well as compulsory able-bodiedness (Hall, 2002). These processes of normalization are reinforced and subjected on bodies that deviate from these norms through "seemingly unrelated technologies such as orthopedic shoes, cosmetic surgery, hearing aids, diet and exercise regimes, prosthetic limbs, anti-depressants, Viagra, and genital surgeries designed to correct intersexed bodies all seek to transform deviant bodies, bodies that threaten to blur and, thus, undermine organizing binaries of social life (such as those defining dominant conceptions of gender and racial identity) into docile bodies that reinforce dominant cultural norms of gendered, raced, and classed bodily function and appearance" (Hall, 2002, p. vii). These deviant or abnormal bodies call into question the notion of single, fixed, able and normal body and instead highlight the multiplicities of bodies with varied capacities and abilities.

People with disabilities depending on the nature and the extent of their disabilities could also be classified not just in terms of their appearance but also in terms of their levels of productivity within the biopolitical framework. Within this framework the population is

---

[6] Adrienne Rich discussed the notion of 'compulsory heterosexuality' in her article on 'Compulsory heterosexuality and Lesbian Existence' in 1994 in which she discusses heterosexuality as a violent institution which emphasizes on the male right over the physical, mental and emotional access to the women.

considered in its entirety by the sovereign and not as individual bodies and is classified as the productive or the not-so-productive populations. With the advent of modernization and industrialization, the human body was not only reconstituted and reshaped but relocated as well from the homes to the factories and created a "new geography of labor" changing the physical relationships between bodies, literally separating workers from owners, the skilled from the unskilled, the men from women and children (Fiedler, 1996, p.11). According to this scale of productivity, people including those with disabilities who do not or cannot contribute through their labour are thus viewed as a burden on society and marginalised. People with disabilities who have the capacity to work and produce may face less marginalisation within society. Their stigma could be countered by them adding on to the productivity of the family as well as the nation state. If the nature and extent of their disability could be cured, they could then be 'fixed' by doctors to make them productive as 'normal' citizens. However, if the nature of their disability is severe, they could be counted among the dependent population therefore sapping the nation of its resources.

Within this biopolitical framework, reproduction or the capacity to procreate also plays an important role in classifying the population. The possession of a womb is an important element to be part of the (re)productive population who can help towards expanding the human species and in particular the national population. Women who possess a functioning womb as well as men who are in possession of women with functioning wombs constitute the normalizing population according to this paradigm. People with disabilities are often not considered as being worthy of procreation. Even in cases where they may have the capacity to reproduce, they are often considered as monstrous and deviant who may procreate more of their own kind thus diminishing the productivity of the nation's population. Under this biopolitical frame, procreation is considered important not just from the lens of expanding one's family but also the nation's population. It is important therefore to give birth to healthy, able-bodied babies who may therefore contribute to the nation's worth. The ability of procreation for people with disabilities is often under suspicion. Not only their capacity to procreate but also their sexuality is suspect and under scanner.

Sexuality is often treated as a soft subject for people with disabilities, to be dealt with when all other needs have been taken care of. However, people with disabilities affirm that although their sexuality is neglected, it remains a significant part of their lives. They are often denied sexual rights including the rights to marry and to have children, to keep them outside of mainstream society; they are often treated as children who are devoid of sexual rights (Silverberg, 2006). "Parents often handle their children as perpetual minors even after they reach puberty. The sexuality of persons with cognitive disabilities is frequently either ignored or perceived as a problem which prevents them from developing into sexually mature adults" (Tarnai, 2006, pp. 161). People with disabilities are more likely to be told that they have got many more important things to deal with and sex is a "luxury" for them. Also, they are often told that talking about interpersonal issues and disability "fragments the cause" (Silverberg, 2006) of disability and keeps people away from discussing the more important issues such as that of employment, mobility, access etc. However, people with disabilities are as sexual as anyone else and the expression of sexuality is unique to each individual.

In cases where people with disabilities can reproduce and chose to do so, their abilities to rear a child effectively to be part of the productive population is also doubted. Since they are considered a burden on the society, their choice to reproduce and rear children is considered as adding to the national burden thus reducing their worth within the society. Both forms of power – disciplinary as well as regulatory, could be used to look at people with disabilities. While disciplinary power could be used to look at individual bodies and fix them as 'normal' ones, regulatory power also plays a significant role with the whole dimension of genetics. More emphasis is increasingly being provided to have ‘normal’ healthy population and reproduce them through generations.

Some people with disabilities are considered to have characteristics of a much inferior race; for example, Down syndrome was initially referred to as ‘mongolism’ as they were considered to represent characteristics and traits thought of as normal in a more primitive population (Rapp, 2000, p.54). Science and biomedicine are thus on the lookout for genes and chromosomes that may indicate the presence of a disability so they could be eliminated before birth. While progress has not been made to the extent that most disabilities could be detected during pregnancy, efforts are being made so that disabilities could at the least be corrected at or soon after birth. From a eugenics point of view, wombs, which produce children with disabilities, are not seen as welcome. Genetics for a long time with the added impetus from biomedicine and public health has been researching ways and means of eliminating the chances of reproducing foetuses which may have problem-causing chromosomes.

Binary systems of normalization that segregate people as able-bodied vs. disabled, (re)productive vs. non-(re)productive therefore work towards classifying the population often ignoring multiplicities and diversity within the population. While acknowledging certain parts of the population as ‘normal’, they work towards correcting, fixing and normalizing the ones that don’t fit. Intersex people born with variant genitalia, chromosomal count or different levels of hormones also fall outside the boundaries of normality. Can intersex people then be considered within the framework of disability?

In chapter four, I will be looking at some of the definitions of disability used by international organizations and explore whether the language of the law includes intersex people. Similarly, I will also be looking at some of the definitions of intersexuality to examine if the language of these definitions uses the discourse of disability. Lastly, I will also explore the language used to define intersex people by a few international organizations working on issues of intersexuality. The purpose in all such explorations would be to find out the ways in which the discourses of intersex people meet with those of disability. I argue that the connections between these discourses are becoming more visible in the language of laws and policies in recent years and may therefore be indicative of a certain logic that guides these discourses. I contend that there is an enmeshing of intersex people in the language of disability and I am interested in exploring some of the ways in which they intersect.

Chapter 4: Discourses of Law and Medicine

Till now, we have looked at intersex people and people with disabilities individually and situated them within the biopolitical framework. Intersex people and people with disabilities are different in certain ways, e.g., for intersex people their sex identity is under the scanner, whereas people with disabilities may not have a conflict with their sex identity; for intersex people, their intersexuality is situated in their bodies, whereas for some people with disabilities, the disability may also be located in their minds giving rise to people with intellectual disabilities etc. However, as the two previous chapters show, both intersex people and people with disabilities share a few commonalities as well. Both groups when analysed under the biopolitical scanner, may be considered the ‘abnormals’ within the regime of normalization which deems some people as normal and worthy and the others as abnormals. Also, increasingly there is trend towards looking at intersexuality as a disability in itself. In this chapter, I discuss some of ways in which discourses on intersex people overlap and find resonance with discourses of people with disabilities within law and medicine.

How do laws and policies address issues of disability and intersex issues? How do intersex issues get framed within international and national laws? Do intersex people get accounted for in laws of disability? How do national and international organisations working on intersex issues define intersexuality? I am interested in looking at the discursive power of language used in defining and managing intersex people. Is the language used disabling for intersex people? Is the language used in these constructions acceptable to intersex people and the organisations they may belong to? These are some of the questions I explore in this chapter.

Laws and policies are significant ways in which governmentality is enforced on populations. They form the basis upon which all administrative procedures of the government are enforced and implemented. These kinds of administrative procedures require people to be categorised in neat boundaries of disabled/non-disabled or male/female. There are however many variations within the spectrum of one's ability and on one's sex. These spectrums are more like continuums with people occupying different points within the extremes of male/female and ability/disability. These points are forever shifting in different contexts and times and even within the lifetime of the same individual. There is no one definition for disability and these definitions keep changing across individuals, societies, contexts, situations, time etc. For example, an obese person may feel disabled when moving through narrow doorways or occupying narrow seats on an airplane. This may not be so much because of the obesity itself but because of uni-dimensional ways of looking at people's bodies and defining normalcy and fitness of the body of a particular size and shape. The concept of disability is also fluid with some people acquiring a disability and losing it later.

Similarly, we have seen that there are no neat alignments of a person's sex with one's gender identity. There are no neat categorisations based on sex as either males or females. In her article, *The Five Sexes*, Fausto-Sterling (1993), talks about at least five sexes with males and females at the opposite ends and with three other sexes in between as: male pseudo hermaphrodites (persons with variant genitals with predominantly male genitals), hermaphrodites (persons with variant genitals with both male and female genitals present) and female pseudo hermaphrodites (persons with variant genitals with predominantly female genitals). Fausto-Sterling (2000) later revised her article as *The Five Sexes Revisited* and discussed that if one were to look at various other biological characteristics apart from the external genitalia, people's sexes would come in an even wider array than just five sexes. In other words, the variability in people's sexes is not limited to the external genitalia alone but could also extend to the internal reproductive organs, the levels of hormones and chromosomes in the body etc as in the case of intersex people. It is therefore difficult to cluster people in neat boxes of able-disabled or male-female.

The need for categorising and clustering people in groups arises when the government feels the need to create administrative procedures to cater to the needs of its ‘population’. Thus, we can see the workings of a biopolitical state in which populations have to be compartmentalised in neat categories with the rationale of catering to them. These categorizations could be made on the basis of people’s ability, their capacity to contribute to the nation’s productivity or contributing to the nation by procreating normal, healthy and able children. These categorisations are usually watertight with minimal slippages. People who slip from these neat categories of the able and the (re)productive are thus termed as ‘the abnormals’. These categorisations become more obvious and visible through the laws and policies of any state. I am interested in looking at how laws and policies frame intersex people as well as people with disabilities, and the language used in these laws and policies. However, looking at most laws and policies on intersex issues and disability can be a colossal project and I would therefore limit my project to looking at certain laws and policies (which I will explain shortly) at an international level in the past decade which have had a bearing on populations worldwide.

I will be looking at some of the international laws and policies on disability that are in place to explore whether its definition includes intersex people. I will be drawing examples from a few other laws and policies across the world to find out if their definitions include intersex issues. I will also be drawing some examples from laws and policies in India. The selection of these laws and policies is however, not so much from the view of selecting certain countries or geographical locations. Instead, I have chosen examples where I find the language of the laws and policies interesting and evoking further debates and discussions. I would like to reiterate that the listing of these laws and policies is by no means exhaustive and is instead a small piece of a work-in-progress. Further, these examples also demonstrate the machinations of a biopolitical state at work. The idea of my study is also not to use certain examples to say whether they are good and therefore replicable (or not) but to look at the language of some of these laws and policies. I will also be looking at some of the definitions of intersex that are being used worldwide by different organisations and agencies to explore if they are used from the lens of disability. For example, I will be looking at how the World Health Organisation (WHO) defines intersexuality and how other international intersex organisations choose to represent themselves. Do definitions of intersex people construct them as disabled through the language of their discourses?

4.1 Discourses of law

Last year, the intersections between disability and intersex issues became more apparent to me with the changes that were being proposed to a draft law on disability in India. There was an impetus to improve upon the national law on disability to incorporate the clauses of the United Nations Convention on the Rights of People with Disabilities (UNCRPD). The UNCRPD is an international convention which was signed by 81 member states and the European Community in March 2007. India was among the first seven countries to ratify the convention which showed its intention to abide by the clauses of the international convention. At the national level, India has in place the Persons with Disabilities (Equal Opportunities, Protection of Rights & Full Participation) Act, enacted in 1995. However, a committee has currently been constituted to propose amendments to the act proposed to be renamed as ‘The Rights of Dignity, Effective Participation and Inclusion of Persons with Disabilities Act, 2010’. The process of constituting the law however, is still in progress and has not been finalised until the time of the completion of this thesis.

The law presently in use in India, the Persons with Disabilities Act of 1995 does not allow for any inclusion of intersex people within the purview of its law. It very clearly includes conditions such as “blindness, low-vision, leprosy-cured, hearing impairment, locomotor disability, mental retardation and mental illness” (Disability India Network, n.d).

Within the specificities of this definition, there does not appear to be any space for inclusion of intersex people.

According to the changes proposed in the draft law for people with disabilities, disability has been defined to include “all such individuals who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may prevent their full and effective participation in society on an equal basis with others” (Karna, 2010). Among the number of conditions and impairments that have been included under the ambit of ‘disability’ are “Disorders of Sexual Development (Hizras/ hermaphrodite/ Intersexual/ Transexual)” *(sic)* which has been defined in the proposed law as “abnormalities in the development of the gonads, the genital tracts, the external genitalia and gender-specific behavior” (Karna, 2010). A *hizra* or hermaphrodite has therefore been defined as "a person having sexual development disorder” (Karna, 2010) and "intersexuals" according to this law have been defined as “individuals born with the physical sexual organs of both genders, although they may not be fully formed” (Karna, 2010).

The inclusion of persons with ‘sexual development disorder’ under this law highlights the interconnections between disabilities with intersex issues. It draws attention to the ways in which intersexuality which according to this law has been defined as ‘abnormalities’ of the development of gonads, genital tracts and the external genitalia, are seen as or constructed as a disability. The framing of the ‘conditions’ as ‘abnormalities’ also highlights the binary ways of looking at organs and bodies as being either normal or abnormal. What is defined as normal or abnormal is however not made clear and therefore left to varying interpretations. The definition of persons with sexual development disorder under this law also includes a gamut of people including “*hizras*/ hermaphrodite/ Intersexual/ transsexual” and assumes all these categories as belonging to the same group. Although this bringing together of these groups of individuals may help in forming alignments and support networks, it also portrays the ways in which these groups may often be confused with one another thus blurring the boundaries between them which could potentially lead to dilution of specific needs and claims of particular communities. The language of the law clearly ascribes them as being ‘abnormal’ and ‘disabled’. The definition of the sex development disorder spells out ‘abnormalities’ in the gonads and external genitalia but does not mention the chromosomal levels which are also considered an important factor in the determination of the intersex status of a person. It is unclear whether it was a lapse in excluding the chromosomal level from the definition or if there was an adequate argument for its exclusion. However, the draft law is still in the process of being worked out. The inclusion of people with sex development disorders met with certain debates and discussions by advocates who are part of the law-formulation process. Advocates emphasized that any such inclusion must be debated and included only with due consultation with intersex and transgender activists and organisations. The draft law has undergone several revisions and in its current state does not include ‘disorders of sex development’ as one of the categories defined under disability. Whether it gets included in the final version of the law is unclear at the moment. However, the fact that a national committee on disability law felt the need to include ‘persons with disorders of sex development’ within the ambit of disability highlights the ways in which these discourses intersect and these intersections therefore become significant loci for debates and discussions.

At the international level, the UNCRPD discusses persons with disabilities as “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (United Nations, n.d). Although there is no clear definition of disability in this convention, it recognises disability as an evolving concept and therefore not fixed (United Nations, n.d). The definition of disability can vary with country, context as well as time. Further, it does not treat disability as something in need of fixing but highlights the negative attitudes and environmental barriers in society that make for a disabling environment rather than the disability in itself; in addition it does not limit the definition of disability to a few people (United Nations, n.d). Through the definition of people with disabilities we can see that the convention aims at keeping it broad so as to include a wide spectrum of people and conditions. Does the language under this convention include intersex people as well? This is not clear as the term intersex or other terms associated with intersex people such as hermaphrodites, persons with disorders of sex development are not expressly mentioned as part of the convention. However, the language of the convention mentions long-term physical, mental and sensory impairments. According to the Merriam-Webster Dictionary, the meaning of the word ‘impair’ is “to damage or make worse by or as if by diminishing in some material respect and the word ‘impaired’ means “being in a less than perfect or whole condition”. With binary alignments in society of people and also their external genitalia (or because of it) as male/female, those that do not fit in could also be construed as ‘impaired’ and their condition therefore as an impairment. Though the convention does not expressly spell it out, intersex condition could be construed as a physical impairment. Intersex people could therefore be included within the definition of this convention although it remains to be explored if they would like to be included within the ambits of disability. Although, the definition of disability with the UNCRPD is quite broad and may consist of intersexuality as well, the UN conventions are not legally binding on the member countries, which means that member states are not legally required to incorporate the UN conventions and declarations in their laws and policies. However, as the UN is an organization at the global level and includes a number of countries as its member states, the definitions under the conventions are usually kept broad to be inclusive of all or most states. Further, UN documents such as the UNCRPD also serves as a guideline for member states and could be influential in the process of formulation of laws and policies. I use the example of the UNCRPD not to present the UNCRPD to be enforceable as an international document but to serve as a guideline that member states could follow in enacting their laws and policies.

Although there is no standard acceptable international definition for disability, the approach followed by the Standard Rules of the Equalization of Opportunities for Persons with Disabilities in 1993, which was adopted as an outcome of the Decade of Disabled Persons by UN General Assembly, is followed by many states. According to the Standard Rules, "the term 'disability' summarizes a great number of different functional limitations occurring in any population [...] People may be disabled by physical, intellectual or sensory impairment, medical conditions or mental illness. Such impairments, conditions or illnesses may be permanent or transitory in nature" (Schulze, 2006, p.29).

According to the International Disability Caucus (IDC), the global network of national and international organizations and individuals working with people with disabilities, a person with a disability is "an individual whose ability to lead an inclusive life in the community of his/her own choice is limited by the separate or concomitant impact of physical, economic, social and cultural environments and/or personal factors that interact with physical, sensory, psychosocial, neurological, medical, intellectual or other conditions that may be permanent, temporary, intermittent or imputed" (Schulze, 2006, p.31). Because this definition is considered quite inclusive and broad, it has been recommended that this definition of disability be used to expand the existing definitions of disability in countries or to use this definition in courts of law where no definition of disability may currently exist.

At the national level, the laws on disability in Australia and the USA also appear quite broad-based and inclusive. According to the Disability discrimination Act, 1992 in Australia, the definition of disability includes "the total or partial loss of person's bodily or mental functions", or a part of the body, "the malfunction, malformation or disfigurement of a part of the person's body” (DREDF, n.d). If we carefully look at the language of this law, we can perhaps see that intersex people could perhaps be included under the ambit of this law. If the external genitalia of a person do not conform to being either male or female, it may often be considered ‘malformed’ and not functioning properly. The reproductive functions of some intersex people may also be curtailed thus manifesting in another ‘malfunction’ or ‘malformation’. Whether the law has actually been used in favour of intersex people could be a topic of further research. However, the language of the Australian law sounds broad enough to include certain conditions of intersexuality as well.

As per the Americans with Disabilities Act of 1990 which was amended in 2008, the definition of disability includes “a physical or mental impairment that substantially limits one or more major life activities of the individual” (ADA, 2009, p.7). The discourse of this law is broad and could be interpreted to include intersex people as well, in certain cases. The major bodily functions as defined by this law comprises among others, “endocrine” and “reproductive functions’ (ADA, 2009, p.7). The law further mentions that the impairment which restricts one major life activity does not have to affect any other to be considered a disability. Whether this law is used to make claims for intersex people under these laws is not clear and beyond the scope of this study. In my thesis, I am more interested in the language of the laws of disability and whether it may allow for inclusion of intersex people. It would be interesting to explore whether intersex people are advocating for inclusion in these laws or making claims against these laws.

4.2 Discourses of medicine

Having looked at some of the laws on disability and whether or not their language allows for inclusion of intersex people, I now proceed to looking at some of the definitions for intersex people in medicine. It would be difficult if not impossible to look at the definitions in every country and therefore I will restrict my study to certain international definitions which I think make an impact at the global level. Also, in terms of the medical community, intersex people are affected and influenced by different sets of experts from the medical community. A number of experts may be involved in the medical management of intersex people including paediatricians, endocrinologists as well as urologists. Each of these teams of experts in different country contexts may have varying sets of definitions or guidelines for the management of these specific cases. It would again be an arduous job to go in-depth at how these different teams of experts may view such cases and would be a fascinating area for further research. However, again due to constraints of time and the scope, I have limited this study to looking at definitions shared and which make an impact at the global level.

The World Health Organization (WHO) which is the coordinating authority in the UN system on matters of health defines intersex as, “a congenital anomaly of the reproductive and sexual system. An estimate about the birth prevalence of intersex is difficult to make because there are no concrete parameters to the definition of intersex” (WHO, 2011). According to the Merriam-Webster Dictionary, the term ‘anomaly’ means an “irregularity”, “deviation from the common rule”, “something different”, “abnormal”. According to the WHO, disabilities include “impairments, activity limitations, and participation restrictions” (WHO, 2011). WHO (2011) further mentions that an impairment is “a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations”. Looking at both the definitions by WHO closely, we can perhaps infer some connections. If intersexuality causes an irregularity or abnormality in the reproductive and sexuality system of individuals, it could perhaps be included in the broader definitions of disabilities which include impairments, activity limitations and participation restrictions. Intersexuality may also lead to situations wherein individuals may be unable to participate in the sexual and reproductive systems as per the norms set by the society. For example, some intersex people may be unable to procreate or be unable to participate in penetrative penile-vaginal sexual activity, which are upheld by the moral codes of the society as signs of normalcy within the hetero-patriarchal order. Inability to participate in these functions could deem them to be included within the scope of disability.

The International Classification of Diseases (ICD) -10, the international standard diagnostic classification system for all epidemiological and health management purposes endorsed at the World Health Assembly in 1990, came into force in the WHO states since 1994 and is currently the latest version of the classification. According to this classification system, congenital malformations, deformations and chromosomal abnormalities are listed in blocks Q50 to 56 of chapter XVII. This includes congenital malformations of the genital organs which further includes congenital malformations of the ovary or of the uterus and cervix or other malformations of female genitalia. This also includes congenital malformation of male genitalia and/ or hypospadias which means that the male urethral opening is not at the tip of the penis where it usually is for most males.

4.3 Discourses on intersexuality by organizations working on intersex issues

In this section, I talk about the definitions of intersexuality by three international organizations: Accord Alliance, ISNA, and OII-Australia. Although that may not be representative of the entire body of work on intersex issues, the work of these three organizations is prominent and I use their definitions as a small sample to talk about the discourses within some of the organizations working on intersex issues.

According to Accord Alliance, a not-for profit organisation working for health care and advocacy for people with disorders of sex development in New Jersey, USA since 2008 defines intersex as:

> “a term sometimes used to refer to the condition of having a sex anatomy that is not considered standard for a male or a female. Like disorders of sex development, it is an umbrella term that covers many different conditions that appear in humans as well as other animals. The term is often used by adults with DSDs to talk about their bodies and their experiences. Using the general term “intersex” has allowed many adults with different kinds of DSDs to come together and work for progress in the way families with DSDs are treated” (Accord Alliance, 2011).

ISNA defines intersex as “a general term used for a variety of conditions in which a person is born with a reproductive or sexual anatomy that doesn’t seem to fit the typical definitions of female or male” (ISNA, 2011). Further, it discusses intersex as a “socially-constructed category that reflects real biological variation” (ISNA, 2011). They discuss the category as a social construction as it is usually humans who decide whether an individual is a man or a woman, a male or a female, what length and measurements of either the penis or the clitoris should individuals have to fit in either category, how many chromosomes and what type one should have to be a male or female and what degree of androgen exposure should the individual have in the pre-natal stage to be identified as a male or a female. Although some doctors do say that a normal hormonal environment in the uterus does have an impact on one’s sex identity, it is still difficult to say how much of it would be enough (Karkazis, 2008). Although these are ‘natural’ processes, these are usually used as parameters to decide one’s sex and consequently one’s gender identity.

Organisation Intersex International Australia Limited (OII-Australia) an organisation working on intersex issues in Australia defines intersex as a “congenital difference in anatomical sex. That is, physical differences in reproductive parts like the testicles, penis, vulva, clitoris, ovaries and so on. Intersex is also physical differences in secondary sexual characteristics such as muscle mass, hair distribution, breast development and stature” (OII-Australia, 2010). They further mention that intersex could also include differences at the chromosomal level or at the hormonal level and thus may not be visible to the eye.

All three international organisations argue that terms such as ‘hermaphrodite’ are inaccurate and therefore problematic. Although both ISNA and Accord Alliance prefer the term ‘disorders of sex development’ (DSD) for intersex people, OII-Australia insists that intersex people should be called just that - intersex. The former organisations argue that there is no consensus on the definition of the term ‘intersex’ and they inadvertently lead to labelling the individuals instead of their medical condition. They prefer DSD as it focuses on the medical conditions and not the person. DSD as a terminology was coined at the International Consensus Conference on the Intersex where fifty experts from all over the world including members of the Lawson Wilkins Pediatric Endocrine Society (LWPES) and the European Society for Paediatric Endocrinology (ESPE) got together and formed working groups to formulate a consensus document. As per the consensus statement, DSD was defined as “congenital conditions in which development of chromosomal, gonadal, or anatomic sex is atypical” (Lee, Honk, Ahmed & Hughes, 2006). There is however no unanimity on the usage of the term and there are individuals and groups who believe that the usage of the term ‘disorder’ in the terminology again focuses on these individuals as anomalies and ‘abnormals’. OII-Australia on the other hand believes that intersex people should be referred to as intersex and not as ‘intersexed’, ‘intersexuals’ or with DSD as they give undue focus on the disorders and the anomalies. They believe that intersex issues should be seen in the same way as differences in height, weight or colour and pathologized as what happens in the case of the usage of DSD (OII-Australia, 2010). They also emphasize that there is no consensus on a single definition for intersex as such a consensus is not what must be aimed for as well.

Differences in definitions, terminology as well as guidelines to approach intersex issues therefore vary across individuals, countries, contexts. Despite a consensus statement on the Intersex, there appears to be no consensus on these issues. I agree with OII-Australia when they say that a consensus is not necessarily desirable or even the ultimate aim. The usage of the term 'disorder' in the consensus statement which has been arrived at in consultation with international experts puts more emphasis on the 'abnormality' and the 'irregularity' in the individual. This abnormality may not be an abnormality in itself but in relation to the stereotypical norms of society which makes strict categories of males and females in order to be able to govern populations.

In the next chapter, I will be exploring how these discourses of abnormality impact both intersex people and people with disabilities. I argue that because both intersex people and people with disabilities do not fit the stereotypes of the normal within the biopolitical state, lack rights at par with other citizens and are resultantly subject to marginalization and abuse within society.

Chapter 5: Intersex people and people with disabilities: points of intersections within the biopolitical framework

In this chapter, I highlight a few of the intersections between intersex people and people with disabilities which have a bearing on and are influenced by the biopolitical framework. Some of these points of intersections include medical (mis)management, genetic engineering and abnormality. Although these points of intersections do not affect both sections of people in the same ways, I will be discussing a few of the commonalities. Intersex people and people with physical disabilities are both considered to have bodies which do not fit normative standards. Both feminist theory and disability theory have critiqued the 'normative' body which is pushed forth in popular media as well as by health specialists. Ideas of normalisation push people into aiming for a certain kind of body through a variety of measures such as corrective surgeries, following rigorous fitness regimes, medication etc. Garland-Thomson (2002) pushes for a feminist disability theory which can help in critiquing interventions that normalise the non-standard body. For example, intersex children are normalised through surgery and correction right after birth. People with physical disabilities also go through a number of interventions through their lifetime in order to fit in the normative stereotypes of the body.

I will be focussing on a few dimensions where intersexuality intersects with disability within the biopolitical framework. Within this framework, although the attention had shifted from individual bodies to the population as a whole, the sovereign still functioned with attention on individual bodies, some of which were rendered normal thus leaving others to be subjected to normalization procedures. Bodies were rendered abnormal when they did not adhere to societal notions of an able and functioning body. These bodies could differ in terms of their appearance and ability to (re)produce, amongst others. At the level of molecular biopolitics as developed by Rose (2007), the procedures of normalization were not restricted to the level of limbs and organs but at more minute levels of genes and chromosomes. When studied at the level of molecules, biopolitics gave the hope of altering and correcting bodies not just at the molar level but also at the molecular level. I will be discussing how disabled and intersex bodies are rendered *abnormal* and therefore in need of correction within this framework. These bodies are considered non-normative and not adding to the nation's worth. In addition, there are also *exceptions*, where both intersex people and people with disabilities are considered not as weak and dependent but instead a threat to the able-bodied. These cases make for an interesting study of how abnormality is construed in exceptional circumstances redefining the norm yet deeming these bodies as abnormal. Within this framework, both people with disabilities as well as intersex people who are considered to possess non-normative bodies are deprived of their rights to *consent and bodily integrity* where decisions about their bodies are made not by them but by others around them. I discuss that the notion of abnormality therefore translates into the deprivation of their rights to consent and bodily integrity. I argue that people deemed as abnormal are considered to have less decision-making power related to their own bodies. Lastly, guided by notions of correction and alteration to these abnormal bodies, both disabled bodies and intersex bodies are subjected to medical management in order to correct and alter bodies. These alterations are also made at the level of genes through processes of *genetic engineering* sometimes bordering on *eugenic practices*. These corrections are aimed not just at children who are already born but also on those who are yet to be born, by making alterations in the pre-natal environment or the genetic make-up.

5.1 Discourses of abnormality

Both intersex bodies as well as bodies of people with disabilities are considered atypical and 'abnormal' as per societal norms. These norms accord more privilege to the so-called 'normal' bodies while dis-privileging and marginalising the others. According to

Garland-Thomson (2002, p.5), the ability-disability system works through differentiating and marking bodies resulting in an unequal distribution of resources and power within the society.

The normalisation of bodies happens not just at the level of ability and/or sex. The public exhibition of Saartje Baartman (referred to in chapter 3) also known as the Hottentot Venus is another example of how raced and different bodies are rendered 'abnormal' and put under the public scanner. Saartje, who was supposed to have an unusual body with large buttocks and enlarged genitalia came from a slave family and was brought into Great Britain in 1810 to be exhibited and objectified by the public at large. Her body therefore did not fit the ideas of a 'normal' body. In another well documented instance, throughout his career as a showman in the nineteenth century, P.T. Barnum conducted a number of exhibitions named '*What is it?*' in which he employed a variety of people such as Hervey Leech, an actor from New York with unusually small legs in proportion to the rest of his body, possibly Caucasian in origin but with disguised hands and face stained as a person of colour who played "monkey" characters depicted as jumping, grunting and eating raw meat etc (Cook, 1996). There was also William Henry Johnson who was a mentally retarded, short African American person from New Jersey (Cook, 1996). These two characters were usually exhibited to depict the liminality and hybridity between man and animal. These people were usually exhibited as 'nondescript' or people who cannot be described and left for the viewers to discuss openly. Onlookers often discussed their animal characteristics in relation to them being people of colour. Similarly, Charles Stratton also known as 'Barnum's General Tom Thumb' and Lavinia Warren also known as 'little Queen' were diminutive people exhibited in Barnum's shows as human curiosities and worked for Barnum's shows as entertainers (Merish, 1996).

In addition, bodies which are rendered too short, too tall, too fat, too thin are also rendered 'abnormal' and therefore pathologized. People are rendered disabled on the basis of either "atrophy or degeneration" or "hypertrophy or enlargement" (Garland-Thomson, 2002, p.7). The able-bodied paradigm is based on the notion of “a whole body, a single and fixed set of physical abilities, while the disabled body is in some way incomplete” (Inahara, 2009). These differences not only render specific bodies as different and therefore ‘abnormal’ but also push for one unique form of body in shape, appearance as well as ability; thus, ways and means are employed to “discipline the body to conform to dictates of both gender and the ability system” (Garland-Thomson, 2002, p.10). This is often done through the means of medicalization and pathologization of bodies. The stress of treatment and cure is not towards improving social, environmental and economic infrastructures but on individual bodies and getting them to conform to one standard norm (Garland-Thomson, 2002, p.14). This medicalization process helps in transforming the horror and fascination often associated with monstrous bodies into the scientific language of an illness which could then be rendered into a classificatory system as ‘normal’ or having the ‘normal’ as an ideal to be attained (Grosz, 1996).

Intersex bodies are also subject to these normalising procedures in order to ‘correct’ their bodies and get them to conform to being strictly male or female through medical management at a very early stage. The medical model accords the intersex body as pathological with claims that if corrective surgeries were not conducted on intersex people, they would lead their lives in misery (Preves, 2002). However, there is no singular idea of being a male or a female, even among physicians. While some physicians may accord greater importance to the size of the external genitals, there are others who lay more significance on the results of gender tests and still others on the person’s ability to reproduce. The ideas of normality are also guided not just by medicine and biomedical discourses but these are influenced by society’s notions of what is normal or what is not. Thus, not only is normalcy constantly constructed, but also it is constantly being produced (Preves, 2002). Under the circumstances when there are a plethora of different opinions and notions of normality, “the medical presupposition that intersex characteristics are inherently disabling to social viability remains the taken-for-granted truth from which clinical practice proceeds" (Holmes, 2008, p.169) although many of these surgeries are known to cause irreversible damage to intersex people (Preves, 2002).

Within the biopolitical environment therefore, bodies undergo a process of classification in terms of which fit the terms of being normal and able and therefore more productive for the state. Both intersex bodies as well as disabled bodies are accorded the status of being the abnormal within this framework and also subjected to processes of corrections and alterations to make them normaller.

5.2 The Exceptions

Through the process of governmentality, as espoused by Foucault, bodies are compartmentalised in different ways – able/ disabled, (re)productive or not. Bodies are therefore neatly categorised and all those who may not fit in within the able-bodied and (re)productive paradigm, fall through the cracks. Both people with physical disabilities as well as intersex people are considered to have bodies that do not fit notions of normality. Parallels can be drawn between intersex people and people with disabilities especially in the arena of sports. People with disabilities are often not considered able and fit to participate in sports activities along with able-bodied people. Representations of people with disabilities portray them as weak, lacking in ability and physical strength. They are also often infantilised. Although the first sports competition for disabled people was held in 1948 for World War II veterans with spinal cord injuries, it was in 1960 that the first paralymic games were held in Rome with Olympic style games. Over the years there has been an increase not just in the number of sportspeople participating in the paralympic games but also the variety of events organised for people with disabilities (IPC, n.d).

Separate sports events for people with disabilities suggests that people with disabilities are not considered at par with able-bodied people and therefore require a separate set of parameters for being judged. Using similar parameters for people with disabilities as well as able-bodied people was considered to put the former at a disadvantage. However, the juxtaposition of ability vs. disability takes a different turn when considering sportspeople such as the South-African sprinter Oscar Pistorius and Aimee Mullins. Oscar Pistorius also known as 'the blade runner' is a double amputee athlete who uses the Cheetah artificial limbs. For the first time he participated in sports events for able-bodied persons in 2007. His participation in sports for able-bodied people however generated debates about him having an unfair advantage over the other players because of his artificial limbs. Aimee Mullins who is an actress, athlete and fashion model and also a double amputee is similarly known for her athletic accomplishments during her college years in Georgetown University when she competed with able-bodied people. Accomplishments such as those of Pistorius and Mullins instantly raise questions such as what constitutes ability, and how much does technology and human perseverance have to do with one's ability. People who have in general been considered to be at an unfair advantage to others because of their bodies which do not fit the stereotypes of a 'normal' body are suddenly considered to pose a threat to other athletes (Mullins, 2009).

Similar debates are raised for intersex people within the sports arena. Athletes such as Caster Semenya and Santhi Soundarajan have been considered to have an unfair advantage over the other women athletes. Caster Semenya, an athlete from South Africa won the gold medal in the 800 metres run at the 2009 World Championships. Although she had won the World Junior Championships the previous year as well, she had improved her own running record by eight seconds approximately and set a world record (BBC News, 2009). Her accomplishment however raised suspicions for her competitors. Although she was not suspected of cheating, she was supposed to possess an ‘unfair advantage’ over the other players because of a ‘rare biological condition’ (The Sunday Times, 2009). Although some news reports discuss Semenya’s ‘rare medical condition’ as “having grown up with the genitalia of a woman but the chromosomes of a male” (The Sunday Times, 2009), it is unclear what the gender tests revealed. Irrespective of the nature of the test reports, Semenya was suspected to have an unfair advantage over the other women competitors because of her biological condition. Semenya was banned from the games for almost 11 months and was finally allowed to compete in July 2010 against other female athletes (Kessel, 2010).

In a similar case, Santhi Soundarajan an Indian athlete was stripped off her silver medal in 2006 Asian games after she failed to pass the gender tests. Reports in the media speculate about her having an intersex condition called the Androgen Insensitivity Syndrome (AIS) with general physical characteristics of a female but with a genetic make-up that includes a male chromosome (Saner, 2008). Soundarajan was reported to have made a failed suicide attempt in September that year (Saner, 2008).

Gender tests were first introduced in 1966 at the European Athletics Championships where female competitors had to parade naked in front of a panel; whereas all participants got cleared in the tests, six players were known to withdraw from the games (The Sunday Times, 2009). Gender tests changed in 1968 when a smear from the cheeks of the participants was taken for examination (The Sunday Times, 2009). The nature of these tests has thus been changing over the years when the parameters for verification of gender have become more fluid and blurred.

The intersection between these two sets of cases, that between people with disabilities and of people who do not conform to being strictly male or female is the normalisation regime around bodies which deem certain bodies as ‘normal by nature’ whether it is in terms of one’s ability or on one’s sex. In the field of sports, bodies are compartmentalised around different norms. These compartmentalisations work towards creating neat boundaries whether it is around those of sex or those of ability. People are required to compete only with people of the same sex so as not to be at a disadvantage or not to pose an unfair advantage over the others. Similarly, people can compete only with others who have similar abilities in order for the competition to be fair. These compartmentalisations often happen in binaries of male-female, disabled-abled not taking into consideration that there may not be neat divisions across gender or ability. Because the occurrence and the experience of disability are not uniform, laws and policies in different countries across the world have different parameters in defining people with disabilities. If the lines of distinction between the able-bodied and people with disabilities could be drawn so neatly, perhaps these laws would not differ. Similarly, sex continues to be considered in binary terms although the points of distinction between males and females are not so clear. Unlike earlier times when the lines of distinction were drawn around the external genitalia of sportspersons, in contemporary times the distinctions become far less conclusive. They are not based on the external genitalia alone but also involve a series of gender tests that are conducted on the participants. If sex was so natural, the results would perhaps have been more conclusive. This blurriness indicates how societal and cultural factors influence notions of sex.

My aim in this section is not to argue for people with disabilities to be mainstreamed with the able-bodied or to argue that intersex people be included within the category of 'females'. I argue instead for questioning the normalisation procedures which compartmentalise people in neat binary categories of sex or ability. I also argue for analysing the administrative procedures that necessitate for making these neat boundaries in different areas including sports. Why does it seem so important to have these fine lines of distinction on the basis of sex or ability? Is it because certain sexes or certain bodies seem more able than others? It is interesting to note here that intersex bodies which are in general construed as ‘abnormal’ are considered more at an advantage to those categorised as ‘females’ at least in the field of sports. The ideas about normalisation however differ according to different parameters. For example, these intersex bodies are construed as ‘not so able’ in matters such as that of reproduction. Bodies therefore get categorised on the basis of certain functions, abilities, size, looks etc. Whereas people with disabilities can have their own sports events, they become more of a threat when they compete and have a winning edge over able-bodied individuals and, suddenly the disabled bodies cease to be weak, incapable bodies due to the use of technology and artificial limbs. Similarly, there has not been an equivalent debate on whether intersex people can compete with males. This is partly because they are not considered a threat to men and their abilities. Although they may be considered stronger than females, they are considered not strong enough as males. Would it matter only if they begin to have a winning edge over the males in the sporting events?

These categorisations and compartmentalisations of bodies could be adjudged perhaps on the process of governmentality which considers some bodies as more ‘able’ and more productive. Although this grid of normality which is meant to apply to the whole population, should work for most people, it is not geared to take care of people and situations where this grid does not work. As an administrative process therefore it does not do justice to people and their realities and experiences. According to this process, the bodies that do not fit whether in terms of their sex or ability get construed as ‘abnormals’ within the biopolitical framework that renders certain bodies as normal while allocating the others to the category of the abnormal therefore influences how the abnormals such as people with disabilities and intersex people are treated. While their bodies may function as any other body and they may be productive in a variety of ways, they are still not seen as equivalent to normal bodies and therefore subjected to medical interventions such as corrective surgeries. They get construed as weak, unproductive and not worthy of the function of reproduction as well. However, situations such as sports as exemplified above where some people with disabilities and intersex people are shown to excel with the use of technology start posing a threat to the able-bodied thus assigning fresh boundaries on acceptable limits of normalcy. In these exceptional circumstances, bodies that surpass the boundaries of normalcy are still not considered the normal and therefore do not enjoy similar rights as them.

5.3 Consent and Bodily integrity

Miller (2007) considers consent and bodily integrity as significant factors that distinguish citizens from partial citizens or non-citizens. Children as such because of their age cannot consent and are therefore not considered as full citizens. The power relationship between adults and children balance most often in favour of the former and make children vulnerable to abuse including sexual abuse. Although they cannot consent, they are protected under the ambit of the law. While all children face vulnerability, children with disabilities as well as intersex children are additionally exposed to abuse and marginalization because of their specific realities. Their double vulnerability due to the varying power dynamics of age and abnormality makes them easier subjects of abuse and discrimination.

People with disabilities often need assistance in their day-to-day functions such as eating, administration of medicines, moving from one place to another as well as taking a shower etc. In countries such as India, they may also complain about basic amenities such as the lack of disabled friendly toilets which can be used by them independently (TARSHI, 2010, p.67). They therefore require assistance to use these amenities. They may also need specialised attention when dealing with issues of sexuality and sexual health for example in the case of menstrual management for women. According to Anita Ghai (TARSHI, 2010, p.67), women with disabilities often need assistance with menstrual management because of spasms, contractions, tremors. They may therefore need help from their parents or other caregivers to assist them during menstruation.

Parents and caregivers of people with disabilities may have to take decisions on sexuality and sexual health for people with disabilities, especially if they are severely intellectually challenged. However, even in cases where people with disabilities can take their own decisions, they are often infantilised and parents and caregivers often consider it their prerogative to make such decisions for them. Parents and caregivers may make decisions keeping the best interests of the person with disability at heart; even so this still keeps people with disabilities from participating in the decision-making processes. For example, parents and caregivers often make decisions on hysterectomy surgeries on girls and women with disabilities. Hysterectomy is often considered as a solution to menstrual management and for preventing pregnancies in cases of rape of women with disabilities (TARSHI, 2010, p.75).

Parents and caregivers may also take time to teach their children not just about menstrual management but also how to affirm their sexuality and sexual rights. Decisions are also taken by them in cases of abortions on women and girls with disabilities. People with disabilities have limited spaces for information on sexuality and sexual health issues. They may often face difficulties in finding sexual partners because of issues such as limited mobility or limited social spaces for interaction with possible sexual partners and may therefore have to be dependent on self-pleasuring for sexual satisfaction.

Sexuality education for children is considered important for children to be aware of notions of their right to bodily integrity, making distinctions between safe and unsafe touch and being aware of their right not to be abused. However, sexuality education is rife with power dynamics be it provided by parents or by school authorities because of the very nature of an adult-child relationship therefore adding to the vulnerability of all children. Within the framework of biopolitics, the structure and pattern of sexuality education in most states also follow the framework of the hetero-normative order which is tilted towards favouring the normal and the ones who adhere to normalization processes Therefore, this framework finds favour with people who are not only productive beings (or possibly so) but also reproductive and can add to the nation's worth. The ones who do not fit within this order, such as intersex people and people with disabilities, not only face the danger of not being acknowledged within this framework but are also subjected to marginalization.

Despite the unequal power relationship between adults and children, sexuality education is considered important for all children. However, in different country contexts such as in India, it is often not included within regular school education including education for people with disabilities. This gives rise to the need for more spaces and avenues for people with disabilities to learn about sexuality and self-pleasure. Debates and discussions continue on how far parents and caregivers can go to teach their children with disabilities about sexuality and sexual health issues. While Shampa Sengupta, a disability rights activist in India, discusses the need to teach girls and women with disabilities including intellectual disabilities about menstrual management (TARSHI, 2010, p. 76), Pramada Menon, a sexuality rights activist in India, questions whether as a community people can help a person who wants to masturbate but cannot do it on their own (TARSHI, 2010, p.78). These situations present ethical dilemmas and provide no easy answers.

Situations where parents and care providers take up the responsibility to either introduce people with disabilities to sexuality education or help them in achieving sexual satisfaction, the lines between sexual abuse and those of helping people with disabilities in affirming their sexuality become blurred. It becomes difficult to distinguish between what borders on abuse and what does not. This blurriness is further enhanced because of issues of trust and dependence (physical, social, economic etc) of people with disabilities on these caregivers.

In a similar fashion, intersex people often do not get to make decisions on their own bodies. Colligan (2004) discusses how both intersex people and people with disabilities are often considered suspect with regard to their sexuality. For many intersex people, decisions on their sexual and reproductive health are often taken when they are infants and do not have the capacity to consent to these decisions. Even when they are older, some of them are not involved in or informed about the surgical and other medical interventions on their bodies. Some of them remain ignorant about their own bodies and specific conditions. Parents and care givers in consultations with medical doctors often consider it their prerogative to decide on the sexual and reproductive health decisions of the child in 'the best interests of the child'. This is not to say that the prerogative of the caregivers and parents does not come from a place of good intentions. Most times, parents and other caregivers including medical doctors work with the best interests of the child at heart so that the child may be able to grow up and be assimilated well within mainstream society. They may also operate according to the best knowledge they may have about medicine and health at that particular time and context. However, most of these decisions do not entail active participation by intersex people themselves.

Some of these children have to undergo multiple corrective surgeries through their childhood, adolescent years and even through adulthood. Medical interventions are often invasive. These interventions differ according to the specific intersex conditions of the child. For example, certain medical interventions include the construction of a vagina. These reconstructive surgeries like vaginoplasty include not just the surgeries but in several cases the children have to undergo procedures such as the insertion of a dilator to expand the vaginal opening. These dilators have to be inserted every day on a routine basis for a considerable period of time. Parents and caregivers are often the ones to conduct these routine medical procedures. In addition, for the purposes of medical treatment many intersex children are often forced to expose their abnormal genitalia not just to a battery of medical experts but also to various others. Experiences of having to expose and talk about their bodies to others not only make them aware of the abnormality or the freakishness of their bodies but can also be traumatic for many. Further, many of these procedures may be undertaken not keeping in mind the sexual desires of the intersex person. For example, surgical procedures are normalized for intersex people in the USA as a standard practice with very few questions being asked about the preservation of erotic sensation in the vaginas (Feder, 2011, p. 243). As discussed in chapter two, many intersex people who have undergone cosmetic surgeries or clitoral surgeries have reported the loss of sexual responsiveness as a result of these surgeries. Organisations such as ISNA have discussed the violations of both consent and bodily integrity that intersex people face. Many of them are treated and have to go through unnecessary multiple surgeries right from when they are born and for a major part of their childhood and adulthood. These interventions are often done without their consent and they are often deprived of any information regarding their own bodies. Though they are often done with 'best interests of the child' in question, the lines between what could be construed as abuse including sexual abuse get blurred and indistinct.

Miller (2007) talks about the right to consent and the right to bodily integrity as important markers of being citizens. She mentions that consent, bodily integrity and reproductive freedom become meaningful only with the attainment of status of citizens. Because bodies of intersex people as well as people with disabilities do not fit easily within the standards of the normative body, their rights to consent and bodily integrity get further jeopardised thus relegating them to the status of partial citizens or non-citizens. While Miller argues that the rights to consent and to bodily integrity get conferred only to citizens, her argument could be extended to infer that people with disabilities as well as intersex people are deprived of these rights possibly because they are not considered as full citizens. If they were considered at par with other citizens, efforts would be made to protect their rights including their rights to consent, bodily integrity and reproductive freedom. Like the refugees within the biopolitical framework, people with disabilities as well as intersex people could be considered as bare lives who are not allowed the right to make decisions about their bodies. These decisions are thus made by their primary caregivers such as parents who also make these decisions in consultation with medical experts. Thus, they are not just deprived of these rights by the society in general, but the state in the form of the medical institutions often colludes to deprive them of these rights as well. This active deprivation of rights of intersex people and people with disabilities is indicative that they are not considered as citizens enough or not as full citizens.

5.4 Genetic Engineering and Eugenics

Efforts to mark the ‘perfect body’ through lenses of sexuality, ability, race etc were evident much before World War II and appeared in one of its most barbaric forms during the second world war with the concentration and the extermination of the lives which were considered not worth living, be they of the Jews, the homosexuals, the disabled or the Roma population. Although the thrust towards eugenics was reduced after the world war, genetic engineering continues even today in its subdued and subtler forms. This becomes visible for example through the medical termination of pregnancies based on disability. Abortions based on disability are often automatically built into the laws and policies of medical termination of pregnancies. For example, in India, medical termination of pregnancies is allowed up to twenty weeks in cases where pre-natal congenital defects have been detected. While these abortions can be allowed only till twenty weeks of the pregnancy, some of these congenital defects can only be diagnosed by the twentieth week (Madhiwala, 2008). This was highlighted in the Niketa Mehta case in 2008 in Mumbai where Niketa’s plea for abortion of her foetus which was diagnosed with a serious heart defect was rejected by the Mumbai High Court because her pregnancy had advanced beyond 20 weeks (Madhiwala, 2008). While the abortion was denied in this case, the medical termination of Mehta’s pregnancy on the basis of disability would have been legal had she approached the hospital within the stipulated time of 20 weeks.

With elimination of foetuses with congenital defects, the idea is to ensure the birth of 'normal' babies without any defects so they may participate effectively in the (re)productivity of the family and the state. Inherent in this logic is the notion that people with disabilities cannot participate productively for the nation state. Apart from diagnosis of congenital defects in foetuses, media is also full of reports on the discovery of the 'gay gene'. According to some studies, the onset of homosexuality within people could be traced to their genes (Connor, 1995). However, why is it important to find out if the occurrence of homosexuality within people is due to genetic factors? Dr. Hamer's research on the gay gene found support in a number of people including a religious leader who were interested in not just the investigation of such a gene but also the possibility of eradication of such cases through processes of pre-natal tests followed by abortion of foetuses which may have a gay disposition (Connor, 1995). These discourses perpetuate the notion of normal bodies thus marking bodies that do not conform to the heterosexual order as 'abnormal'. This search for the gay gene thus continues to aim towards rearing the perfect heterosexual reproducing couple so they could continue to reproduce healthy, heterosexual and by that logic 'normal' babies. Thus, notions of abnormality are not restricted to discourses of disability alone but rather on the notion of what is considered normal in contemporary society at any period of time, although these practices of elimination happen too often on disabled bodies.

According to Garland-Thomson (2002, p.15), the "socio-medical project of eradicating disability all too often is enacted as a program to eliminate people with disabilities through such practices as forced sterilization, so-called physician-assisted suicide and mercy killing, selective abortion, institutionization, *(sic)*, and segregation policies". On the one hand, she talks about the abortion of foetuses based on disability as a form of genocide against the disabled. On the other, she discusses the right of the woman to choose whether to retain her pregnancy but at the same time questions the ethics behind abortions of foetuses based on disability (Garland-Thomson, 2002, p.15). Apart from these processes, people with disabilities may also be exposed to processes of growth attenuation to keep them small and therefore more manageable for caregivers. For example, in the controversial case of Ashley from Washington state in the USA who has undergone a number of medical procedures such as growth attenuation, hysterectomy and double mastectomy that question the acceptable limits of medical intervention (Koyama, 2009). Although she can live normally like any other person, she has been subjected to a number of procedures that would restrict her physical growth including her weight and height to a child of nine years (Pilkington, 2007). These procedures could be explained in certain instances from the perspective of the caregivers who may find it difficult to care for people with disabilities as they grow older and thus heavier and also because of structural limitations where caregivers find little support from the state or the community in the process of care-giving thus making it taxing and difficult. However, it is still significant to notice that in this initiative where priority is accorded to the needs of the parents and caregivers, very little attention is paid to the right of the person with disability to consent and bodily integrity in these situations thus reaffirming their position as partial or non-citizens.

For intersex people, parents and physicians are rarely able to predict their condition before the birth (Frader et al., 2004). However, with the advancement of science it has become increasingly possible to predict anomalies at the chromosomal and genetic level before birth. In the case of intersex people where it is not as easy to diagnose the intersex condition of the child before birth, this advancement in science and technology takes other forms. For example, in a recent development in India, there are reports of genital surgeries being conducted on children after birth to convert them from females to males (Kadam, 2011). In a country obsessed with son preference, medical agencies are not just proliferating with promises of sex selective abortions on the sly, but also with promises of converting biological females into males. While these surgeries were initially available to 'correct' children who are born with genitals that are not perfectly aligned as males or females, these surgeries are now geared towards re-converting females into males. This is reportedly being done in consultation with parents even when they are aware that as an adult the person would possibly be infertile although not impotent (Kadam, 2011). Hardly any surgeries are however conducted to convert males into females, although it is surgically considered easier to construct a vagina rather than a penis. The preference for perfectly aligned sex and particularly as the male sex (at least in the context of India) seems to be gaining more ground. Forms of governmentality, how it administers populations and the preferences it makes towards the 'perfect sex' thus seems to be taking newer dimensions. Although speculative at this juncture, it may not be long before science makes sufficient progress to be able to predict if the foetus is intersex. Intersex people may then be subjected to a similar fate to that of people with disabilities.

My aim in this thesis is not to argue against processes of genetic engineering but to evaluate the aim behind these strategies. Advancement in technologies of medicine and health has also helped achieve better conditions of living. Medical advancement has not just helped human beings to live longer, achieve better health standards but has also helped people to relieve pain and distress in bodies. The shift from the molar level to the molecular level in biopolitics, as instantiated by Rose (2007) has also become inevitable in certain ways. Thus, "molecularization is conferring a new mobility on the elements of life, enabling them to enter new circuits – organic, interpersonal, geographical, and financial" (Rose, 2007, p. 15). This focus in looking beyond the molar level of organs, limbs etc to looking at the molecular level such as genes, chromosomes, cells and tissues also comes with benefits not just for people in general but also for intersex people and people with disabilities, who I focus on in my study.

As Miller (2007) argues for the womb as a paradigmatic space for biopolitics, therefore (re)productive politics play a major role in the attainment of rights as citizens. Reproductive technologies therefore play a vital role in determining who fits as normal citizens and who does not. Those who possess wombs that produce normal, healthy and able-bodied children are higher up on the hierarchy. With the advancement of reproductive technologies, the womb is however separable from the body of woman, e.g., through test-tube babies etc. “The elements of reproduction – eggs, sperm, and later embryos – also become separable from any particular body, mobilized around circuits of laboratories, clinics, and other bodies” (Rose, 2007, p. 14). Although this may mean that women stand to lose in not being the sole possessor of the womb, this could also signify the attainment in power of people who may generally not be considered within these power circuits. For example, these methods could be of help to infertile couples including some intersex people and people with disabilities in participating in reproductive processes and therefore be more assimilable within society.

Therefore, there are clear advantages to these kinds of medical and scientific procedures including molecular technology and genetic engineering. However, I think there is a need to examine and question the aim for these procedures and what it entails. For example, we need to examine why it may be considered okay for an infertile couple to seek an egg donor with particular characteristics of height, weight and intelligence[7] but not okay for lesbian couple who were hearing impaired to seek a sperm donor who had a history of

---

[7] Sandel (2007, p.2) discusses a case where an infertile couple sought an egg donor “who was 5’10 tall, athletic, without major family medical problems and to have a combined SAT score of 1400 or above”. The couple offered a payment of $50,000 to such egg donor.

deafness within the family so that they may have a deaf child[8]. Public condemnation towards opting for a deaf child may come from a place where at a systemic and structural level, people with disabilities and their caregivers have a more difficult time adjusting within society. However, is it not more important to work on these systems and structures that inhibit wider access and resources to people who may not be considered normal, rather than to prevent the birth of children with different needs altogether? What determines boundaries of normality, who decides and on what basis. Why does it become so important that people with all their diversities have to be assimilated within narrow standards of normality?

Standards of normalization have therefore been used to benefit some people who adhere to these norms while marginalizing others. It is therefore supremely important that we examine these ideas of normality within biopolitics and explore how they impact people's lives. Molecularization therefore cannot stand alone and must instead be combined with standardization, regulation and ethics and therefore as Rose (2007, p.15) "at this molecular level, [...] life itself has become open to politics".

---

[8] Sandel (2007, p.1) also discusses the case of Sharon Duchesneau and Candy McCullough who preferred to have a deaf child by seeking a sperm donor "with five generations of deafness in family". Sandel (2007) also discusses how this story published in the Washington Post received extensive condemnation from the public.

Conclusion

Identities are hardly constant. They overlap. They collide into one another. Some of these identities breed spaces of extreme marginalisation and discrimination. When I began working on intersex issues, I could see points of intersections between intersex people and people with disabilities. That was not a new revelation. Marginalised groups and communities have constantly learned from the victories and failings of other discriminated groups throughout the history of advocacy and movement building. People of colour have learnt from and contributed to the feminist movement building processes through the past few decades. That there were points of intersections between intersex people and people with disabilities was therefore not new. It was only when I began learning about biopolitics and its influences on individual bodies as well as populations that riveted me towards exploring more. Developing an understanding of biopolitics has enhanced my knowledge of how disciplinary power as well as regulatory power works on people (individuals as well as collectives) through techniques and procedures that categorise people as normal and those who are not. Through this thesis, I attempt to make meaning of how the biopolitical framework influences intersex people as well as people with disabilities.

Within the biopolitical framework, normalising procedures work through classifying and hierarchizing people into binary categories such as male/ female, able/ disabled, (re)productive/ non-(re) productive. Classifying and arranging people around the norm, this system works towards hierarchizing people in terms of their worth and value towards the nation. Within this framework, people who are able-bodied and healthy are considered of more value not just for themselves or for their families but also for the nation state. People who fit the parameters of normalcy are therefore considered worthy and fit to contribute to the state through processes of (re)production. However, those that do not fit these modes of normalcy are however relegated to the periphery and subjected to marginalization. Examining how these processes of normalization work is therefore crucial to understanding the interconnections between varied forms of oppression (Hall, 2002).

Intersex people are often considered as incomplete as they do not fit in the binary of male/female and occupy a space in between. They belie notions of absolute sex and question the parameters of being judged as male or female. Similarly people with disabilities are often treated as the abnormal as they do not fit within the conceptions of a normal, able and healthy body. They are therefore the monsters and the freaks and are therefore not considered worthy to contribute to the nation's worth through either being part of the productive work-force or being able to reproduce normal, able and healthy children to strengthen the state power. Whether or not they may actually be able to (re)produce, the general conception in the society is that of their abnormality and therefore their inability to be part of the (re)productive work force.

Although intersex people and people with disabilities are different groups with varied needs, there often collide and intersect with each other. The language of laws on disability is often broad enough to include intersex people. Similarly, the language used for defining intersex people often uses similar discourses as that of disability. These intersections are indicative of the meanings these identity groups have in the public imaginary. Collision of intersex people within the group of people with disabilities is significant as it questions how normalisation procedures work towards classifying and relegating people within binary understandings of able/disable, healthy/unhealthy or normal/abnormal. Understanding these normalisation practices is crucial to our understanding of how larger processes of marginalisation work within society.

Within this framework therefore, intersex people along with people with disabilities share a few commonalities. They are both relegated as the abnormals within society and this influences how they are treated. They are both subjected to constant and routine medical interventions including corrective surgeries. The situation however reverses in particular situations such as in the field of sports where both these groups are considered ‘more than the normals’ and viewed as threats to the population. Even in these exceptional circumstances where they excel over the others, they are still not considered within the category of the ‘normals’. Because of their abnormality, both intersex people as well as people with disabilities are considered less worthy to make decisions about their own bodies, are considered less than other citizens, lack equal rights and maybe also be additionally vulnerable to abuse. Medical interventions are focussed not just on correcting ‘the abnormals’ who are already born but also on the future generations through processes of genetic engineering as well as eugenics. Medical termination of foetuses with disabilities is often incorporated within the laws of some nations. Because intersex people are often considered as disabled, it could be speculated that they could be subject to similar procedures.

Normalisation procedures in themselves may not be more than a classificatory system. However, they lead to processes in which people who do not fit the codes of normalcy are considered unworthy. This manifests in not just corrective procedures without consent of people involved but also processes of genetic engineering as well as eugenics. The problem with these normalization procedures including genetic engineering, does not exist only at the level of autonomy of individuals as people are inherently different with varying capacities (Sandel, 2007) due to their genetic/ chromosomal or bodily make-up. Sandel (2007) argues that it is actually a process of hyperagency and an attempt to reconstitute nature through actively making changes and trying to reach beyond the norm. Would it be better if these procedures were initiated not by the state but by the people themselves? Perhaps, not. These normalisation processes may manifest in non-coercive ways as well with people themselves opting for certain kinds of bodies. In the absence of state led genetic engineering mechanisms, individuals could still be opting for measures that fit them within the ‘norm’ as long as the idea of one ‘normal’ exists within society. The idea would be to therefore make do with the idea of the normal and make that expendable. This could come about through an understanding of the diversity and multiplicity that is manifested among humans that makes complex any singular uni-dimensional understanding of normalcy. Thus, physical disability can be reconfigured “not as a category of certain kinds of body, but *as a moment of recognition in the process of being embodied*, a recognition of vulnerability, of fluidity and change. If one is positioned in a fluid system of embodied subjectivity, the notion of a fixed subject can be questioned” (Inahara, 2009, p.54) [italics in original].

To conclude, it is in rejecting the idea of a single, sexed and able-bodied conceptualization of the body and the acceptance of a fluid and multi-dimensional one that the idea of a singular normative body can be countered. It is in accepting that there is no singular conception of the body or a singular conception of ability either. It is also in recognize that each of us is constantly traversing the terrain between ability and disability and therefore between being normal and abnormal and therefore there is no single destination.

References

Accord Alliance, 2011. Glossary of Terms. [Online] Available at: [http://www.accordalliance.org/component/glossary/Glossary-of-Terms-1/I/intersex-33/] [Accessed 2 June 2011].

ADA, 2009. Americans with Disabilities Act of 1990, As Amended. [Online] Available at: [http://www.ada.gov/pubs/adastatute08.pdf] [Accessed 2 June 2011].

Agamben, G., 1995. Homo Sacer, Sovereign Power and Bare Life. Stanford: Stanford University Press.

BBC News, 2009. Birth Certificate Backs SA Gender [Online] Available at: [http://news.bbc.co.uk/2/hi/africa/8215112.stm] [Accessed 30 May 2011].

Butler, J., 1993. Imitation and Gender Insubordination - Decking Out: Performing Identities. In: D. Fuss, ed. Inside/Out: Lesbian Theories, Gay Theories. New York: Routledge. pp.13-31.

Colligan, S., 2004. Why the Intersexed Shouldn’t Be Fixed: Insights from Queer Theory and Disability Studies. In: B. Smith & B.Hutchinson, eds. Gendering Disability. New Brunswick, N.J.: Rutgers U. Press. pp.45-60.

Connor, S., 1995. The ‘gay gene’ is back on the scene. The Independent, [Online] 1 November. Available at: [http://www.independent.co.uk/news/the-gay-gene-is-back-on-the-scene-1536770.html].

Cook, J.W., 1996. Of Men, Missing Links, and Nondescripts: The Strange Career of P.T.Barnum’s ‘What is it?” Exhibition. In: R. Garland-Thomson, ed. 1996. Freakery: Cultural Spectacles of the Extraordinary Body. New York and London: New York University Press. pp. 139-157.

Disability India Network, [n.d]. The Persons with Disabilities (Equal Opportunities, protection Of Rights And Full Participation) ACT, 1995. [Online] Available at: [http://www.disabilityindia.org/pwdacts.cfm] [Accessed 2 June 2011].

Disability Rights Education & Defense Fund (DREDF), [n.d]. Disability Discrimination Act 1992. [Online] Available at: [http://www.dredf.org/international/Ausdda.html#_Toc463338525] [Accessed 1 June 2011].

Fausto-Sterling, A., 2000. Sexing The Body: Gender Politics and the Construction of Sexuality. New York: Basic Books.

Fausto-Sterling, A., 1993. The Five Sexes: Why Male and Female Are Not Enough, Sciences, [Online]. Available at: [http://www.uta.edu/english/timothyr/Fausto-Sterling.pdf] [Accessed 2 June 2011].

Fausto-Sterling, A., 2000. The Five Sexes Revisited, Sciences, [Online]. Available at: [http://abouthomosexuality.com/five-sexes.pdf] [Accessed 3 June 2011].

Feder, E. K., 2011. Bioethics and the Disciplines: Recent work on the medical management of Intersex. Katrina Karkazis and Elizabeth Reis. International Journal of Feminist Approaches to Bioethics, 4(1/ Spring), pp. 241-249 (Review).

Fiedler, L.A., 1996.Foreword. In: R. Garland-Thomson, ed. 1996. Freakery: Cultural Spectacles of the Extraordinary Body. New York and London: New York University Press. pp. xiii-xvi.

Foucault, M., 1990. The History of Sexuality: An Introduction. Volume I. New York: Random House, Inc.

Foucault, M., 1997. The Abnormals. In: P. Rainbow, ed. Ethics: Subjectivity and Truth. London, Allen Lane: The Penguin Press, pp. 51-58.

Foucault, M., 2003. From the power of sovereignty to power over life. Lecture (17 March 1976). In M. Foucault, Society must be Defended. Lectures at the College de France 1975-1976, Mauro Bertani and Alessandro Fontana, eds, New York: Picador, pp.239-264.

Frader, J. et al., 2004. Health Care Professionals and Intersex Conditions. Archives of Pediatrics & Adolescent Medicine, 158(May), pp. 426-429.

Garland-Thomson, R., 1996. Freakery: Cultural Spectacles of the Extraordinary Body. New York and London: New York University Press.

Garland-Thomson, R., 2002. Integrating Disability, Transforming Feminist Theory. NWSA Journal, 14(3), pp. 1-32.

Gordon, C., 1991. The Foucault Effect: Studies in Governmentality. Chicago: University of Chicago Press.

Grosz, E., 1996.Intolerable Ambiguity: Freaks as/at the Limit. In: R. Garland-Thomson, ed. 1996. Freakery: Cultural Spectacles of the Extraordinary Body. New York and London: New York University Press. pp. 55-66.

Hall, K.Q., 2002. Feminism, Disability and Embodiment. NWSA Journal, 14(3), pp. vii-xiii.

Inahara, M., 2009. This Body Which is Not One: The Body, Femininity and Disability. Body & Society, 15(1), pp. 47-62.

Irving, D., 2008. Normalized Transgressions: Legitimizing the Transsexual Body as Productive. Radical History Review, 100 (Winter), pp.38-60.

ISNA, 2011. What is Intersex? [Online] Available at: [http://www.isna.org/faq/what_is_intersex] [Accessed 10 May 2011].

ISNA, 2011. How common is Intersex? [Online] Available at: [http://www.isna.org/faq/frequency] [Accessed 7 May 2011].

Kafer, A., 2004. Inseparable: Gender and Disability in the Amputee-Devotee Community. In: B. Smith & B. Hutchinson, eds. Gendering Disability. New Brunswick, N.J.: Rutgers U. Press. pp.107-118.

Kadam, A. U., 2011. Docs turn baby girls into boys. The Hindustan Times, [Online] 26 June. Available at: [http://www.hindustantimes.com/News-Feed/madhyapradesh/Indore-doctors-turn-scores-of-baby-girls-into-boys/Article1-713863.aspx].

Karkazis, K., 2008. Fixing Sex: Intersex, Medical Authority, and Lived Experience. Duke University Press, Durham and London.

Karna, G. N., 2010. The Rights of Dignity, Effective Participation and Inclusion of Persons with Disabilities Act, 2010. [Online] Available at: [http://www.disabilitystudiesnalsar.org/Preamble_Definitions_Act_2010.php] [Accessed 10 June 2011].

Kessel, A., 2010. Caster Semenya May Return to Track This Month After IAAF Clearance. The Guardian, [Online] 6 July. Available at: [http://www.guardian.co.uk/sport/2010/jul/06/caster-semenya-iaaf-clearance] [Accessed 1 June 2011).

Kessler, S., 1998. Lessons from the Intersexed, New Brunswick, New Jersey and London: Rutgers University Press.

Koyama, E., 2009. One in 1,000 children may become subjected to growth attenuation. What Sorts of People, [Online] Available at: [http://whatsortsofpeople.wordpress.com/2009/01/28/one-in-1000-children-may-become-subjected-to-growth-attenuation/] [Accessed 5 August 2011].

Lee, P.A., Honk, C.P., Ahmed, S.F., & Hughes, I.A., 2006. Consensus Statement on Management of Intersex Disorders. Pediatrics, 4118(2), pp. e488-e500.

Madhiwala, N., 2008. The Niketa Mehta case: does the right to abortion threaten disability rights? Indian Journal of Medical Ethics, [Online] Available at: http://www.issuesinmedicalethics.org/164ed152.html] [Accessed 26 June 2011].

Merish, L., 1996. Cuteness and Commodity Aesthetics: Tom Thumb and Shirley Temple. In: R. Garland-Thomson, ed. 1996. Freakery: Cultural Spectacles of the Extraordinary Body. New York and London: New York University Press. pp. 185-203.

Miller, R., 2007. The Limits of Bodily Integrity. Ashgate.

Minto, C. L. et al., 2003. The Effect of Clitoral Surgery on Sexual Outcome in Individuals

Who Have Intersex Conditions with Ambiguous Genitalia: A Cross-Sectional Study. The Lancet, 361, pp.1252-1257.

Mullins, A., 2009. Racing on Carbon Fiber Legs: How Abled Should We Be? Gizmodo, [Online] 12 November. Available at: [http://gizmodo.com/5403322/racing-on-carbon-fiber-legs-how-abled-should-we-be] [Accessed 30 May 2011].

Organisation Intersex International Australia Limited (OII-Australia), 2010. What is Intersex? [Online] Available at: [http://oiiaustralia.com/information/intersex/] [Accessed 10 May 2011].

Pilkington, E., 2007. Frozen in time: the disabled nine-year-old girl who will remain a child all her life. The Guardian. [Online] Available at: [http://www.guardian.co.uk/world/2007/jan/04/health.topstories3] [Accessed 5 August 2011].

Preves, S.E., 2002. Sexing the Intersexed: An Analysis of Sociocultural Responses to Intersexuality. Signs, 27(2), pp.523-556.

Rapp, R., 2000. Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America. New York: Routledge.

Rose, N., 2007. The Politics of Life Itself : Biomedicine, Power, and Subjectivity in the Twenty-first Century. Princeton: Princeton University Press.

Sandel, M.J., 2007. The Case Against Perfection: Ethics in the Age of Genetic Engineering. Cambridge, Mass: Belknap Press of Harvard University Press.

Saner, E., 2008. The Gender Trap. The Guardian, [Online] 30 July. Available at: [http://www.guardian.co.uk/sport/2008/jul/30/olympicgames2008.gender] [Accessed 7 May 2011].

Schulze, M., 2009. Understanding The UN Convention On The Rights Of Persons With Disabilities [Online] Handicap International. Available at: [https://8953499920627000589-a-nileshsingit-org-s-sites.googlegroups.com/a/nileshsingit.org/uncrpd-and-new-disability-act/uncrpd-downloads/HI_CRPD_Manual_sept2009_final.pdf?attachauth=ANoY7coikcANLyMsU5K_fch9bOTP6y24dTEaJeudbdROGeWHpTeYW9ZPjw56V60avhMEi2HKwSB0c7

-loetmGD5A_1qPwD581_9OCg5SZyjIHbxg6LM1 Jy_PDSwAgte2H2Io5lgVPvQOzsgQTL04vuCuSLfr81zya3sgABkOWfgBueC7NFddz_Cg7eWUEOjtgsG_7-YdmjcqifókBVJXYu8JmhB0P6yZPSVA3wcNVCb92mePXDU4fqjahkzNlwCuF4Yt0sbP7BJX2AX3BCpvtR0Ulbi1K7c1og%3D%3D&attredirects=2] [Accessed 1 June 2011].

Shildrick, 2002. Embodying the Monster: Encounters with the Vulnerable Self. London: Sage Publications.

Silverberg, C., 2006. Sexuality and Disability Myths and facts. About.com, [Online] 15 December. Available at: [http://sexuality.about.com/od/disability/p/disability_sex1.htm] [Accessed 10 June 2011].

Tarnai, B., 2006. Review of Effective Interventions for Socially Inappropriate Masturbation in Persons with Cognitive Disabilities. Sex and Disability, 24, pp.151-168.

TARSHI, 2010. Sexuality and Disability in the Indian Context. [Online] New Delhi, India. Available at: [http://tarshi.net/downloads/Sexuality_and_Disability_in_the_Indian_Context.pdf] [Accessed 3 June 2011].

The International Paralympic Committee (IPC), [n.d]. Paralympic Games. [Online] Available at: [http://www.paralympic.org/Paralympic_Games/] [Accessed 10 June 2011].

The Sunday Times, 2009. Caster Semenya Faces Sex Test Before She Can Claim Victory. [Online] Available at: [http://www.timesonline.co.uk/tol/sport/more_sport/athletics/article6802314.ece] [Accessed 1 June 2011].

Thomas, C., 2004. How is Disability Understood? An Examination of Sociological Approaches. Disability & Society, 19(6), pp. 569-583.

United Nations, [n.d]. Frequently Asked Questions regarding the Convention on the Rights of Persons with Disabilities. [Online] Available at: [http://www.un.org/disabilities/default.asp?navid=24&pid=151#bp4] [Accessed 8 May 2011].

United Nations, [n.d]. Article 1 – Purpose. [Online] Available at: [http://www.un.org/disabilities/default.asp?id=261] [Accessed 8 May 2011].

Warne, G. & Bhatia, B., 2006. Intersex, East and West. In S. E. Systsma ed. Ethics and Intersex. Netherlands: Springer. pp.183-205.

World Health Organization (WHO) & the World Bank, 2011. World Report on Disability 2011. Geneva: WHO Press.

World Health Organisation (WHO), 2011. Gender and Genetics. [Online] Available at: [http://www.who.int/genomics/gender/en/index1.html] [Accessed 2 June 2011].

World Health Organisation (WHO), 2011. Disabilities. [Online] Available at: [http://www.who.int/topics/disabilities/en/] [Accessed 2 June 2011].