

## **DEVELOPMENTAL ARTICLES**

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### **TRANSITIONS TO ADULTHOOD FOR YOUNG PEOPLE WITH DISABILITIES IN INDIA: CURRENT STATUS AND EMERGING PROSPECTS**

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#### ***ABSTRACT***

*In 2001, it is estimated that 270 million Indians belonged in the 12-24 years age group. While attention is being focused on these young people's potential for social transformation, some of them - such as those with disabilities - remain alienated from mainstream debates on development. It may be estimated that there are somewhere between 5 and 5.5 million persons with disabilities in the 12-24 years age group, hence, a significant minority. However, little is known about how they and those around them make sense of their lives and perceive their transitions to adulthood, as their surrounding milieu is transformed. This paper adapts the framework of transitions proposed by the World Bank's 'World Development Report 2007', to examine opportunities for young people with disabilities in the areas of learning, work and citizenship. The authors draw on existing literature and secondary data to analyse the lived experiences of young people with disabilities. What are their prospects in a time of optimism for Indian youth?*

#### **INTRODUCTION**

##### **Optimism of the 'youth bulge'**

Collective identity and action necessitate points of inclusion, but conditions of poverty, disability, delinquency, disease and conflict, with their accompanying features of lack of access to food, health care, education, employment, media, markets and political institutions, serve as points of exclusion of young people (1).

The World Development Report 2007 (2), (Development and the Next Generation is only the latest of several reports [ for example, those listed in (1)] that appear to bring a typically

neo-liberal approach to their attempts to bring ‘youth’ into mainstream development concerns. There has never, says WDR 2007, been a better time to invest in young people living in developing countries. Of the 1.5 billion people in the 12-24 years age group worldwide, 1.3 billion are living in developing countries, the most ever in history. WDR 2007 points out with great enthusiasm to this ‘window of falling dependency rates’: an expanding work force that has fewer children and elderly to support, thus providing the opportunity to spend on developing human capital. The arguments here are not merely economic (though that remains an important imperative), rather the need to invest in the young is essential as they are the next generation of parents and heads of households, with significant ability to impact and shape the lives of their children.

Youth also have a political potential, however, one that is addressed ambivalently: Herrera notes that there is ‘mounting awareness of the potential roles of young people in forging more stable, democratic and economically prosperous societies’, while also acknowledging them as potential ‘forces of instability, radicalism, and impoverishment’ (1). Herrera points out the issues highlighted by the emerging new global discourse on youth, and more significantly, to those it leaves hidden. In this paper the authors wish to draw attention to one of these in particular – the lives of young people with disabilities – through considering the case of India in some detail.

India is one of the countries with a low dependency window of opportunity, where only 7.1 percent of the population is 60 years and above (3). Approximately 51 percent of its population of 1.1 billion is under 25 years and two-thirds is under 35 years. In India, the euphoria around generation X is evident in reports suggesting that it is the driver behind the retail boom, providing a large proportion of the new consumers of the technology revolution (4).

In general, it is argued that while attention is focused on young people’s potential contribution to social transformation (both positively and negatively), some young people – such as those with disabilities – remain alienated from mainstream debates. Consistently across the globe, especially in developing countries, mainstream policies and programmes working with young people overlook the needs of those with disabilities, while efforts aimed at people with disabilities tend to focus either on children or adults. Thus the unique social, psychological and physiological concerns of young people with disabilities tend to go unaddressed. Young people with disabilities ‘are among the neediest and most overlooked

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of all the world's children' (5) and are subject to a double marginalisation, being overlooked in the literature and policies focused on youth, as well as in literature and policies addressing issues related to people with disabilities.

The Biwako Millennium Framework for Action highlights the gravity of the situation by noting that, 'persons with disabilities, and especially women, youth and those in rural areas, remain disproportionately undereducated, untrained, unemployed, underemployed and poor' (6). The vulnerability of those living in poverty is especially marked, as 'disability is both a cause and consequence of poverty' (7). The poor are more likely to be disabled by impairments that are preventable or treatable (8). Additionally, a higher proportion of people with disabilities are likely to experience severe and chronic poverty than the proportion of non-disabled people (9), in both developed and developing countries.

The global total for adolescents and young adults with disabilities is between 90 million and 180 million, 85 per cent in the developing countries (10). Significant increases in their numbers are predicted over the next few decades, not just reflecting the increasingly youthful age structures in developing countries, but also because medical advances allow those who might not have been able to do so earlier, to survive, and all people with disabilities to live longer lives. Young people are also at a greater risk of acquiring a disability due to work related injuries, risk taking behaviour such as extreme sports, motor vehicle accidents, experimentations with drugs, unprotected sex, and indeed through violence and warfare. Global and regional estimates of the injury-specific causes of disability are lacking, but some estimates suggest that up to one quarter of disabilities may result from injuries and violence, though studies on violence-related injuries that result in disability are poorly documented (11). Evidence from developed countries suggest that the incident rates of spinal cord injury are high (12), especially amongst those aged between 15 and 24 years (13).

On one hand, the lifestyles of rising numbers of affluent young people in developed and developing countries may contribute to additional accidents and injuries, leading to impairments. On the other hand, in developing countries poor immunisation regimes, growing numbers of under nourished children and the spread of avoidable infectious diseases contribute to increasing numbers of young persons with disabilities.

A UNICEF (1999) report uses vignettes of experiences of youth with disabilities across the globe, to highlight their lack of participation in education, employment, their increased risk of substance abuse, sexual exploitation, social isolation, prejudice and inappropriate care (5). It raises significant concerns regarding the opportunities available for participation and development of capabilities and the resultant transitions that young people with disabilities make into adulthood.

Focusing on transitions is important, because it is more than just an administrative point or a biological marker, rather, the ‘transition process implies changes in status, both in how we see ourselves as well as how others see us’ (14). Cultures have different rituals and rights to mark the passage of time - and grant rights and place responsibilities- to give a sense of direction and purpose to life. These markers vary, for instance different cultures emphasise different degrees of autonomy and relatedness. While in some countries, young adults moving out of the family house is essential, in others young adults taking on greater care and responsibilities is desirable.

Dee regards transition as a process and uses three complimentary perspectives to examine it: (1) phase-related model, which regards transition to adulthood as one of a number of stages through which individuals pass through a lifetime, such as paid employment, granting of legal and civil rights, friendships and family roles and responsibilities; (2) agency-related model, which reflects the degree of agency or control that a person has in determining the course of their lives; finally, (3) time-related model, which states that development is more than getting older (14). Rather, it is ‘intertwined with the historical context in which one lives, as well as the social expectations of a particular culture at a particular point in time’ (15). These three perspectives allow one to acknowledge the structural and the individual factors which shape the lives of young people.

This paper focusses specifically on the lives of young people with disabilities in the Indian context. As far as possible, the discussion of ‘young people’ in this paper is limited to the 12-24 years age group that is the focus of WDR 2007. This category overlaps with ‘adolescents’, as referred to by UNICEF (10-18 years) and ‘youth’, as referred to by the United Nations (19-24 years). Indeed, many of the needs of a 24 year old individual are different from those of a 12 year old, disabled or otherwise. However, they are brought together in this paper to focus on a time in an individual’s life which is marked by

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physiological and psychological maturation, acquisition of essential skills, greater control over making own choices and decisions and the transformation of social relationships, to equip them in taking their place in the adult world.

### **Youth with disabilities in the Indian context**

One problem with dealing with young people aged 12-24 is that the Indian Census uses different age categories in its presentation of data, both on disability and more generally. The figures used in this paper, except where an alternative source is cited, are derived from Table C 20 (3). The authors estimates for the 12-24 population (total and for young people with disabilities) are calculated by adding 80 percent of the figures for the age category 10-19 to 50 percent of the figures for the age category 20-29, unless figures are available for 15-19 and 20-24 separately. The authors also draw on data from the 2002 National Sample Survey, where similar problems of age grouping can be found.

**Table 1. Distribution of young people by reported impairment**

	Seeing	Speech	Hearing	Movement	Mental	Multiple	Total PWD
Census							
12-24	2158063	530215	206581	1673873	647018		5215749
Percent	41.4%	10.2%	4.0%	32.1%	12.4%		100
NSS							
12-24	180480	255120	181920	2461860	465960	463080	4008520
Percent	4.5%	6.4%	4.5%	61.4%	11.6%	11.6%	100

Notes: In the table for NSSO, Blindness and Low Visibility have been combined into a total for visual impairment; mental retardation and mental illness have been combined for mental impairment.

There is no separate reporting of multiple impairments in the Census data.

Census figures for age group 12-24 are created by taking 80% of the age group 10-19 and 50% of the age group 20-29.

NSS figures for age group 12-24 are created by taking 60% of the age group 10-14 and the whole of age groups 15-19 and 20-24

**Table 2. Number of persons by usual activity status per 1000 disabled persons of age 20-24 years for any disability**

Any Disability	Employed					Not in the Labour Force				Estimated number in the total population	
	age- group 15-24	self- employed in non- agricul- ture	regular employee	casual labourer	total	unemploy- ed	attended educa- tional institution	attended domestic duties	beggar	others	
<i>Males</i>											
Urban Male	9.8%	8.9%	11.1%	9.7%	39.5%	6.7%	19.8%	1.7%	0.1%	32.2%	100%
Rural Male	12.2%	17.5%	4.3%	15.2%	49.2%	4.4%	8.3%	1.8%	0.1%	36.2%	100%
All Male	11.6%	15.4%	6.0%	13.8%	46.8%	4.9%	11.2%	1.8%	0.1%	35.2%	100%
<i>Females</i>											
Urban Female	2.5%	1.6%	3.5%	1.8%	9.3%	2.1%	9.9%	46.3%	0.0%	32.4%	100%
Rural Female	2.3%	4.5%	1.4%	6.1%	14.2%	0.6%	4.5%	50.7%	0.1%	29.9%	100%
All Female	2.3%	3.7%	1.9%	5.0%	13.0%	1.0%	5.9%	49.6%	0.1%	30.5%	100%
All	8.4%	11.4%	4.6%	10.8%	35.1%	3.6%	9.3%	18.3%	0.1%	33.6%	100%
											1,331,400

Source: [25: Table 13]

**Table 3. Approximate Percentages of males and females with disabilities aged 20-24 unemployed or not in the labour force, by type of impairment**

Type of Impairment	Percent unemployed or not in the labour force	
	Female	Male
<b>Locomotor</b>	87	49
<b>Hearing</b>	78	36
<b>Visual – Severe</b>	94	83
<b>Visual – Lesser</b>	87	52
<b>Speech</b>	83	51
<b>Mental retardation</b>	98	89
<b>Mental illness</b>	95	85

Source: [25: Table 13]

**Table 4. Marital status: general population and those with disabilities**

	Percent never married		Percent currently married		Percent widowed/ divorced	
	General	Disabled	General	Disabled	General	Disabled
<b>Age 25+</b>	5.30	16.28	84.98	62.19	9.72	21.50
<b>Age 15+</b>	22.74	28.51	70.16	53.35	7.09	18.12
<b>Age 15-24</b>	66.34	91.93	33.13	7.49	0.53	0.57

Source: General population, Census 2001

Disabled population: NSS 58<sup>th</sup> Round

In India, while infant mortality rates have dropped, some child immunisation rates have worsened in the past 10 years. National data sets, such as those from the National Family Health Survey, indicate that ‘the pace of annual progress after 1998 in many reproductive and child health indicators is slower than before and a few indicators (e.g., child-immunisation) have worsened, despite the expenditure on the programme being doubled’ (16). While the national pulse polio campaign has decreased the number of children and adults suffering from polio, eradication is elusive and critics of the campaign point to evidence that cases of lower-limb paralysis have fallen far less than the claims of the programme managers would suggest, and the focus on polio has contributed to deteriorating rates for protection against other childhood diseases (17, 18). Thomas, quoting a study undertaken in Gujarat, notes that ‘70 percent of the disabled people identified were disabled before school age’ and points to high rates of malnutrition among the under fives, maternal mortality and poor early childhood care as the main causes (19). Evidence about changes in poverty levels in India is highly contested, but nutritional and food availability data suggest that hunger remains a substantial problem today (20). The authors are therefore sceptical that India’s ‘disability transition’ (from communicable, maternal, perinatal, and nutritional disorders to non-communicable diseases and injuries) will be as rapid as Murray and Lopez suggest (21). There is no reason to believe that the causes of disability that flow from poverty will be rooted out soon. In parallel, India’s affluent middle classes with changing lifestyles are at greater risk of acquired impairments. As in many other spheres, in India, the ability of the state to deliver a wide range of social services (including those designed for people with disabilities) has been severely compromised in much of the country, by processes of liberalisation (22). In these circumstances, relatively small groups of well-placed citizens are often able to ensure that they benefit both from public and private resources, whereas those less well-placed (because of poverty, rural residence, ethnic group membership or other household features), find it hard to access even those small public resources to which they are nominally entitled (23).

It is very difficult to find reliable data about the prevalence of disability in India. In general, the search for a single prevalence rate is a chimera: different estimates should be used according to the specific purpose at hand (24). Even so, the range of estimates in India, and their varied origins, makes it difficult to say very much with assurance about people with

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disabilities in general, or young people with disabilities in particular. The two main large data-sets are the 2001 Census (3) and the 2002 National Sample Survey 58th Round (25). Unfortunately, as Mitra and Sambamoorthi point out, the definitions of disability used by these two enquiries differ in some fundamental ways (26). In addition, the distributions of impairments by age show some worrying inconsistencies. The 2001 Census, covering five types of disabilities, recorded a prevalence rate of 2.13 percent, or 21.91 million people with disabilities out of a total population of 1028 million. The National Sample Survey Organisation (NSSO) 58<sup>th</sup> round (July-December 2002) survey reported that 1.8 percent of the population (18.5 million) had a disability (25). While 18-22 million people with disabilities is a large number, this may arguably be a gross underestimation. A leading Indian disability NGO, the National Centre for Promotion of Employment for Disabled People (NCPEDP), argues that 5 to 6 percent of the population has a disability. The World Bank (27) says that, ‘the real prevalence of disability in India could easily be around 40 million people, and perhaps as high as 80-90 million if more inclusive definitions of both mental illness and mental retardation in particular were used’.

The Registrar General of India (2001) agrees that the Indian data on disability are unreliable, due to few well-trained field investigators, and issues of social stigma. Underreporting due to stigma is also noted by the World Bank report on India, which suggests that people with mental illness and mental retardation are most likely to be missed in surveys, and argues that this is closely related to explanations of the ‘cause’ of such disorders being attributed to *karma* [fate, or the effects of actions in a previous life (27)]. Additionally, a study of 1600 rural households in South India noted that ‘the factors that influenced the identification were: local perceptions and definitions of disability; social dynamics, particularly those of gender and age; ... type of disability and the associated social implications and stigma of that disability’ (28). Similar factors were highlighted by Erb and Harriss-White, who noted a significant bias in the prevalence of disability towards upper caste Hindus, in rural Tamil Nadu (29). It is not clear why such trends exist, but, it is likely that a greater willingness to define oneself as disabled exists when there are certain benefits in doing so. Changes in India since the research of Harriss-White and Erb, in particular the effects of the Persons with Disabilities Act 1995 (30), may mean that their conclusions no longer hold, or not with the same force, as when they wrote (31).

Current survey methods are unable to minimise and/or account for these factors. They are not only unsuccessful in providing a reliable picture of prevalence rates of disability, but there is also a greater likelihood of the identification and reporting of some easily identifiable impairments, while others remain hidden. Thus, it is difficult to state if differences in estimates provided by various data are 'real' differences in impairments, or due to other factors. Survey approaches also tend towards an individualistic approach, which may underestimate the extent to which disability has collective, rather than just individual effects. Where extended kin groups retain significant rights and obligations (as in much of Indian society), the impact of disability will be broader than where kinship groups are smaller and more individuated. The lack of reliable estimates and underestimations impact on the kind of policies and provisions framed, for people with disabilities and indeed those for their families.

### **The emerging trends of youth disability**

There is no alternative but to work with the available data on disability, despite all the earlier mentioned caveats. About 35 percent of the people with disabilities are identified in the 10-29 years age group in both the Census and the NSS. These data-sets also suggest that prevalence rates reported amongst females are lower than those reported amongst males: Census figures are 1.87 percent for females and 2.13 percent for males, while NSSO rates for males (2.12 and 1.67 per cent in rural and urban India, respectively) are higher than those for females [1.56 and 1.31 per cent (25)]. No obvious explanation is offered for these differences in either source.

By comparison with 1991, incidence rates amongst the 0-9 years age group have shown a decline, but there has been an increase in the incidence rates among the age groups of 10-29 years. The decreasing trends could be attributed to immunisation coverage for polio eradication, especially since the figures for movement disabilities among the 0-4 age group in 2001 are well below those for the 5-9 and 10-19 age groups. The increasing rates among young adults could be due to factors such as accidents, on the road or at work. The prevalence rates for this age group were higher in the urban areas than in the rural areas, unlike the pattern noted for the total disabled population. The prevalence rate was lower in urban (1.93 percent) than in rural areas (2.21 percent).

Despite the many uncertainties that remain about the lack of reliable data and inadequate research on young people with disabilities, one needs to consider what is known about their lives and the opportunities available to them. *WDR 2007* suggests that the five areas of youth transitions; continuing to learn, starting to work, developing a healthy lifestyle, beginning a family, and exercising citizenship, ‘have the biggest long-term impacts on how human capital is kept safe, developed and deployed’ (2). A focus on these five areas is important and essential for all young people, but for some young people these remain ambivalent and ambiguous through their continued exclusion and participation in mainstream society. Here, the authors consider the lives of youth with disabilities in three areas, namely: learning, work, and social participation. By doing so, it is not argued that these are the most important areas, nor do we wish to desegregate the lives that people lead, however, by doing so the authors wish to argue that such a focus will allow a critical examination and also hold true to the belief, that transition goals for young people with disabilities should be the same as those of their age groups (32). Thus, examining the status of young people with disabilities in such a manner will enable all to reflect on their lived realities.

### **Participation in the education system**

The unreliability of data on the educational participation of young people with disabilities is marked, both in terms of estimates of children with disabilities in the school going age group and indeed the numbers actually attending school. Mukhopadhyay and Mani quote an NCERT survey, suggesting that about 84,000 children with disabilities were enrolled in schools in 1998; and unpublished data gathered for the Ministry of Human Resource and Development (MHRD) suggested that approximately 55,000 children with disabilities were enrolled in schools in 1999. Hence, these authors state that ‘the picture (of school enrolment for children with disabilities) is dismal’, since (by these counts, and using the highest estimate of the total population of children with disabilities) less than 1 percent of children with disabilities attend school (33). Even using the Census estimates for the total population of children with disabilities, rather than the 5 percent figure preferred by Mukhopadhyay and Mani, would only increase the figure of those attending school to about 2 percent of the disabled age cohort.

A position paper drafted by the NCERT notes that, ‘the Office of the Chief Commissioner of Persons with Disabilities stated that not more than 4 percent of children with disabilities have access to education’ (34). Yet, the MHRD claimed in 2004, that 1.08 million children with disabilities were being educated, and by using a very low estimate of the total number of children with disabilities, thus arriving at an estimate of 67.5 percent of children with disabilities receiving education (35). Again, a different figure would be found by using the Census estimates for the total number of children with disabilities, and the MHRD data would then suggest that around 28 percent of children with disabilities were enrolled in school.

These discrepancies are so huge - from less than 1 percent to over 67 percent - and so little information is provided in these sources about how the figures were calculated, that the obvious explanations (different definitions of disabilities, varying notions of education, whether enrolment or attendance data are used, and so on) are inadequate to make sense of what is going on.

Similar issues surround estimates of one of the main supposed outcomes of schooling - the extent of literacy among the adult population of people with disabilities. Data gathered from the NSSO 58<sup>th</sup> round survey (Jul- Dec 2002), suggest that about 45 percent of people with disabilities are literate (25). In contrast, the 2001 Census literacy rate of the total population is 64.8 percent. According to the NSSO data, 25 percent of the literate population of people with disabilities had received education up to the primary level (five years of schooling), 11 percent up to the middle level (eight years), while a mere 9 percent had nine or more years. Interestingly, enrolment ratios for those with disabilities aged 5 to 18 years in a mainstream school were higher in rural areas than in the urban areas. This is not surprising because there is some empirical research to the effect that children with disabilities in rural areas are more likely to attend mainstream schools. Miles refers to this as ‘casual integration’ (36). Moreover, it is also possible that with the advent of increased bureaucratic reporting, children may get listed on the enrolment register but never attend school. The classroom may remain an alien space in which they are not seen as equal participants.

In urban areas, around 11 percent of those with disabilities in the 5 to 18 years age group were enrolled in special schools, while this was less than 1 percent in rural areas. This reflects the significant recent growth in the number of special schools, especially in urban

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areas. In the early 1990s, there were about 1,035 special schools (37). Nearly a decade later, it was estimated that there were about 2,500 special schools in the country (38). Most of these schools are in urban areas, with Mumbai having the highest number of schools (33). This rise of special schools has gone unchallenged even though there is evidence from other countries, that building such a parallel system will only perpetuate the continued exclusion of this group from mainstream society and support the continued fostering of stigma and prejudice.

Since 1990, there have been some important developments in the provision of educational opportunities for children and young people with disabilities. In 1987, the Integrated Education for Disabled Children (IEDC) scheme was launched at a national level, but it did not meet with much success. Few people knew about the scheme and only a few children received any equipment and services, while teachers remained untrained and unable to respond to their needs. In 1995, the education of children with disabilities came under renewed focus in the District Primary Education Programme (DPEP) and this has continued in the more recent *Sarva Shiksha Abhiyan* (SSA or Education for All).

The First Joint Review Mission of SSA in 2005 (39), referring to the education of children with disabilities, noted that ‘whilst invariably improving, coverage remains incomplete and an examination of the physical and financial progress reported by States thus far for the current year shows implementation to be poor, suggesting that this area is not receiving sufficient priority. Interventions reported tend to follow a medical model with attention to providing aids and appliances to physically challenged children’. Similar views were expressed in the Third Joint Review Mission for Bihar undertaken in Jan. 2006, where it was noted that while enrolment was being considered ‘attention will now need to be given to the provision of quality education to children with disabilities’ (40). Thomas, reporting a conversation with a government official, states that:

“the significant financial resources allocated to the SSA programme were actually a problem,... there is great pressure on education staff to spend, and be seen to be spending, their budgets. The result is that money is thrown at very visible and easy areas. Shiny new ramps and rails are a suitable quick fix.” (19).

Indeed there is growing evidence that the focus in the field continues to be on identifying and assessing children with disabilities, and responding to their needs through the provision of assistive aids and appliances. This focus on changing structural issues, rather than reviewing the teaching and learning processes in the classroom, is very limiting. The perception of disability as a problem located in the child and needing to be corrected at an individual level still dominates. Little focus is placed on examining the environmental factors that might be negatively impacting on the child's ability to participate. Overall, the emphasis is primarily on giving access to children with disabilities, with little regard being given to their participation in the classroom, its culture or the curriculum (41,42).

While enrolments have seemingly increased for children with disabilities, data still suggest that only very few of them complete the primary cycle of education and even fewer make it to the secondary, let alone higher levels of education. This has a notable impact on their employment opportunities later in adult life, especially in the context of a rapidly changing market economy. Tilak notes that 'while primary education gives the basic three R's, rarely does it provide skills necessary for employment-self employment or otherwise-that can ensure a reasonable level of wages and economic living' (43).

This comparative exclusion of children and youth with disabilities from education unarguably results in their inability to access some very significant opportunities for further development, particularly reducing their access to vocational training, employment and involvement in other income generation activities.

### **Work participation rates**

The ability and the opportunity to earn a livelihood - whether in a formal job or through some kind of self-employment - is an important determinant for an individual's well-being. In addition, and indeed apart from education, vocational training is an important way in which people with disabilities can become economically independent.

While the Ministry of Labour has set up various Vocational Rehabilitation Centres (VRCs), only a small percentage of people with disabilities receive vocational training. In 2002, the figures were an appalling 1.5 percent and 3.6 percent of the people with disabilities in rural and urban areas respectively, who received any training. These figures have not changed much since 1991. Other government initiatives encourage people with disabilities to explore

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avenues for self-employment through schemes such as the *Sampoorn Gramin Swarozgar Yojana* (SGSY). This scheme promotes self employment opportunities through self help groups and, according to official estimates, it has assisted 24,235 people with disabilities from 1999-2003 (44). Additionally, the National Handicapped Finance and Development Corporation (NHFDC) under the Ministry of Social Justice and Empowerment (MSJE) is involved in forwarding loans at low rates of interest for encouraging persons with disabilities, to establish their own micro-enterprises either on an individual basis, or by establishing self-help groups. However, there is no appreciable information to indicate how successful these attempts have been.

Since 1995, under the Persons with Disability Act (30), there has been a 3 percent reservation in all categories of jobs in the government sector and a strategy of giving incentives to private sector employers for promoting employment of people with disabilities. Such a strategy would take some time to have an impact on the employment status of young people with disabilities, especially since formal sector employment is a very small part of the Indian labour force, and within that, public sector recruitment has slowed down considerably since 1991. NSSO (2002) data shows that for urban males aged 15-24 years, 8.7 percent were 'salaried-wage employees', but the picture for rural males, and for urban and rural females is well under 3 percent. Rural and urban, males and females, were all about 30-35 percent out of the labour force and not in education, or involved in domestic duties, and how they spend their days is unclear. In general, for all age groups, the chances of a person with disability being in employment of any kind were roughly 60 percent as compared to those of the general population. In a multivariate analysis of the factors that increase or reduce employment prospects, for example, 'being married strongly increases a man's probability of being employed while it reduces that of a woman's' and that 'surprisingly, education has a limited effect on the probability of being employed for persons with disabilities. Although vocational training was associated with a higher probability of employment, this finding is not consistent across samples' (45). Work participation varies quite dramatically by the type of impairment, and young men with locomotor, hearing, lesser visual and speech impairments were more likely to be in employment, compared with those with severe visual or mental impairment, while women in all categories were much less likely to be in employment (25).

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Across the board, irrespective of the type of impairments, most people with disabilities tend to be casual labourers, or attending domestic services, but (at least as far as the NSS is concerned) not likely to be beggars. The 2001 Census reports that 52 percent of those not working are ‘dependents’, with another 15 percent engaged in ‘household duties’ and 25 percent ‘students’ (3). Unemployment and underemployment for young people with disabilities continues to be higher in comparison to that of non-disabled people in similar age groups (3). Zutshi, using NSSO data, notes that the majority of the vocationally trained people with disabilities received low profile non-engineering training (46). He argues that while only 1.8 percent and 7.3 percent in rural and urban areas respectively were in regular paid employment, even the nature of their employment was in low profile low-income jobs.

Reporting the results, a survey conducted of the top 100 companies by the NCPEDP during 1999, Zutshi further noted that the average percentage of employees with disabilities in the public sector (23 companies) was 0.54 percent, in the private sector (63 companies) was 0.28 percent, and in multinationals (14 companies), 0.05 percent (46).

A disturbing feature is the high likelihood that people lose or have to change their job after the onset of disability. Quoting NSSO (2002) data, Zutshi suggests that about 56 percent and 53 percent of those who had been working before the onset of their disability lost their job after the disability, in urban and rural areas respectively, and another 13 percent had to change their job (45).

Even though enabling legislation exists, its implementation is likely to be slow, and faced with weaknesses such as poor political will, low financial support and excessive bureaucracy. Additionally, not only is there little awareness of the Act amongst the general population, but this ignorance is prevalent even in government departments. There are also no strong monitoring mechanisms for its implementation, and the absence of strong advocacy groups makes it even more difficult to influence decisions and policy makers on this front.

### **Social participation**

In addition to education and employment, other important dimensions in the lives of young people are those related to ‘developing a healthy life style, beginning a family, and exercising citizenship’ (2). While concerns related to the education and employment of young people

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with disabilities get acknowledged in legislation and sometimes in practice, they remain excluded from other important areas of social participation. Their right to be an individual, a parent and to companionship often get overlooked.

Health care services have a very poor record in responding to the need of young people with disabilities. Mainstream sexual and reproductive health programmes, for example, do not consider them in the information provided and/or in the training of health workers. Groce notes that often health professionals refuse to provide reproductive health information to young people with disabilities because it is felt that they do not need it (10). The health system seems to operate with a notion that people with disabilities are non-sexual. This perception of people with disabilities as being asexual is widespread and their sexual and reproductive rights continue to be overlooked.

NSSO data for 2002 and Census data for 2001, suggests that 16.3 percent of people with disabilities aged 25 or more have never married, compared to only 5.3 percent of the population as a whole. Amongst young people aged 15-24, only 7.5 percent of people with disabilities were currently married in 2002, compared to 33.1 percent of the total population of the same age in 2001. Young people with disabilities get married at a later age than the rest of the population, and are about three times as likely to remain unmarried. They are also twice as likely to be widowed or divorced.

Data from the NSSO on the residential patterns of young people with disabilities suggest that men and women 15-24 years (82.9 percent and 75.2 percent respectively) are most likely still to be living with their parents. Young women were more than twice as likely to be living with a spouse (16 percent) than were young men (7.5 percent), reflecting their earlier age at marriage. By the age group 25-29 years, however, as many as 43.9 of men and 49.3 percent of women were living with a spouse, while 45.5 percent of men and 40.4 percent of women were living with their parents, without a spouse. These young people may be very vulnerable to exploitation after the death of their parents, the risk factors for women being more marked than for men. There is overwhelming anecdotal evidence to suggest that if a woman becomes disabled after her marriage, in most cases the husband will leave her for another wife, or if she has children she will be judged as incapable of looking after them and they will be placed in the care of grandparents (47).

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Young women with disabilities are most at risk of sexual assault and exploitation. Quoting a strategy paper written by Rao for the National Commission for Women, Mohapatra and Mohanty note that ‘women and girls with disabilities are particularly vulnerable to violence within their home situation. Sexual abuse is quite common, especially among women with mental and/or hearing disabilities. Abuse by physicians and caregivers, e.g., forced sterilization, is common’ (47). In their study which covered 595 women with physical disabilities, and 134 with mental challenges covering 12 districts of Orissa and focusing on ‘domestic violence against disabled women’ Mohapatra and Mohanty concluded that:

“there is no question that abuse of women with disabilities is a problem of epidemic proportions that is only beginning to attract the attention of researchers, service providers, and funding agencies. The gaps in the literature are enormous. For each disability type, different dynamics of abuse come into play....certain commonalities exist across disability groups, such as economic dependence, social isolation, and the whittling away of self esteem on the basis of disability as a precursor to abuse”(47).

While the existing literature does not highlight the abuse faced by young men with disabilities, Addlakha draws on four case studies to portray vividly the ‘deep sense of personal devaluation and foreboding’ faced by the two young men with visual and physical impairments (48). In contrast to the young women with disabilities, these men expressed a preference for a non-disabled partner, so that they were able to compensate for their impairment by aligning themselves with ‘a non-disabled spouse in a society which equates absence of vision with individual invalidation and social disfranchisement’. Addlakha asserts that ‘both preferences show the importance of the “us-them” (disabled, non-disabled) distinction in the experiences of some persons with disabilities, be they in the area of education, employment or sexuality’ (p.121).

It is interesting to note the seemingly complete absence of literature that addresses issues around civic participation of people with disabilities. At a time when there is renewed focus on the involvement of young people in building a strong democracy there is little to suggest how these issues are being made sense of, by and for young people with disabilities.

People with disabilities, particularly young adults, continue to live at the margins of mainstream society, even though at the international and the national levels commitments have been made to significantly reduce poverty and accelerate the pace of economic, social and human development. While poverty results in various forms of social exclusion, these intersect further with disability to form multiple layers of disadvantages. This scenario is further complicated when differing combinations of structural factors (such as caste, gender, religion etc), life cycle factors (being young or elderly, household composition) and other idiosyncratic factors (ill health, the nature and severity of the impairments) create and maintain the poverty of some, while giving others the chance to avoid or escape it (49). While structural factors and the various intersectionalities are indeed very important, there are broad commonalities in the lives of people with disabilities which transcend divisions based on gender and class. This commonality is illustrated in the significant deprivation that these people face as a result of their status of being a person with disabilities (50). DfID rightly notes that ‘given the high proportion of people with disabilities among the poor, it is unlikely that these targets (international targets of poverty eradication etc.) can be properly achieved without specific efforts to tackle disability’ (7). Addressing issues around disability needs to become an important focus and must generate political commitment and indeed academic and research focus.

## **MOVING FORWARD**

### **The need for reconceptualising understanding of disability**

An important concern in the Indian context is the current understanding of disability. Within the Indian legislative framework the identity of disability is contingent on the certification process carried out by the state constituted boards which work on the basis of a medicalised ‘degree of impairment’. People with disabilities are defined as those suffering from less than 40 percent of any ability as certified by a medical authority (30). Based on this labelling process, the individual is then granted some privileges. Not only is it rather difficult to get these certificates, but also different states or different hospitals within the same state operate in widely discrepant ways in issuing certificates (51). Furthermore, the assumptions underlying this process are fraught with complexities.

By giving a certificate, the person is labelled for life, as there is no reassessment of her/his disability after the age of 18 and the person is never really re-examined. As Ghai points out, that the fact that ‘there might be appreciable change in given conditions such as muscular dystrophy or polio is therefore not reflected in the definitional closures inherent in a one time certification process’ (51). The assumption here is that disability is a fixed category, a static state located within the individual. Even at the most basic level, it fails to acknowledge biological development.

Consequently, it is not surprising that the primary focus in India is on providing people with disabilities with various aids and appliances, immunisation, etc, that can help them function like others, rather than addressing social barriers that result in their exclusion or non-participation from the mainstream. However, even though most government programmes primarily focus on provision of aids and appliances, quoting a study undertaken in Gujarat, Thomas notes that only 25 percent of the people with disabilities were using aids and appliances (19). People found it difficult to access these provisions, as rehabilitative services tend to be concentrated in urban areas, and the devices given were inappropriate, difficult to repair and maintain in rural areas. Appliances from the Artificial Limbs Manufacturing Corporation of India, the government provider, were generally recognised as being poor in quality, and accessing them was time consuming and bureaucratic. This becomes especially problematic for young people, who would require replacements at regular intervals, especially of some prosthetic devices, such as artificial limbs and wheel chairs.

An understanding of disability as a medical, preventable condition holds some merit, because, as noted earlier, many of the factors resulting in various impairments are preventable or treatable. However, the dominance of this perspective has led to a scenario where the naturalness of these labels remains unquestioned and there is a continued neglect of social factors. Such an understanding does not acknowledge that disability is a fluid category and changes character not only as a consequence of the development that a person undergoes, but also as a consequence of the shifting conditions around her/him. Coker notes that, ‘disability, like most dimensions of experience is polysemic – that is, ambiguous and unstable in meaning – as well as mixture of truth and fiction that depends on *who says what, to whom, when and where*’ [(52) emphasis added].

In addition to the prevalent medical discourse, the dominant cultural beliefs suggest that disability is a personal affliction. It is seen as resulting from the wrath of fate—retribution for past *karmas* (*past life deeds*) and punishment for sins committed in a previous life (53). Such perceptions serve many purposes. Firstly, regarding someone as the victim of their (or their family's) sins leads to the manifestation of pity towards these sinners. This pity gives rise to benevolent acts of charity, which are further reinforced by the strong religious orientations. For example, it is observed that during '*shrads*' (acts of charity undertaken to mark the death of family members), alms are given to individuals with disabilities. Secondly, such a perception reinforces a distancing of one's own responsibility in the acts of exclusion.

The dominance of the medical and charitable perceptions had led to a failure where there is little acknowledgement of the fact that since an individual's functioning and disability occurs in a context, it is useful to regard disability in terms of impairments of body structures and functions, but also limitations of activities and restrictions of participation placed by social and cultural structures (54). An understanding of disability thus needs to be located within a specific context, the context which is the lived reality of the individual with disability.

Such a reconceptualisation of disability, though challenging, will have a significant impact on not just how data are collected but also how to respond to the needs of people with disabilities. It is no longer about focusing only on the impairments, which can indeed be challenging, but it is also about re-examining the provision of various services. Simply put, it is not only about providing someone with a wheel chair but it is also about ensuring that there are accessible roads on which these can be used safely, and more importantly, it is about a change in societal attitudes which acknowledges the individual rather than just the wheelchair.

### **Equal is not enough: notions of equity and development**

Focusing on 'opportunities' is an important step forward in ways of thinking how far policies and institutions allow for young people to develop their future skills- not just work related, but also social skills (2). Indeed, 'the distribution of opportunities matters more than the distribution of outcomes' (55). It has been argued in this paper that young people with disabilities face very different opportunities than their able-bodied peers. Furthermore, whereas young able-bodied people living in chronic poverty have two important exit routes

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— high dependency on their own labour (in the absence of financial and material assets) and formal education, which improves the quality of their labour — neither of these is likely to be available to young people with disabilities (49). For example, people with disabilities are less likely to be economically active, more because of the discrimination and societal perceptions that they are likely to encounter, than because of the inherent quality of their impairment. Similarly, limited opportunities (lack of trained teachers, restrictive curriculum, physically inaccessible buildings etc) and negative perceptions (stigma, low expectations etc) about their ability to participate in the formal education system, makes access to educational institutions also very difficult. Thus, societal beliefs and norms may limit the possibilities of escape from poverty for these young people, who are also at a greater risk of being systematically excluded from basic health care services, political and legal processes, pushing them into the margins of mainstream society.

While the government is drafting disability legislations and policies, it is failing to engage with underlying issues of exclusion and marginalisation. Providing reservations is just one step and much more needs to be done to convert these into actual usable opportunities. In the terms of a capabilities approach, one can argue that reservations or financial compensation can be conceptualised as specific types of asset – ones that are not meaningful – i.e., constitutive of capability – until people can both access reservations and use compensation to improve the quality of their lives. Sen further elaborates on this issue with specific reference to people with disabilities. He proposes the notion of a ‘conversion handicap’: not only do people with disabilities have difficulty earning an income (which he terms as the ‘earning handicap’), but the disability also ‘makes it harder to convert income into the freedom to live well’ (56). Sen adds that ‘the conversion handicap applies, thus, not only to converting personal incomes into good living, but also to converting social facilities into actually *usable opportunities*’ (p. 5, emphasis added). Therefore, identifying factors that enable or hinder young people with disabilities to make use of the facilities that are available to their non-disabled peers is an important concern. To make this feasible, it is essential that mechanisms are established that enable a greater involvement and participation of people with disabilities in the policy making process, both at the levels of national and local policy. Greater focus must be placed on listening to the voices of people with disabilities, to enable the development, implementation and evaluation of truly disabled friendly policies and programmes.

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