

## **RECOUP Working Paper 10**

# **Conceptualising Disability and Education in the South: Challenges for Research**

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**RECOUP Working Paper No. 10****Conceptualising disability and education in the South: Challenges for research<sup>1</sup>**

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**Abstract**

The aim of this paper is to discuss some of the methodological challenges underpinning the “Disability, Education and Poverty Project” (DEPP) to be carried out by the Research Consortium on Educational Outcomes and Poverty (RECOUP). The DEPP aims to explore the role that education plays, if any, in the lives of individuals with disabilities living in poverty. It aims to understand the effect of education (of various kinds) on social, human and learning outcomes. In working with young persons with disabilities (in the age group of 14- 25 years) and their significant others, this research will explore the local meanings that persons with disabilities and others around them attach to disability, poverty and education. It will focus on the role that education and other enabling factors play in helping young people with disabilities make transitions into adulthood and in some instances move out of poverty. Although the Disability, Education and Poverty Project is based in four countries, (Kenya, Ghana, India and Pakistan) the arguments developed in this paper draw primarily upon literature from India and Kenya. This paper begins by exploring the relationships between disability and poverty and then discusses three central challenges facing the conceptualisation of this research project.

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## **Relationships between disability and poverty: cyclical and multi-dimensional**

“Disability is both a cause and consequence of poverty” (DFID, 2000:1). There is increasing evidence to suggest that being poor dramatically increases the likelihood of being born with impairment. Being poor also increases one’s probability of becoming impaired and then disabled. This is not surprising as people living in poverty 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. The World Health Organisation (WHO, 1999) estimated that more than 500 million people, or 7- 10 percent of the world’s population, are likely to be disabled by impairments that are preventable or treatable. This assertion about the causes of disability is supported by a recent report “*The Indian Child*” published by Child Relief and You (CRY), 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. Similarly, since people with disabilities are systematically excluded from basic health care services, political and legal processes, formal/informal education and employment, they are likely to have significantly reduced income-generating opportunities, thus leading to poverty (Yeo & Moore, 2003). This cyclic relationship between disability and poverty results in a scenario where people with disabilities are usually disproportionately found amongst the poorest of the poor. Elwan (1999) suggests that people with disabilities may account for as many as one in five of the world’s poorest. Yeo (2005:1) 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”. Even though much is written about the cyclical relationship between poverty and disability, however, due to the lack of data these linkages have not been systemically examined (Elwan, 1999).<sup>2</sup>

Harriss-White (2003: 5) notes that “chronic sickness and disability seems to affect both short term and long term poverty”. Evidence suggests that disability interacts with poverty in a variety of ways. Poverty itself is not a singular concept, and disability tends to be associated with particular forms of chronic poverty<sup>3</sup>, depending on factors such as the age at which an individual becomes impaired, the type of impairment, and her/his position in the household. For example, Brauhnoltz

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<sup>2</sup> For instance, it would be too naïve to assume that as people and countries get richer disability reduces. Rather there is evidence to suggest that, with development, there is an increase rather than a decrease in the proportion of a population with disabilities, due to factors such as increased survival rates from disabling accidents and disease, and increasing life expectancy (Elwan, 1999). Therefore, even as national income grows, total incidence of disability may rise, and may even be greater than in poorer countries. However, in all societies at any stage of development- the poorest sections of the population are at greatest risk of becoming disabled rather than richer ones.

<sup>3</sup> Brauhnoltz (2007: 2) notes that poverty is a dynamic condition. Those who fall under the category of the chronically poor are not just those who are always below the poverty line, rather it comprises of those who are “usually poor”, those who are on average poor although they may temporarily escape from poverty for short periods, and the fluctuating poor, those who live around the poverty line and are vulnerable to chronic poverty.

(2007) states that not all chronically poor people are born into long term deprivation. Many slide into chronic poverty after a shock or series of shocks that they cannot recover from: these shocks include ill health and injury. He goes on to suggest that the long-term poor who are not economically active because of health, age, physical or mental disability, are more likely to face enduring poverty, as the exit routes available to them are limited. Braunholtz notes two important exit routes, namely high dependency by the 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. In the case of individuals with disabilities, neither of these routes 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 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 it hard for them to access these institutions. Thus, societal beliefs and norms may limit the possibilities of escape for this group of people. It therefore seems that not only are people living in poverty 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 the next generation. I discuss some of these interrelationships briefly below.

While poverty results in various forms of social exclusion, these intersect further with disability to form multiple layers of disadvantages. The 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, 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 *et. al*, 2001).

Disability does not affect only the individual, but it also has a profound impact on the family unit within which this individual operates. It is not only the individual who incurs various economic and social costs, but the family is also disadvantaged in various ways. The economic costs can be characterised as: the direct costs of treatment and access to medical services; the indirect costs incurred by those who are not directly affected (carers); and the opportunity costs of income foregone from incapacity (Erb & Harriss-White, 1999).

It has been reported that the average income is significantly lower for households affected by disability; they are thus more likely to have lower savings, higher debts, and lower levels of land and assets ownership. In a study involving consultations with the poor across 10 different sites in the two

Indian states of Bihar and Andhra Pradesh, researchers found that expenditure on health emerged as a major causal factor of impoverishment and continued deprivation. In large families, particularly, and in families with old and disabled people, this problem was more poignant (PRAXIS, 1999).

In addition, the indirect costs of disability are also very significant: the burden of care in developing countries primarily falls on family members, who have to take valuable time away from earning daily wages and/or schooling. In Nicaragua (World Bank, 2005a) family members spent on average 10 hours a day caring for a disabled family member<sup>4</sup>, thus having a considerable impact on their employment prospects and home production.

Research also indicates that the available opportunities to work are significantly reduced after the onset of disability. A national government survey conducted in India in 2002 found that 46 percent of people with disabilities were without work. Over half of these lost their job after the onset of disability (55.8 percent and 53.1 percent in rural and urban areas), and another 13.2 percent had to change their job due to onset (Zutshi, 2004). Furthermore, a Ugandan study (Hoogeveen, 2004) noted that disabled people are less likely to be included in the labour market and are more likely to be self employed: they tend to undertake subsistence farming (27 percent) and petty trade (25 percent). Similar trends were noted in Kenya. Ndinda (2005) argues that while there are no reliable statistics, it is clear that disabled people are more likely to be unemployed or underemployed in Kenya. Thus across the developing economies persons with disabilities are more likely to work in manual and lower skilled occupations and less likely to work in managerial, professional and high skilled occupations. This marginalisation in the labour force impacts on their earning potential.

The economic costs of disability are not only felt in the private sphere (at the level of the individual and the family), but disabilities also result in significant public costs. A World Bank study estimated the annual loss of GDP globally, due to having so many people with disabilities out of work, at between US\$1.37 trillion and US\$ 1.94 trillion (Metts, 2000 quoted in Zadek & Scott-Parker, 2001). The WHO in 1989 noted that the aggregate costs of blindness to the Indian national economy, including a minimal subsistence allowance for blind people, amounted to approximately US\$4.6 billion per year (Gooding, 2006).

While all kinds of disability have significant costs, the economic and social impacts of different types of impairment are likely to be different. For example, the economic opportunities available to a hearing-impaired person are likely to be different from those available to a physically impaired individual in an agrarian society. However, there is a lack of research to illuminate these issues.

As suggested earlier, the costs of disability are not merely economic, but a range of associated costs in terms of unmet capabilities and forgone opportunities both at the level of the individual with

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<sup>4</sup> Indeed the type of impairments does play an important role, with some requiring more care and support than others. There is evidence to suggest that some people with disabilities take on caring roles in the family.

disabilities and her/his family are also evident. Moreover the impact of disability varies significantly according to the age of onset of impairment. Not surprisingly, the onset of impairments at an early age means lost opportunities for education, employment and leisure, in comparison to an onset in old age.

### *Young people with disabilities*

The associated impact of disability is especially noticeable in the case of young people with disabilities making transitions to adulthood.<sup>5</sup> A UNICEF (1999: 1) report stated that, “Adolescents and youth with disabilities are among the neediest and most overlooked of all the world’s children”. 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 and this situation is reflected in the more recent *World Development Report 2007: Development and the Next Generation* (World Bank, 2006).<sup>6</sup>

This is a significant oversight considering that WHO estimates suggest that there are between 120-150 million children, adolescents and youth with disabilities. UNICEF (1999: 4) reported that

...with half of the world’s population under 15 years old, the number of adolescents and youth with disabilities can be expected to rise markedly over the next decade. This rise will not simply reflect an increasing birth rate. Adolescents and youth are at increased risk for acquiring a disability due to work related injuries and risk taking behaviour (including motor vehicle accidents, experimentations with drugs and unprotected sex)...

It goes on to elucidate the bleak prospect facing young people with disabilities. Using small vignettes of experiences from youth with disabilities across the globe, it describes the lack of

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<sup>5</sup> ‘Transitions’ are multifaceted, active processes of social orientation that imply status and role changes, as individuals move from child-focused to adult-focused roles and responsibilities. Dee (2006) usefully summarises three complementary perspectives for understanding transitions: (1) A phase-related model, that regards transition to adulthood as a number of stages through which an individual must pass during a lifetime, such as getting paid employment, adopting new family roles and responsibilities etc.; (2) An agency-related model, that reflects the degree of agency or control that individuals have in determining the course of their lives; and finally (3) A time-related model, one that brings a more multidisciplinary perspective (drawing together biology, social psychology and sociology) and states that three dimensions of time—historical time (impact of long term social, economic and legislative changes in the lives of individuals), life time (the predictable, age related changes) and social time (rights, duties, responsibilities and expectations that are conferred on individuals at different stages of their life)—influence the development of adults. These ‘transitions’ approaches thus reflect changes in how we see ourselves as well as in how others see us.

<sup>6</sup> This 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 frameworks being used in the Report show at best very limited awareness of the complexities and struggles faced by young people with disabilities.

participation of this group in education, employment, their increased risk for substance abuse, sexual exploitation, social isolation, prejudice and inappropriate care. Groce (2004) states that the exclusion of young people with disabilities is often formally sanctioned, and they are barred from participation in formal cultural and religious ceremonies that mark their changing status from childhood. They are “also often left out of the less formal rites of passage such as joining a sports team, courting, learning to drive the family vehicle” (p. 22).

Focusing on this group of young people is particularly important for the South because the number of people with disabilities in these countries tends to be higher in the earlier, productive years (Coleridge, 1993). While little is known about the lived experiences of these young people, in terms of how they make sense of the transitions in areas of learning, work, health, family and citizenship (World Bank, 2006), evidence from the field suggests that these transitions are significantly ambiguous and ambivalent when examined using a disability lens. Indeed when young people with disabilities are not included in debates around transitions, the resultant frameworks and markers are too restrictive and simply do away with the possibility of individuals with disabilities being capable of making transitions to adulthood (an example of this is evident in the discussions in Lloyd, 2005). 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, 1993) in a context where “parents frequently expect the child to contribute his labour to the domestic productive unit and when mature, to support his aging parents” (LeVine, 1977, this scenario remains the same decades later)? In the same vein, legal markers for transition from student to work life, as suggested in the Indian context, are different for people with disabilities and those without disabilities. The Persons with Disabilities Act (Ministry of Law and Justice, 1996) states that a person with disabilities has the right to access free education till s/he attains the age of 18 years, unlike the 14 years of age mandated for the non-disabled population. Another important marker of adulthood is the ability to form relationships, especially sexual ones. However, in Kenya, on the one hand, sexual relationships for the disabled are regarded as taboo, yet on the other, sexual exploitation of women with disabilities is not unheard of (Kenya Society for the Mentally Handicapped, 2006). Largely, people with disabilities tend to be sheltered and not allowed to take on responsibilities. Thus, in a socio-cultural context where rights and responsibilities are strongly intertwined, the individual rights of people with disabilities are also most likely to be compromised.<sup>7</sup>

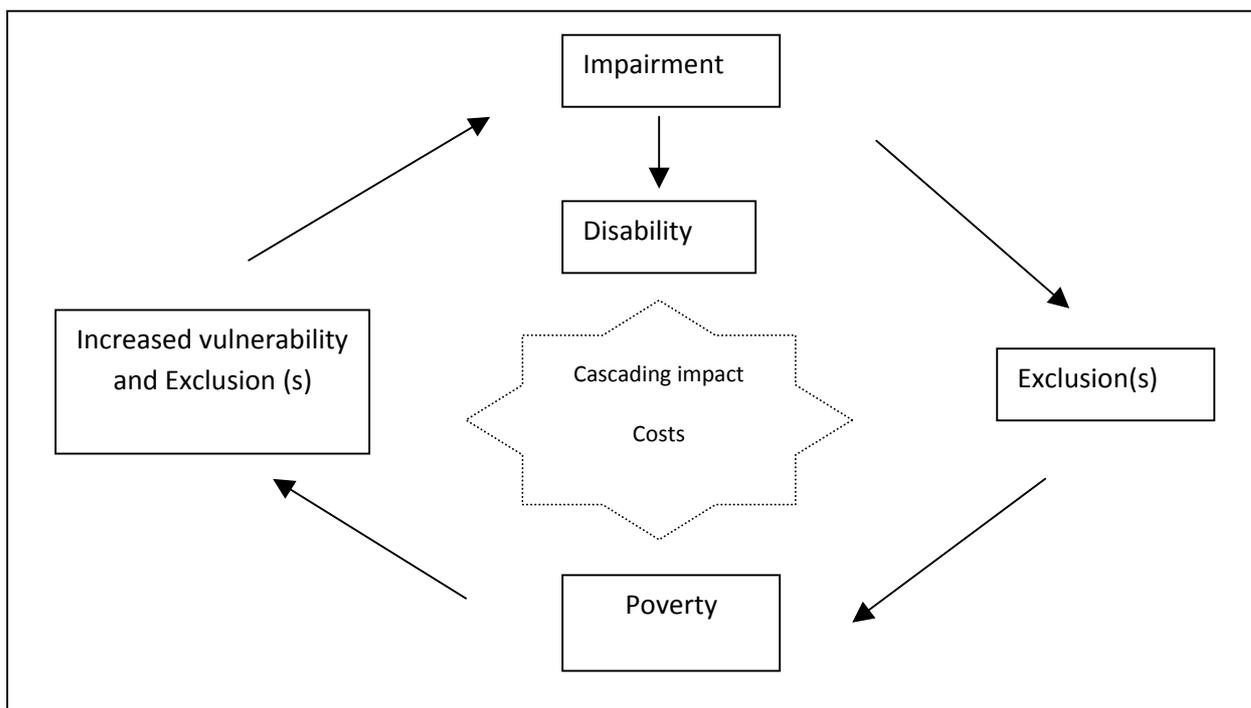
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<sup>7</sup> In many southern (using the term rather loosely, and reflective of collective cultures that are not always or only found in the global South) the focus is not solely on individual rights, rather rights and responsibilities are seen as intertwined. For example, the Indian constitution clearly outlines a set of fundamental duties alongside a set of fundamental rights. Thus, to have certain rights one should also fulfil certain duties, and the rights of those who are unable to fulfil those duties are ambiguous.

### *Disability: a cascading impact*

While a range of challenges operate for the individual with disabilities, her/his disability has a cascading impact on the family unit. For example, while access to school for children with disabilities is an important concern, less emphasis is placed on how having a sibling or a parent with disabilities might compromise another child's schooling and push him/her into 'adult carer' roles. Dennis (1997) notes that many of the children who work on the streets of Tamale, Ghana support disabled adults at home. Similarly, Hoogeveen (2004) noted a significant "education deficit" in Ugandan households headed by a disabled person, as children in these households received less education. While this deficit could be attributed to children being pushed into adult carer roles, it could also be due to the reduced ability of the household to afford school fees because of the direct costs of disability. Thus, to the extent that education drives the ability to earn an income in the future, there is a greater likelihood that the "currently disabled are more likely to pass their poverty on to their children" (Lwanga-Ntale, 2003:7). 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 capital (Moore, 2001 discusses the intergenerational transfer of financial/material capital, socio-cultural capital and socio-political capital amongst poor families). Furthermore, social perceptions of stigma and fear associated with disability, which is commonly regarded as the result of a curse, past sins etc., may further exclude families and reduce the number of relationships and networks that they can actually establish. Thus the impact of disability needs to be studied at the level of the individual, at the level of the family and even at the level of the communities (a context that is often overlooked in the literature).

Attempting to understand these multi-dimensional relationships between disability and poverty is the first step in acknowledging the complexities inherent in designing and undertaking the *DEPP*. Figure: 1 attempts to illustrate the perceived relationship between the important variables of disability, poverty, education and outcomes, in this research project. While each of these variables in itself can be the focus of considerable debate, this paper focuses on three paramount challenges that we are engaging with in undertaking this study. The first two challenges engage with the multi-dimensional and complex concepts of 'disability' and 'outcomes', and the third challenge discusses issues around the outcomes of the research process itself.



*Adapted from DFID (2000)*

**Figure 1: Disability and Poverty: cyclical and multidimensional relationships**

**Challenge 1: The “invisible” minority. Researching disability: issues of identification**

Disability is a multi-dimensional and complex construct and there is no single universally accepted, unproblematic definition of disability. Disability is defined in different ways in different countries and these definitions differ and change within a country with evolving legal, political and social discourses. Harriss-White (2003) notes that “disability is a relative term because cultures define differently their norms of being and doing” (p. 3). Not surprisingly, there are no reliable estimates of the number of people with disabilities in any of the four partner countries, a situation that is shared across the Southern context. Even within established economies, prevalence rates vary from 8 percent to over 20 percent, depending largely on the definitions used. For instance, in one context an individual who controls diabetes with diet alone is considered disabled, while in others someone is disabled only if s/he has impairments that permanently and completely prevent the individual from working. Harriss-White (2003) observes that “conditions such as asthma and TB, which are classified as “sickness” are experienced as disabling in agrarian economies still based substantially on manual labour” (p. 3). However, it is important to note here that not only do overall prevalence rates vary across countries (and there are contrasting views about the relationship between development and

disability) but the prevalence rates of different types of impairments also vary, and the “profile of impairments types changes with medical advances and demographic factors” (Coleridge, 1993). An illustrative example is the rise in the prevalence rates of impairments such as cataracts and arthritis in the developed countries, as the number of people living into old age increases.

A report by the International Labour Organization (2002: 9) states that “in Kenya, there are no recent data on the situation of persons with disabilities. Some statistics are available, although it is generally agreed that these do not give an accurate picture of the actual prevalence of disability. According to the Kenya Population Census of 1989, an estimated 0.7 per cent of the total population (estimated at 21.4 million in 1989) was disabled”, thus putting the numbers of people with disabilities at approximately 149,800. Quoting estimates provided by the UNICEF, Oloo (2005) states that “the proportion of people with disabilities in Kenya is about 10 percent of the total population or just over three million people”; these figures were supported by the Karugu, *et al* (1995), report. Such discrepancies in recorded prevalence rates are also evident in the Indian context. According to the most recent Census data there are 21.9 million people with disabilities, about 2.13 percent of the total population. The numbers suggested by the census seem to be an underestimate if one accepts the WHO argument that 10-12 percent of the population in any country is likely to be disabled.

As disability is the social outcome of a physical, sensory and/or mental impairment, it is shaped within existing macro discourses (medical, legal, and socio-cultural) and micro realities (influenced by an individual’s knowledge and personal experiences). These factors do not exist independently, rather they influence each other, and it is essential to explore these in some depth as they have an impact on how we understand disability in the research being undertaken.

### **Macro discourses shaping an understanding of “disability”**

Understandings of disability in any country are influenced by the existing official rhetoric- the manner in which disability is defined and addressed in government documents and in legislation. In both India and Kenya, an analysis of the policy documents suggests that the focus is primarily on the identification and rehabilitation of individuals with disabilities. Disability is seen as located within the individual, it is regarded as a problem of the individual arising from her/his functional limitations and inherent in her/his mind and/or body. This “medicalisation” (Oliver, 1996) of disability results in a scenario where it is regarded as a problem that must be diagnosed, cured or catered for, so that the person can function like ‘others’. Therefore being regarded as a medical infliction it is not surprising that the primary focus in these countries 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 (Singal, 2006). This results in instances where governments give grants for wheelchairs without addressing the need for building ramps or even roads in more rural parts of India and Kenya. Nevertheless, an understanding

of disability as a medical, preventable condition holds some merit, because in developing countries most disability is the result of preventable or treatable factors. However, this 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. The naturalness of this medical condition is further reinforced by the faith placed in the knowledge of an “expert(s)”. The expert is regarded as being paramount, and her/his standing is evident in assertions where disability is defined as, “...not less than 40 percent, as certified by a medical practitioner”, as noted in India’s Persons with Disabilities Act.

In addition to political and legislative discourses, there also exists a cultural repertoire of beliefs about disability, existing discourses of charity and rights, which influence society’s response to people with disabilities. Disability, in addition to being seen as an individual condition, is commonly regarded as 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; Miles & Miles, 1993; Kisanji, 1993). Such perceptions of “primitive retributivism” (Bickenbach, 1993: 189), which are commonly noted in case studies and anecdotal accounts from the Asian and African context, suggest that people who are manifestly defective 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. 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 existing in many societies. For example, it is observed that during “*sharads*” a particular event in the Hindu calendar, alms are given to individuals with disabilities. This is regarded as a good charitable act which secures the person making the donations and his ancestors a place in heaven. Secondly, it also enables society to continue to overlook its own role in the construction and/or elimination of barriers that people with disabilities face.

Notions of charity, welfare and care of persons with disabilities continue to be the dominant features in official Indian rhetoric. While the language in some official documents has moved away from “social welfare” (in the 1<sup>st</sup> Five-Year Plan, 1947-1952), to the current use of “empowerment” (9<sup>th</sup> Five-Year Plan, 1997-2002), this has happened only for ‘other’ historically marginalised groups, such as women and those belonging to scheduled castes/tribes. In the 10<sup>th</sup> Five-Year Plan (2002-2007: 475) persons with disabilities continue to be grouped under “other special groups” combined with “deviants”, and other disadvantaged groups, such as the aged, street children, orphans, and abandoned children. The plan stresses the “care and protection of the state” for these groups (including people with disabilities), because of “the breakdown of the traditional social structures and increased urbanisation, industrialisation and modernisation”.

Thus, the dominant social and cultural representation of people with disabilities in both Kenya and India is underpinned by a conceptualisation of disablement in terms of tragedy, the

impaired body and the “otherness”, with a focus on care, charity and containment. This raises important implications for how disability is defined and researched in this project.

### **Identifying people with disabilities: a challenge**

A review of the research studies conducted at both the national and community levels, especially those undertaken in developing countries, suggests that identifying persons with disabilities is a common concern. Most notable are issues related to the use of language and the influence of various socio-cultural factors.

Lwanga-Ntale (2003:4) describing his research on chronic poverty and disability in Uganda states that defining disability was “rather problematic”, as the term was commonly used for those with physical impairment, mostly of upper and lower limbs. Hence there was an increased likelihood of ignoring those with learning difficulties, blind, deaf, epileptic, etc. He noted that in most dialects, there is no single word that translated into the English word ‘disability’. Similarly, in Hindi the word “*viklang*” used commonly for ‘disability’, does not encompass all types of disabilities but is only indicative of physical disabilities. Moreover, some of the language that is used to identify people with disabilities is stigmatising in itself. Ndurumo (2003) notes that the original Kiswahili word “*wasiojiweza*” used to refer generally to persons in all categories of disabilities, embodies an assumption that the individual is incapable of gainful employment.

Other studies aimed at establishing prevalence rates of disability suggest that not only local perceptions and definitions of disability but also “social dynamics, particularly those of gender and age; ...type of disability and the associated social implications and stigma of that disability” influenced the identification of disability (Kuruvilla & Joseph 1999: 189 undertook a study in rural South India). Similarly, Erb and Harriss-White (2001) state that in rural Tamil Nadu the reported rates of disability were significantly biased towards upper caste Hindus. It is suggested that “scheduled caste people have to be more severely disabled than inhabitants of the caste settlement before they will publicly acknowledge their infirmity” (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. For instance, in richer industrialised countries where social security benefits are available, the issue of stigma is balanced against the advantages in identifying oneself as disabled (Yeo & Moore, 2003).

Another factor which influences people’s decision to disclose information regarding disability in family-oriented cultures is related to the presumption that there will be an inevitable transfer of the damaged life of the individual with disability to that of the other individuals in the family network. Here Das’s (2001) notion of “connected body-selves” is very useful as it first links the physicality of the body to an individual’s identity and experience, and second, the meaning of personhood is fused to a network of other body selves. Thus, by acknowledging the existence of an individual with disabilities in the household there is an increased risk of the exclusion of other members from the

community. Elwan (1999: 29) notes that “having a disabled person in the family is sometimes thought to damage marriage prospects”, and such an observation is supported by anecdotal evidence from India and Kenya.

### **Approaching disability in our research project**

The *Disability, Education and Poverty Project* (DEPP) is adopting a two pronged approach in identifying people with disabilities. It is using a household survey and household census approach with pre-identified markers for noting an individual’s abilities to function, and is also using a more open ended approach to explore the local meanings and understandings of disability at the community level.

As discussed earlier, disability in these countries is primarily regarded as a medical issue and the focus is on impairments. While it is rather difficult and not necessarily useful to move away from a medical approach to disability in a developing country context, there is a need for greater appreciation of the individual and the environmental elements that need to be understood in a wider totality. While it is important to address social factors, there is a danger of adopting an over-socialised view of disability. This is likely to create a reductionist perspective which does not acknowledge the pain and anguish experienced by the individual (this is especially evident in discussions around the social model of disability in more developed economies). The approach adopted in this project is to focus not only on bodily issues but also on the impact that these have on activity and participation. Thus the questions are anchored not in an impairment based approach but rather suggest an activity limitation approach. It is argued that since an individual’s functioning and disability occurs in a context, it is useful to regard this in terms of impairments of body structures and functions, limitations of activities and restrictions of participation (WHO, 2001). The International Classification of Functioning, Disability and Health (or the ICF model), on which our questions draw, has been a significant step for WHO in attempting to develop a common cross-national language around disability and also moving forward in its thinking to acknowledge the complexities in understanding disability.

Figure: 2 shows the questions that have been adopted for the RECOUP survey work. The six functions are supported by questions related to severity, duration and the impact it has on participation in the areas of home, school/work and leisure.

These questions are based on a review of the recent efforts being undertaken by the UN Statistics Division to implement this new thinking in the collection of disability data. While the ICF holds exciting opportunities for shaping research and practice, being a new classification, as yet there is little evidence of its application in policy and practice.

Initial findings emerging from Pakistan which completed the RECOUP survey work in June 2007 supports the enthusiasm noted in the World Bank (2005a) report. This report notes that by using this new approach where questions address specific functional capacities such as walking, hearing

etc., rather than merely asking “Are you disabled?” more reliable prevalence rates have been recorded. For example, the 1991 Brazilian census reported only a 1 percent to 2 percent disability rate, but the 2001 census, using the improved approach, recorded a 14.5 percent disability rate. Similar jumps in the measured rate of disability have occurred in Turkey (12.3 percent) and Nicaragua (10.1 percent). Initial analysis of the data emerging from the Pakistan survey suggests that approximately 21 percent of the population identified themselves as having a disability. While this figure seems like an over-estimation more in-depth analysis will most likely reveal some interesting trends. An important issue that these figures highlight is that the ability distribution in a population is a continuum. While many people who identify themselves as disabled lie towards one end of the distribution, others, such as those with stammers or slight deafness, report themselves (or are reported by others) as disabled but would be well placed on all other measures of capabilities. The larger ‘disabled’ population also includes those at the other end of the continuum whose impairments, functioning and participation are much more restricted. To use these larger disability statistics for policy-making requires more complex unpacking of their meaning(s) and indeed has significant implications for policies and provisions.

By using questions that capture these complex interactions (between impairment, functioning and participation) across the four partner countries we expect to engage in more depth with a less culture-bound concept of disability than would otherwise have been possible.

Another important dimension of the *DEPP* is the community-level research being undertaken in the partner countries. Here the focus is on approaching the members with an open set of questions. Using techniques such as a household census (here the questions are similar to those asked in the survey) and more contextually sensitive approaches such as transect walk, interviews with stakeholders such as community and religious leaders, the primary health officer, teachers etc we will begin to explore the locally held meanings that people attach to disability. Indeed here the focus on the individual with disability and her/his family members will be a significant dimension. Considering that other RECOUP sub-projects are also working in these communities it is hoped that this extended engagement in the field will allow us to develop rapport with the community and will allow us to engage with potentially sensitive issues, such as disability.

|        |         |          |         |          |   |
|--------|---------|----------|---------|----------|---|
| Seeing | Hearing | Speaking | Walking | Learning | Personal Care (such as washing oneself, caring for body parts, toileting, dressing, eating, drinking) |
|--------|---------|----------|---------|----------|---|

The following sub-sections are used within each of the above types of disabilities.

|                   |  |                 |  |                       |  |
|-------------------|--|-----------------|--|-----------------------|--|
| Yes = 1<br>No = 2 | Degree<br>1 = mild<br>2 = moderate<br>3 = severe | Since what age? | Does this reduce the amount or kind of activity --- can do |                       |  |
|                   |  |                 | At home?   | At work or at school? | In other areas, for example, transport or leisure? |
|                   |  |                 | Yes sometimes  | Yes sometimes         | Yes sometimes                                      |
|                   |  |                 | Yes often  | Yes often             | Yes often  |
|                   |  |                 | No   | No                    | No   |

**Figure 2: Questions addressing disability in the household survey (RECOUP)**

## **Challenge (2): Conceptualising educational outcomes for young people with disabilities in developing countries**

In the Northern context there is a steadily growing body of literature which addresses issues related to the education of young people with disabilities. This work has primarily focused on issues, such as increasing the access and participation of youth with disabilities in the formal education system and supporting their transitions to adulthood. For example, the National Centre for Educational Outcomes in Minnesota (USA) aims to increase the retention and participation of those with disabilities in post-secondary and higher education, by focusing on issues of assessment and curriculum delivery (NCEO, 2007). Other aspects of the research have focused on the role that education can play in helping these young people make transitions to adulthood through work programmes leading to some kind of employment. In this area the focus on developing person-centred approaches has been especially noteworthy. More recently, the notion of life-long learning has come to the forefront and debates have begun to challenge the rather singular focus on linking education to employment, rather than focusing on enhancing the quality of life.

However, literature addressing educational outcomes for young people with disabilities is relatively non-existent in Southern contexts. Moreover, exploring the outcomes of education for this group in these contexts is particularly challenging. Here we undertake a discussion of the challenges inherent in such an exercise and outline the framework being proposed by the DEPP.

### *(1) Education: Looking beyond the formal system*

Global estimates suggest that fewer than 5 percent of children with disabilities achieve the goal of primary school completion (Peters, 2003). Official figures within India about the educational participation of children with disabilities in primary education are rather disparate- ranging from less than 1 percent (Mukhopadhyay & Mani, 2002), not more than 4 percent (National Council for Educational Research and Training, 2005) to some reports even suggesting estimates as high as 67.5 percent<sup>8</sup> (Ministry of Human Resource Development, 2004). In a planning document published by the Department of Higher Education (2005) it is noted that “despite efforts over the past three decades by the government and the non-government sector, educational facilities need to be made available to a substantial proportion of persons with disability.” It states that according to NSSO 2002 figures, “of the literate disabled population only 9 percent completed secondary and above education”. Compared to a national literacy figure of around 65 percent, the percentage of literacy levels of the disabled population is only 49 percent. The literacy rates for women with disabilities are lower than those for

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<sup>8</sup> This MHRD report was published to map India’s progress towards EFA. It notes that of the 1.6 million children with special needs (a term which is not defined, but tends to be synonymously used to refer to children with disabilities in the Indian context) in the 6 to 14 years age group, 1.08 million children with disabilities are attending schools.

men with disabilities – 37 and 58 percent respectively (in comparison to over 54 percent and 76 percent for the non-disabled population). Estimates from Kenya with regard to the participation of young people with disabilities in secondary and higher education are not very encouraging either.

Thus, the participation of young people with disabilities, living in poor communities, in the formal education system is unlikely to be very high. However, evidence suggests that various alternative forms of education might be available to this group. Both India and Kenya have seen a significant rise in the number of special schools and in the number of Non-Governmental Organisations (NGOs) working with people with disabilities. For example, in India in the early 1990s there were only 1035 special schools (Ministry of Human Resource Development, 1992), a decade later it was estimated that there are about 2,500 special schools in the country (Rehabilitation Council of India, 2000). Over the past few decades there has also been a growing focus on Community based Rehabilitation (CBR) programmes, which have undertaken significant work in the areas of education, training and employment of people with disabilities. It would therefore be useful to understand the nature and purpose of education delivered in these settings. The challenge in the DEPP is thus to develop an understanding that moves beyond equating education with formal schooling, rather to begin to acknowledge that education occurs in a range of different contexts, which may be both formal and non-formal. Thus, it will be essential to understand and focus on the various “educational arrangements” that are available to young people with disabilities – how these are characterised and their role and purpose in the lives of youth with disabilities.

## *(2) Outcomes: capturing the complex lives of young people with disabilities*

The majority of the literature on outcomes of education uses the markers of knowledge, employability, earnings, and more recently, citizenship. However, these markers do not seem adequate enough for capturing the complex and often marginalised lives of people with disabilities. In a study exploring the aims of education, as perceived by head teachers of special schools and units in Nairobi and Central Provinces of Kenya, Muuya (2002) noted the central purpose of education remained focused on control, containment and care. Head teachers regarded instilling knowledge of personal care and obedience to fit in with the rest of the population as being of fundamental concern in educating young people with disabilities. Issues around employability and citizenship did not feature high on their list of priorities. This study raises some important issues around exploring in more depth the aims and outcomes of education that is provided for people with disabilities. It also highlights a need to explore:

- the kind of lives that people with disabilities currently live and/or aspire to live and
- the role that education plays, does not play or is perceived as being capable of playing, in helping them achieve the capabilities that they think will allow them to live the lives that they would like to live.

While earnings and employability are powerful markers for assessing the outcomes of education and have frequently been used in mainstream debates, they are rather restrictive in understanding the lives of persons with disabilities (and indeed one could argue these markers are insufficient for understanding the lives of non-disabled people too). Moving away from an economic concern is even more difficult in a context where the focus is on pro-poor development and an assumption holds that well-being can be achieved only through economic progress. However, there is some merit in undertaking an exploration of “other” outcomes. Deepa *et al* (2000) noted that when defining their perceptions of well being, people living in poverty did not focus purely on economic well-being but highlighted the need to be regarded as valued members of society as an important variable. Thus, it would be noteworthy to explore the role of education in this broader framework.

The 2007 *World Development Report* (World Bank, 2006) with its focus on “The Next Generation” identifies five areas of youth transitions as “continuing to learn, starting to work, developing a healthy lifestyle, beginning a family, and exercising citizenship” and notes that these have “the biggest long term impact on how human capital is kept safe, developed, and deployed” (p. 2). The Report’s focus on ‘opportunities’, ‘capabilities’ and ‘second chances’ available to the young, provides a useful framework for analysis. However, it seems to reflect a somewhat mistaken belief that all young people go through all these five transitions (p. 10). While it acknowledges that these transitions have different trajectories across gender, it does not indicate how these might look for youth with disabilities. Indeed, some of its assumptions are misplaced. For example, the report argues that “...in the transitions towards sustaining a healthy lifestyle and forming families, for example, outcomes are influenced most by young people’s behaviour, so the emphasis would be on capabilities” (p.11). In contrast one could argue that for a young person with disabilities living in a rural area of a developing country, sustaining a healthy lifestyle is less likely to relate to her/his capabilities, but is more likely related to the lack of opportunities to access adequate and efficient health care services. Nonetheless, the areas of transition that are identified in this report are useful as a starting point and are somewhat in line with the goals of education for young people identified in a major OECD/CERI (1986, quoted in Bradley *et. al.*, 1994) study. While these goals in principle might apply to all young people but there are some groups that are more vulnerable and face greater barriers in moving towards them, while for some young people these transitions might not even be appropriate. For example, for some individuals’ employment might not be plausible, yet engagement in meaningful activities might be more valued. Within the Northern context where these debates are more advanced there is a growing appreciation of the need to develop more culturally nuanced understanding of the processes underpinning transitions. For example, in the UK context, Maudslay *et. al.*, (2003) researching the lives of young people with learning difficulties from South Asian backgrounds noted that while ‘independence’ is a valued dimension in transitions and is often interpreted as living away from the family, it may not always be a desirable goal in the family-oriented South Asian culture, especially for young people with disabilities.

Thus, notions of transition are not constant across cultures, and this is reflected in some of the debates in the ‘quality of life’ (QOL) literature. Most of the QOL literature is Northern based; however some of the discussions undertaken here are useful for consideration in the Southern context. The quality of life movement arose in part with the community care movement and since then has taken on various meanings, but its central thrust has been on understanding the way in which people with disabilities experience the quality of their daily lives. Holst (2000) provides a useful overview of the quality of life literature and examines the different ways in which it has developed over the years. The quality of life debates in North America have focused on making objective tools for evaluation and monitoring of services and support arrangements offered by society to people with disabilities (this is reflective of the significant role that the state plays in providing services for people with disabilities).

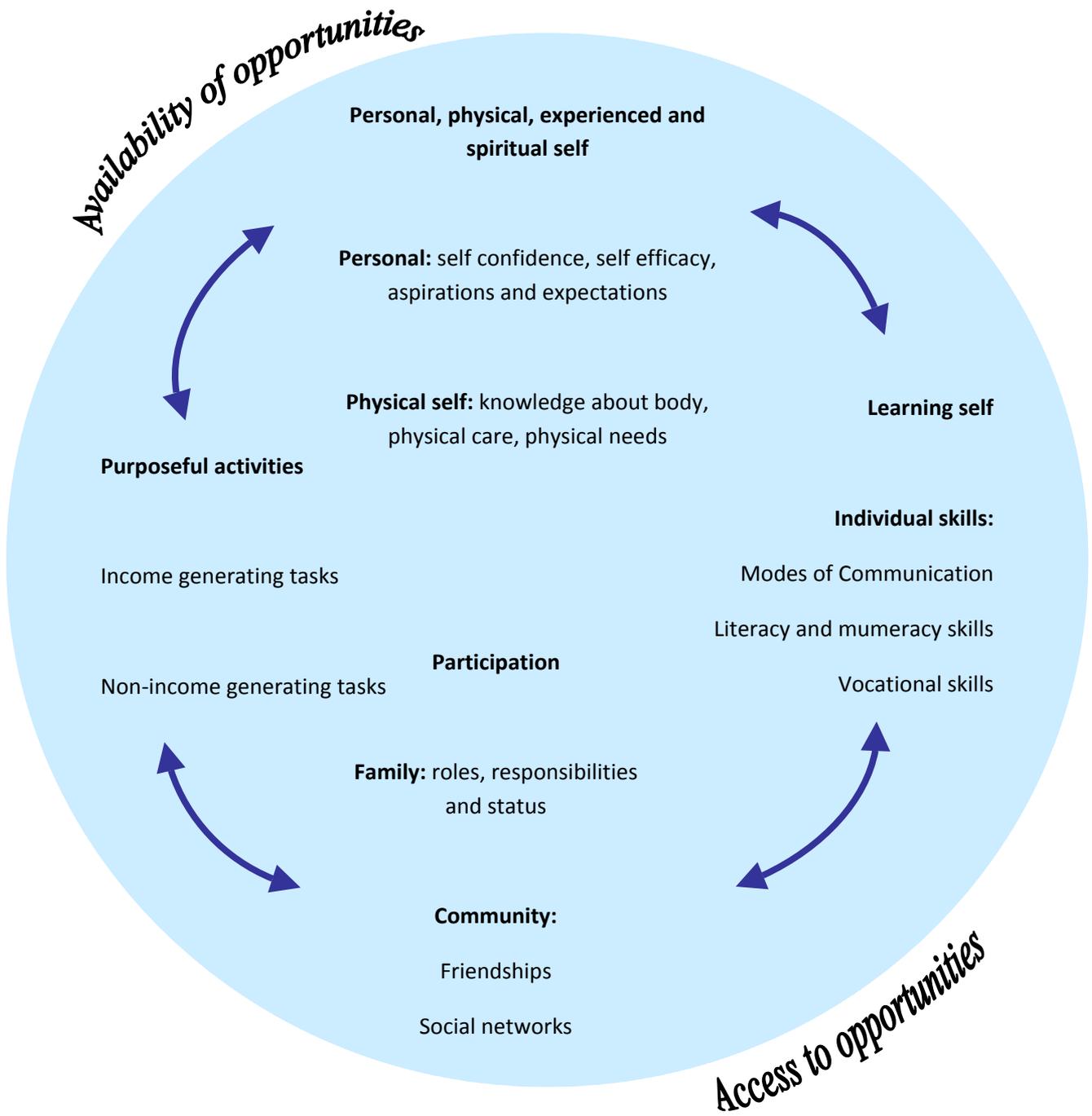
However, the assumption here holds that indicators and measures of quality of life are constant and common, which is not necessarily correct. Rather there is a need to acknowledge that “quality of life can be understood as something quite subjective and culture-related” (ibid, p.: 36). Therefore it may be more useful to focus on understanding the “the way in which people with disabilities experience the quality of their daily lives”, their visions and ideas about quality of life they might wish to lead and hence use these formulations for development of appropriate policies and practices. However, the danger in adhering too closely to this understanding is that “our experience, understanding and visions about quality of life are coloured by the culture and social environment of which we are a part. Thus, we are all limited by the natural inevitability of the world created by the social and cultural environments we form part of throughout our lives”. In such a scenario, daily life in a special institution might seem so natural that a person might have difficulty in imagining that life could be radically different, especially when one has most likely always been seen in a position of dependency. However, casting ourselves in the role of knowing what others (those dependent on us) might perceive as a good quality of life might result in a scenario “where we aspire for the objective of quality which might lead to a kind of tyranny of the normal.” Thus while the basic idea of quality of life is useful, it would be useful to draw on its objective side (which can be studied by registering the actual conditions of life on a framework which is illustrative of certain dimensions), and also develop its subjective side, which is focused on exploring the extent to which people themselves feel satisfied about their lives.

The role of education in preparing young people with disabilities to lead a good quality of life, however defined, should not be underestimated. UNESCO (1996) noted that education should serve a bigger purpose for children and young people, “...while education is an ongoing process of improving knowledge and skills, it is also - perhaps primarily - an exceptional means of bringing about personal development and building relationships among individuals, groups and nations” (p: 5). This report elucidated the “four pillars of education”: learning to know, learning to do, learning to live

together, and learning to be, as a powerful framework for examining the continued role of education throughout an individual's life.

Thus the aim here is to develop a framework that has the potential to contribute to the quality of life for young people with disabilities. There is a need to develop a framework which is person-centred and above all culturally sensitive. For example, it will not be useful to situate debates concerning young people with disabilities in an individualistic approach to transitions (as has been the case in the Northern literature), rather it is essential to explore more collective understandings of perceptions towards disabilities, and of the opportunities, aspirations and expectations for people with disabilities as perceived by their families and significant others. However, while such an understanding is in line with cultural underpinnings in Kenya and India, it cannot be overlooked that the voices of young people with disabilities have historically been silenced and overshadowed. Thus the central concern is to listen to these predominantly marginalised voices, but also to locate them within their larger milieu.

In accordance with this thinking, figure 3 sets out the proposed framework for understanding the social and human development outcomes for young people with disabilities. This thinking is taken further in figure 4, where the focus is on locating the individual within the context of their family and the broader community. The four broad dimensions of: the self, the learning self, participation and purposeful activities, are central to the framework. The following discussion presents a rationale and description of each of these areas. At the outset it is important to highlight that these dimensions are highly interrelated.



**Figure 3: Outcomes at the individual level**

| <b>INDIVIDUAL</b> |  |  |   |  |
|-------------------|--|--|---|--|
|                   | <b>SELF</b>  | <b>LEARNING SELF</b>   | <b>PARTICIPATION</b>  | <b>PURPOSEFUL ACTIVITIES</b>   |
| <b>FAMILY</b>     | Attitudes towards; expectations from; and aspirations for PWD                            | Perceived value and purpose of education for PWD;<br><br>Responsibility for education within the household;<br><br>Knowledge and understanding regarding the individual with disabilities and her/his rights | Impact on areas of education, work, leisure of non-disabled family members<br><br>Care responsibilities   | Responsibilities given to PWD; perceived role in management of household and in income generation          |
| <b>COMMUNITY</b>  | Understandings of disability; perceptions towards, expectations of; aspirations from PWD | Perceived value and purpose of education for PWD;<br><br>Knowledge and understanding regarding the individual with disabilities and her/his rights   | Perceptions towards and opportunities available to form friendships, met PWD<br><br>Role of the church, NGO and political bodies<br><br>Social spaces occupied by PWD | Opportunities available school and/or get vocational training (what types);<br><br>Attitudes of employees, |

*Note: PWD – Persons with disability*

**Figure 4: Conceptualising Outcomes using a systemic approach**

### **Self**

The notion of self is a rather powerful and important aspect to explore especially with regard to people with disabilities as they are likely to be hidden behind labels and associated stereotyping. Therefore the focus here is on understanding the individual: the personal, the physical and the experienced self. It entails an exploration of how the individual feels about her/himself and her/his disability. What does it mean to be disabled? The aim is to move beyond the use of medical terminologies and classifications to a reflection on the lived reality of the individual. Here the

individual's perception of how others understand her/him is also important (the experienced self). Additionally, the focus on aspirations is significant as they are central to a sense of being. While aspirations of young people with disabilities are not likely to be very different from those of their non-disabled peers the opportunities (and capabilities) available to them are likely to be rather different (Dee, 2006).<sup>9</sup>

The systemic approach places the individual within the family and the community; hence the focus here is on their understandings and perceptions of disability. How they perceive disability and the kind of expectations and aspirations they hold. Expectations that our significant others place on us have a noteworthy impact on the opportunities that are made available to us and also influence the capabilities that we are likely to foster. As Dee *et al.*, (2007), note “research into the lives of people with learning difficulties shows that more often than not their identities are bound by the assumptions and expectations of others about who ‘people with learning difficulties’ are and what is best for them”. A pertinent example here are the findings of a survey of young people with disabilities in Mexico where it was noted that they had a greater desire for “education, psychosocial support and rehabilitation than for job training” (UNICEF, 1999). In contrast, the focus of most community based efforts tends to be primarily directed towards providing some kind of job training on the assumption that it leads to economic independence, however outdated and monotonous that training might be.

### **Learning self**

This aspect explores the capabilities that the individual has acquired--her/his skills, knowledge and understandings. Here the focus is on identifying the modes of communication that the individual uses and their effectiveness. It focuses on the young person's skills which might be related though not limited to, numeracy, literacy, vocational and other social skills. It also attempts to identify the individual's awareness of her/his rights and knowledge of the available resources. Amongst other things it is reflective of the quality of education that the person has received.

At the levels of the family and the community it enables an exploration of the purposes (why should they be educated?) and processes (how should they be educated?) of the education available for young people with disabilities.

### **Participation**

This dimension focuses on exploring levels of participation for the young person in their family and the community. The role, responsibilities and status that the individual has in her/his family and the voice s/he has in the decisions that shape her/his present and future (such as decisions

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<sup>9</sup> Dee (2006) used a case study approach with young people with a range of people with special educational needs and noted aspirations such as becoming a film star, having a girlfriend, being a full-time house wife, carpenter etc.

about getting married, having a family, working) and that of the larger household. What role does the young person with disabilities play in the community—what are the nature and types of interactions that s/he has with people outside her/his household?

As previously discussed in the paper, having a person with disability in the household can have a significant impact on other family members- their education, employment, leisure and quality of life. Park *et al*, (2002), in a study undertaken in the US, noted that having a disabled family member significantly strained family interactions, their emotional well being, health and productivity. In Southern countries where services provided by the state are rather limited, the responsibilities and demands placed on the family are higher and hence need to be examined. At the level of the community, the focus is on identifying social networks and friendship patterns, and any involvement with NGOs, religious and/or political bodies. Here attention will also be focused on identifying the social spaces that are open to young people with disabilities and those which are restricted.

### **Purposeful activities**

This dimension acknowledges that focusing only on employment is restrictive in terms of exploring the types of activities that might be undertaken by young people with disabilities. Hence the focus here is on identifying not only the income generating tasks, but also the activities that might be undertaken at home (e.g., doing chores, caring for siblings) or others outside the house, which might be voluntary. In a study undertaken in Scotland, Riddell *et al*, (2001) noted that in the absence of employment, adults with learning difficulties find themselves without any valued social role. However, more interesting was the finding that women with disabilities, because of the traditionally associated gender roles, were required to undertake domestic work and caring work, which in the absence of paid work provided them with purposeful activity and enabled them to resist the label of dependency and child-like status. An important aspect which tends to get neglected is that of leisure: although poverty itself restricts the kind of activities that can be undertaken, nonetheless it would be useful to explore if this notion exists and if so, what it entails.

At the level of the family, the focus will be on understanding the kind of contributions that the young person with disabilities is regarded as capable of making (within and outside the household) and the kind of support systems available to her/him to develop the skills needed. These contributions could be monetary and/or in sharing the responsibilities in the household. Finally, the community offers an important site for examining the opportunities that are available to young people with disabilities to get a job- the types of activities available and those which are as seen as 'fit' for the person with disabilities.

## Opportunities

As noted earlier, these four dimensions are highly interrelated, but they are also nested within the kind of opportunities available to (and accessed by) young people with disabilities. World Bank (2006) 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. Thus, it is important to examine the extent to which existing structures of education, health services and leisure allow for youth with disabilities to develop the outcomes that allow them to participate in the larger society. An examination of opportunities (as these exist, and in relation to how these are perceived by people with disabilities- both of these might be different) is also important from an equity perspective. The World Development Report, 2006—*Equity and Development* (World Bank, 2005b)—noted that “the distribution of opportunities matters more than the distribution of outcomes” (p. 4). People with disabilities face very different opportunities than their able-bodied peers. Sen (2004) further elaborates on this issue with specific reference to people with disabilities. He proposes the notion of “conversion handicap”, which argues that 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” (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 essential and a cross cutting concern.

The framework proposed here offers the possibility of unpacking and elucidating the multi-faceted concept of “outcomes” for young people with disabilities, while capturing the rich lives and the “multidimensional forces which sculpt the lives of this group” (Beck, 1999) of the next generation.

### *Challenge (3): Building research relationships: engaging with emancipatory and participatory approaches to research*

A central issue that all research, but more so, research focusing on disability needs to engage with is that of “who will benefit from this research?” This is a particularly important issue for disability research in developing countries because of the existing lacuna of information and the rather limited funds that are directed towards undertaking research on such issues. In attempting to address this issue there are no simple answers or pathways to ensure that there is a direct benefit to those who have been involved in this research.

Rioux and Bach (1994) make a rather vivid observation in their book titled, “Disability is not Measles”. They contend that:

What does most research in the field of disability look like? It looks a great deal like the research into measles. The goal is prevention. Cures are sought. However, disability is not a medical condition that needs to be eliminated from the population. It is a social status and the research agenda must take into account the political implications attached to that status. A new research framework seeks to prevent the conditions that make disability a liability in social and economic participation. It identifies ways to increase individual control over social well-being rather than defining social well-being as the absence of disability.

Rioux and Bach not only successfully capture how the very act of research can be disabling but also suggest a useful alternative research stance. Research addressing issues of disability in developing countries is rather limited and tends to be dominated with concerns such as establishing the prevalence of various disabilities and effectiveness of various programmes of rehabilitation. In a comprehensive review of literature on issues addressing disability and educational outcomes, RECOUP researchers in Kenya and India noted an absence of research on these issues. Apparent from these reviews was also a lack of research which provided “thick descriptions” of the lives of people with disabilities. The Chronic Poverty Research website (2006) notes that

Whilst few research or development organisations would consider working with all male respondents or beneficiaries, it is still common practice to work with only non-disabled people. This is despite recognising that disabled people are disproportionately among those living in chronic poverty.

It is rather recently that research has begun to capture the lived experiences of persons with disabilities; most of this work has been located in the Northern context (e.g., Shakespeare *et al*, 2000). This has led to a growing appreciation of the need to undertake research which focuses on listening to the voices of marginalised groups and acknowledges that people have a desire to be heard. Such perspectives have been captured in research with persons with disabilities undertaken by Leicester (1992) in UK. He notes that “our interviewees were pleased to share their experiences and opinions with us. Many of them commented that they had not before had anyone from outside their family to listen to these experiences and feelings” (p. 143). He goes on to note that “the process of the research, the actual experience of the interviews, proved to be a positive experience for our interviewees”, especially in lives where they was a significant lack of “communication flow”, both in terms of lack of emotional support and that of information about existing services etc. Providing opportunities to persons with disabilities to make their voices heard in developing country contexts, where they are most likely to have been excluded and silenced, is thus rather challenging. The absence of voices of those researched is consistently noted across the few studies and the many commentaries available in the literature on disability and poverty (Robson & Evans, 2005).

In mapping the changing nature of research on disability issues, interesting parallels can be drawn with the changing trends in poverty research. Kothari and Hulme (2003:1) note that “the study of poverty dynamics has largely been dominated by the quantitative analysis of panel data sets collected by questionnaire surveys”. They go on to note the inadequacy of such approaches by stating that “these analyses tend to be ‘lifeless’ and contrasts with more qualitative approaches that deepen the understanding of why some people are poor and cannot escape poverty while others can, and are more ‘life full’. That is, they provide a wealth of data about people and their experiences rather than aggregated classifications, categories and characteristics of poverty”. In this research terrain participatory approaches have become significant.

Participatory approaches have been evolving in recent years, while being subject to different interpretations. Helander (1999), amongst others, favours the use of participatory approaches in researching issues of disability in developing countries. He argues that researching and evaluating the needs of people with disabilities should be the starting point in any plan for determining the provision required in meeting those needs. As such, an analysis needs to take into account a range of cultural and contextual factors, such as political, religious and economic issues. Participatory approaches are developed primarily from a qualitative research tradition, with a focus on meaning, interpretation and giving the participants “a right of voice”. This research stance reflects the concerns and views of research participants with disabilities and thus tends to reflect a social model of disability. The focus is on listening to the research participants who are the real experts in knowing their situation. Therefore, the role of the researcher, as suggested by Turmusani (2004) is to “get involved in a learning process from and within the locality. Thus, the research acts as means to facilitate greater involvement of disabled people in the research process” (p. 8).

### **The DEPP Approach**

The focus in the DEPP is therefore on capturing the voices and lived experiences of people with disabilities. The aim is to use a range of qualitative methods, such as life history, visual images, and interviews to gather insights on how education has played a role in the lives of persons with disabilities. Research conducted by Kitchin (2000) provides insights into how people with disabilities view research and would like it to be conducted. All the research participants expressed strong support for qualitative methods, especially interviews. Participants noted that these methods provide the opportunity “to express and contextualise their true feelings, rather than having them pigeon-holed into boxes with no or little opportunity for contextual explanation” (p. 43). In another study (Duckett & Pratt, 2001) with the same research focus and undertaken with visually impaired people, participants noted the experience of research as being akin to a doctor-patient relationship. In such a setting participants occupy a “compliant and passive role” (p. 827), minimum information is provided, and there is greater compliance and inability to question the doctor. Thus it is important to endeavour

that our research process does not mimic the power dynamic of a doctor-patient relationship. Also building on the socio-cultural context of the partner countries, in-depth interviews will be undertaken with significant others (such as, parents, siblings, school teachers, medical professionals in the village etc) to draw upon their understanding of disability and the impact it has on various aspects of life.

While we endeavour to build mechanisms for listening to voices, we are also conscious that more recently there is a growing emphasis on greater involvement of participants in the research process, not just as suppliers of information but also involving them in making sense of the information produced, by using their 'insider expertise'. Mike Oliver, who is considered to be the proponent of this research approach—the emancipatory approach—advocates that ultimate control should be given to the research subjects and that the research (the process and its product) should be available and accessible to this group in their struggles to improve the conditions of their existence (Oliver, 2002). The fundamental principles shaping emancipatory approach resonates rather closely with the issues that are being discussed at length in research on poverty. This relationship is briefly acknowledged by Bennett & Roberts (2004) and French & Swain (2004). Participatory research approaches in poverty are questioning who participates in the research; how the participants are involved in the research; and what is the best way of allowing the voices of the research participants to be heard.

While these are very important and critical questions which need to be revisited there is a danger that all other research is seen as being unworthy. Additionally, while the emancipatory approach is very powerful and has had much success in more developed economies there are inherent limitations in this approach with regard to its usefulness in researching disability issues in a developing country context. Emancipatory research takes the social model of disability as the basis of research production (Priestley, 1999). It is strongly anchored in the social model and is a part of the struggle of disabled people to control the decision making processes that shape their lives and to achieve full citizenship (p: 19). While this is a useful focus in contexts where disability rights movement and debates around it have greatly evolved, in a developing country context, its relevance can be challenged and it would be “condemned for irrelevance where disabled people’s struggles revolve around daily survival rather than political emancipation” (Stone & Priestley, 1996: 711). Moreover, while the social model is relevant to developing countries it should not be overemphasised in contexts where disability is most likely the result of accident, disease, malnutrition or other treatable or preventable factors. Within western discourses, emancipatory approaches have come under increased scrutiny by feminist writers and others for not taking note of the experience of the body and pain in their research (Morris, 1992; Lang, 2000). Turmusani (2004) further argues that emancipatory research with its greater focus on individualism is not well suited for developing countries where disability has an important familial dimension. Moreover, in methodological terms, emancipatory research focuses primarily on political issues and adopts a rather doctrinaire approach to participation. Methodologically, it argues that independent research should be carried out by disabled

researchers, which raises significant concerns in the existing socio-political context of developing countries.

The emancipatory approach is powerful in the ways in which it allows one to critically challenge and strive for a process where persons with disabilities have greater ownership, and encourage the researcher(s) to be more conscious of the ways in which the research will impact on policy and practice. Nevertheless, within existing contextual realities it should not stop us from becoming facilitators at the disposal of people with disabilities to help make their lives better.

The challenge for DEPP is therefore to explore different ways that will enable research participants to have greater control over some aspects of the research process and also over the messages that would be conveyed at the end of the process. Finally it is useful to reflect on the assertion by Chambers (1983, quoted in Stone & Priestley, 1996), the originator of participatory approaches, that “it is often best to get on with doing whatever can be done, however small” (p. 714).

In moving our work forward we hold true to the belief that the purpose of this research is driven by an assumption that the existing social order needs to be critiqued and changed. The focus is on empowerment of those participating in research in terms of knowledge, skills and action. Here we would argue that this change is not only for the research participants, but the researchers themselves. It is important to recognise that disability is not merely a political but also an emotive issue and there is a need to make increasingly transparent our own assumptions, values and beliefs, as researchers. Such attempts have been an important aspect of the initial stages of the DEPP, and this has had some unintended but important consequences. In engaging with the design of this research has been an opportunity for us (those involved in this project) to explore our own knowledge of disablement and to examine the kind of beliefs we hold and their implications. When describing “disability” our own assumptions come to the forefront. This is evident in the responses to a query regarding what are the words and images that come to mind when we think about “disability”, at workshops in India and Kenya, comprising of members of the research team:

**Responses generated at the India workshop:**

Wheelchair; limitations; barriers; deformities; incapacities; insensitivity; less privileged; dependency; excluded; stigma; they make you feel uncomfortable; neglected; begging; feelings of sympathy; indifference; their feelings of anger, loneliness, hopelessness, frustration; seen as a different group –them and us; impatience of other people; labelling; ‘stories of personal triumph over tragedy, for example that of Helen Keller’

**Responses generated at the Kenya workshop:**

Blind—people who can’t see; hopelessness; pity; dependency; burden; abnormal; can sing; sympathy; carers; support; needy; costs; useless; rejection; hidden; conspicuous/visible; curse; embarrassment

Even though the words used were different, common themes of limitation, stigma and marginalisation are paramount. However, most significant is the emotional reaction that undertaking such an exercise generated. Thus, it is not surprising that there exists no neutral language with which to discuss disability. However, such feelings of sympathy and dejection have the inherent danger of reproducing the misery faced by people with disabilities in the research project rather than focusing on the positives and the enabling factors that play an important role in the lives of some people with disabilities. Moreover, if the focus is on regarding people with disabilities as dependent and in need of care there is the inherent danger that leads to their *voicelessness*. There are many examples where it is seen to be more important to speak to the family of the person with disabilities rather than to the individual, who is seen as lacking in the ability to make sound judgments or describe her/his own situation. Reflecting upon the assumptions that we hold is an uncomfortable but essential process as herein comes into focus the distinction between researching “with” or “on” people with disabilities.

In contexts where people with disabilities are not only marginalized but have also been systematically made invisible in macro and micro discourses, the value of research which attempts to give voice to them is difficult to exaggerate. Thus, it is intended that our research will be participatory in nature, with a “transformative” and “emancipatory” potential, notwithstanding the many challenges facing the implementation of this research approach.

## **Conclusion**

In attempting to address issues of disability and poverty, one cannot overlook the many similarities inherent in these two concepts and the similar ways in which debates around conceptualising poverty and disability have evolved. Over the past few decades, understandings about disability have moved away from an exclusive focus on factors within the individual to a greater appreciation of the barriers that are inherent in society. Similarly, commentaries on poverty no longer focus solely on physical deprivation, but highlight the need to examine social barriers and exclusions that people living in poverty face. Thus, both poverty and disability can be regarded as symptoms of the way that society is organised and how various existing structures and processes continue to marginalise and isolate certain groups of people. In attempting to interrogate and challenge these existing arrangements the role of education is central. Education has an important role not only in shaping the lives of people with disabilities, but also in shaping the perception of those around them. A research project bringing together a focus on poverty, disability and education will hopefully make some worthy contributions to the field.

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