

Indian Journal of Gender Studies

<http://ijg.sagepub.com/>

Disability, Gender and Society

Renu Addlakha

Indian Journal of Gender Studies 2008 15: 191

DOI: 10.1177/097152150801500201

The online version of this article can be found at:

<http://ijg.sagepub.com/content/15/2/191>

Published by:



<http://www.sagepublications.com>

On behalf of:



[Centre for Women's Development Studies](#)

Additional services and information for *Indian Journal of Gender Studies* can be found at:

Email Alerts: <http://ijg.sagepub.com/cgi/alerts>

Subscriptions: <http://ijg.sagepub.com/subscriptions>

Reprints: <http://www.sagepub.com/journalsReprints.nav>

Permissions: <http://www.sagepub.com/journalsPermissions.nav>

Citations: <http://ijg.sagepub.com/content/15/2/191.refs.html>

>> [Version of Record](#) - Aug 13, 2008

[What is This?](#)

Disability, Gender and Society

RENU ADDLAKHA

The most recent addition in the well-established grid of categories of oppression such as class, caste and gender is disability. Although it has been an intrinsic element of the human condition since time immemorial, disability remained lost in the shifting terrain between other related concepts and experiences, namely, disease, impairment, illness and sickness. Today, it has emerged as a critical axis of oppression in its own right: indeed, the disability movement is perhaps the youngest civil rights movement the world over. The global recognition of disability is marked by the recent adoption of the Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol by the United Nations (UN) General Assembly on 13 December 2006. It is a major step towards according recognition to the needs and aspirations of the disabled population, which continues to be marginalised and stigmatised in most parts of the world. Till date over 100 members, including India, have signed it.¹ One of the highlights of the Convention is a separate article on women with disabilities. In light of these developments,² it is only apt that the *Indian Journal of Gender Studies* brings out a special issue on disability. The eight articles in

Acknowledgement: This special issue would not have taken shape without the commitment and co-operation of the *Indian Journal of Gender Studies*. I am especially grateful to Ms. Leela Kasturi for her insightful comments and painstaking editing of all the papers.

Renu Addlakha is Senior Fellow, Centre for Women's Development Studies, 25 Bhai Vir Singh Marg, New Delhi 110 001. E-mail: renu@cwds.ac.in.

Indian Journal of Gender Studies, 15:2 (2008): 191–207

SAGE Publications Los Angeles/London/New Delhi/Singapore
DOI: 10.1177/097152150801500201

this issue address a range of core concerns around disability, gender and society in the Indian context, such as the interface between the women's movement, the disability movement, civil society and the state, female embodiment, identity and disablement, prenatal testing, motherhood and caregiving.

But what is a disability and what does it mean to be disabled in the first place? Disabilities may be congenital, that is, from birth. For instance, most intellectual disabilities are congenital. Malnutrition, micronutrient deficiencies and infections may result in childhood disabilities, polio being the most obvious example. 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's Disease also fall in this category. A disability may be static, such as the loss of a limb due to an amputation. Then, there are hidden and visible disabilities, diabetes and epilepsy being a couple of examples, while leprosy and blindness are visible conditions. Disabilities may be temporary or permanent. A mild fracture may result in temporary disablement, while a spinal cord injury sustained in an automobile accident might result in a permanent condition. In addition, there are many gradations of disability, ranging from mild to severe.

A disability generally has two interconnected components—medical limitation(s) and social prejudice—which often get translated into discriminatory behaviour towards the person with a disability. In legal documents and policy statements, disability is defined in terms of what qualifies for public assistance. Keeping in view the sheer diversity of this overarching category, the CPRD includes within its ambit those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with physical, social and attitudinal barriers, may hinder their full and effective participation in society on an equal basis with others.

According to conservative estimates derived from the 2001 Indian census, 1.8 to 2.1 per cent of the population of 1.2 billion suffers from some form of disability, which in absolute numbers comes to 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 an identifiable physical or mental disability. That comes to over 70 million persons in India.³ Phenomena such as war, ethnic conflict, HIV/AIDS, natural disasters, industrial injuries and road accidents are increasing the number of persons with disabilities. Ironically, enhanced life expectancy has also increased manifold the incidence of age-related, chronic disease-induced disabilities worldwide.

The 2001 census estimates that there are over 9 million women with disabilities in India, constituting around 1.87 per cent of the population. Some researches put the number of women with disabilities in the country at over 35 million (Bacquer and Sharma 1997). Others put the figure at 20 million, 98 per cent of them being illiterate; less than 1 per cent can avail of health care and rehabilitation services (Action Aid 2003). The violation of rights of persons with disabilities through multiple physical, economic, health, educational, legal and attitudinal barriers are too well known to be repeated. Nonetheless, it will suffice to bear in mind that the impact of these barriers is magnified manifold when it comes to gauging the level of neglect, isolation, stigma and deprivation that characterise the lives of women with disabilities. The majority of women with disabilities in India suffer the triple discrimination of being female, being disabled and being poor. Indeed, not only are they a socially invisible category, but their plight is worse than that of men with disabilities and of non-disabled women.

Disability: A New Paradigm of Oppression

Political economy and historical contingency have intersected to give rise to a distinct discourse of disability in the latter half of the 20th century. After World War II countries in Western Europe, Japan and the United States were faced with the challenging task of rehabilitating a huge number of soldiers with disabilities. This historical necessity placed disability at the centre of social welfare policies in both Europe and the United States. The subsequent organisation of persons with disabilities themselves into a vibrant social movement, along the lines of the women's movement,

resulted in a redefinition of the concept not as personal tragedy requiring therapy, but as collective oppression necessitating political action (Oliver 1996). 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 environments to adapt to their needs and aspirations. As advocates of equal rights for persons with disabilities, these 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 and economic rights to which all citizens are entitled.

Internationally, however, the situation only started changing from the 1980s with the passing of specific UN declarations for the welfare of persons with disabilities.⁴ The year 1981 was declared the International Year of Disabled Persons. A World Plan of Action on Disabled Persons was adopted by the General Assembly in 1982, for the implementation of which the period 1983–92 was proclaimed as the United Nations Decade of Disabled Persons. In 1993 the General Assembly adopted the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities.⁵ The 1990s saw a spate of pro-disability legislation, beginning with the Americans with Disabilities Act 1990 and the Disability Discrimination Act 1995 in the United Kingdom, among others. The landmark UN Convention on the Rights of Persons with Disabilities appears to be the logical culmination of these developments. In the contemporary international political climate in which the UN plays a significant role in steering national policies and programmes, Amita Dhanda's analysis in this volume of the in-depth country-level discussions that went into arriving at a mutually acceptable approach for engendering the Convention is an intriguing case study of the development of international legal instruments. The 'twin track approach' that the Convention embodies attempts to both mainstream and provide special measures for ameliorating the lives of women with disabilities in the laws, policies and programmes of member states.

In India, however, the situation has been slow to change. Persons with disabilities are technically entitled to the same rights under the Indian Constitution as other citizens, and no discrimination is

allowed on grounds of disability. Even though the Constitution recognises socially disadvantaged groups, such as Scheduled Castes, Scheduled Tribes, religious and linguistic minorities, and even women and children, there is a total invisibility of the category of disability in constitutional provisions guaranteeing rights to individuals and groups. Disability is absent both from Article 15, which prohibits discrimination on grounds of caste, class, sex, religion and place of birth, and Article 16, which guarantees equality of opportunity in employment. So, while the idea of special rights accruing to groups derives from the constitutional framework that acknowledges group rights, there is no specific enumeration of disability (Addlakha 2007a).

Instead of giving rights to citizens with disabilities and empowering them, a culture of charity and welfare has been systematically promoted in India since the colonial period. Medical rehabilitation, distribution of assistive aids and appliances, special schools, and vocational training in low-end occupations and sheltered employment have been the pillars of state policy. Furthermore, electoral politics of caste and gender have pushed persons with disabilities 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, focusing on human rights and empowerment of marginal groups, impelled the Indian 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.

The impact of the international human rights movement and anti-poverty initiatives have turned in the issue of disability from one 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 into account, then social development in the true sense of the word has not taken place.

Disability is both a cause and a consequence of poverty. They reinforce each other, leading to increased vulnerability and exclusion. Poverty decreases the opportunities of persons with disabilities, further marginalises them, making it impossible for them to have access to the basic conditions of life like health, education, transportation and employment. For women with disabilities, there is the added burden of gender bias and discrimination. In this volume, Hans, Patel and Agnihotri show that allocating resources is not enough when social, political and cultural realities block access of persons with disabilities, and particularly of women with disabilities, to such resources. One of the important findings of their research is the steadily diminishing utilisation of resources in the disability sector in some of the poorest states of the country, like Orissa, Andhra Pradesh and West Bengal. Bad governance and lack of awareness of such programmes among persons with disabilities and their families are major reasons for this underutilisation. This trend does not bode well for the welfare of persons with disabilities, particularly women and tribal persons with disabilities.

Disability, Feminism and Eugenics

Disability has historically been conceptualised overwhelmingly in terms of biological abnormality or dysfunction necessitating medical intervention and rehabilitation. The medical model looks at the impairment as a personal tragedy, and at the individual through the lens of patienthood. Through self-advocacy by persons with disabilities, the concept of disability was redefined not as an individual affliction necessitating therapy, but as a form of social oppression necessitating political action. The social model of disability⁶ locates disability, which is viewed as an important dimension of inequality, in the social and economic structure and culture of the society in which it is found, rather than in the bodies of individuals with disabilities.

Despite the ideological vortex generated by the international women's movement and the emerging social model of disability during the 1960s and 1970s, women with disabilities continued to remain an invisible constituency. The body has been a key construct in feminism, but it was more often than not the able-bodied

perspective that dominated theory construction and advocacy work. It was mainly during the 1990s that the theoretical innovations and social activism of feminists with disabilities catapulted women with disabilities as a separate identity category. Consequently, it is only in the course of the past two decades that the masculine bias in disability theory has been questioned and the exclusion of women with disabilities from feminist theory and praxis highlighted, primarily by women with disabilities themselves (Corker 1999, 2001; Meekosha 2002; Morris 1991, 1993, 1996; Thomas 1999; Wendell 1996).

The beginnings of a critical feminist analysis of disability in a multidisciplinary perspective has been initiated in the Indian context by a number of feminist scholars like Renu Addlakha (1997, 1998, 1999, 2001, 2005, 2007a, 2007b), Bhargavi V. Davar (1999, 2001), Amita Dhanda (2000), Anita Ghai (1998, 2000, 2001, 2002a, 2002b, 2003) and Asha Hans (Hans and Patri 2003), among others. Historically, the Indian women's movement has focused on issues like poverty, caste inequalities, employment, social practices like *sati* and dowry, population policies and technologies, female foeticide, sexuality and domestic violence. But disability-based oppression did not feature in its agenda. Only very recently has the issue been raised in the movement from two distinct and apparently disconnected perspectives: first, the experiences of women with disabilities within the movement, discussed in this volume by Davar; and, second, sex-selective abortion, which is the theme of the joint article by Ghai and Johri.

In her autobiographical account of her engagement with the Indian women's movement over the past two decades, Bhargavi V. Davar delineates the tensions between a feminist politics of empowerment that seeks social transformation in gender relations and the personal experiences of distress of individual women in search of healing. Using the emerging concept of 'psychosocial disability', Davar feels that the disability paradigm offers both theoretical validation and strategic opportunities for making understandable and conferring legitimacy on women's experiences of mental distress and illness. Her discussion is framed within a political economy of women's mental health promoted by the medical profession and pharmaceutical industries.

Again, while women's mental health and distress were explored even earlier (Davar 1999, 2001; Dhanda 2000), women with physical or sensory disabilities did not find a separate discursive space in the Indian women's movement. While Dalit women, women workers, agricultural labourers, and minority status groups have been highlighted as marginalised groups, women with disabilities are only now being recognised as a distinct marginal category. The use of genetic screening for aborting fetuses with disabilities does not feature in female foeticide and infanticide debates, which have been critical pillars of the movement. This is a serious lacuna. Anita Ghai (2002a, 2002b) points out that the reason given for such exclusion by representatives of the movement is the non-participation of women with disabilities in advocacy. But the same invisibility that marks their lives in their families and the community has prevented them from taking part in meetings and other activities. To say that their invisibility is the cause of their non-participation reflects a lack of understanding of the existential reality of their lives, wherein moving out of the home and using public transport are painful and difficult goals often beyond their reach. On the other hand, we know that choice of issues in advocacy is dependent on needs and priorities of participants; and a simple majoritarian logic operates in such selection processes.⁷

While the invisibility of women with disabilities in the male-dominated disability movement is, to some extent, understandable, their absence from the women's movement cannot be so easily overlooked. Women with disabilities did not figure in international conventions and policies till the Beijing Declaration (Platform of Action) of 1995, which clearly mentions women with disabilities as one of the groups facing barriers and suffering violations of basic human rights. Even in the case of abortion debates within the women's movement, the right to survival of fetuses with disabilities has not been brought into discussion. Ghai and Johri, in this volume, show that the pro-choice stance, promoting antenatal testing for elimination of defective fetuses, feeds into prevailing notions of bodily perfection. Drawing upon arguments of free choice in the context of female foeticide and disability selection, the authors question the uncontested abortion of fetuses with disabilities, a practice that is not only legitimised by the dominant

medical and legal discourses but is also accepted by the women's movement in India. Drawing upon testimonies of mothers of children with disabilities and of young women with disabilities in Delhi, Ghai and Johri make a case for a more nuanced understanding of the disability experience and the importance of diversity in social life. Indeed, the real tussle between the medical and social models of disability is illustrated by predictive eugenic testing. Medical definitions of disability collide with socially-based value judgements of flaw and perfection, and the unequal distribution of material resources to manage differences.

Anatomy is not destiny. It is inconsistent with a feminist ethic to eliminate a category of persons who do not fit into the socially constructed (oppressive) categories of normal, healthy and fit. This argument is also forcefully articulated by Mehrotra and Vaidya in their discussion of the emasculation of the intellectually challenged male in this volume. Combining multiple data sources (historical, anthropological and medical) with ethnographic fieldwork in NGOs working with the intellectually challenged in Delhi and in the neighbouring state of Haryana, the authors explore the ecological, cultural and gendered underpinnings of competent personhood. The fact that the intellectually challenged are more socially integrated in the rural areas of Haryana than in the urban landscape of Delhi undercuts any attempt to universalise norms of intelligence and competence that are not context-specific. In the face of declining extended family structures, the authors highlight the need for greater NGO participation in caregiving activities in the disability sector, especially for adults with severe intellectual disabilities.

Despite some omissions and points of contention, feminist disability activists also share the basic premises of feminism in general, such as questioning the validity of universalising norms, challenging the politics of appearance and naming, and actively working towards the creation of positive identities. As Carol Thomas (1999: 28) points out: 'forms of disabilism⁸ are refracted in some way through the prism of gendered locations and gender relations'. Feminists and disability advocates are both opposed to a norm assumed to be innately superior; patriarchy and ableism⁹ are the ideologies that they oppose, respectively. Then, in keeping with

the credo of plurality, heterogeneity and identity politics of feminism, feminist disability studies, challenge, not only the universal category of woman, but also the unitary category of woman with a disability.

Care Work and Caregiving

The family has been the major caregiving institution in society, providing ongoing care to its dependent, ailing and disabled members, be they children, the elderly, the chronically ill or the disabled (Shelton and John 1996). Intra-familial division of caregiving labour is a gendered phenomenon in which the primary caregiver is a woman (Coward et al. 1992; Dwyer and Coward 1992; Horowitz 1992; Pavalko and Woodbury 2000). The costs and rewards accruing to the carer vary depending on the duration and nature of care work and the availability of resources. Caregiving may be temporary or long-term. Even though long-term caregiving involves the participation of all family members sharing a common residence in various ways, the bulk of daily care work falls more often than not squarely on the mother (even extending to her natal family) or other female member for whom it is a lifelong 'career' (Aneshensel et al. 1995). Chronic psychological stress is a necessary aspect of the subjective experience in the latter case (Schulz et al. 1990; Schulz and Williamson 1991), often accompanied by adverse health outcomes (Pavalko and Woodbury 2000).

Caring for adult persons with disabilities further complicates the relationship. Issues central to care work and caregiving in the Indian context are raised from different perspectives in this volume by Mehrotra and Vaidya, and by Chakravarti. While Ghai and Johri look at parental rights, parental choice and parental autonomy, Mehrotra and Vaidya, and Chakravarti, examine parenting through the lens of ongoing caregiving in a social context where the entire responsibility is squarely put on the family.¹⁰ The non-availability of state-sponsored support and limited family resources for the care of members with disabilities also highlight another important issue, namely, that it is not just individual medical care that persons with disabilities require, but families also require a range of support services to be able to successfully care for a member with a

disability. Families, require, not only material resources but also continual psychological support, as highlighted by Chakravarti's interviews with mothers of young adults with cerebral palsy. Many issues germane to their day-to-day lives, such as feelings of anger and helplessness, apprehensions about the child's future, especially after the death of the primary caregiver, and religious faith, are discussed. Unfortunately, these concerns are invisibilised by society and the resulting personal and social suffering and ignored.

Self-affirmation and Assertion of Difference

Identity politics is epistemology inextricably tied to praxis. The underlying ideas are that some social groups are oppressed; that one's identity as a woman or as a person with a disability makes one peculiarly vulnerable to cultural imperialism (including stereotyping, erasure or appropriation of one's group identity), violence, exploitation, marginalisation and powerlessness (Young 1990). Identity politics not only involves a common group experience of injustice and a collective effort (in the form of a social movement) to overcome the common oppression, it also involves cultivating a sense of pride and reclaiming a positive identity. The second half of the 20th century has seen the emergence of large-scale political movements—black civil rights in the US, second wave feminism, gay and lesbian liberation, and, more recently, the disability movement.

A prime example of the success of the disability–identity–politics paradigm is in what has come to be called 'Deaf studies' (Breivik 2005; Ladd 2003; Lane et al. 1996). Working on the boundary between deafness (with a small d) defined as a medical condition with disabling social consequences, and Deafness (with a capital D) referring to a linguistic and cultural minority group, Michele Friedner makes a strong case for engendering Deaf studies in this volume. Her interviews with members of the Delhi Foundation of Deaf Women help her examine how discursive flows contribute to the constitution of (D)deaf identity in a context where ideas and resources flow from the global North to the global South.¹¹ How do deaf women belonging to a lower socio-economic urban context negotiate with such concepts as Deaf culture and Deaf

identity? Friedner comes to the conclusion that culture plays a critical role in their construction of selfhood. The universality and cultural neutrality underlying Deaf Studies are challenged by their privileging of their kinship identities over all other identities (including Deafness). This transcultural investigation of deafness also alerts us to the dangers of a culture-blind acceptance and application of identity politics, perspectives and paradigms generated in specific politico-economic and socio-cultural contexts.

While Friedner looks at Deaf identity in the context of global flows and transnational discourses, Sandhya Limaye presents two detailed case studies of hearing-impaired adolescent girls in Mumbai in this volume. Framing her discussion in the context of the developmental tasks of adolescence,¹² she shows how Radha and Hasina challenge the discrimination and marginalisation meted out to them by their families, teachers and the wider society. They attempt to exercise autonomy by choosing life partners, planning careers and forging social lives that contest the notion of deaf persons as secluded and dependent. These adolescents' efforts at self-affirmation notwithstanding, the gap between being deaf and being Deaf is starkly brought out in the articles by Limaye and Friedner respectively. For instance, the emphasis on oral communication in the case studies of Limaye, as against the use of sign language among Friedner's informants, highlights the differences between hearing impairment, embedded in the medical model of disability, and Deaf pride, deriving from the social model of disability.

A Note on Terminology

As language is a key tool of oppression, naming is critical when a socially disadvantaged section of the population seeks recognition and rights. Analysis of key linguistic terms and the replacement of pejorative with more value-neutral and positive terms are essential preliminary steps in any movement towards collective self-affirmation and empowerment. The disability movement has promoted a move away from a language of handicap towards a more empowering language that emphasises self-determination and personhood. In the American context, this 'people first' language approach (Vaughan 1993) has given rise to the use of the term

'person with disabilities'. On the other hand, due to the impact of the social model that emphasises structural and attitudinal barriers as a source of oppression lying outside the individual, 'disabled person' has become more common in Britain. In the Indian context the tendency is to use a mix of terms like 'differently-abled', 'challenged', 'person with a disability' and 'child with special needs' in media reports and by disability activists.

No attempt has been made in this volume to standardise terminology about disability across the different articles. Choice of language is not just about political correctness, but more about reality construction. Hence, when such terms as 'madness', 'impaired person' and 'handicapped person', regarded as inappropriate if not downright stigmatising, have been used by authors, they have not been edited because they carry a semantics that might have been erased had they been replaced by other, more politically correct substitutes.

In conclusion, it is hoped that this special issue of the *Indian Journal of Gender Studies* on disability, gender and society contributes to situating disability within mainstream research and advocacy in the Indian context. The articles address different aspects of disability, raise complex questions, and make a case for culture, class/caste and gender-sensitive interdisciplinary and multidisciplinary research. They lay the foundation for beginning a serious engagement with disability studies in the academy and in public policy in this country.

Notes

1. Interestingly, the United States has not yet signed the CRPD. As far back as 2003, it declared that it would not be a party to the proposed Convention on Disability. Some of the reasons put forward were that disability measures should be a matter of domestic policy, and that the US already has a comprehensive set of such measures, precluding the need for adopting an international convention.
2. Prior to the CPRD, the Ministry of Social Justice and Empowerment, Government of India, responsible for policies and programmes for persons with disabilities, released the National Policy for Persons with Disabilities on 10 February 2006. The policy document has a set of recommendations to improve the lives of women with disabilities.

3. 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 disabling conditions.
4. 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 to basic human rights like everyone else, but they also have special rights corresponding to their special needs in medical, educational and social fields. In 1975 the Declaration on the Rights of Disabled Persons was adopted, which proclaimed equal civil and political rights for persons with disabilities.
5. These rules were aimed at facilitating the development of national disability programmes of member states. These standards provide a scheme to address the needs of persons with disabilities in accordance with the principles of human equality, dignity and respect. They deal with the provision of medical services, education, employment and social security, etc.
6. As against the medical model, the social model of disability asserts that material barriers, social prejudice and exclusion define who is disabled and who is not in a particular society. While some people have physical, intellectual or psychological differences from a statistical norm, these do not have to lead to disability unless society fails to accommodate and include them in the way it would those who are 'normal'. The term 'social model of disability' was put forward by the disabled British academic Mike Oliver in 1983. Subsequently, it was extended and developed by other academics and activists in the UK, the US and elsewhere.
7. Ironically, the forced hysterectomies of inmates of a home for the mentally disabled in Pune district of Maharashtra, India, in 1994 did not elicit any response from the disability movement in India, which, as Ghai (2003) points out, has continued to be the preserve of elite men with disabilities. It did, however, ignite a debate around disability in the women's movement and the medical profession in the country, but it was a fleeting engagement that ended as abruptly as it began.
8. Disablism may be defined as discrimination on grounds of disability.
9. The obverse of disablism is ableism, which is discrimination in favour of the able-bodied.
10. Although disability pensions and other minimal welfare measures are provided to persons with disabilities by the state in an ad hoc way, there is no assistance to families caring for an adult with disabilities.
11. Many disability activists feel that the minority view predominates in the international disability movement, that is, the perceptions and experiences of disability prevailing in the Western world (Priestly 2001; Stone 1999). As Majjet points out: 'If one looks at the [disability] agenda, we can ask who sets the agenda globally for human rights. My impression and humble opinion, is that this agenda is very much set by the North and that we need to take issue with that' (cited in Priestly 2001:3). While the focus in the South is more on

nutrition, education, employment and other issues of survival, in the North independent living services, assistive technologies, leisure and recreation are regarded as of prime importance because issues of basic survival have been taken care of. Disability studies privilege the minority world-view since the theoretical perspectives and empirical data largely come from accounts in Western Europe and North America, which comprise a minority of the total world population of persons with disabilities.

12. The reference is to the psychosocial development theory put forward by the psychoanalyst Erik Erikson (1982). This theory describes eight developmental stages from infancy to late adulthood through which a healthy developing human being should pass. At each stage new challenges have to be mastered before the individual can pass on to the next stage. Adolescence is one of the critical developmental stages involving a distinct set of developmental tasks.

References

- Action Aid. 2003. *Just People—Nothing Special, Nothing Unusual*. Bangalore: Books for Change.
- Addlakha, R. 1997. 'The Marginalisation of Gender in Mainstream Psychiatric Theory and Practice', *Indian Psychologist*, 1(2): 9–15.
- . 1998. 'Nisha: Who Would Marry Someone Like Me?' in A. Bhaiya and L.F. Lee (eds.), *Unmad: Findings of a Research Study on Women's Mental and Emotional Crisis: The Voice of the Subject*, pp. 60–73. New Delhi: Jagori.
- . 1999. 'Living with Chronic Schizophrenia: An Ethnographic Account of Family Burden and Coping Strategies', *Indian Journal of Psychiatry*, 41(2): 91–95.
- . 2001. 'Lay and Medical Diagnoses of Psychiatric Disorder and the Normative Construction of Femininity', in B. V. Davar (ed.), *Mental Health from a Gender Perspective*, pp. 313–333. New Delhi: Sage Publications.
- . 2005. 'Affliction and Testimony: A Reading of the Diary of Parvati Devi', *Indian Journal of Gender Studies*, 12(1): 63–82.
- . 2007a. 'Gender, Subjectivity and Sexual Identity: How Young People with Disabilities Conceptualise the Body, Sex and Marriage in Urban India'. Occasional Paper No. 46, Centre for Women's Development Studies, New Delhi.
- . 2007b. 'How Young People with Disabilities Conceptualise the Body, Sex and Marriage in Urban India: Four case studies', *Sexuality and Disability*, 25(3):100–113.
- Aneshensel, C.S., L.I. Pearlin, J.T. Mullan, S.H. Zarit and C.J. Whitlatch. 1995. *Profiles in Caregiving: The Unexpected Career*. San Diego: The Academic Press.
- Bacquer, A. and A. Sharma. 1997. *Disability: Challenges vs Responses*. New Delhi: Concerned Action Now.
- Brevik, J.K. 2005. *Deaf Identities in the Making: Local Lives, Transnational Connections*. Washington, DC: Gallaudet University Press.

- Corker, M. 1999. 'Differences, Conflations and Foundations: The Limits to Accurate Theoretical Representations of Disabled People's Experience', *Disability and Society*, 14(5): 627–42.
- . 2001. 'Sensing Disability', *Hypatia*, 16(4): 34–52.
- Coward, R.T., C. Horne and J.W. Dwyer. 1992. 'Demographic Perspectives on Gender and Caregiving', in J.W. Dwyer and R.T. Coward (eds.), *Gender, Families and Elder Care*, pp. 18–33. Newbury Park, CA: Sage Publications.
- Davar, B. 1999. *Mental Health of Indian Women: A Feminist Agenda*. New Delhi: Sage Publications.
- . (ed.). 2001. *Mental Health from a Gender Perspective*. New Delhi: Sage Publications.
- Dhanda, A. 2000. *Legal Order/Mental Disorder*. New Delhi: Sage Publications.
- Dwyer, J.W. and R.T. Coward. 1992. 'Gender and Family Care of the Elderly: Research Gaps and Opportunities', in J.W. Dwyer and R. T. Coward (eds.), *Gender, Families and Elder Care*, pp. 3–17. Newbury Park, CA: Sage Publications.
- Erikson, E.H. 1982. *The Life Cycle Completed: A Review*. New York: W.W. Norton and Company.
- Ghai, A. 1998. 'Living in the Shadow of My Disability', *The Journal*, 2(1): 32–36.
- . 2000. 'Towards Understanding Disability', *Psychological Studies*, 45(3): 145–49.
- . 2001. 'Marginalisation and Disability: Experiences from the Third World', in M. Priestly (ed.), *Disability and the Life Course: Global Perspectives*, pp. 26–37. Cambridge: Cambridge University Press.
- . 2002a. 'Disabled Women: An Excluded Agenda of Indian Feminism', *Hypatia*, 17(3): 49–66.
- . 2002b. 'How Indian Mythology Portrays Disability', *Kaleidoscope*, 45(1): 6–10.
- . 2003. *(Dis)Embodied Form: Issues of Disabled Women*. Delhi: Shakti Books, Haranand Publications
- Government of India. 2001. *Census of India*. New Delhi: Director General of Census.
- Hans, A. and A. Patri (eds.). 2003. *Women, Disability and Identity*. New Delhi: Sage Publications.
- Horowitz, A. 1992. 'Methodological Issues in the Study of Gender within Family Caregiving Relations', in J.W. Dwyer and R.T. Coward (eds.), *Gender, Families and Elder Care*, pp. 132–50. Newbury Park, CA: Sage Publications.
- Ladd, P. 2003. *Understanding Deaf Culture: In Search of Deafhood*. Clevedon, UK: Multilingual Matters.
- Lane, H., R. Heifmeister and B. Bahan. 1996. *Journey into a Deaf World*. San Diego: Dawn Sign Press.
- Meekosha, H. 2002. 'Virtual Activists? Women and the Making of Identities of Disability', *Hypatia*, 17(3): 67–88.
- Morris, J. 1991. *Pride and Prejudice: Transforming Attitudes to Disability*. London: The Women's Press.
- . 1993. 'Feminism and Disability', *Feminist Review*, 43(1): 57–70.
- . (ed.). 1996. *Encounters with Strangers: Feminism and Disability*. London: The Women's Press.

- Oliver, M. 1983. 'The Individual and Social Models of Disability'. Paper presented at the Joint Workshop of the Living Options Group and the Research Unit of the Royal College of Physicians on People with Locomotor Disabilities in Hospitals, University of Leeds, Leeds.
- . 1996. *Understanding Disability: From Theory to Practice*. London: Macmillan.
- Pavalko, E.K. and S. Woodbury. 2000. 'Social Roles as Process: Caregiving Careers and Women's Health', *Journal of Health and Social Behaviour*, 41(1): 91–105.
- Priestly, M. 2001. 'Introduction: the Global Context of Disability', in M. Priestly (ed.), *Disability and the Life Course: Global Perspectives*, pp. 3–14. Cambridge: Cambridge University Press.
- Schulz, R., P. Visintainer and G.M. Williamson. 1990. 'Psychiatric and Physical Morbidity Effects of Caregiving', *Journal of Gerontology: Psychological Sciences*, 45(5): 181–91.
- Schulz, R. and G.M. Williamson. 1991. 'A 2-Year Longitudinal Study of Depression among Alzheimer's Caregivers', *Psychology and Ageing*, 6(4): 569–78.
- Shelton, B.A. and D. John. 1996. 'The Division of Household Labour', *Annual Review of Sociology*, 22: 299–322.
- Stone, E. (ed.). 1999. *Disability and Development: Learning from Action and Research on Disability in the Majority World*. Leeds: Disability Press.
- Thomas, C. 1999. *Female Forms*. Buckingham: Open University Press.
- UN. 1995. 'Fourth World Conference on Women: Action for Equality, Development and Peace'. Beijing, China, <http://www.un.org/womenwatch/daw/beijing/platform/>, accessed 4 December 2007.
- Vaughan, C. 1993. 'People First Language: An Unholy Crusade', *Braille Monitor*, 36(8): 868–70.
- Wendell, S. 1996. *The Rejected Body: Feminist Philosophical Reflections on Disability*. London: Routledge and Kegan Paul.
- Young, I.M. 1990. *Justice and the Politics of Difference*. Princeton: Princeton University Press.