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Forgotten Youth: Disability and Development in India

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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, so they form a significant minority. Little is known about their experiences, however, nor how they and the others around them make sense of their lives and perceive their transition to adulthood as their surrounding milieu is transformed. In this paper I adapt the framework of transitions proposed by the World Bank's *World Development Report 200 7* to examine opportunities for young people with disabilities in the areas of learning, work and citizenship. I use existing literature to review secondary data and to analyse the lived experiences of young people with disabilities. What are their prospects in a time of optimism for Indian youth?

Keywords: Disability, development, education, India, Youth

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Optimism of the "youth bulge"

According to *World Development Report 2007: Development and the Next Generation* (World Bank, 2006), there has never 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. The Report points out with great enthusiasm this "window of falling dependency rates" (p. 4) where there is a considerable expansion of a 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. Herrera further argues that they are critical actors in development. She 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" (Herrera, 2006, p. 1426).

India is one of these countries with a low dependency window of opportunity, where only 7.1 percent of the population is 60 years and above (Registrar General of India, 2001). 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 these are the drivers behind the retail boom and significant consumers of the technology revolution (e.g., Ahmed, 2004). The Report suggests that being part of the cohort of those 12-24 year-olds who are on average more educated and healthier than the generations before them, they have in them the potential to contribute to national growth and reduce poverty (World Bank, 2006).

While attention is being focused on young people's potential for social transformation, some of them – such as those with disabilities – remain alienated from mainstream debates on development. Consistently across the globe, especially in developing countries, mainstream policies and programmes working with young people seem to 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. Not only is knowledge about their numbers unreliable but little is known about the kind of lives they live from their own perspective. Moreover, the policies that seem to serve their interests have apparently made little difference. This group of young people with disabilities are thus subject to double marginalisation, by being overlooked in the literature and policies focused on the youth, but also in literature and policies addressing issues related to people with disabilities.

Young people with disabilities: a global overview

A UNICEF report stated that, "Adolescents and youth with disabilities are among the neediest and most overlooked of all the world's children" (UNICEF, 1999, p. 1). Groce notes that the global total for adolescents and young adults with disabilities is between 90 million and 180 million (Groce, 2004).[2] In the developing countries this figure is between 75 and 150 million, with significant increase in their numbers predicted over the next few decades. This increase is not just a reflection of the increasingly youthful age structures in developing countries, but also of factors such as medical advances allowing those to survive who might not have been able to do so earlier, and for 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.[3] Evidence from developed countries such as Canada and Australia suggest that the incident rates of spinal cord injury are highest amongst those aged between 15 and 24 years (UN, 2007). Data from the US suggest that each year, approximately 70,000 to 90,000 individuals incur a traumatic brain injury resulting in a long-term, substantial loss of functioning (National Institutes of Health, 1999).

While 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 other factors contributing to these increasing numbers are the inadequate provisions to protect young people from the effects of avoidable infectious diseases, poor immunization regimes and growing numbers of under nourished children. At a global level, survival rates for low birth-weight infants have increased 70-fold over the past 25 years, directly affecting the prevalence of developmental conditions and learning impairments (Fujiura, 2001). Even in countries like India health indicators such as child immunization have worsened. Thomas quoting a study undertaken in Gujarat, notes that “70 percent of the disabled people identified were disabled before school age. This is a surprisingly high figure, and points to the impact of India’s high rates of malnutrition among the under fives, maternal mortality and poor early childhood care. Malnourishment is a major cause of developmental delay and long-term intellectual disability” (Thomas, 2005, p. 21). While immunisation programmes such as the national polio drive are likely to have decreased the number of children and adults suffering from polio, the country still continues to have a rather bleak record on other diseases. Srinivasan *et. al.* use national data sets, such as those from the National Family Health Survey, to indicate how “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” (Srinivasan,

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[2] This reflects the variation in prevalence rates: WHO and UNICEF argue a prevalence rate of 10 percent of the population with a disability, while others use the more conservative figure of 5 percent.

[3] Global and regional estimates of the injury-specific causes of disability are lacking. However, estimates from some countries suggest that up to one quarter of disabilities may result from injuries and violence. In Mexico studies show that 17.7 percent of disabilities result from unintentional injuries alone, while for Hungary and Sierra Leone the figures are 12.7 percent and 14.3 percent respectively. The results from studies on violence-related injuries which result in disability are not well documented (WHO, 2007).

Shekhar, & Arokiasamy, 2007, p. 2931). These factors can have significant impact on life as a young adult.

Even though the number of young people with disabilities is a growing issue, both policies and research have overlooked this group. Two recently publishes texts focusing on young people, the *World Development Report 2007: Development and the Next Generation* (World Bank, 2006) and *Growing up Global* (Lloyd, 2004), overlook the concerns and issues pertaining to youth with disabilities. For instance, the World Development Report mentions the word "disability" (and its many variants) only six times. Although word count is not a sufficient measure of the extent to which the authors consider the issue of disability, it is also true that the discussions undertaken in the Report show at best very limited awareness of the complexities and struggles faced by young people with disabilities. In the case of *Growing up Global*, the authors include within their definition of successful 'growing up' the notion that this includes having good health, thus suggesting that it is impossible by definition for young people with disabilities to make successful transitions to adulthood!

Not all global agency reports on young people ignore those with disabilities, of course. For example, a UNICEF report used small 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 (UNICEF, 1999). Indeed this raises significant concerns regarding the opportunities available for participation and development of their capabilities and the resultant transitions that they make into adulthood. For instance, what are the markers of being an adult for an individual with disabilities, who is regarded as dependent, in need of care and "overprotected" (Coleridge, 1996) in a context where parents frequently expect the child to actively participate in the family unit through economic contribution and to support them in their old age?

The Biwako Millenium Framework for Action towards an Inclusive, Barrier- Free and Rights-Based Society for Persons with Disabilities in Asia and the Pacific highlights the gravity of the situation by noting that:

> The challenge of integrating and including persons with disabilities in the economic mainstream has not been met. Despite international standards and the implementations of exemplary training and employment legislation policies and practices in some countries, persons with disabilities, and especially women, youth and those in rural areas, remain disproportionately undereducated, untrained, unemployed, underemployed and poor.
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> (Economic and Social Commission for Asia and the Pacific, 2002, p. 5)

There is, therefore, a need to focus on the increasing numbers of young people with disabilities—young people who currently remain doubly marginalised from policies, provisions and research literature. This paper will now specifically focus on young people with disabilities in the Indian context. By bringing together the existing literature, I will reflect on the opportunities available to, and the lived experiences of this group of youth. I will also endeavour to unpack the assumptions that underpin current policies and practices, and propose alternatives in thinking to help us respond to their needs and concerns.

The term "young people" in this paper falls broadly in line with the 12-24 years age group which is the focus of the World Development Report (World Bank, 2006). This category encompasses both "adolescents" as referred to by UNICEF (those between 10-18 years) and "youth" as referred to by the United Nations (those in the age range of 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, I bring them together in this paper as 12-24 are the years within which young people experience physiological and psychological maturation, are expected to acquire skills, transform their social relationships and develop an identity for taking their place in the adult world.

Youth with disabilities in the Indian context[4]

It is very difficult to find reliable data about the prevalence of disability in India. The 2001 census covering five types of disabilities recorded a prevalence rate of 2.13 percent. This procedure generated a figure of 21.91 million people with disabilities out of a total population of 1028 million. This is significantly different from the past estimates where in 1931 a prevalence rate of 0.31 percent was recorded and later in 1981 a prevalence rate of just 0.2 percent was recorded. While 22 million people with disabilities is a large number, this is still arguably a gross underestimation especially when one considers that WHO estimates a global prevalence rate of 10 percent. This figure also falls considerably short when one compares these rates with those of more developed countries, such as USA (20 percent) and UK (12 percent), and indeed more recently, with other developing countries such as Brazil (14.5 percent), Turkey (12.3 percent) and Nicaragua (10.1 percent).[5] In India various estimates are used by different authorities. The National Sample Survey Organisation (NSSO) 58th round (July-December 2002) survey reported that 1.8 percent of the population had a disability (NSSO, 2003), while a leading Indian disability NGO, the National Centre for Promotion of Employment for Disabled People (NCPEDP) argues that 5 to 6 of the population has a disability.

Problems with identification

The Registrar General of India (2001) highlighting the unreliability of the Indian data on disability, notes that it is well accepted that there are serious difficulties in carrying out a survey of

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[4] 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 cited in this paper, except where an alternative source is cited, are derived from Table C 20 (Registrar General of India, 2001). My 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.

[5] However, undertaking cross-national comparisons on disability data are fraught with complexities, an issue which I discuss later in the paper.

persons with disabilities due to reasons such as the lack of well-trained field investigators and the reluctance on the part of families to disclose information about members with disability due to social stigma.[6] In addition, the language used to describe disability may be of important consideration. For instance, in Hindi *'viklang'*, the most commonly used word to refer to a person with disabilities refers primarily to those with physical impairment, mostly of upper and lower limbs. Hence there is an increased likelihood of ignoring those with learning difficulties, blind, deaf, epileptic, etc. Thus, encapsulating the range of impairments in a single word that is easily translated is very difficult.

The issues of underreporting due to stigma and a range of associated reasons are also commonly discussed in the international literature, especially in the context of developing countries. Additionally, in 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" (Kuruvilla & Joseph, 1999). 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. They suggest that "scheduled caste people have to be more severely disabled than inhabitants of the caste settlement before they will publicly acknowledge their infirmity" (Erb & Harriss-White, 2002, p. 16). It is not clear why this discrepancy exists. However, it is likely that a greater willingness to define oneself as disabled exists when there are certain benefits in doing so.

The current survey methods are unable to minimise and/or account for these factors. They are not only unsuccessful in providing us 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 get ignored, overlooked or hidden. Thus, it is difficult to state if differences in estimates provided by various data are 'real' differences in impairments or if these reflect differential reporting patterns due to reasons such as social roles, stigma etc. The lack of reliable estimates and underestimations impact on the kind of policies and provisions framed for people with disabilities.

The emerging trends

Working with the data on disability emerging from the Census 2001 highlights some interesting trends. Overall, at a glance the Census data show that 48.55 percent of people with disabilities reported a seeing disability and a little over one-fourth had a disability in movement. The gender component was also interesting as prevalence rates reported amongst females (1.87 percent) were lower than those reported amongst males (2.13 percent). The severity of impairment, not surprisingly, varied among the disabled population. Around 60 percent of people with disabilities can

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[6] For a fuller discussion of issues of definition and differences between the Census and the National Sample Survey estimates, see (Mitra & Sambamoorthi, 2006a).

function without any assistive devices, while 13 percent cannot function even with supporting aids and appliances.

Rather noteworthy for our consideration here is the fact that about 35 percent of the people with disabilities are in the 10-29 years age group. By comparison with 1991, incidence rates amongst the 0-9 age group have shown a decline, but there has been an increase in the incidence rates among the age groups of 10-29. The decreasing trends could be attributed to immunization 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 and/or at work. The prevalence rates for this age group were higher in the urban areas than in the rural areas, unlike the trends noted for the total disabled population.[7]

Another important variable in understanding disability in developing country, such as India, is that of economic well-being, or rather the lack of it. While engaging with issues of types of impairments, gender and rural-urban variations are important; these *intersectionalities* are further complicated by the variable of poverty, and hence needs to be acknowledged. For instance, not only is the life of a young man with visual impairment living in Delhi likely to be different from a young woman with visual impairments living in rural Bihar, but the life of a young man with impairments belonging to an affluent family in Delhi is likely to be different from that of his counterpart belonging to a family living in an urban slum.

Disability and poverty

There is increasing evidence to suggest that being poor dramatically increases the likelihood of being born with impairment, it also increases the probability of becoming impaired and then disabled. This not surprising as the poor have limited access to basic health care, have insufficient and/or unhealthy food, poor sanitation facilities, and an increased risk and likelihood of living and working in hazardous conditions. DFID notes that "disability is both a cause and consequence of poverty" (DFID, 2000, p.1).

The World Health Organisation (WHO, 1999) estimated that more than 500 million people, or 7- 10 percent of the world's population is likely to be disabled by impairments that are preventable or treatable. This assertion is supported by a recent report "*The Indian Child*" (CRY, 2001) which lists factors such as communicable diseases, infections in early childhood, nutritional deficiencies, and inadequate sanitation as being the most significant factors causing disability in India. All of these factors are preventable or treatable, but are most likely a reality for people living in poverty.

The vulnerability of those living in poverty thus continues to be very high. Braunholtz identifies two important exit routes for people living in poverty, namely high dependency by the

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[7] The prevalence rate was lower in urban (1.93 percent) than in rural areas (2.21 percent).

chronically poor person on their own labour (in the absence of financial and material assets) and formal education, which improves the quality of their labour (Braunholtz, 2007). In the case of individuals with disabilities, neither of these options seems viable. For example, people with disabilities are more likely to be prevented from becoming economically active, not because of the inherent quality of their condition, but more because of the discrimination and societal perceptions that they are likely to encounter related to their impairment. Similarly, limited opportunities (due to lack of trained teachers, restrictive curriculum, physically inaccessible buildings etc) and negative perceptions (stigma, low expectations etc) about their inability to participate in the formal education system, makes access to these institutions also very difficult. Thus, societal beliefs and norms may limit the possibilities of escape from poverty for this group of people. Also, they are 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.

Not only are poor people likely to be at a greater risk of impairments, but once disabled they are more likely to stay poor and are also at a greater risk of passing on this deprivation to their next generation. This cyclic relationship between disability and poverty results in a scenario where people with disabilities are usually amongst the poorest of the poor. World Bank estimates (Elwan, 1999) suggest that people with disabilities may account for as many as one in five of the world's poorest. Yeo provides an even more disturbing picture, stating that, "50,000 people, including 10,000 disabled people, die every day as a result of extreme poverty" (Yeo, 2005, p.1). Even though much is written about the cyclical relationship between poverty and disability, due to the lack of data these linkages have not been systemically examined (Elwan, 1999).

Indeed it would be naïve to assume that all people with disabilities are always amongst the poorest in a community or indeed that the poorest are at the greatest risk of getting all impairments. With development there is an increase, rather than a decrease, in the proportion of population with disabilities, due to factors such as increased survival rates from disabling accidents and disease, and increasing life expectancy (Elwan, 1999).[8] However, what cannot be overlooked is that a higher proportion of people with disabilities may experience severe and chronic poverty than the proportion of non-disabled people (Yeo, 2001), in both developed and developing countries.

Disability and its impact on family

The degree to which disability is seen as a collective, rather than just an individual responsibility, varies among societies. 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

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[8] Another factor associated with increasing numbers of disability is emerging conditions, such as multiple chemical sensitivity and chronic fatigue syndrome around which there is recent recognition and consensus. Also, there appears to be a growing prevalence of established conditions such as asthma, autism, learning disorders, though it can be disputed whether these represent growth in actual incidence, greater awareness and better surveillance, or simply the reduction of stigma in reporting (Fujiura, 2001).

groups are smaller and more individuated. Undertaking a global review on disability and poverty, Elwan makes a broad but useful assertion noting that one family in every four has an immediate family member with a significant disabling condition and the impact of disability is multi-faceted, with significant economic and socio-cultural dimensions (Elwan, 1999).[9] Not only does disability result in significantly reduced opportunities for the individual with disabilities it also results in lost opportunities and reduced choices for other members of the household, irrespective of the position of the person with disabilities in the household structure.

For example, having an adult/parental figure with disabilities might place additional burden on young children in the family who might have to go out to earn a living to support/ supplement the family income. Thus, having to take on such responsibility at an early stage is likely to impact on their participation in the education system. In other instances it might be the case that the child is unable to attend school due to the reduced ability of the family to pay fees because of the additional direct costs of disability on the family. Research by Hogeeven in the Ugandan context highlighted some of these issues (Hoogeveen, 2005).[10] Thus, because of the extent to which education drives the ability of an individual to earn a living in the future, the "currently disabled are more likely to pass their poverty on to their children" (Lwanga-Ntale, 2003, p.7).

Not only is there an increased likelihood of inter-generational transfer of economic deprivation but it is also likely to be the case that in managing their day-to-day survival poor families with a disabled member do not have as much time to build social networks (or have different, possibly truncated ones) and hence have fewer mechanisms of support and limited social or socio-political capital. Furthermore, social perceptions of stigma and fear associated with disability may further exclude families and reduce the number of relationships and networks that they can actually establish. Thus the impact of disability is not only at the level of the individual but also at the levels of the family and the community.

While prevalence rates provide approximate estimates about the number of persons with disabilities in a given society, these numbers do not capture the complex lives that individuals with impairments lead. Nor do they capture the myriad ways in which an individual interacts with the world around her/him, the restrictions imposed by structural and cultural issues; and the resilience of young men and women with disabilities that results in small acts of triumph in a society that is largely shaped for the able-bodied.

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[9] Placing people with disabilities in a household structure should not make us forget that many people with disabilities are destitute (as suggested by Harriss-White, 2003). Destitution is an extreme condition of monetary poverty, and in such a scenario, begging is often the only option for survival.

[10] Hoogeveen noted a significant "education deficit" in Ugandan households headed by a person with disabilities, as children in these households received less education (Hoogeveen, 2005).

Despite the many uncertainties that remain about the lack of reliable data and inadequate research, I shall now turn to consider what we know about how these young people manage their lives at a stage in life when they are being equipped to make transitions into adulthood. The World Development Report suggests that the five areas of youth transitions; "continuing to learn, starting to work, developing a healthful lifestyle, beginning a family, and exercising citizenship, "have the biggest long-term impacts on how human capital is kept safe, developed and deployed" (World Bank, 2006). 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 I consider the lives of youth with disabilities in three areas, namely: learning, work, and social participation.

Participation rates in the education system

The unreliability of data, highlighted in my discussion of prevalence rates, becomes even more marked when looking at the information on the educational participation of young people with disabilities. The first problem is with the estimates of the number of children of school-going age with disabilities. Mukhopadhyay and Mani estimate the total population of children with disabilities in the 5 to 14 years age group at about 10.39 million (i.e. 5 percent of the age group) (Mukhopadhyay & Mani, 2002). In complete contrast, the Ministry of Human Resource Development states that there are 1.6 million children with disabilities in the 6 to 14 years age group (Ministry of Human Resource Development, 2004), while a later document from the same Ministry gives a figure of 1.85 million children (Ministry of Human Resource Development, 2005). Census figures from 2001, however, suggest that about 1.92 percent of the children of the 5-14 age group have disabilities, at 3.88 million, while NSS figures for 2002 are 3.12 million.

The second problem is that different sources generate very different estimates of the numbers of children with disabilities in school. Quoting the figures of a National Council for Educational Research and Training (NCERT) survey carried out in 1998, Mukhopadhyay and Mani (2002) note that about 84,000 children with disabilities were enrolled in schools. They also quote unpublished data gathered for the Ministry of Human Resource and Development in 1999 which suggested that approximately 55,000 children with disabilities were then enrolled in schools. 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 (Mukhopadhyay & Mani, 2002, p. 101). 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.

But 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" (National Council of Educational Research and Training, 2005). Yet previously the Ministry of Human Resource Development (2004) had claimed 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. 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, differences in what is considered to be education, whether enrolment or attendance data are used, and so on) are inadequate to make sense of what is going on.

Data gathered from the NSSO 58th round survey (Jul- Dec 2002) suggest that about 45 percent of people with disabilities are literate (NSSO, 2003). In contrast, the 2001 Census literacy rate of the total population is 64.8 percent. The NSSO data highlighted that 25 percent of the literate population of people with disabilities had received education up to the primary level, 11 percent up to the middle level, while a mere 9 percent continued up to or beyond the secondary level. Interestingly, though not surprisingly, enrolment ratios for children 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 support the fact that children with disabilities in rural areas are more likely to attend the mainstream, Miles refers to this as 'casual integration' (Miles, 1997). This casual integration might be a result of the fact that considering there tends to be only one government school in a village, there is an assumption that all children will attend it, without any alternative provisions being made. While this might be a useful inference, it does not question the quality and/or relevance of education that these children might be receiving in such settings. 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 areas. In the early 1990s there were about 1,035 special schools (Ministry of Human Resource Development, 1992). Nearly a decade later it was estimated that there were about 2,500 special schools in the country (Rehabilitation Council of India, 2000). Most of these schools are in urban areas, with Mumbai having the highest number of schools (Mukhopadhyay & Mani, 2002). 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.

Over the past decade or so 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. However, this scheme did not meet with much success as 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 the needs of these children. 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 (Department of School Education and Literacy, 2005), 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" (Department of School Education and Literacy, 2006). Thomas states that conversation with a research informant suggested that,

> significant financial resources allocated to the SSA programme were actually a problem, noting that 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 (Thomas, 2005, p. 45).

Indeed there is growing evidence to suggest 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 rather limiting. The perception of disability being a problem which is located in the child and hence needs to be corrected still dominates and 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 (Singal, 2006a, 2006b).

While enrolments have seemingly increased for those with disabilities, data also 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" (Tilak, 2005, p. 3).

This exclusion of children and youth with disabilities from education unarguably results in their exclusion from 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 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 (Singh & Dash, 2005). 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 (Ministry of Law and Justice, 1996), 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. Using NSSO (2002) data, Mitra and Sambamoorthi note that "among all working age PWDs, we found that 37.6 percent were employed" (Mitra & Sambamoorthi, 2006b, p. 200).[11] Only 4.8 percent of all working age PWDs were 'salaried-wage employees' (p. 201), and in general, the chances of a PWD

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[11] Working age population consists of individuals who are in the age group 15 to 64.

being in employment of any kind were roughly 60 percent of 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 PWDs. Although vocational training was associated with a higher probability of employment, this finding is not consistent across samples’ (pp. 201-02).

In understanding work participation the type of impairment is also an important variable, For example, the percentage of people with locomotor disabilities was found to be highest among the employees with disabilities and those with mental impairment were found to be the lowest.

Table 1: Approximate percentages of people with disabilities not in employment by type of impairment, 2002

Type of Impairment	Percent not in employment	
	Rural	Urban
Locomotor	40	39
Hearing	61	57
Visual	80	68
Speech	40	42
Mental retardation	82	80

Source: (NSSO, 2003), adapted from Zutshi, (2004).

Thus, across the range of impairments the number of people not in employment remained high, with the percentages being highest for mental retardation both in rural and urban areas. For people with visual impairments the difference between rural and urban settings seemed particularly significant.

Data suggest that, across the board, irrespective of the type of impairments, most people with disabilities tend to be casual labourers, or attending domestic services or indeed begging. 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’ (Registrar General of India, 2001, Table C 24). Thus, unemployment and underemployment for young people with disabilities continues to be higher in comparison to that of non-disabled people in similar age groups (*ibid*). Zutshi uses NSSO data and notes that the majority of the vocationally trained people with disabilities received low profile non-engineering training (Zutshi, 2004). 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 jobs with low-income.

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 (Zutshi, 2004).

A disturbing trend evident is the significantly high numbers of people having to face loss or change of job after the onset of disability. Quoting NSSO (2002) data, Zutshi suggests that about 55.8 percent and 53.1 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 13.2 percent had to change their job (Zutshi, 2004).

Thus, even though enabling legislation exists, its implementation is likely to be slow, and faced with weaknesses such as the lack of political will, financial support and excessive bureaucracy. Additionally, not only is there a lack of awareness of the Act amongst the general population, but this ignorance is prevalent even in government departments. There is also an absence of strong monitoring mechanisms for its implementation. Finally, 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” (World Bank, 2006). While concerns related to education and employment get acknowledged in legislation and sometimes in practice, people with disabilities remain excluded from other important areas of social participation: their rights to be an individual, a parent and to companionship get overlooked.

Evidence suggests that health care services have a very poor record in responding to the need of young people with disabilities. Mainstream sexual and reproductive health programmes do not consider their needs 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 (Groce, 2004). 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.

According to the NSSO data, 43 percent of people with disabilities have never married, while 39 percent are currently married, 15 percent are widowed and around 1 percent are divorced or separated. No differences between urban and rural areas were reported. Significantly, 27.8 percent and 32.4 percent of people with disabilities were never married in the ages above 15 years in rural and urban areas respectively in 2002. Information related to the current living arrangements of people with disabilities suggests that nearly 40 percent of people with disabilities were living with their parents without spouses (Zutshi, 2004). These people are vulnerable to exploitation or may be left at the mercy of the community after the death of their parents. While Zutshi does not analyse the NSSO data from a gender perspective, it seems likely that young women with disabilities are more vulnerable than young men. Not only is there greater likelihood of a young women with disabilities not getting married, but 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 (Rajah, quoted in Mohapatra & Mohanty, 2004).

In fact due to various vulnerabilities, young women with disabilities are most prone to 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" (Mohapatra & Mohanty, 2004, p. 8). In their study 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" (Mohapatra & Mohanty, 2004, p. 35).[12]

While the existing literature does not highlight the abuse faced by young men with disabilities, Addlakha's article (based on four case studies) vividly portrays the "deep sense of personal devaluation and foreboding" faced by the two young men with visual and physical impairments (Addlakha, 2007, p. 119). 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 people with disabilities, 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

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[12] This study covered 595 women with physical disabilities, and 134 with mental challenges.

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 (Braunholtz, 2007). While structural factors and the various *intersectionalities* are indeed very important, there is evidence to suggest that there are broad commonalities in the lives of people with disabilities which transcend divisions based on gender and class, and this commonality is illustrated in the significant deprivation that these people face as a result of their status of being a person with disabilities (Riddell, Baron, & Wilson, 2001). 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" (DFID, 2000, p. 2). 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 our 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 (Ministry of Law and Justice, 1996). 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 (Ghai, 2003). 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" (Ghai, 2003, p. 33). The assumption here is that disability is a fixed category, a static state located within the individual. It is therefore regarded as a problem of the individual arising from her/his functional limitations and inherent in her/his mind and/or body.

Consequently it not surprising that the primary focus in India is on providing people with disabilities with various aids and appliances, immunization, 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 policies and programmes primarily focus on 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 (Thomas, 2005). Not only was it difficult to access these provisions, as rehabilitative services tend to be concentrated in urban areas, but the ones who did access these devices found them to be inappropriate, and difficult to repair and maintain in rural areas. Appliances from the Artificial Limbs Manufacturing Corporation of India (ALIMCO), 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, where as a growing individual they are likely to require replacements at regular intervals of some prosthetic device, 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 the medical 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 rather 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"* (Coker, 1999, p. 115, emphasis added).

The second significant assumption here suggests that undue power and influence that has historically been accorded to medical professionals in determining important life decisions for the person with disability. It is the "expert" who determines where the person with disabilities should live or be educated, and medical expertise indeed is reflected in many of the selection criteria for employment, which function within narrow boundaries of ability. Using medical expertise in this way also results in a scenario where the society removes itself from any responsibility of addressing the needs and concerns of people with disabilities.

In addition to this 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* and punishment for sins committed in a previous life (Ghai, 2002). Commonly held perceptions suggest that people with disabilities are living out a just punishment for sins, vices, or other moral faults, known or unknown, that have been inflicted by some powerful and moral force on them and their family. 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 *"sharads"*, alms are given to individuals with disabilities. Secondly, such a perception reinforces a distancing of one's responsibility.

However, adopting a purely medical and charitable stance is limiting and has not resulted in any effective and sustainable policies and/or practices. Moreover, such perceptions overlook the dynamic and fluid nature of disability. There is thus a need for a greater 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, limitations of activities and restrictions of participation (WHO, 2001). 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 we collect data but also how we 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

The World Bank Report notes that focusing on "opportunities" is an important variable in making policies for youth friendly and hence calls for an examination of the extent to which policies and institutions allow for young people to develop their future skills- not just work, but also social skills (World Bank, 2006). Thus, focusing on the existing structures of education, employment and health services to facilitate the involvement of youth with disabilities is essential. The World Development Report, 2006—*Equity and Development*—noted that "the distribution of opportunities matters more than the distribution of outcomes" (World Bank, 2005, p. 4). As argued in this paper, young people with disabilities face very different opportunities than their able-bodied peers. While the government is drafting disability legislations and policies, it is failing to engage with underlying issues of education and marginalisation. Providing reservations is just one step and much more needs to be done to convert these into actual usable opportunities. 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" (Sen, 2004, p. 4). Sen goes on to elaborate 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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