

**FROM INVALIDATION AND SEGREGATION TO  
RECOGNITION AND INTEGRATION:  
CONTEMPORARY STATE RESPONSES TO DISABILITY IN  
INDIA**

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## **DISABILITY-LINKED DEPRIVATION: A NEGLECTED DIMENSION OF SOCIAL EXCLUSION IN INDIA\***

### **Abstract**

Persons with disabilities are amongst the most disempowered groups. Due to their marginal status, they are denied the fundamental civil, political, social, economic and cultural rights that are the prerogative of all citizens in a democracy. They are constantly faced with discrimination and are subjected to neglect, prejudice, revulsion, rejection and pity. They face economic, educational, architectural, legal and health barriers, which prevent them from leading a fulfilling life and achieving their full potential. Historically in India as elsewhere in the world, there has been a deep-rooted cultural antipathy to persons with disabilities. Throughout the ages the disabled have been looked down upon with disdain, almost as if they were sub-human. They have been portrayed as medical anomalies, helpless victims and a lifelong burden for family and society.

Conservative estimates show that 18.49 to 21.92 million persons suffer from some form of disability in India (Census of India 2001). The World Health Organisation estimates that around 10 per cent of the population at any given time suffers from some form of disability or other. That comes to more than 70 million people in the country. Ironically, while other socially disadvantaged groups, such as women, the scheduled castes and tribes and religious minorities have been formally accepted as victims of historical injustice and their claims to redressal have been recognised, persons with disabilities continue to be marginalised in state-sponsored empowerment policies and programmes. While a number of enabling legislations, such as the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995, have been enacted, the social obligation and moral imperative to ameliorate the life conditions of the disabled population remain rudimentary.

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This paper traces the engagement of the Indian state with the issue of disability over the past three decades as a discourse of charity and welfare gives way to one of equality and human rights. Using Census data, it highlights the extent of economic marginalisation and social deprivation of persons with disabilities. The paper underscores the need to make disability a legitimate category in the discourse of social exclusion at par with caste-based exclusion and discrimination.

## Introduction

According to conservative estimates derived from the 2001 Indian Census, 1.8% to 2.1% of our population of 1.2 billion suffers from some form of disability which in absolute numbers is approximately 18.49 to 21.92 million persons. Using a wider definition of disability which includes conditions like diabetes and cardiovascular disease, the World Health Organisation (WHO) estimates that 6 to 10 per cent of the population suffers from identifiable physical or mental disability. That comes to over 70 million persons in India.<sup>1</sup> Such phenomena as war, ethnic conflict, HIV/AIDS, industrial injuries and road accidents are increasing the number of disabled persons. Ironically, enhanced life expectancy has increased manifold the incidence of old age-related, chronic disease induced disabilities worldwide as well.

But what is a disability and what does it mean to be disabled in the first place? Disabilities may be congenital or from birth. For instance, most mental retardation is congenital. Malnutrition and micronutrient deficiencies may result in disabling conditions in children in the form of stunted physical and mental growth. When disabilities are acquired later in life due to accidents, injuries or advancing age, they may be characterised by episodic upsurge of symptoms and/or progressive degeneration. Many mental illnesses like schizophrenia, multiple sclerosis and Alzheimer disease fall in this category. A disability may be static such as the loss of limb due to an amputation. Then, there are also hidden and visible disabilities. Diabetes and epilepsy are hidden disabilities while leprosy and blindness are visible conditions. A disability generally has two components i.e. the medical limitation and social prejudice, which often gets translated into discriminatory behaviour towards the disabled person. In legal documents and policy statements disability is defined in terms of what qualifies for public assistance.

Historically, there has been a deep-rooted cultural antipathy to persons with disabilities. Throughout the ages the disabled have been looked down upon with disdain, almost as if they were sub-human. They have been portrayed as medical anomalies, helpless victims and a lifelong burden for family and society. Even in religion and mythology, negative characters were attributed some form of deformity, be it Manthara, the hunchback in the *Ramayana* or Shakuni, the lame of the *Mahabharata*. Indeed, the law of karma decreed that being disabled was the just retribution for past misdeeds. Such construction of the disabled by the non-disabled has the dual effect of not only justifying the complete marginalisation and disempowerment of a whole population group but also leads to the internalisation of such negative stereotypes by disabled persons themselves.



This acceptance translates into passivity, dependency, isolation, low self-esteem and a complete loss of initiative. Pity, segregation, discrimination and stigmatisation became normalised in the management of persons with disabilities.

After the Second World War, countries in Western Europe, Japan and the United States were faced with the challenging task of rehabilitating a huge number of disabled soldiers. This historical necessity placed disability at the centre of social welfare policies in both Europe and the United States leading to a marginal mitigation of the negative social perceptions. The civil rights movement and the women's movement in the 1960s and 1970s gave impetus to self-advocacy by persons with disabilities and their families into a vibrant social movement. Through such self-advocacy, the concept of disability was redefined not as personal tragedy necessitating therapy but as collective oppression necessitating political action (Oliver 1996: 44). In this perspective the focus shifts from the inability of persons with disabilities to adapt to the so-called 'normal' environment to the failure of the social and structural environment to adapt to the needs and aspirations of the disabled. As advocates for equal rights for disabled persons, disability organisations lobbied with national governments for a barrier free environment, inclusive education, and affirmative action in employment in addition to the whole range of civil, political social, economic and cultural rights to which all citizens are entitled.

The Universal Declaration of Human Rights<sup>2</sup> by the United Nations in 1948 introduced a rights based approach to disability. Every person has certain natural or inalienable human rights by virtue of being a person. These rights cannot be violated under any circumstance. They constitute what in essence it means to be human. Article 25 of this UN Declaration explicitly states that each person has the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in the circumstances beyond his control. Persons with disabilities are entitled to all the rights upheld by the Human Rights Charter as also other rights instruments such as the International Covenant on Civil and Political Rights (1966a) and the International Covenant on Economic, Social and Cultural Rights (1966b).

The international climate was made more disable-friendly by subsequent UN declarations specifically for the welfare of persons with disabilities<sup>3</sup>. The year 1981 was declared as International Year of Disabled Persons. A World Plan of Action concerning Disabled Persons was adopted by the General Assembly in 1982 for the implementation of which 1983-1992 was proclaimed United Nations Decade of Disabled Persons. In 1993 the General Assembly adopted the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities<sup>4</sup>. The

Convention on the Rights of Persons with Disabilities (2006) which India has signed and ratified is the culmination of these efforts with unprecedented policy ramifications at the global level.

The impact of the international human rights movement and anti-poverty initiatives have transplanted the issue of disability from that of social welfare to one of social development. Development essentially means inclusion. If the needs and aspirations of a whole population group are not taken account of, then social development in the true sense of the word has not taken place. Disability is both a cause and consequence of poverty. They reinforce each other leading to increased vulnerability and exclusion. Poverty exacerbates the opportunities of persons and disability further marginalises them making it impossible for them to have access to basic conditions of life like health, education, transportation and employment.

Instead of giving rights to disabled citizens and empowering them, a culture of charity and welfare has been systematically promoted in India since the colonial period. Medical rehabilitation including distribution of assistive aids and appliances, and special schools, vocational training in low-end occupations and sheltered employment have been the pillars of state policy for the disabled. Furthermore, electoral politics of caste and gender have pushed the disabled to the margins of the political landscape making them a weak political constituency. They have, in fact, been systematically disenfranchised by the political system. Things began to change marginally after 1981 (International Year of Disabled Persons) when the issue of disability was opened up at the national level. The changing international climate focussing on human rights and empowerment of marginal groups impelled the government to make some policy changes such as token reservations in educational institutions and employment. But real progress in the form of concrete legislation to deliver the promise of equality of opportunity and social justice only came in 1995 with the passage of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act. Other legislation soon followed<sup>5</sup>. One of the positive outcomes of economic liberalisation and globalisation has been the introduction of a view of disability as a human rights and development issue rather than simply a matter of charity and welfare. This perspective is slowly entering deliberations primarily due to the efforts of voluntary groups like the Disability Rights Group in Delhi<sup>6</sup> that lobbied with the government both for the passing of the 1995 legislation and incorporation of disability in the 2001 Census.

In order to set the stage for the debate for understanding disability as a prime example of social exclusion, the paper begins with presenting a socio-

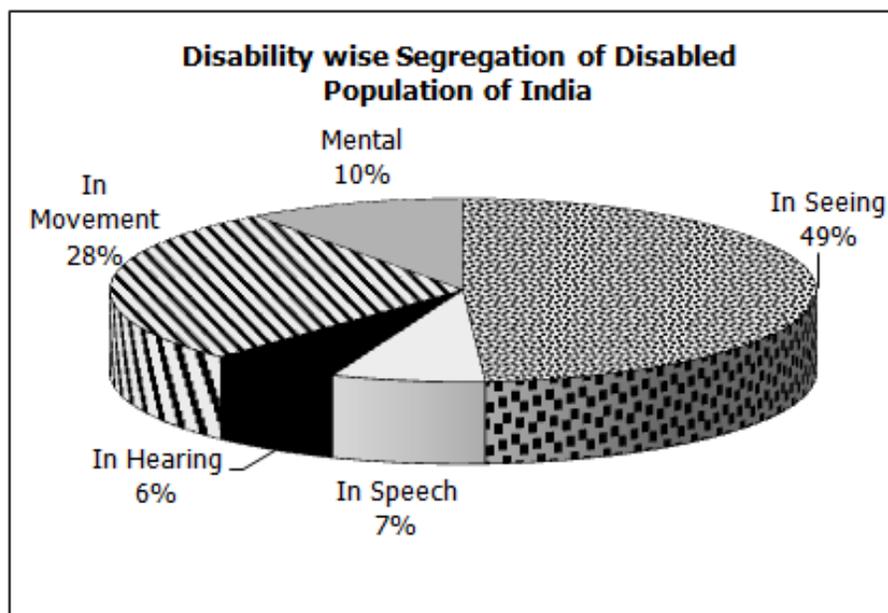
demographic profile of disabled persons in India drawn from the 2001 Census, providing a macro-level understanding of the disabled population in terms of types of disabilities, degree of disability, age of onset, course, literacy and employment status. Against this backdrop, the need to recognise it as an explicit category of social exclusion, along the lines of caste and gender, is discussed.

### Profile of Persons with Disabilities in India

As already mentioned, the Indian Census pegs the total disabled population at 18.49 to 21.92 million persons. Since there is no universal definition of disability, its prevalence and magnitude in a given country depends on the operational definitions adopted and the methodology used to gather data. The Indian Census recognizes five categories of disabilities, namely visual, locomotive, mental, speech and auditory<sup>7</sup>

While visual and movement disabilities show the highest prevalence, hearing and speech disabilities combined constitute 13 per cent of total disabilities (see Graph No. 1).

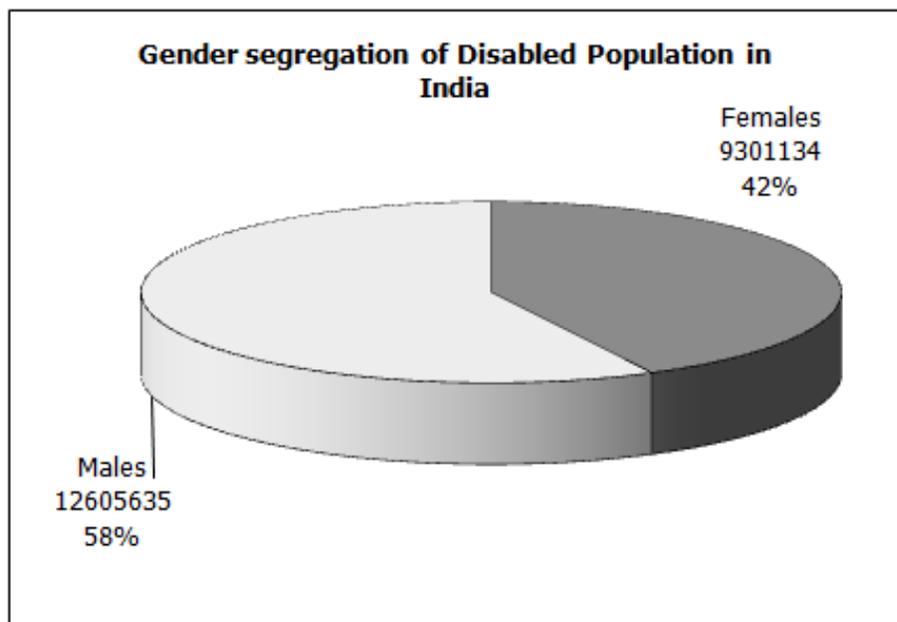
Graph No. 1



Source: Derived from Census of India 2001

The sex-wise shows that males outnumber females in prevalence of disabilities (see Graph No 2).

Graph No. 2

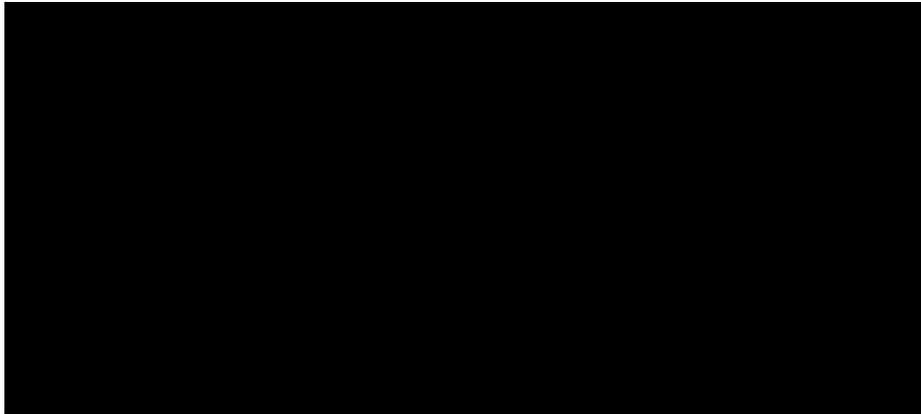


Source: Derived from Census of India 2001

Although there may be some biological basis for the differences in prevalence rates between males and females, the role of socio-economic and cultural factors cannot be overlooked. Lack of adequate nutrition and healthcare of the mother during pregnancy combined with the neglect of the female infant may be responsible for higher mortality rates in disabled females. Furthermore, female foeticide and infanticide may also play a role in differential survival rates of females and the prevalence of disabilities.

The classification of the disabled population in different categories by sex shows higher rate of prevalence of disabilities among males, especially in the case of movement and mental disabilities (see Table No. 1).

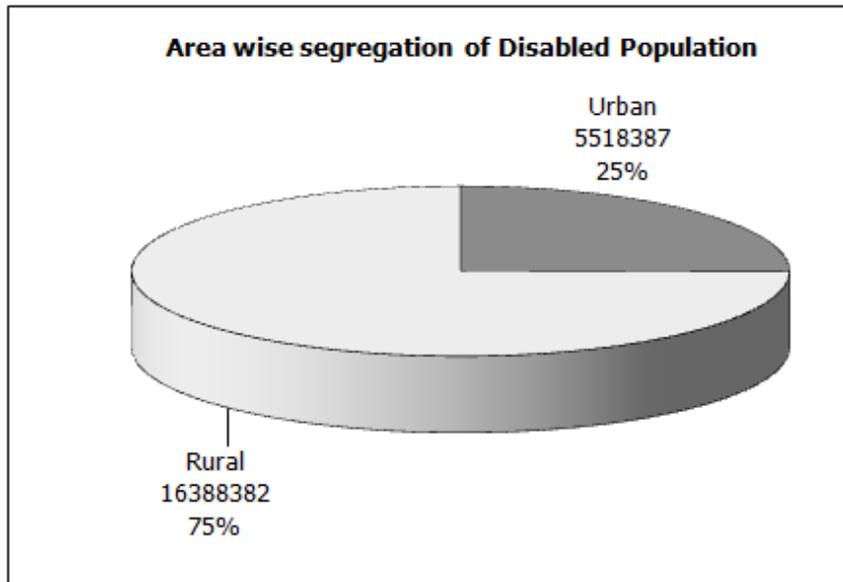
**Table No. 1: Classification of Disabilities by Sex**



Source: Calculated from Census of India 2001

More visual and hearing disabilities are reported in females. The reasons for these gender differences in prevalence rates of different disabilities need more analysis. For instance, it is possible that because women are expected to be more home-bound, many locomotive disorders may be normalised for them than for men who are expected to be the primary breadwinners and engage more actively in the public sphere.

**Graph No. 3**

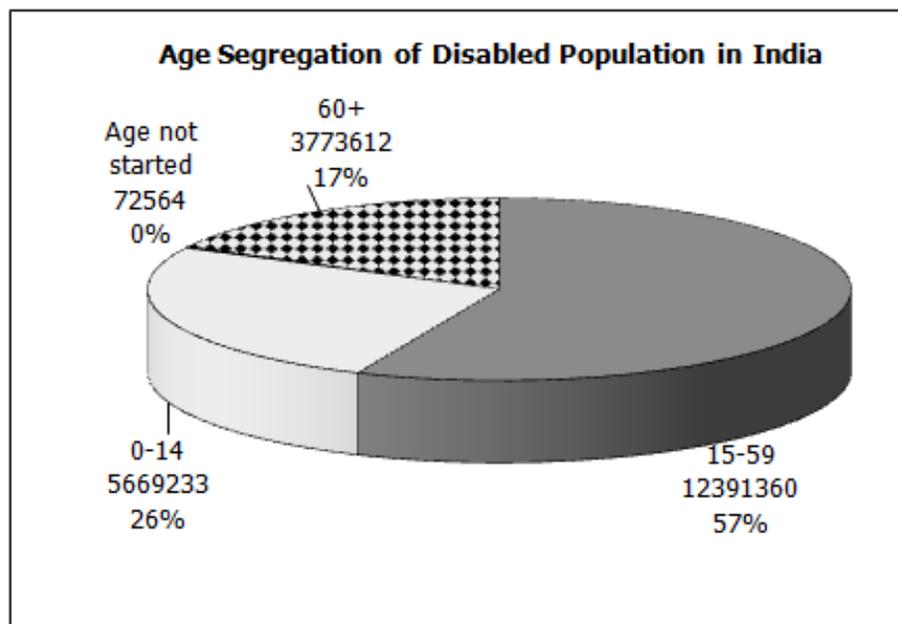


Source: Derived from Census of India 2001

The rural urban ratio in prevalence of disabilities directly correlates with patterns in the general population (see Graph No. 3). More disabled persons live in the rural areas simply because the Indian population is largely rural. The existence of a large number of persons with disabilities in rural areas also means that their access to medical and educational opportunities is restricted, since these facilities are concentrated in urban areas.

A majority of persons with disabilities fall within the productive and reproductive age group of 15-59 years followed by children below 14 years of age (see Graph No. 4). Given this demographic profile, there is an urgent need to invest in a comprehensive package to address the needs of this socially critical group such as health, education, employment, leisure and family life.

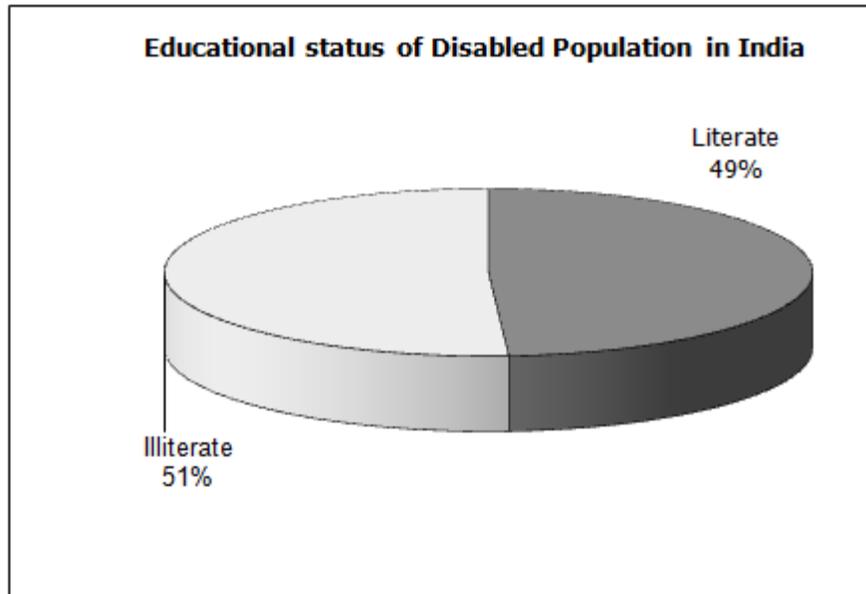
Graph No. 4



Source: Derived from Census of India 2001

The literacy rate in the disabled population is lower than the national rate of 65.38% highlighting the lack of access to education of this group, particularly women with disabilities (see Graph No. 5).

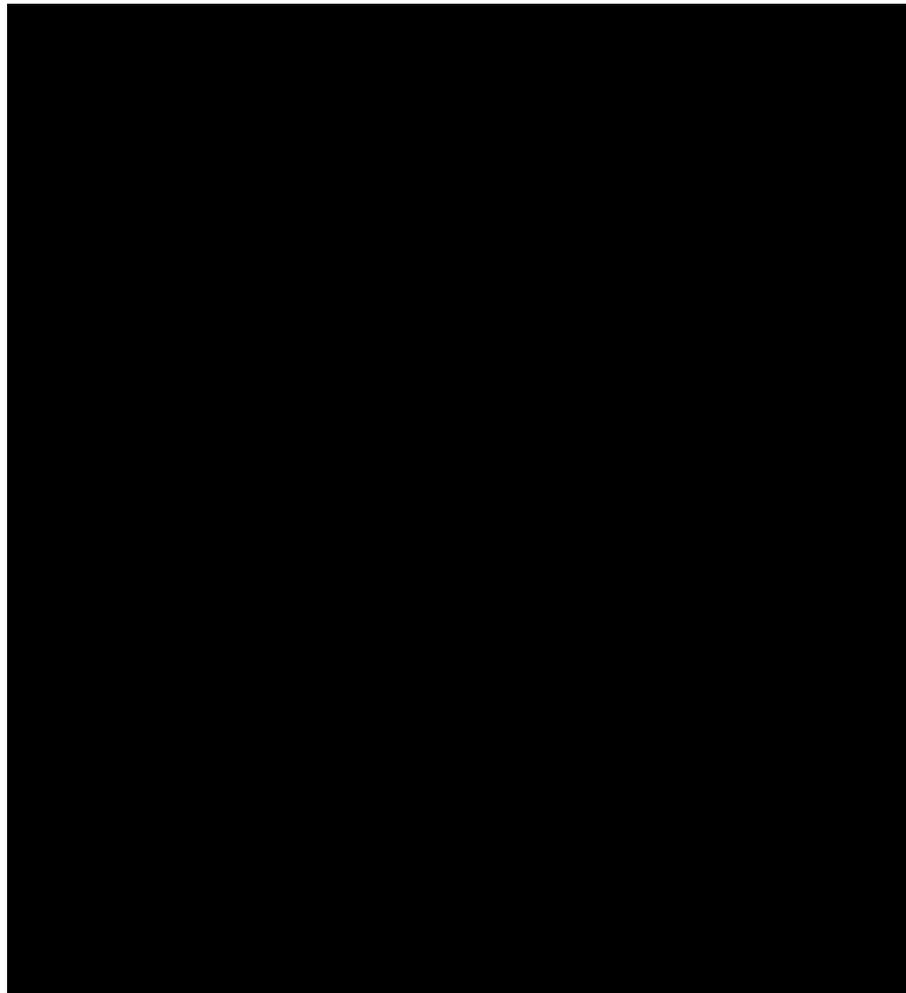
Graph No. 5



Source: Derived from Census of India 2001

When the literacy levels are disaggregated area-wise and disability-wise, there are more disabled literate persons, both male and female, in urban areas, which is understandable given the high concentration of educational institutions in cities (see Table No. 2). The male-female gap is also lesser in urban areas highlighting the fact that disabled women in rural areas have the least access to educational facilities. In terms of different disabilities, the highest literacy rates are found among those having movement disability followed by visual disability, and the lowest are among those having speech and mental disabilities highlighting the inability of the educational system to address the special needs of these two groups. There are no major gender differences in this regard.

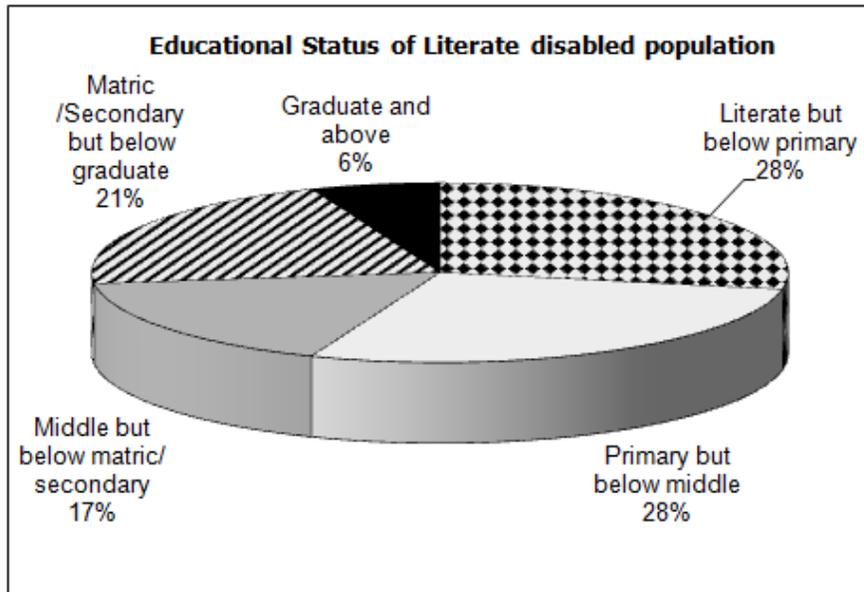
**Table No. 2: Literacy Rate among different categories of Disabled Population**



Percentage of persons in each category  
Source: Calculated from Census of India 2001

Dropout rates appear to be very high at the primary level because more than 56% of total literate disabled persons drop out of school before reaching middle school (see Graph No. 6). There is a need to strengthen primary education infrastructure to make it more disable-friendly. The dropout rates are higher for girls with disabilities, a trend in keeping with the general population.

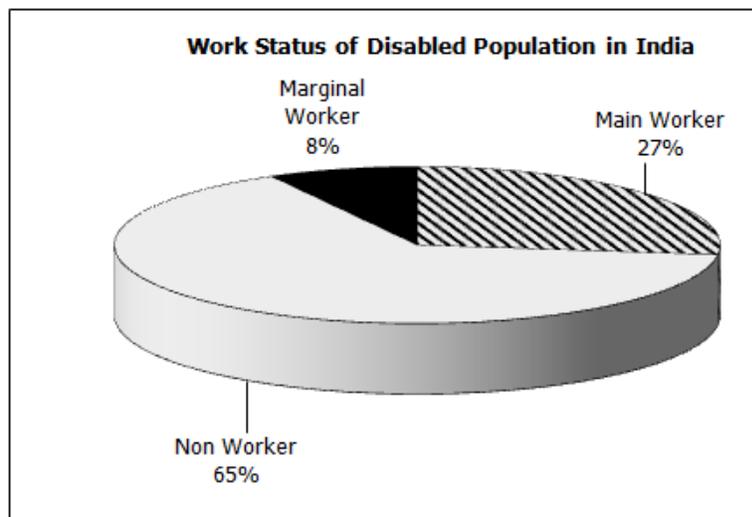
Graph No. 6



Source: Derived from Census of India 2001

When we move from educational to occupational status, we find that more than 60% of the disabled population is classified as non-working, which means not engaged in remunerative work (see Graph No. 7). As with the status of housework in general, a lot of domestic labour which persons with disabilities may engage in, particularly women with disabilities, is simply not counted.

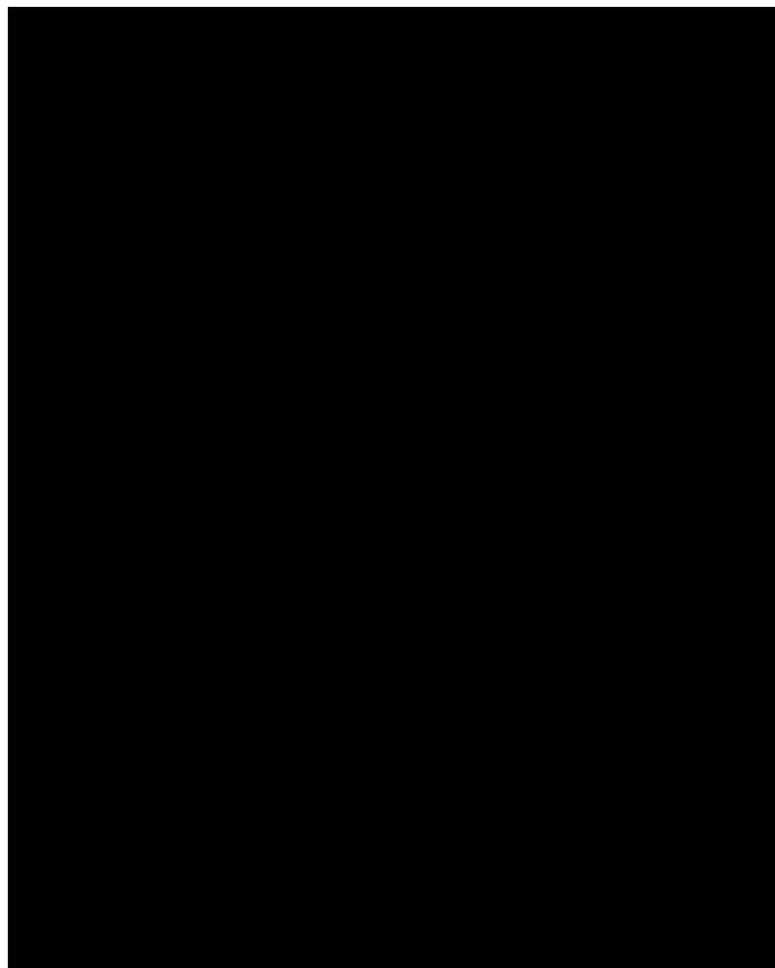
Graph No. 7



Source: Derived from Census of India 2001

While the educational status of urban disabled is better than their rural counterparts, work participation rates are higher in rural areas possibly due to the greater flexibility of the agricultural economy to absorb a larger number of disabled persons in gainful work. Interestingly, the highest work participation is among the visually challenged followed by those with hearing disability, while the lowest work participation is among those with mental disability (see Table No. 2). There are no gender differences in this ecological pattern of work participation.

**Table No.3: Work Participation Rates among different categories of the disabled Population**

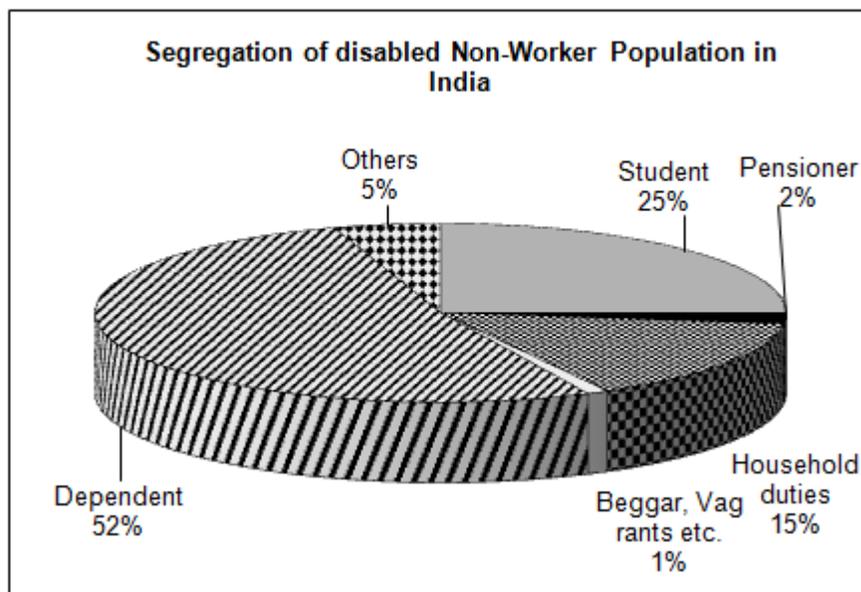


Percentage workers in each category

Source: Calculated from Census of India 2001

But what are the 65% of disabled persons outside the workforce doing? Over 50% of them are reported to be dependent on their families followed by another 25% falling in the category of student (who are also dependent. See Graph No. 8. This finding highlights the need to provide support to families and caregivers. Interestingly only 2% of persons have access to the much touted government-sponsored disability pension scheme.

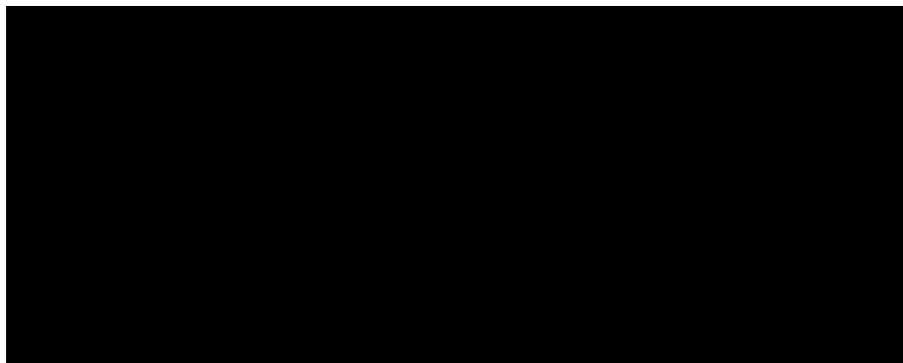
Graph No. 8



Source: Derived from Census of India 2001

One of the most critical socio-demographic variables from a gender perspective is marital status. More disabled males were found to be married in comparison to females. But the rates for separation, divorce and widowhood were uniformly higher among female disabled persons.

**Table No. 4: Marital Status of the disabled population**



Source: Calculated from Census of India 2001

While 43.8% of total persons with disabilities were married, the male female rates are 60.8% and 39.2% respectively. On the other hand widowhood and divorce rates are clearly higher among women with disabilities highlight the role of gender bias in the matrimonial market. Often, disabled women are married to older men or men in poor health, which may account for higher rates of widowhood. Annulment of marriage on account of disability is a major factor in the lives of women with disabilities. Very often this happens because the natal family chooses to conceal the disability, especially if it is an invisible one like mental illness at the time of marriage. At other times the disabled married woman may be expelled from the marital home for other reasons, ranging from her inability to satisfactorily perform household chores to bearing a disabled child.

### **Disability-Based Social Exclusion in India**

Although the concept of social exclusion is largely associated with issues of poverty and deprivation in a more general way, it is interesting to note that it was originally used in connection with a range of biologically and socially marginalized groups, including the disabled by Rene Lenoir in 1974 with regard to France. Among the excluded groups, he identified were:

...physically and mentally handicapped, suicidal people, aged invalids, abused children, substance abusers, delinquents, single parents, multi-problem households, marginal, asocial persons, and other social 'misfits' (Cited in Sen 2000: 1).

Analyzing social exclusion in the context of dialits, Sukhdeo Thorat provides an operational definition of this very widely used concept:

The manner in which it has been developed in social science literature, the concept of social exclusion, thus, essentially refers to the processes through which groups are wholly or partially excluded from full participation in the society in which they live. It emphasizes on two crucial dimensions involving the notion of exclusion, namely the 'societal institutions (of exclusion), and their 'outcome' (in terms of deprivation). In order to understand the dimensions of exclusion, it is important to understand the societal interrelations and institutions, which lead to exclusion of certain groups and deprivation in multiple spheres – civil, cultural, political and economic. (<http://www.empowerpoor.org/downloads/castepovertypaper.pdf>)

Social exclusion is embedded in a historical experience of group injustice, a social arrangement that systematically marginalizes large numbers of people, who as a result experience a whole range of social economic and cultural deprivations. If following Hiliary Silver, we examine the manifestations of social exclusion in terms of concrete criteria; we find that the majority of persons with disabilities in India experience every single one of them in a most stark fashion. Among the criteria she mentions are:

A livelihood; secure, permanent employment; earnings; property;, credit, or land; housing; minimal or prevailing consumption levels; education, skills and cultural capital; the welfare state; citizenship and legal equality, democratic participation; public goods, the nation or dominant race; family and sociability; humanity, respect, fulfillment and understanding (1995: 60).

The levels of social and economic discrimination have already been highlighted in the socio-demographic profile of the disabled population in India, particularly women with disabilities, culled from the latest Census. Although the Indian Constitution technically guarantees freedom and equality to all citizens: and there is some legislation for social protection and quota-based reservation in education and employment like the Persons with Disabilities Act 1995 and other welfare measures, lack of awareness, bureaucratic red tape, inaccessibility and sheer callousness on the part of authorities prevent even existing benefits from percolating down to those in need. The general quality of life of persons with disabilities is riven with multiple social, economic, civil and cultural deprivations

(Addlakha 2005; Bacquer and Sharma 1997; Bhambani 2003; Ghai 2001; World Bank 2007), particularly in rural areas (Harris-White 2002; Klasing 2007).

Social exclusion crates a vicious circle of adversity. In addition to basic privations like hunger and homelessness, there is high physical and mental morbidity, short life expectancy and high mortality. Disability (even congenital disability) is not a truly random or unpredictable phenomenon; poverty is both a cause and outcome of disability. People at risk of becoming disabled are also those who are already poor. Pre-existing malnutrition and morbidity are strong predictors of disability status. The intersections (and subsequent cumulative impact) of poverty, disability and gender create one of the most excluded social groups, namely women with disabilities whose life conditions are worse than both men with disabilities and non-disabled women of the same socio-economic status.

The core value of the concept of social exclusion lies in its relational nature, wherein deprivation is not simply due to paucity or lack of income but due to the nature of the social system that systematically compels certain groups to lead impoverished lives. A poor quality of life due to systematic exclusion from access to recourses that enable persons to realize their capabilities and attain well being through not only a fulfillment of personal needs but in being able to participate meaningfully in the life of the community. This in Amartya Sen's rendition, social exclusion can be *constitutively a part of* capability deprivation and *instrumentally a cause of* diverse capability failures (2000: 5, italics in original).

Persons with disabilities experience a denial of social and economic opportunities due to the combined impact of income deprivation, social segregation/isolation, cultural marginalization, political neglect and individual dehumanization. Their isolation has occurred in varying forms all over the world, ranging from segregation within institutions like leprosy colonies and schools for the blind and deaf to concealment within the home. Denial of access to the public sphere creates a whole cycle of deprivation and miseries ranging from lack of access to health and education to political disenfranchisement and cultural invisibility.

Social inclusion necessarily implies equal participation, social integration, dignity, respect and empowerment, which are key concepts in disability rights discourse embedded in the human rights perspective. In keeping with the core features of social exclusion, the state's legislative and executive efforts to mainstream person with disabilities must focus on enhancing access to education and employment on the one hand and creating social protection and social security nets on the other. These attempts are aimed at diminishing, if not overcoming, failure of access and entitlements, because its apathy notwithstanding, the state

is the most powerful ally against discrimination and exclusion. Over time such measures will attenuate the historical injustice that has been the plight of persons with disabilities.

### (Endnotes)

<sup>1</sup> Estimates of the total number of persons with disabilities in a country vary depending on the definition of disability used, degree of impairment, survey methodology including use of scientific instruments for identification and measurement of the disabling conditions.

<sup>2</sup> Human rights may simply be defined as those natural and fundamental rights essential for a decent life as a human being. They are possessed by every person simply by virtue of being human, irrespective of nationality, race, religion, sex, class or disability.

<sup>3</sup> In 1971 the General Assembly adopted the Declaration on the Rights of Mentally Retarded Persons which stipulated that the mentally retarded are not only entitled basic human rights like everyone else but they also have special rights corresponding to their special needs in medical, education and social fields. In 1975 the Declaration on the Rights of Disabled Persons was adopted, which proclaimed equal civil and political rights of disabled persons.

<sup>4</sup> These rules were aimed at facilitating development of national disability programmes of member states so that disabled persons can exercise all the rights and freedoms as their non-disabled counterparts. These standards provide a scheme to address all the needs of persons with disabilities in accordance with the principles of human equality, dignity and respect. They deal with provision of medical services, education, employment and social security, in fact, all aspects that contribute to raising the quality of life of this group..

<sup>5</sup> The Mental Health Act had already been passed in 1987. In 1993 the Rehabilitation Council of India Act was passed. This was followed by the landmark Persons with Disabilities (Equal Opportunities, Protection of Rights and full Participation) Act in 1995. The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act was ratified by Parliament in 1999.

<sup>6</sup> The Disability Rights Groups is a cross-disability coalition of NGOs working in different parts of the country that has played a pivotal advocacy role with the government.

<sup>7</sup> Note the discrepancy between categories of disabilities recognized by the Persons with Disabilities Act 1995 and the 2001 Census. The Act recognizes the following categories: blindness; low vision, leprosy-cured, hearing impairment, locomotor disability, mental retardation and mental illness.

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## **DISABILITY-SELECTIVE ABORTIONS IN INDIA: Individual Choice, Disabling Environments and the Socio-Moral Order\*\***

### **Abstract**

A recent case before the Mumbai High Court in India ignited a public debate around disability, parental choice and the ethics of prenatal testing. A young middle-class urban couple, along with their doctor, approached the court for permission to terminate the woman's pregnancy in the 25<sup>th</sup> week due to the discovery that the foetus might be born with a serious congenital heart defect. According to the Indian Medical Termination of Pregnancy Act (1971), the upper limit for abortion of a foetus is 20 weeks. The court constituted a medical team, and after much deliberation and media hype the plea of the petitioner was rejected. Within one week of the judgment, the woman had a miscarriage.

This paper will seek to capture the nuanced nature of the debate that this case threw up, the arguments of the couple who decided to take this step, the perspective of the court that rejected the couple's petition and different voices from the medical community and the general public as reported in the media. The analysis will highlight that this is not just a case of ethical dilemmas in the use of burgeoning prenatal technologies, but there are social, economic, cultural, moral and of course legal issues at stake. A neo-liberal, globalised Indian economy in which medical tourism is an emerging industry, an ever-enlarging middle-class which is rapidly replacing a socio-centric cultural ethos with a highly individualized notion of selfhood, and an ever deteriorating urban environment which makes the daily commute to work a nightmare are the over-arching realities which frame this issue. The situation is further complicated by the widespread practice of son-preference and sex-selective abortions, particularly in the urban and affluent sections of Indian society. Indeed, a single event can give us invaluable insights into what it means to be disabled in a disabling world that endorses diversity more at the level of rhetoric than reality.

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## An Unprecedented Case

**Pregnant pause:** Harshad and Niketa Mehta wait outside the high court yesterday, with Dr Nikhil Datar (left) their gynaecologist, Niketa is 25 weeks pregnant and wants an MTP, as the foetus has heart defects. Available at <http://www.mid-day.com/news/2008/aug/020808MehtaCase.htm> last accessed 30 January 2009.



Between 22nd July and 15th August 2008, the daily newspapers provided extensive coverage of a case filed in the Mumbai High Court challenging the 20 weeks upper limit on abortion under the Medical Termination of Pregnancy Act (MTP) 1971. The petitioner was a 31-year-old schoolteacher named Niketa Mehta. She, along with her 37-year-old stockbroker husband Hareesh Mehta and gynaecologist Dr Nikhil Datar, sought an amendment to the law that would enable her to legally terminate pregnancy, as prenatal testing in the 24<sup>th</sup> week had indicated the presence of a major cardiac anomaly in the foetus. The couple learnt about the complete congenital heart blockage during a routine echocardiogram. Their lawyer pleaded that extensive surgeries, to firstly implant a pacemaker and then to replace it every five years, would be economically unviable for the Mehtas, as well as traumatic for the child.

After hearing the case, a division bench of the court appointed a medical committee of the government-run Sir Jameshedji Jeejeebhoy (JJ) Hospital comprising a gynaecologist, cardiologist and paediatrician to file a report on the health status of the foetus.

Dismissing Niketa Mehta' petition, the court observed that medical experts did not express any 'categorical opinion' that if the child is born it would suffer from serious disability. The court noted that even if the couple had approached it before 20 weeks on the same grounds, it would not have been possible to allow abortion, as the medical opinion was not definitive.

The court based its decision on three sets of medical reports. Firstly, it held that the reports of private doctors, on the basis of which the couple was seeking the abortion, were not satisfactory; and hence it ordered a special committee from JJ Hospital to 'give an additional confirmed opinion'. The first report of the JJ Hospital medical team stated:

1. There are very fair chances that the child will be born incapacitated and handicapped (for survival).
2. A sonogram has shown a complete heart blockage with low ventricular rate.
3. The great artery is malpositioned but the heart is without any other structural damage and is viable for normal life provided there is no other anomaly in the heart.
4. Only a small percentage of kids will experience symptoms of the condition and will require implantation of a pacemaker costing less than 1 lakh<sup>1</sup> rupees, which can be replaced by an adult pacemaker at later date that will help the person lead a normal life.
5. The private gynaecologists' findings may not be cent per cent correct.

Medical reasons do not substantially support the finding that doctors will have to resort to termination of pregnancy' (*Sunday Times of India (TOI)* 3 August 2008).

The judge was not satisfied with this report. Justice P B Majmudar was quoted as saying:

We find contradictions in the report where a part states that there is not enough medical substance to justify a termination and in other parts, states that there is a fair chance that the child, if born, will be too incapacitated and handicapped to survive... (*TOI* 2 August 2008).

The medical team was asked to submit an additional report. In the second report the adverb 'fair' was replaced by 'least': but the report also said, 'It is the liberty of the patient to choose continuation of pregnancy after knowing reality' (*TOI* 5 August 2008).

In the light of the second report, the court observed, 'The J.J. report is clear that the child is not deformed. Once there is life, can you ask for it to be killed now? Is it any different from mercy killing?' (*ibid.*).

Eight days after the Bombay High Court rejected her petition to abort her foetus then in its 26th week, Niketa Mehta suffered a miscarriage. Newspapers

described this occurrence with such captions like 'Not allowed to abort, Niketa has miscarriage' and 'Court failed but God did justice' (*TOI* 15 August 2008).

In September 2008, the government of India announced that it was planning a re-examination of the MTP Act to bring it up to speed with changing realities a lingering suspicion in the public imagination that the abortion may have been induced.

### **Freedom of Choice or the Tyranny of Circumstances**

A few dissenting voices notwithstanding, the media reports adopted a pro-abortion stance in this case<sup>2</sup>. It was felt that Niketa Mehta had the right to choose to have a healthy child, since the state does not have a programme for supporting families that have special children. Besides, some provisions like an upper limit for abortion of the MTP Act were archaic, because due to advances in medical science, abortion after 25 weeks does not carry the same risks as it did earlier.

After the couple's petition was dismissed, an editorial in the Times of India summed up the general public perception as follows:

For the Mehtas, this is a very difficult time, and our heart goes out to them. It'll be everyone's prayer that the child is born without any serious complications and grows up healthy. If the baby is normal the Mehtas must not be blamed for seeking abortion – after all, they approached the court on the basis of medical evidence that suggested a congenital heart block. At least, they had the courage and the honesty to take the legal route instead of aborting illegally. The Mehtas, for their part, must now put the legal battle behind them and focus on what is ahead. There have been cases where children have been born out of extremely complicated pregnancies and gone on to lead normal lives. Also, advances in medical science bring new hope every day (*TOI* 5 August 2008).

A cursory review of the media representations of the case clearly testifies to the presence of the three arguments against prenatal testing set forth by disability rights advocates Erik Parens and Adrienne Asch (2000)<sup>3</sup>. In fact, no where were these positions more clearly expressed than by the petitioner herself. The expressivist argument states that prenatal testing reflects negative attitudes about people with disabilities. Niketa Mehta was quoted to have said: 'Of course I was excited about my first pregnancy. I still am excited. But I want a healthy baby. I want a normal baby' (*TOI* 3 August 2008).

Indeed, the undisputed acceptance of taken-for-granted notions of health and normality was one of the most disturbing features of the reportage. Consequently, disability remained an unpacked black box that had to be avoided instead of a state of being like any other with both positive and negative dimensions. There were no interviews soliciting the opinions of persons with disabilities and very few with parents with children with disabilities.

The parental attitude argument claims that choosing disability selective abortion signals a problematic conception of parenthood which is based on unconditional acceptance. In her interactions with the media, Niketa was careful to balance her acceptance of her child with an equally strong rationale for abortion. When told that some NGOs were willing to take care of the baby, she said:

I am not heartless. My child is not a burden. But it is less painful to end it now that to see your child in front of you. Our doctor said that the baby could have blocked and malpositioned arteries and it could prove risky. One of them even told us that there could be sudden death and the pacemaker surgery could be risky for a newborn (*TOI* 5 August 2008).

And yet, three days earlier when the court had asked for a second medical report, she had said:

I don't want to spend for the treatment of the child. We didn't expect this delay. The JJ Hospital committee has given a safe report. The issue here is of choice. (*TOI* 3 August 2008).

While not conforming to the maternalist assumption (what Ruddick (2000) defines as a perspective that when a woman wants a child, she should accept any child she gets); there were several negative assumptions in Niketa's perspective, namely that disabled persons cannot have a happy life, that parenting a disabled child is all pain and agony, that normality and health are critical goals striving for. Are these ideas the product of misinformation as Parens and Asch (2000) would opine? Would the Mehtas have considered changing their mind if they had been given more definitive information about the cardiac defect? It is not the intention of this paper to apportion blame but to highlight the extent to which apparently neutral positions are put forward to configure disability (and by extension persons with disabilities) as highly undesirable and required to be eliminated, wherever and whenever possible. Underlying these perceptions is an ideology of perfection and mastery of the self and the world.

And yet, the reasons put forward by the Mehtas for abortion carry a potent social logic. Economic barriers and values of freedom of choice and democratic

citizenship were seized upon by the couple in support of their decision. In her reaction to the court's negative ruling, Niketa burst forth:

It is as if we are a democracy (sic) but we don't have a right to choose about our own life. This fight has drained me mentally and emotionally. My parents and in-laws support us. But I will now have to stop working. We are not that rich to afford full time nannies. Finances will certainly be one concern. But what is disappointing is that we have been proven to be fools. We are educated fools. People in remote areas go to a quack for an abortion. The lesson here being sent out is "don't follow the law". We are being punished for being law-abiding citizens. (TOI 5 August 2008).

While the credo of free choice was marshalled by the couple and a majority of the general public in support of the decision to abort, we know that free choice is an ideal like the ideal of perfection. Individual decision-making is a situated process, highly context dependant and influenced by the web of social relationships (Gilligan 1982; Rapp 1999). Personal circumstances, including ethnic, class, residence, forms of privilege and disadvantage frame these choices. Niketa's decision was very much influenced by her middle-class location as a schoolteacher living in a Mumbai suburb with her elderly in-laws.

While it is difficult to disentangle the intricate connections between developments in medical technology, global capitalism and increasing individuation, there is no doubt that these factors are generating a different notion of personhood in the Indian context, particularly in urban areas. A socio-religious ethos steeped in fatalism is now being replaced by a vision of life and the world that refuses to accept the uncontrollability of events.

### **Disjunctions between Law and Medicine**

Among a litany of drawbacks, the Indian legal system is accused of being one of the most regressive in the world. While the Indian Constitution guarantees right to life (but not the right to decide when to end one's life) and liberty, the Indian Penal Code criminalises suicide and homosexuality. The Medical Termination of Pregnancy Act 1971 and the Pre-Conception and Prenatal Diagnostic Techniques (Prohibition of Sex Selection) Act (PCNDT) 1994 both conditionally permit abortion on grounds of disability. The Mehtas and their gynaecologist challenged the MTP Act of 1971 asking that a provision be made to allow abortion beyond 20 weeks not just when the pregnant woman's life is at risk (section 5), but also when the

newborn may have a severe congenital mental or physical disability. Section 3 of the MTP Act allows for abortion between 12 and 20 weeks, if the baby's health is at risk after two doctors certify the condition 'in good faith'.

An internal contradiction marked the Mehtas litigation: they sought amendment to an existing legislation but amending laws is the function of the legislature (and it is a long drawn out process) not of the judiciary. Running a race against time, they hoped that medical evidence would be sufficient for their case to be treated as an exception under the existing legislative regime, because judicial interpretation involves reading into laws in order to gauge their full intent. So, when their petition was declined, they did not make an appeal to the Supreme Court. But the medical evidence itself became a bone of contention that went against them. Not only was there a difference of opinion between the private practitioners' reports that the Mehtas placed before the court but there were patent contradictions between the two reports submitted by the JJ Hospital medical team, as also disagreement among the different specialists appointed by the court. But as many researchers have pointed out genetic information is always incomplete. According to Sarah Franklin (2003), it is partial – in both senses of being already imbued with presumptions and always incomplete in scope. In an earlier paper on judicial intervention in the context of the 1996 outbreak of dengue haemorrhagic fever in Delhi (India), Adlakha (2001) has shown that when faced with a threat to its integrity, different organs of the state like the legislature, judiciary and bureaucracy (including the public health system) maintain equilibrium by closing ranks. This could be another reason for the ambiguity found in the medical reports.

## **Discussion and Conclusion**

The proliferation of medical technologies, the development of the disability movement within a human rights paradigm and the contested discussions around abortion have all contributed to the debate around prenatal testing sparked by the Mehta's petition.

Sex selective abortions in favour of the male child have proliferated illegally in India to the extent that the juvenile sex ratio is skewed (Government of India 2001). Patriarchal structures ensure that in most cases women willingly opt for abortion after learning through ultrasonography that they are carrying a female foetus. The profit margins are so alluring that radiologists and gynaecologists have developed ingenious methods to bypass the law. In a society where parents can use prenatal technology without compunction to prevent the birth of female

children even when it is against the law, how can we expect that disabled fetuses will not be aborted, especially when the law is itself biased against disability? The Mehta case, in fact, threw up an anomaly in the Medical Termination of Pregnancy Act and the Pre-conception and Prenatal diagnostic Techniques Act that allow the legal termination of pregnancies of disabled fetuses within a specific time limit. In Niketa's case, the heart anomaly could only be detected after the 20 weeks legal age for abortion. With advances in biomedicines, it is possible to detect more traits prenatally at different stages of the pregnancy. In fact, the battery of prenatal investigations proffered as routine tests is increasing manifold. And prenatal diagnostics makes no sense without the option of prenatal abortion.

Interestingly, most opponents of disability selection are pro-choice. India has fairly liberal abortion laws and the heated opposition between pro-life and pro-choice lobbies found in the West do not exist here. It is maybe because of such liberal laws that female foeticide has become so rampant. Does the right to abort a possibly disabled foetus come in conflict with the rights of the disabled? The pro-choice perspective would be that it does not because the foetus is not a person. It is the women's rights and choices that should be given precedence over that of the foetus (Madhiwalla 2008). Other disability rights advocates would say that allowing the abortion of a possibly disabled foetus already sends out a negative message about disability in society as something that is to be avoided at all costs. This, in turn, conflicts with other more positive messages that one may want to disseminate about persons with disabilities in general.

If people with all kinds of disabilities were socially integrated, then there would be no need for prenatal testing. Ironically, the case starkly highlights this point because the reasons put forward for abortion were not the risk to the health of the mother but to the possible consequences for the health of the child after birth<sup>4</sup> and the social consequences of having such a child on the family that are more socio-economic and cultural than medical in nature. And yet prenatal testing is not the solution to the elimination of disabilities (if indeed that is a realistic goal) either because accidents, environmental degradation, old age and other life contingencies account for a far larger number of disabilities. We know, however, that once a technology is commercially viable, whether it is prenatal testing, surrogacy or embryonic stem cell therapy, people will use it. Hence, regulation is the pathway for its ethical utilisation. In the case of prenatal testing, 'this presents a conflict between a genetic counselling ethic that values non-directiveness and a medical ethic that values eradication of disease' (Patterson and Satz 2002: 130). In India, we do not yet have a body of trained genetic counsellors. Doctors take on that function in the few genetic counselling centres

that exist, and doctors are perhaps one of the most biased sections of the population against disability.

We cannot escape the reality that the majority of people all over the world want healthy children. Although retrospectively research on life satisfaction of persons with disabilities and their families may show they lead more or less the same kind of lives as non-disabled persons and their families (Ferguson, Gartner and Lipsky 2000), most prospective parents would not willingly take on the extra work- physical, financial and care – that a serious disability may entail. Very positive autobiographical accounts of living with a disability and caring for a family member with a disability in Western societies testify to this (Berube 1996; Kent 2000; Kingsley and Levitz 1994). In the face of such complexity, we conclude with an unanswered (and perhaps ultimately unanswerable question) that others like Ghai and Johri (2008) have posed before us, namely, 'where do we draw the line?'

### (Endnotes)

<sup>1</sup> 1 lakh in Hindi is 100,000.

<sup>2</sup> Interviews by journalists with pregnant women and with parents of both children with and without disabilities showed overwhelming support for the Mehtas. One father of a child with a disability wrote:

We are parents of a special child and know the trauma parents, who have children with disabilities, go through. Our prayers are there for the brave Mehtas. A child with malfunctioning organs causes unlimited and cannot-be-explained tribulation. No human being or court shares the sufferings of the family. Broader discussions as well as rules are badly needed for 'mercy abortion' (TOI 6 August 2008).

<sup>3</sup> It is not as if there is a unanimous opposition to prenatal testing in the disability community. For instance, in the same volume Bailey (2000) and Kittay (2000) discuss why they would terminate a foetus with significant genetic disability; while Jennings (2000) strikes a pessimist note highlight the extent to which medical technology, market forces and parental choice are inextricably intertwined.

<sup>4</sup> The couple was reported to have refused to give up the child after birth to an NGO which offered to look after it. Haresh Mehta said that with the implantation of a pacemaker, there could be many complications He was reported to have said:

What if the surgery fails? It could get septic. The child will have a tough life. As it is life in Mumbai is such a struggle and so fast. The child would be at a disadvantage right from the start. How can the child travel? By train? We have thought it over a lot in the past few weeks. How can a mother and father watch their own child die, whether it is with us or anyone else? That is why we said no to the NGO (TOI 4 August 2008).

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**Commentary: C.W.P. No. 8760 of 2009 in the Punjab and Haryana High Court (Chandigarh Administration versus Nemo) and Civil Appeal No. 5845 of 2009 in the Supreme Court of India (Sucheta Srivastava and Anr versus Chandigarh Administration)#**

The reader is familiar with details of this landmark case: in the first instance, the Chandigarh Administration petitions the Punjab and Haryana High Court (HC) to terminate the pregnancy of a 19-20 years old unmarried, mildly/moderately mentally retarded orphaned, pregnant woman residing in a state-run institution for the mentally challenged in Chandigarh. The HC in its orders dated 9<sup>th</sup> June and 17<sup>th</sup> July 2009 permits termination. Subsequently, the young woman petitions the Supreme Court (SC) through her advocate, Ms. Tanu Bedi, to be allowed to continue with her pregnancy against the order of the HC. Due to the urgency of the situation requiring a decision before the statutory 20 week limit of legal abortion, the SC passes an order immediately in favour of the petitioner to continue with the pregnancy.

The case has opened up an unprecedented discussion on the reproductive rights of persons with disabilities. Existing disability legislation, such as the Persons with Disabilities (Equal Opportunities, Full Participation and Protection of Rights) Act, 1995 addresses issues of prevention of disabilities, medical rehabilitation, education and employment and the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 focuses on guardianship issues. During the past few years a handful of researchers and activists in the disability rights movement, such as Renu Addlakha (2004, 2005a, 2005b, 2007a, 2007b, 2008 and 2009) Anita Ghai (2003), Kuhu Das (2009) and Shampa Sengupta (2008) among others have initiated discussions on this issue. The Convention on the Rights of Persons with Disabilities (CRPD 2006) and its Optional Protocol, which India signed and ratified in 2007, have created the legal space for engagement with the whole range of issues around disability, including sexuality and reproductive health that were hitherto invisible

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in public discourse. Furthermore, it is now binding on India to make existing legislation compliant with the CRPD. It is against this backdrop that the present commentary should be read.

Underlying the legal proceedings of this case is a strong ideology of genetic determinism, moral conservatism and normalisation in the articulation of notions of motherhood, family and childhood. The petitioner was considered incapable of producing a normal healthy baby because of her anatomical and mental deviations. As the report of the First Medical Board constituted by the Punjab and Haryana HC, which the court endorsed, stated:

4. Continuation of the pregnancy in this case can be associated with certain complications considering her age, mental status and previous surgery. There are increased chances of abortions, anaemia, hypertension, prematurity, low birth weight babies foetal distress and more chances of operative delivery... ( Punjab and Haryana High Court. C.W.P. No. 8760 dated 9 June 2009).

Even if the baby was without disease and disability, her capability to parent was summarily dismissed because, as the same medical reported, said:

5. Being mildly mentally retarded, she is unable to look after herself and cannot fend for herself if left to her own devices. She was aware that there is a child inside her, although she had absolutely no idea how it came to be there. She cannot mother a child. Motherhood is not only holding the child but it is a complex relationship which is beyond her capability and comprehension. (ibid.).

Furthermore, if allowed to proceed with the pregnancy, the petitioner would carry the identity of an unwed mother and the child would be an illegitimate child who, in addition to having a mentally retarded mother, would end up growing up in a dilapidated environment with other mentally retarded inmates in a state-run home. To make matters worse, the petitioner was herself an orphan with no social or financial support. Phrases like 'Pregnancy of an unwed mentally retarded girl' and '...this Court should avert the tragedy of a 'child' bearing another 'child...'' (*ibid.*) underscore the underlying prejudices.

All these factors 'logically' militate against having the child. And yet missing from this equation is the fact the medical boards and high courts, which claim the power of decision-making, are themselves the organs of an inert state: a state that vociferously claims to uphold human rights of its citizens but shows no

willingness to protect the most vulnerable among the vulnerable. The CRPD clearly affirms the right of persons with disabilities to a family and parenthood for which state parties are duty bound to provide the necessary assistance and resources. In the face of such apathy and indifference, one wonders what course the SC would have taken in the absence of a more or less literal reading of the amended<sup>1</sup> Medical Termination of Pregnancy Act (MTP), 1971 wherein the consent of a mentally retarded adult woman is essential for termination of her pregnancy before 20 weeks.

In the exercise of its *parens patrie* jurisdiction, the HC argued that an orphaned mentally retarded woman cannot be equated with one with legal guardians, parents and kin, and hence the issue of giving consent takes on a different hue. Consequently, the 9th June and 17th July orders rejected a literal reading of section 3(4) of MTP Act requiring the consent of a mentally retarded adult woman in the best interest of the ward. One can ask why the state could not in its *parens patrie* function challenge prevailing norms of marriage and the heteronormative family and put forward alternative ideas of care.

While biomedical knowledge is cloaked in a garb of facticity, variability in biomedical practice is taken for granted, which is why the opposing decisions of the two medical boards constituted by the Punjab and Haryana HC, did not come up for interrogation. While the first board recommended termination on grounds of substantial risk to the physical and mental health of the woman and the strong possibility of serious physical or mental abnormalities as to result in serious handicap in the child, the second board gave a more nuanced verdict. While it noted several health problems including the petitioner's positivity for the hepatitis B surface antigen (HBsAg), it did not categorically rule in favour of termination of the pregnancy. It opined:

Her physical status poses no major physical contraindications to continue the pregnancy. The health of the foetus can be monitored for any major congenital defects. Her mental state indicates limited mental capacity (intellectual, social, adaptive and emotional capacity) to bear and raise the child. Social support and care for both the mother and child is another crucial component. Therefore, any decision that is taken keeping her best interests as well as her unborn child has to be based on the holistic assessment of physical, psychological and social parameters. (Punjab and Haryana High Court C.W.P. No. 8760 dated 17 July 2009).

In its order of 17th July 2009, the HC directed termination of the pregnancy in the best interest of the petitioner in spite of the Medical Board's findings that the petitioner had expressed her willingness to bear a child and was physically fit to do so. Working from another set of premises, the Supreme Court stayed the order of HC primarily because termination of the pregnancy at this late stage (19 weeks) was not in the best interest of the petitioner. If she were a minor, then the welfare institution would be her guardian; and it could legally sanction abortion in her best interest, but since she was a major, her consent was vital. Taking cognizance of reproductive rights, it ruled that a woman's right to reproductive decision-making is a dimension of the fundamental right to liberty under article 21 of the Constitution. The SC ruling is path-breaking as it unequivocally endorses respecting the autonomy of mentally retarded persons in the area of reproductive choice.

There are those who would argue that since the petitioner was not provided with the necessary supportive assistance to arrive at giving an informed consent, it was unethical to force her to continue with the pregnancy considering she did not have a clear understanding of its consequences. But is it not also true that if this case had occurred in a family context, abortion would have been the automatic choice of the kin? This is not say that allowing the petitioner to continue with the pregnancy should be a test case to push for recognition of reproductive rights of mentally challenged persons, but the reality is that precedents arise out of unique situations: and when codified, they can have beneficial consequences in future judicial interpretations. In that sense, this case is a watershed development in disability jurisprudence in the country, which is still in its infancy (Addlakha and Mandal 2009).

It is hoped that the Supreme Court will monitor the National Trust for Welfare of Persons with Autism, Cerebral Palsy and Multiple Disabilities, which came forward to take responsibility for the welfare of the petitioner and her child during her lifetime. That will be the ultimate test of the Indian state's commitment to the overall well-being of its citizens with disabilities.

### **(Endnotes)**

<sup>1</sup> Amendment introduced vide Act No 64 of 2002 that though mental retardation may be incurable, yet the person has a fundamental right to be a part of the social mainstream. A mentally retarded woman above 18 years of age has the right of self-determination with regard to the continuation or otherwise of her pregnancy.

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