

Prenatal Diagnosis: Where Do We Draw the Line?

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Feminists in India have been concerned about the declining sex ratio in the country. The Prenatal Diagnostic Techniques (Regulation and Prevention of Misuse) Act 1994 or PNDT Act, which outlaws sex-selective abortions, has been welcomed by feminists, even though they remain concerned with bottlenecks in its implementation. A relatively unnoticed but critical issue, however, is the possibly unwitting legitimisation of the abortion of potentially disabled children. This article endeavours to question the ideology that regards abortion as the only option when prenatal testing reveals a birth abnormality, an option sanctioned by the PNDT Act. We contend that disability is, to a great extent, socially constructed: its conceptualisation reflects societal attitudes that view the lives of disabled people as tragic, worthless and a burden. The article recognises the tension between the feminist and disability activists around the issue of women's choice. These issues are discussed through the voices of the mothers of both non-disabled and disabled children in Delhi. We contend that: (a) the concept of individual choice, which is reified through the PNDT Act, is socially constructed and contextually located, and (b) while a pro-choice perspective is important to feminists, the thoughtless use of prenatal testing could reduce, rather than expand, women's choices.

Introduction

When prenatal diagnosis first became a part of the Indian reality, feminists were quick to point out that the techniques aimed to detect foetal abnormalities were also capable of providing information about the sex of the unborn child. It seemed evident to them that given the extremely patriarchal nature of much of Indian

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society and the marked preference for male children, such techniques were more likely to be used for sex-selective abortions. The history of the debates between the state and activists is well known (Patel 2007; Rao 2004). Responding to the massive protest generated by the spread of sex-selective abortions, the central government passed the Prenatal Diagnostic Techniques (Regulation and Prevention of Misuse) Act or PNDT Act in 1994. Despite the legal regulation, the 2001 census showed an alarming decline in the juvenile sex ratio in the under-5 category.¹ In 2003 a public interest litigation (PIL)² prompted the central government to place the onus of action against providers of sex-selective abortions on the state governments. In recent years there has been a noticeable increase in media attention, although criminal action³ against medical practitioners is only now becoming a reality.

In this article, however, we are interested in exploring a less visible aspect of the PNDT Act. A careful reading of it shows that while selection on the grounds of sex is unambiguously banned, there is a positive sanctioning of selection on the basis of disability. Consequently, this results in the legitimisation of one kind of selection, that is, on the basis of disability, while prohibiting it on grounds of sex. The debate on whether selection on the grounds of disability should be legal evokes mixed reactions. The existing arguments suggest that antenatal screening is not understood in any uniform way, either within feminism or in the disability movement, particularly in India.

While many scholars writing on the interface between feminism and disability activism see the right to abortion as creating a gulf between the two perspectives (Hubbard 1997; Shakespeare 1998; Sharp and Earle 2002), others (Parens and Asch 2000; McLaughlin 2003; Menon 2004) think that there is a possibility of reconciliation between the two apparently divergent perspectives. The former believe that for feminists the critical factor in all abortion debates is women's uncontested right to choose. Proponents of this perspective do acknowledge the fact that choice is not always unconditionally autonomous and free. However, many activists in the disability movement object to this unqualified right to abortion, as it has serious implications for the discrimination experienced

by disabled persons.⁴ This anomaly has been noticed by feminists like Sunita Bandewar, who says:

A new problem comes up when considering the right to abortions of a foetus with a disability. One might argue that the same reasoning can be applied: since women face the most profound impact of such children upon their birth, they should be the sole decision-makers to either continue or terminate pregnancy (2005: 20).

This position potentially strengthens the normative conceptualisation of disability, which is value-laden. It sets a precedent for elimination of so-called unfit people. Nivedita Menon echoes both Sharp and Earle (2002) and Bandewar, when she warns that:

Once we accept that there can be a hierarchy of human beings based on physical characteristics, and that it is legitimate to withhold the right to be born to those at lower levels of this hierarchy, then this reasoning can be extended to other categories, whether female, inferior races or any other (2004: 96).

One line of reasoning taken by pro-life supporters like Marsha Sexton (1998) and Mary Jane Owen (1992) is that the right to abortion is at the root of all discrimination against disabled persons. However, while we are of the opinion that women must retain an unfettered right to abortion, it is also apparent to us that the construction of abortion as individual choice needs considerable rethinking, since women face familial, social and cultural constraints in the exercise of free choice in their everyday lives. Data from across the world, and particularly from India, show that even when the legal system allows abortion, many abortions are illegal, thus increasing the morbidity for women. In a review of several researches, Visaria et al. (2004) found that husbands and mothers-in-law play a predominant role in decision-making around abortion. Two other interesting features emerged from this review. First, women reported that while abortion is an immoral act per se, it could be condoned if it was performed for the sake of family honour. Second, women who opt for abortion after giving birth to several

daughters, receive more support than those who do so for other reasons. Many women also reported being forced violently to undergo abortions. Furthermore, in the case of sex determination and subsequent female foeticide, families make the decision after a cost–benefit analysis factoring in the relative long-term gains of saving on dowry.

Feminists are, therefore, in the difficult position of supporting abortion, even while they recognise the limited agency that women possess in the exercise of free choice. The underlying logic is that abortion rights are necessary in an imperfect system, even where a woman has limited capacity to control her reproductive life. The question, both practical and ethical, is that if women have the right to choose, how can a distinction between abortion and selection be maintained? We believe that it is the category of the unborn child, the foetus, which is the critical variable in this debate. Before prenatal diagnosis came into routine use, debates around abortion focused almost exclusively on the mother’s ability to bear and rear a child. Such decisions were largely guided by the legitimacy of motherhood for the woman: they did not involve the ‘qualities’ of the foetus. With the advent of prenatal diagnosis in clinical practice, the conception of the foetus has changed from a generic entity to one with specified properties. The first of these properties, namely, the sex of the child, has already shown itself to be problematic. The case of sex selection points to a critical need to differentiate between abortion and selection. The latter needs to be located within discussions of hegemonies of gender, normalcy and normativity, be it male sex or absence of disability. This article seeks to draw upon both the feminist and disability rights discourses to interrogate the unqualified right to abort foetuses with disability, as articulated in the PNDT Act.

Context of Sex Selection

The Indian context provides us with a setting to reflect on the ethics of selection. Since sex selection is pervasive in India, feminists have had no choice but to grapple with the dialectic of structure and agency within which the issue is framed. The majority of feminists argue that since women possess limited agency, legal systems have

to be strengthened to protect them. At the same time, as highlighted by Menon (2004), individual women who have 'opted' for sex selection should not be punished. Instead, the onus of responsibility lies with the medical practitioner who provides the information about the sex of the unborn child, and the socio-cultural context that valorises sons over daughters.

The intricacy of the issue is evident in the perspective of feminist Manjula Padmanabhan, who asks whether there can be:

anything more grotesque than to be forced to carry an unwanted living presence within the sanctum of one's own body?... In a twisted sort of way, women who abort their female foetuses are voting against their own misogynist culture and in that sense, are subverting it.... Given the world we have now, it is far better to enable women to take this life-denying decision of their own accord under medically and legally safe conditions than to saddle them with babies whom they will revile and devalue as they were reviled and devalued (1993).

It is important to understand the mindset of the woman who aborts her unborn daughter as a partial protest against her own oppression, because women do participate consciously in sex selection. In the absence of an alternative viewpoint, a woman, who is rejected for bringing yet another daughter into the world, is likely to hate her and see in her the reasons for her own oppression.

When sex selection has evoked so much debate, the issue of selection on grounds of disability is clearly even more contentious. Again, central to this discussion is the difficulty in conceptualising women's agency. Both the mother of an unwanted daughter and that of a disabled child face tremendous difficulties. To choose to give birth to a child with disability is to challenge dominant social constructions of both motherhood and childhood. If it is possible to argue that the desire to abort a female foetus arises from the conditions of patriarchy, is a similar logic not applicable to disability selection? We try to delineate this nuanced picture by drawing upon research on gender, motherhood and disability carried out by the two authors in the course of several research projects.

We come to this debate from different vantage points: Anita Ghai is a disability researcher and activist, and Rachana Johri, a researcher on motherhood.

The article draws upon data from three qualitative research studies, primarily involving in-depth interviews with mothers. The first set of voices are from an ongoing study by Rachana Johri (2001) in which mothers of young children are asked about the specific circumstances under which they would opt for abortion. One of the issues discussed in detail is what the informants would do in the face of a potentially disabled foetus. All the participants in this study are college-educated and belong to the urban middle classes. At the time of writing, interviews had been conducted with 20 mothers with one or two children. The selection of the participants was based on the age of their children. Thus, mothers with children below 6 were chosen as they are at the peak of their reproductive lives. A second data source is ongoing research in which 30 mothers of children with developmental disabilities are being interviewed. Again, the women belong to the middle class and are residents of Delhi. The third study that has been cited is research conducted by Sanjana Singh (2005) as part of her bachelor's degree under the supervision of Anita Ghai. The participants were 14 visually impaired girls between the ages of 16 and 18 years studying in a residential school for the blind in Delhi. Among other issues on which detailed qualitative interviews were conducted, the students were also asked to respond to a dilemma about prenatal testing for the determination of potential disabilities.

We argue that, as in many other issues, there is no homogenous or essential woman's voice concerning the legitimisation of the abortion of a disabled foetus. Nonetheless, despite an absence of homogeneity, the dominant voice does favour abortion of the disabled foetus. Exploring the underlying reasons for justifying or rejecting such action helps to better comprehend the context in which such choices are made and to arrive at an alternative rendering of the question of abortion of disabled foetuses. In the remaining part of the article, our attempt is precisely to foreground the voices of a sample of women on disability selection and abortion. But

before proceeding any further, it will be worthwhile to develop a better understanding of the dynamics of disability construction.

Medicalisation of Disability

As Anita Ghai (2003) has argued elsewhere, part of the difficulty in understanding disability lies in that it is unequivocally embedded within the medical model. The location of the problems as residing within the individual's body perpetuates the image of the disabled person as sick, flawed, afflicted and suffering. Consequently, the medical model sees the availability of reproductive technologies, such as prenatal diagnosis, as a blessing that may pre-empt and consequently prevent congenital disability. This perspective is well represented in the advice columns of popular magazines like *Parenting India*.

Responding to a query about the safety of ultrasound examination during pregnancy, the gynaecologist in the advice column begins by highlighting the benefits of ultrasound to detect the age of the foetus, its position and other features. Then, she proceeds to emphasise the need for a second ultrasound during the 13th week of pregnancy to:

look for certain congenital abnormalities like Down's syndrome or anencephaly.⁵ In these cases *timely intervention* can prevent a lot of mental trauma to parents as these pregnancies can be easily terminated at that stage. A third ultrasound is done at 22 weeks as most organs have developed at that stage and parents can be given proper counselling (2007: 97, emphasis added).

The discursive construction of the perfect pregnancy and hence the perfect child is apparent in this brief extract. Indeed, most medical professionals would not find this scenario exceptional. It is worth noting that the advice does not contain any information on the nature of disability, its severity and the possibility of raising a disabled child. If professionals, such as obstetricians and counselors, are ethically committed to assisting prospective parents make informed choices, they should also provide detailed and reliable information about what life is like with a disabling condition, so

that their clients can imagine the ways in which such a life can be both rewarding and difficult for themselves and their potentially disabled child. However, not only do medical professionals tend to medicalise non-medical conditions like normal pregnancy and menstruation, they adopt a directive approach when they should be helping clients engage in a process of autonomous decision-making. Thus, procedures like prenatal diagnoses are not only projected as usual, but highly necessary and desirable.

Green (1994) studied consultant obstetricians and found that they favour selective abortion when they come across any foetal abnormality. Although Green's research comes from a different cultural context, the power of medical discourse seems to be quite universal. This is evident in the narratives of young mothers in our research, who were overwhelmingly in favour of aborting a disabled foetus. They were greatly influenced by medical practitioners who strongly urge pregnant women to have tests. The fact that doctors and genetic counsellors speak from the position of experts makes their suggestions all the more critical.

As Puneeta, a homemaker with a 10-month-old daughter, puts it: 'My doctor told me this when she sent me for the first ultrasound. "We want to check if there is any abnormality. After the third month if there is any abnormality, then abort the child."'

Thus, the medical discourse appears to 'empower' couples by offering tests for a growing range of conditions. Medical professionals claim to provide non-directive counselling,⁶ enabling parents to make their own choices. Yet, the ethical issues and the theoretical and practical possibilities of non-directive counselling have remained largely uninterrogated. Recent research voices serious concerns about the extent to which a genetic counsellor simply reproduces the biases of the larger society. As Annette Patterson and Martha Satz point out:

Serving both as purveyors of genetic information and as guides in decision-making, genetic counsellors often preside over prenatal sessions where parents are considering whether to continue or terminate pregnancy. This process has profound implications for society in shaping attitudes about what constitutes

a 'life...worth living' and, potentially, the provisions society will make for those with disabilities (2002: 119).

Examples abound of mothers who were told at the time of the birth of their disabled children that they would not survive for more than a few years, or would show extremely poor intellectual development. Many such children have survived for years and often reached levels of capability exceeding medical expectations. A particularly poignant account is presented in the autobiographical film *39 Pounds of Love*. Ami Ankilewitz⁷ was diagnosed with an extremely rare and often fatal form of spinal muscular atrophy that severely limits his physical growth and movement. He is 34 years old, having outlived the doctor's prediction of his life expectancy by 28 years. The film follows Ami's journey in search of the doctor who predicted his early demise.

One of the mothers from the study on the choice of abortion being done by Johri, narrated the case of a friend who was advised to undergo an abortion, but whose baby was ultimately born without any disability. It is clear that although medical knowledge is uncertain and disability is often used as a catch-all phrase for all kinds of avoidable conditions, experts push decisions towards abortion. With the detailed mapping of the human genome under way, medical technology will enable the detection of individual predispositions to a number of diseases, such as diabetes, depression, Alzheimer's, heart disease, arthritis and breast cancer in the not so distant future. Will the fantasy of a perfectly able-bodied society entail the elimination of all foetuses predisposed to developing a spectrum of possible conditions?

Cost of Disability

Yet another reason, and possibly a very effective one, reminds parents that the rearing of a disabled child would invariably entail extra time, money and suffering⁸ for the child as well as the family. Multiple costs are involved in bringing up a child with disability, which may include emotional pain and suffering, loss of a child, loss of opportunities, loss of freedom, isolation, loneliness, fear, guilt, stigmatisation and financial hardship. In fact, people who

argue in favour of disability selection often accuse activists of being insensitive to the 'costs' to women that such a choice entails. As Rayna Rapp reminds us:

Women judge the acceptability of specific foetuses for entry into their communities because there are so few limits on women's responsibility for the quality of the life that the child would have. In other words our gendered responsibilities for producing acceptable children as well as our embodied responsibilities for the pregnancies that produce them over-determine our need to think deeply about the consequences of knowing about and possibility eliminating disability prenatally (2000: 308).

Since patriarchy determines the social location of care, caretaking usually gets added to the unpaid labour of women in the home. As a result, it is both the disability as well as perpetual motherhood that shape genetic decision-making. The fear of extensive caretaking and responsibility are evident in the voices of the young mothers in our research. Sudha, a homemaker with a 4-year-old son, for example, was sure that she would definitely have an abortion if she discovered that her unborn child might be disabled. She said, 'There is no doubt about it. I am very clear about it.' Her clarity stems from the fact that her mother's friend had a son who was intellectually challenged. She said:

I've seen the mother suffering and the child suffering. Maybe it is not the case now because people are more open-minded. But even then people don't look at physically or mentally handicapped children as equal to theirs.

Mothers fear the greater responsibility that comes with a disabled child, a responsibility that they often have to bear the brunt of. As one of the young mothers commented:

Have tests to find out if there are any abnormalities? I suppose so. Sounds selfish but probably I think I would abort the child. I guess you feel the amount of responsibility. You're not strong enough to bring up a special child.

In a similar vein, another mother said, 'To bring up that child is the responsibility of a lifetime. No one else will take care [of the disabled child] especially after you die.' In her case the doctors indicated a problem with the heart. She continued:

I had to go to Escorts.⁹ Then, I had thought that if there was a problem, I'd get an abortion done. The thought of the baby being born and getting tubes and all put all over was very uncomfortable. Any deformity would make a difference. If you don't know, then you cannot help it, but once you find out, then don't take up the responsibility. If she is born, then you have to take care of it, but otherwise it is better to prevent [it].

From the point of view of mothers the responsibility is particularly frightening, since it is routine to blame them for anything that is considered amiss with the child, be it female sex or disability. Many women who participated in Johri's doctoral study (1999) described how they were blamed and ostracised by their conjugal families and the larger community for their failure to give birth to a son. Archana, a mother of three daughters, who was the principal of a school, narrated the painful days following the birth of her first daughter. When her mother-in-law finally came to visit her in the hospital, Archana said:

She behaved as if I had committed a crime. On the nurses asking for a gift [*inaam*] she commented; 'You are asking for a gift. We are bereft [*Hum to kahin ke na rahe*]. She may as well have not survived''.

Archana was devastated and said, 'I felt very bad. Today if I had a son, everyone would have gathered around me: celebrations would have taken place. And they had not even brought me food.'

Archana's trauma was heightened because her husband did not support her at all in the face of the hostility and ostracism inflicted upon her by his family and community. After the birth of their third daughter, her mother-in-law stopped eating for three days. Such is the lamentation following the birth of daughters that her community conducted a '*shok sabha*' (mourning meeting) for her,

the poor woman who has three daughters, none of whom died. The psychological costs of bearing the less than perfectly desired child are indeed considerable for the mother.

Apart from psychological costs experienced directly by the mother, the disabled child is viewed as an economic liability, and, therefore, a burden on both family and society. Such a child is perceived to contribute little and require disproportionate investment from society. The parallel with the girl child is evident. In a globalising context where the profit paradigm predominates, the justification for preventing the birth of disabled children is that society has to bear the cost of disability. While the billions spent on wars (that are the major source of disablement) are not lamented, the money spent on disabled people is constructed as high cost. Economic factors are at the root of the persistent devaluation of disabled lives. This rationale is, however, flawed. Prenatal diagnosis creates an illusion that disability will be wiped out if research in genetics is successful. However, under no circumstances is a total erasure of disability possible. We know that barely 2 per cent of all births are affected by disability in the womb.¹⁰ Disability may occur at any time during pregnancy, delivery or at any other time during the lifespan. Many impairments have no clear aetiology. And since prenatal testing can carry some risk for the foetus, it is likely that only women with high-risk pregnancies will go through with it. Though many disabilities, such as sickle cell anaemia, Down's Syndrome, adult onset Huntington's, cystic fibrosis and haemophilia, are considered grounds for abortion, in reality many persons with these disabilities do become independent and lead productive lives, if given the opportunities to do so. This is not to say that there would be no disabled persons who will require care, but such an expectation is legitimate within a just society.

Enrichment of Parental Autonomy

Another rationale offered in support of prenatal screening is the enrichment of parental autonomy. Peter Singer, a well-known contemporary bioethics scholar, uses this argument to justify genetic/

prenatal testing and subsequent termination of a disabled foetus. According to him:

There are many things that people who are paralysed below the waist could not do in any society, no matter how constructed. They cannot visit untracked wilderness, go ice skating, or play football. And many other things that they can do, they can do only with difficulty and with more time than it would take those who have the use of their legs.... The decision to abort a foetus that has, say, Down's syndrome, is not a decision that is 'anti-children', still less 'anti-life'. It is a decision that says: 'Since I will only have two children, I want them to have the best possible prospects for a full and rich life. And if, at the outset, those prospects are seriously clouded, I would rather start again.'¹¹

In this discourse the choice to determine the nature of the foetus is constructed as a parental right. But a reading of the narratives from our research indicates that parental rights and autonomy are differently constructed, depending upon a mother's social location and experiences. Although some mothers of non-disabled children did argue in favour of this right, other mothers of disabled children held a different view. These children were, however, born before the technology was routinely available for clinical use. For instance, Shanti, a 60-year-old disability advocate and mother of a 28-year-old disabled son, admits that she would have had the abortion had the choice been made available to her. She said, 'I was too [much of a] perfectionist—too intellectual.' However, when asked whether she would give similar advice to young mothers, she responded in the negative. She feels living with a Down's Syndrome child has given her an opportunity for deep learning. She would not like to exchange this experience for anything. Many parents like Shanti will attest to the potential for self-transformation that comes about as a result of bringing up a child who has Down's Syndrome.

Prenatal screening and other future selective technologies make us lose sight of the possibility of transforming the hostility and prejudices that we carry for anyone who is different. The changing understanding of disability within the social model¹² challenges

us to question the assumption that disability is to be avoided at all costs. As Meeta, mother of two sons, who works in an NGO for disabled children, puts it:

There is no problem in accepting the baby. Suppose the disability happened after birth, the baby loses an eye, and then you will accept it. You won't throw it away. There is a girl here at our NGO, she is handicapped but she has gone to England. Since I work here, I have seen how a mentally retarded child can take out a comb from the drawer. I have told my husband that in case I cannot have another child, I would like to adopt a disabled girl. That feeling of pity [*bechaari*] has gone. A 6-year-old has gone abroad, can we think of doing it?

Parental choice can only be meaningful within a society that provides knowledge about disabled lives. There is considerable difference between living with the disabled and their stereotypical portrayal in the popular imagination. The gap between stereotype and lived reality is evident in the narratives of visually impaired girls in the research study by Singh and Ghai referred to earlier. While visual disabilities are often not genetic, the issue concerns the difference between the construction of disability and the experience of living it. Therefore, we thought that it would be insightful to look at the views of those who are stigmatised to ascertain how they view the issue of disability and parental autonomy. Radhika is a 17-year-old visually impaired girl, originally from a remote village in Uttar Pradesh, and now studying in a residential school for the blind in Delhi. Responding to a hypothetical query regarding what she would say to a mother who might give birth to a disabled child, she said: 'There are good and bad traits in everyone. I would tell her not to abort the child, but help the child to develop an identity, to teach him/her how to live in this world.'

Similarly Puja, her schoolmate, added: 'I'll also tell her that you should be teaching your child to live, to face this world.... And we should be doing something throughout our life, so that they [society] can remember us.'

In focus group discussions the right of the disabled to life was affirmed by visually challenged adolescent girls. Like non-disabled

girls growing up in a patriarchal society, some disabled children may internalise the dominant voice of the culture and argue for the abortion of disabled fetuses. Many others, as the narratives show, disagree.

From another perspective, it is in the context of potential motherhood that the issue of disability takes on added meaning in the lives of disabled women. This issue is poignantly addressed by Deborah Kent when she writes about the gulf between herself and her beloved husband, between herself and her parents, regarding her blindness, a gap she was herself unconscious of until she and her husband decided to have children. She writes: 'What I understood was that Dick, like my parents, was the product of a society that views blindness and all disability, as fundamentally undesirable' (Kent 2000: 58). Thus, Kent does not look at life with disability as one of unmitigated suffering.

If, nevertheless, some mothers of disabled children believe that they would advise a prospective mother to abort the foetus, what might be the underlying process? Diya, a 72-year-old middle-class woman, is actively involved in advocating the rights of intellectually challenged adults. She herself has a 24-year-old son with Down's Syndrome. Though committed to caring for her son, she points to the discrepancy between her own feelings and the dominant construction of disability. This is reminiscent of the arguments put forward by mothers who have daughters. Diya is of the view that if a young mother discovers any genetic defect, such as intellectual impairment, she should abort the child. She feels that although there is greater awareness about disability over the past two decades, the negative mindset of people has not really changed. She recalls with horror the agony and turmoil that she experienced while getting her daughter married because the whole family was stigmatised. She was equally perturbed by the frustration of her son, who was not allowed to be present at many social events. Her relatives would often explicitly tell her to leave her son at home.

Similarly, another mother who has a 37-year-old son with Down's Syndrome, was distressed when her son expressed a desire for marriage: she has no solutions to offer him. Then, Kamal, mother of a grown-up son with developmental disability, said that although

she herself did not do so, she would advise a mother expecting a potentially disabled child to get the foetus aborted. She feels that even though society might have changed, disability is still perceived negatively.

All the interviews indicate that disabled children are perceived as socially unwanted. Although the narratives included here refer to mothers with intellectually challenged children, we feel that the findings apply in the case of other disabilities as well. While it is possible to deconstruct the voices of mothers with or without disabled children, the contrasting narratives of visually impaired girls bring out the real paradox in the notion of choice and disability selection. Indeed, the disabled often do not experience their life as one of unmitigated suffering.

Many feminists have repeatedly cautioned against the notion of universal womanhood. We are of the view that the specificity of their locations will generate a difference in the voices of mothers and daughters on disability. Nonetheless, what is not disputed is that women have an inalienable right to free choice in the area of reproduction. Health professionals and the wider society do not sanction the birth of a disabled child. Therefore, if women make choices that go against the societal norm, they are likely to be blamed. Even in the case of polio, it is often presumed that the mother must have been at fault by not having had the child immunised. Instead of getting support, counselling, understanding and information, people are pressurised into conforming to societal norms and expectations. It is important to note that a focus on individual reproductive choice overlooks the underlying assumption of prenatal diagnosis, namely, that only certain kinds of people should be born in this world. The very existence of prenatal tests assumes that parents will want to select against atypical results. Consequently, is there really a notion of free choice in the true sense of the word in decisions related to elimination of disabled foetuses? As a parent, Michael Bérubé, the father of a boy with Down's Syndrome, feels:

I obviously can't and don't advocate abortion of foetuses with Down syndrome; indeed, the only argument I have is that such decisions should not be automatic. A foetal diagnosis of Down

syndrome should not be understood, either by medical personnel or by parents, as a finding to which abortion is the most logical response.... Nonetheless, although this is my belief, it is only my belief. I would not want to see it become something more than belief—something more like a coercive social expectation (1996: 79).

Individual Choice: Myth or Reality?

It is evident that an emphasis on individual rights does injustice to the complexity of the woman's as well as disabled person's experiences. Let us consider the scenario that disabled people confront in a society where being normal is the ruling ideology. Considering that disability is defined in medical terms and normality is defined by powerful social normative standards, choice can be anything but free. Furthermore, there are people with a range of different disabilities, different life experiences, different material needs and different ideological perspectives. Although technological developments enhance the sense of choice, in reality they tend to push decisions in a predictable socially desirable direction. In contemporary India the technology of prenatal determination of foetal characteristics has disadvantaged both girls and the disabled. With the advent of these technologies more and more pregnant women are encouraged by doctors to go in for prenatal screening. In such a context, the pressure on women to exterminate that which seems to depart from the norm is immense. But as Veena Das (1986) has argued, this decision is in itself by no means based on autonomous choice implied in discussions on the morality of abortion. Furthermore, as she points out, it is not inscribed in the nature of things that a physically or mentally retarded individual should have a poor quality of life. It is the great value accorded to autonomy and competition that appear to make this a self-evident fact.

Indeed, new technological innovations have already made it possible to select an embryo at the outset rather than to abort an unwanted foetus afterwards. The abortion debate may thus become irrelevant in the not so inconceivable future. The critical question, then, is the issue of choice. As a recent report on assisted

reproductive technologies by SAMA Resource Group for Women and Health states:

It is difficult to distinguish between latent choice and social choice shaped by family, market, and other agents. Unless we draw this line, there is no limit to theoretical choice and everything, including sex selection, can be justified in the language of choice. What society does is to promote one variety of choice while silencing the range of options. The society closes the option that women can be happy without children [or daughters, or disabled children] (2006: 101).

While individual choice must be promoted, what needs to be addressed is that this choice takes place in a particular social space in which disability has a negative connotation. Consequently, it is difficult to say how much real choice is involved. If you choose to bear and rear a disabled child, it appears to be illogical and ridiculous. As Adrienne Asch (cited in Blumberg) has written:

Suppose Down syndrome, cystic fibrosis or spina bifida were [*sic*] depicted not as an incalculable, irreparable tragedy but as a fact of being human? Would we abort because of those conditions or seek to limit their adverse impact on life?¹³

To communicate that 'You must have a test' or 'You must have a termination' without analysing the implications needs to be problematised. We need to provide mothers and fathers with multiple accounts of how they might lead a life with a disabled child. As Jason Kingsley, a 17-year-old boy with Down's Syndrome, puts it:

I have a disability called Down syndrome. My bad obstetrician said that I will never learn and send me to an institution and never see me again. No way Jose! Mom and Dad brought me home and taught me things. He never imagined that I could write a book. I will send him a copy of the book so he will know. I will tell him that I play violin, that I make relationships with other people, I make oil paintings, I play the piano (Kingsley and Levitz 1994: 27–28).

What needs to be clarified is that these choices are made in a context where disability is accepted as an oppositional category to normality. Disabled lives are not considered worthwhile. Whether the argument stresses suffering or economic cost, disability is conceived of only as a medical category. Such a framing misses the socially constructed nature of disability. The fact that some part of the body or mind is limited in functioning is not the problem. But the barriers in society are the real problem: for instance, stairs without lifts or ramps, information not available in Braille or in digital format, and, most importantly, people's negative attitudes. These represent a complex form of institutional discrimination which is as deep-seated in our society as gender bias, caste structures and heterosexism/homophobia. Thus, the 'cure' to the problem of disability does not lie in medical technology, but in the restructuring of society. Marsha Sexton eloquently sums up the sense of outrage experienced by disability activists when she says:

The message at the heart of the widespread selective abortion on the basis of prenatal diagnosis is the greatest insult: some of us are 'too flawed' in our very DNA to exist; we are unworthy of being born [F]ighting for this issue, our right and worthiness to be born, is the fundamental challenge to disability oppression; it underpins our most basic claim to justice and equality—we are indeed worthy of being born, worth the help and expense, and we know it (1998: 391)!

For a feminist audience it might be worthwhile to understand the role played by capitalist economies in casting disability as a deficit, something extensively discussed in the social model of disability. As Mike Oliver has written:

Whatever the fate of disabled people before the advent of capitalist society . . . with its coming they suffered economic and social exclusion. As a consequence of this exclusion, disability was produced in a particular form; as an individual problem requiring medical treatment. Old age (and I would suggest, madness and distress) suffered a similar fate (1996: 127).

It is not uncommon to find people impaired due to work-related injuries forced to lead a marginal life thereafter because of the disabled-unfriendly environment. Thus, disabled people are disempowered because bodies that do not fit in or require additional resources to become a part of the production process are rejected in a system that emphasises profit. Factors such as the reluctance to provide disabled-friendly environment, and the non-availability of materials in alternative formats for visually and hearing-impaired people, are all geared towards keeping the employment rates for the disabled abysmally low. This image of not being able to contribute to production constructs the disabled as dependent, which is ultimately the root cause of their exclusion.

For a mother the realisation that her disabled child may never be able to attain fulfilment of all his/her needs is very painful. As the narratives show, many mothers will choose not to go ahead with a pregnancy in such circumstances. A woman's choice to abort a disabled foetus is constructed within dominant notions both of motherhood and disability. To feel fulfilled as a mother, it is assumed that she must produce a healthy, non-disabled baby. Any deviation will not only produce dissatisfaction, but will also increase her burden and result in mother-blaming. Consequently, it is not difficult to empathise with a woman who selectively aborts a disabled foetus. The difficulty, both logical and ethical, arises when a similar argument is used for the abortion of female foetuses. Mothers report that a woman without sons is barren (*banjh*) and that life without a son is a life spent in darkness. They fear their husbands will leave them, and indeed many do (Johri 1999). If mothers' desires are not sufficient grounds for aborting female foetuses, the same rationale applies to the case of disability. Clearly, the notion of individual choice is problematic.

The new reproductive technologies have eugenic potential as they reinforce the notion that there is an ideal of physical and mental perfection that humanity must aspire to. Such a position considers most differences as deficits. It is, however, a slippery slope to other forms of selection, and thus eventually to a world of a new designer baby eugenics. If new technologies make it possible to fulfil desires and satisfy preferences, is that reason enough to use them? More precisely: if we can, does that mean we should?

If one is going to be consistent about choice, then why stop at impairment? But then can women never be conscious agents? To cite Jennings (2000: 130), the notion of free choice only provides an 'illusion of freedom'. Then, how are we to make sense of the situation? Equating choices that women are compelled to make, that is, aborting a female or disabled foetus, is not the same as saying that they are participating in discrimination. Instead, it points to the ways in which women are themselves constrained by the burden of knowledge. Our fantasy might be that women should avoid selection. However, it is unjust to expect that they would not abort when the problem is not a matter of autonomous choice, but the context in which such choice is made. What is perhaps required is an analysis of prenatal screening in the light of the social values and structural inequalities that influence the decision to abort. Therefore, if prenatal screening is to be made available, it must be accompanied by efforts to re-educate the public, including prospective parents, about disabled people's lives. It has to be coupled with efforts to improve financial and other support systems for them and their families. If the danger of increased prejudice is real for sex, then it is even more real for disability. Our contention is that there is a critical need to interrogate the silence around the routinisation and rapid growth of prenatal testing. To our mind, a public debate is extremely important to understand whether elimination of disability is a legitimate goal. Marcy Darnovsky (2004) reminds us:

This constellation of technological, economic, cultural, and ideological developments has revived the issue of sex selection, relatively dormant for more than a decade. The concerns that have always accompanied sex selection debates are being reassessed and updated. These include the prospect that selection could reinforce misogyny, sexism, and gender stereotypes; undermine the well-being of children by treating them as commodities and subjecting them to excessive parental expectations or disappointment; skew sex ratios in local populations; further the commercialization of reproduction; and open the door to high-tech consumer eugenics.¹⁴

The belief that marginalised communities need to be empowered is equally true for both women and the disabled. As Roger S. Gottlieb, a philosopher with strong Marxist leanings, suggests:

Whether or not someone is disabled is partly a function of what resources are available at a given time, what conveniences are 'standard' in a society, and how we are expected to behave.... The nature of paraplegia will change when wheelchair ramps are as standard as elevators.... Similarly, the question arises: what changes are to be made—the institutional equivalents of wheelchair ramps—in equalising the participation of caretakers of the disabled to make our society more just? (2000: 231–32)

Conclusion

This article has argued that in both sex selection and disability selection, discursive constructions of socially acceptable and desirable traits completely eclipse the wide range of subjectivities that are involved in such decisions. What appears to be free choice is largely determined by the dominant social ideologies and institutions. Supporters of the right to determine characteristics of the unborn need to remember that in an era marked by unprecedented technological interventions on the body, the tendency to construct desirable babies is likely to work to reinforce already existing hierarchies. It is opening a Pandora's box as selection of one trait implies the legitimisation of other traits as well. Therefore, the ethics of what appear as free choices need to be interrogated. The disability community in India is so involved with issues of basic survival that there is as yet no space for discussion of the implications of new reproductive technologies. We need to make efforts to incorporate the perspectives of disabled individuals in genetic counsellors' education and practice, thereby reforming society's view of the disabled. This will help in lessening possible negative effects of genetic counselling on the self-image and material conditions of disabled individuals.

As part of a campaign aimed at the Human Fertilisation and Embryology Authority, the UK-based bioethics group Human Genetics Alert writes:

If we allow sex selection it will be impossible to oppose 'choice' of any other characteristics, such as appearance, height, intelligence, etcetera. The door to 'designer babies' will not have been opened a crack—it will have been thrown wide open.¹⁵

Do we want that to happen?

Notes

1. See <http://www.india-seminar.com/2003/532.htm>, accessed 29 August 2007.
2. The PIL was initiated in February 2003 by three petitioners: Dr. Sabu George, The Centre for Enquiry into Health and Allied Themes (CEHAT), Mumbai, and the Mahila Sarvangeen Utkarsh Mandal (MASUM), Pune, in the Supreme Court. It called for the implementation of existing legislation banning prenatal sex-selection, as well as taking cognisance of newer reproductive technologies for sex determination of the foetus.
3. According to Sandhya Srinivasan (<http://www.infochangeindia.org/analysis/121.jsp>, accessed 29 August 2007), there are some 350 cases filed under the PNDT Act. Of these, 226 are for running a diagnostic clinic without registration, 26 are for not maintaining accounts. Just 37 are for communicating the sex of the foetus, and 27 are for advertising sex selection. The first conviction involving a prison term was ordered on 28 March 2006, when a doctor and his assistant were sentenced to two years in prison and a fine of Rs. 5,000 in Palwal, Haryana. More recently, a sex-selective abortion racket was unearthed in Pataudi, a town 40 km from New Delhi. The police say that A.K. Singh, the quack arrested for the murder of several unborn children and for conducting illegal diagnostic tests, has confessed to aborting over 260 female foetuses in the past decade.
4. See *New York Times* (7 May 2007) for a discussion on prenatal diagnosis.
5. Anencephaly is a fatal birth defect that happens when the neural tube does not fully close at the top. As a result, part of the skull and brain are missing. Babies with anencephaly die before or shortly after birth.
6. Psychotherapeutic or counselling technique in which the therapist takes on an unobtrusive role in order to encourage free expression and problem resolution by the client or patient.
7. Ami, who weighs only 39 pounds, works in Israel as a 3-D graphic designer and creates his art despite the fact that his bodily motion is limited to a single finger on his left hand. Through his efforts, he continues to redefine notions of a 'normal' life.
8. It is interesting that while suffering associated with disability is assigned a negative value, suffering that is inflicted voluntarily on the self in order to achieve physical perfection is valorised. As Welsch puts it, 'The current aestheticization seems to attain its consummation in individuals. We are experiencing everywhere a styling of body, soul and mind—and whatever these

fine people might want to have (or acquire for themselves) in beauty saloons and fitness centers they pursue the aesthetic perfection of their bodies.... Future generations should then have it easier straight away: genetic technology will have come to their aid ahead of them, this new branch of aestheticization which holds the prospect of a world full of perfectly styled mannequins' (Welsch 1996: 6).

9. The reference is to Escorts Hospital and Research Centre, a private specialty hospital in Delhi.
10. See <http://www.ias.ac.in/currensci/nov25/articles9.htm>, accessed 20 August 2007.
11. See <http://www.apa.udel.edu/apa/publications/newsletters/v99n2/medicine/article-singer.asp>, accessed 22 August 2007.
12. As against the medical model of disability, which conceptualises bodily difference in terms of impairment requiring medical intervention, the social model puts the onus of disability not on the individual, but on the society in which he or she lives. Architectural, educational and employment barriers created by society disable the individual, not his body.
13. See <http://www.ragged-edge-mag.com/0798/a798ft1.htm>, accessed 24 October 2007.
14. See <http://www.gene-watch.org/genewatch/articles/17-/darnovsky.html>. Accessed 30 April 2007.
15. 'The Case against Sex Selection, Human Genetics Alert Campaign Briefing', December 2002. Copy of report was obtained from Human Genetics Alert, Unit 112 Aberdeen House, 22-24 Highbury Grove, London N5 2EA.

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