CHAPTER 1

Introduction: Men and Women (with disabilities) at Work

World over, youth is associated with optimism and possibilities. As future thought-leaders, policy makers and change catalysts, youths symbolize hope and aspiration. With 85 percent of the world's youth living in the developing world (UNFPA 2005), countries like India are exciting hubs of youth-powered development. Young Persons with Disabilities (YWD) comprise an important section of the youth population. Throughout the world they have made significant contributions as scholars, sportspersons, scientists, musicians, etc. Other than such extraordinary achievements, many YWDs have successfully negotiated challenges of everyday lives to lead a meaningful life as contributing members of their families and of society. However, despite this, YWDs continue to be an excluded minority. As development literature proclaims the power of youth to transform countries like India (World Bank, 2006), YWDs remain at the periphery- their contributions unrecognized and their potential unexplored.

Debunking the perception of their leading an inactive and dependent life, this study is an attempt to understand and illustrate the dynamic and multifaceted work-lives of YWDs. With a focus on their livelihoods, this study brings to fore experiences, opportunities and barriers in their livelihood pursuits. As the title of the chapter suggests, YWDs are men and women at work, actively undertaking a range of activities.

According to World Health Organization (WHO) estimates, approximately 15 percent of a population has disabilities (WHO 2011). According to Census of India estimates, over 21 million people in India have some form of disability. Among the Persons with Disabilities (PWDs), there are, approximately, between 5 and 5.5 million in the 12-24 years age group in India (Singal 2008). While the numbers are contested, there is little doubt that PWDs constitute a sizable section of the Indian population, both in percentage and in absolute terms.

Among the PWDs, the young persons are further neglected. They are a group that finds itself ‘neither here, nor there’. While Children with Disabilities (CWD) find mention in policies and actions on education, YWDs find themselves subsumed under the broader category of PWDs.
Arguably, the needs of YWD are fundamentally very similar to those of any other young person. These include aspects such as acceptance, vocational readiness and socio-economic inclusion. However, what distinguishes them is not the common nature of needs but the fact that these basic needs remain largely unmet (Groce 2004, cited by Singal 2008). Barriers erected by the functional limitations of their impairments are accentuated by negative societal responses.

Livelihood is one aspect of life where the negative responses get highlighted and expressed with presumptions about their general ‘incapacities’. Popular imagery concerning PWDs conjures up ‘heroes’ who have excelled despite their impairments. However, this thesis is not about such inspirational figures. Rather, it concerns itself with ‘…ordinary people doing ordinary things’ (Oliver 1990:91). Emphasizing that heroic images reinforce the extreme stereotypes often associated with disability, Wendell (1989: 116–17) argues,

> While disabled heroes can be inspiring and heartening to the disabled, they may give the able-bodied the false impression that anyone can “overcome” a disability. Disabled heroes usually have extraordinary social, economic and physical resources that are not available to most people with those disabilities. In addition, many disabled people are not capable of performing physical heroics, because many (perhaps most) disabilities reduce or consume the energy and stamina of people who have them and do not just limit them in some particular kind of physical activity.

The present study, therefore, engages with ordinary people who grapple with the barriers of their day to day life- people who find themselves excluded from mainstream thought and action on both disability and livelihood.

Livelihood is an essential precondition for generating resources for survival. Studies demonstrate far reaching negative economic consequences of loss of earning arising out of non-participation in livelihood. Existing studies also show the symbolic significance of work as a marker of identity and acceptance. Thus work, as in engagement in livelihood, has manifold significance for people, touching upon not just economic but also social and cultural dimensions of life.
For the YWD, engagement in livelihood has crucial significance for the ‘rites of passage’ into adulthood and indeed personhood. In a society where the ability to support a family through productive work is an important marker of adulthood, these young individuals find themselves in an ambivalent situation. They continue to be (or seen as) dependent themselves, needing care and protection (Singal 2008). They either remain, as Bjarnason (2002) describes, in ‘paternalistic world of eternal childhood’ or experience ‘early adulthood’ through marriage and family responsibilities. Both these states highlight their dependence and preclude planning for livelihood.

The exclusion from mainstream livelihood is reflected in low rates of employment (Mitra and Sambamoorthi 2006a, Klasing 2007). In 2002, amongst all working age PWDs, only about 36 percent were employed (NSSO 2002). In addition, these rates showed great variations across sub-population groups, i.e., men versus women, rural versus urban, and type of disability. According to United Nations figures, only about 100,000 persons with disabilities have succeeded in obtaining employment (UN Enable 2010). All these figures reflect a state of exclusion of the PWDs from livelihoods.

While the above figures present the ‘quantity’ aspect of livelihood in terms of numbers, it is useful to ascertain the quality of livelihood that the PWDs are engaged in. Only 4.8 percent of all working age PWDs were ‘salaried-wage employees’ (NSSO 2002, cited by Mitra & Sambamoorthi 2006a). Majority of the PWDs in rural areas of India are employed as wage labour in agriculture (NSSO 2002), one of the lowest return occupations. Inability to engage in skill based occupation and limited options in the rural areas to engage in industrial work limit their option to physical work in agricultural fields (Klasing 2007). Agriculture labour is also often difficult for those with orthopedic and visual impairments due to the physical nature of the work and hand-eye coordination it demands. Low levels of education and skill significantly restrict livelihood options. Finally, few PWDs in India engage in livelihoods as a matter of choice. Often what they engage in are the only options that they are able to exercise.

Given that such a situation persists nearly two decades after the passing of the Persons with Disabilities (Equal Rights and Opportunities) Act 1995, is a matter of concern. This is especially
so as the Act introduced a number of interventions to promote livelihoods for the PWDs. Clearly, there is disconnection- between the macro and macro level -of policy and the context and experiences of the PWDs. This takes us to a range of questions. Where is the disconnection? Do YWDs engage in any work or do they lead dependent lives? If they do engage in work, what are their experiences in pursuit of livelihood? Are their life-stories only about disadvantages and failures? Alternatively, do they also have certain resources or opportunities that they use? Who are the stakeholders who play a role in creating such assets? Finally, are there platforms for these individuals to voice their livelihood concerns? Are there adequate efforts to capture these voices? These are some of the questions that this study engages with. In order to seek to answers to these questions, the present study undertaken in Mandirbazar Block of 24 Parganas (South) district of West Bengal, sets out with the following objectives:

i) Capture the livelihood experiences of the Young Persons with Disabilities (YWDs)
ii) Describe their opportunities in terms of assets they posses
iii) Identify barriers in converting these opportunities into livelihood options
iv) Analyze the role of important structures and processes that impact asset building and utilization

With YWDs and their experiences at the core, the study engages in an in-depth dialogue with them charting the course of their work-life. It also engages with their families, communities and the web of institutions and stakeholders around them that have a bearing on their livelihoods.

Before going further, it is important to explicitly clarify two important terms that the study uses frequently- impairment and disability. This is important because these are at the core of much of theorizing around disability. Rejecting a medicalized understanding of disability, Disabled Peoples’ International in the United Kingdom (UK) proposed a definition of impairment and disability that stated:

Impairment is the lack of part of or all of a limb, or having a defective limb, organ or mechanism of the body. Disability is the loss or limitation of opportunities that prevents people who have impairments from taking part in the normal life of the community on an
equal level with others due to physical and social barriers.' (Cited in Swain et al eds 1993).

However, such a definition remains challenged by assertions that emphasize the importance of the individual experience of impairment (Thomas 2004).

In India, according to the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, "Person with Disability" means a person suffering from not less than forty per cent of any disability as certified by a medical authority. "Disability"- refers to blindness, low vision, leprosy-cured, hearing impairment, loco motor disability, mental retardation and mental illness. The present study covers individuals with blindness, low vision, hearing and speech impairment and loco motor impairment. The following section provides the definition of each based on the PWD Act 1995 and proceeds to describe the implication of each on the livelihood prospects in the given context.

As per the PWD Act 1995, blindness refers to a condition where a person suffers from any of the following conditions, namely: total absence of sight; or visual acuity not exceeding 6/60 or 20/200 (snellen) in the better eye with correcting lenses. In the study, four persons were covered with similar conditions. Person with low vision means a person with impairment of visual functioning even after treatment or standard refractive correction but who uses or is potentially capable of using vision for the planning or execution of a task with appropriate assistive device.

This type of impairment had significant impact on capability development as the local schools were ill-equipped to handle blind children. Despite a national level program, Sarva Siskha Abhiyan and a favorable policy, Right to Education, promoting inclusive education, there was no educational or vocational training facility for the blind in the area (the nearest was in Narendrapur, about 50 kms away and only for boys) that severely restricted access to education and livelihood based on same. Such individuals were also unable to take up agricultural activities as it required hand-eye coordination. Based on their condition, such individuals could take up work that did not require eye-sight. Given that they were familiar with the area and its landscape, they could be mobile. Earlier such persons were often employed in such jobs as Telephone Operators. However, such opportunities have always been in the urban areas. With the advent of
technology, these jobs have largely become redundant. At the same time, technology has also introduced a range of computer aids and software for those with visual impairment making it possible for people with visual impairment to engage in a range of activities. However, these are available only in the urban areas and as such access of most of those in the rural areas is severely restricted. Thus, despite technological innovation, given that the social arrangements continued to deny such individual their basic and fundamental right to education, implied that they were unable to take advantage of these. Consequently, livelihood opportunities for most of such individuals remained restricted.

According to the PWD Act 1995, Hearing impairment means loss of sixty decibels or more in the better ear in the conversational range of frequencies. This type of impairment had significant impact on capability development as the local schools were ill-equipped to handle deaf and/or mute children. There was no educational or vocational training facility for such individuals in the area that severely restricted access to education and livelihood based on same. However, these individuals could engage in work that required physical integrity. In the rural areas, such as the study area, they engaged in agriculture and other manual labour related work. They could also engage in any job that did not require communication including such work as carpentry or piece rate tailoring. Their physical abilities and mobility improved their chances in the rural areas. However, as the study will demonstrate, stigma associated with their impairment often restricted their engagement in rural works program. Also, such opportunities were available mainly to the men. The women were culturally not involved in agricultural field work. They could engage in all house-work. They could also engage in work (including piece rate work) that did not involve communication. With access to modern medical intervention and assistive technologies it would be possible for those with hearing and speech impairment to access education and engage in a wide range of work. However, the inability of the schools to teach such children restricted such opportunities. This also restricted them from accessing new opportunities such jobs as data entry and desk top printing that were slowly getting introduced in the area. Therefore, more than their impairment, inadequate institutional arrangements made it difficult for such individuals to expand the range and quality of livelihood opportunities available to them.
According to the PWD Act 1995, Cerebral Palsy means a group of non-progressive conditions of a person characterized by abnormal motor control posture resulting from brain insult or injuries occurring in the pre-natal, peri-natal or infant period of development. In the study area, those with Cerebral palsy experienced very few livelihood opportunities - an outcome of physical, institutional and social issues. Physically, their mobility was an issue. However, they were denied education as the schools were inaccessible and had no facility or infrastructure to accommodate such individuals. While individuals with Cerebral Palsy can engage in a range of work including complex academic work as research, denial of education leaves them with little choice. Location of the nodal institution, Institute for Cerebral Palsy in Kolkata and little awareness about it in the rural areas, implied that individuals in Cerebral Palsy in the study area could not access any support from the institute. The mobility issues associated with the condition also stigmatized such individuals reducing livelihood choices. The only individual with Cerebral Palsy working in the area engaged in very low-pay job under exploitative conditions and exercised little choice in terms of other avenues available. Thus, despite their potential, they experience little support to develop these into skills and talents that can enable them to pursue livelihoods based on same. As a result of poor social and institutional support, their capacities remain largely unexplored.

According to the PWD Act 1995, loco motor disability means disability of the bones, joints or muscles leading to substantial restriction of the movement of the limbs or any form of cerebral palsy. In the study area, those with such impairment could access education and get into stable livelihood based on this. However, for those who could not take up education, this impairment hugely restricted their livelihood choices as they could neither engage in agriculture or natural resource based activity such as fishing, nor engage in any form of manual labour. This also restricted their chances of being a part of rural works programme.

World Health Organization using the international Classification of Functioning, Disability and Health (ICF) presents disability in a comprehensive manner. It distinguishes between impairments that are understood as ‘problems in body function or alterations in body structure’ activity limitations as ‘difficulties in executing activities’ and participation restrictions as
‘problems with involvement in any area of life – for example, facing discrimination in employment or transportation’ (WHO 2011).

Thus disability is a complex phenomenon, reflecting an interaction between ‘features of a person’s body and features of the society in which he or she lives’ (WHO website). It refers to difficulties encountered in any or all three areas of functioning. “Health conditions” are diseases, injuries, and disorders, while “impairments” are specific decrements in body functions and structures, often identified as symptoms or signs of health conditions. Disability arises from the interaction of health conditions with contextual factors – environmental and personal factors (WHO 2011).

While the WHO definition is one of the most frequently used in development literature concerning disability, the most relevant from the point of view of the study is the understanding proposed by Corker and Shakespeare (2002) who argue that experience of disability for people across the world is complex and cannot be adequately understood by a unitary model. They specifically talk about the ‘Range of impairments under the disability umbrella; ... the different ways in which they impact on individuals and groups over their lifetime; ... the intersection of disability with other axes of inequality; and ... the challenge which impairment issues to notions of embodiment....’ (Corker and Shakespeare, 2002: 15). This idea of ‘axes of inequality’ is very important for the present study that calls attention to the context of vulnerability for the people.

Rejecting the binary distinctions between impairment and disability, Williams (1998) describes disability as ‘...neither the sole product of the impaired body, or a socially oppressive society. Rather, it is ...an emergent property, one involving the interplay of physiological impairment, structural enablement/constraints and socio-cultural elaboration over time’ (Williams, 1999: 801).

The present study locates itself at the site of such ‘interplays’, trying to capture these nuances to inform the disability discourse. Therefore, it does not do away with the idea of ‘body’ or ‘impairment’ but considers the dividing line between disability and impairment to be blurred. As
such, it uses impairment to refer to the physical attribute and disability to a general condition or functioning in which these individuals find themselves. However, it emphasizes on the ‘fluidity’ rather than the compartmentalized distinction between disability and impairment.

**Livelihood and Employment**

Also, given that the study engages with livelihoods, it is in order to make a distinction between somewhat similar concepts of livelihood and employment. To understand engagement in productive labour in the rural perspective, it is important to distinguish between employment and livelihood. Employment is a formal agreement between two parties- employee and employer with stated job description and expectations in return for remuneration. Sen (2000) describes three aspects of employment:

- The income aspect- employment provides income to the employed
- The production aspect- employment results in the production of an output
- The recognition aspect- employment gives a sense or recognition of contributing to a cause

However, such a straightforward understanding of employment is incomplete in situations where people engage in diverse forms of self-employment with the help of the family members (Sen 2000). In the context of the study, such forms of engagements are common with families engaging in a range of work that remains unpaid (such as thrashing, husking, drying and boiling of grains during agricultural seasons). This makes it important to look at a wider concept that can encompass the range of work undertaken by individuals.

Livelihood, a broader concept, is about the ways and means of ‘making a living’ (of which employment can be thought of as a part). While ‘livelihood’ has been extensively discussed amongst academics and development practitioners (Chambers and Conway 1992, Ellis 1998 Carney 1998), the most widely accepted understanding of livelihood stems from the work of Chambers and Conway who conceptualize livelihood as comprising: ‘the capabilities, assets (including both material and social resources) and activities required for a means of living’
(Carney 1998:4). Ellis (2000) suggests a definition of livelihood that includes activities, assets, and importantly, access that together determine the ways in which individuals or families make a living. Across these definition is the underlining theme that livelihood is people-centric and it deals with resources of individuals and what they are able to do with these. It also refers to the deeply embedded nature of livelihoods in the political, economic and socio-cultural circumstances. An exercise on Rural Livelihood System (RLS) with the farmers in Gujarat, elicited that people captured their notion of a sustainable livelihood as “keeping the house(-hold) going” (Ludi, 2008). This simple yet profound statement illustrates the need to go beyond heuristic definitions and capture meanings people ascribe to their situations.

**Problem Statement**

Existing studies on employment, while reflecting low levels of livelihood engagement, do not adequately comment on the range of issues that shape the experiences of the PWD. Specific types of impairment and their severity impacts the chances of finding livelihood based on the context. For example, in the study area, those with mild to moderate orthopedic impairment had better access to education that those with hearing impairment and therefore a better chance to engage in livelihood based on education. However, given the nature of impairment and the absence of assistive devices and equipment, persons with orthopedic impairment could not engage in agriculture. Similarly, those with hearing impairment remained excluded from education and skill development as the local schools and training programs were ill-equipped to help them. They also could not access support towards language development given their distance from the city-based centralized institutions. This restricted their livelihood choices to a large extent. Similarly, those with visual impairment were denied education as a result of lack of facilities in the schools. Education as a means towards stable livelihood was available only to visually impaired individuals who could access the of expenses special school based out of the cities. Similarly, those with Cerebral Palsy remained largely excluded from livelihoods due to the nature of impairment, inability of institutions like schools to include them and finally societal reluctance to engage them in livelihood emanating from stigma. Thus, analyzing livelihood and disability essentially entails engaging with a wide variety of issues pertaining to the interaction of the biological and the social, the individual and the institutional.
The following section provides signposts that help to elicit the issues pertaining to livelihoods for this group embedding these in the wider livelihood scenario. In many ways, these also provide pointers to understanding the relationship between disability and livelihood. While each of these will be taken in greater details in the subsequent chapters, the idea here is to introduce to the key issues by providing a broad overview.

i) Wider livelihood scenario and its implications for the livelihoods of the young persons with disabilities:

Livelihood issues pertaining to the YWDs can only be understood in the context of wider livelihood scenario (discussed in details in Chapter 4). Mandirbazar block is characterized by mono-cropping patterns of agriculture. Also, with land reforms and population increase, the size of land holding is fragmented. With increasing input costs and no proportional increase in prices of food grains, returns from agriculture have fallen. With the inability of agriculture to support year round livelihood, people have been pushed to engage in casual and vulnerable occupations (DHDR 2010). This has important implications for overall livelihoods and within it for those with disabilities. In the block, only about 19 percent of the population reports no shortage of food, indicating widespread poverty (DHDR 2010). Given the overall situation, the YWD find their opportunities further curtailed.

The livelihood crisis in the area has several consequences for the YWD:

i) It further depresses the livelihood opportunities available to them – with shrinkage of options like agriculture, those without impairment, who could be absorbed in these, also compete for the same work.

ii) An army of unemployed youths without impairments depresses the overall wage rates and specifically for the PWDs (Klasing 2007)

iii) It de-prioritizes the needs of those with impairments as a ‘minority group’
iv) It takes away the role that those with impairments could take in a traditional agricultural setup with a collective nature of work (Dalal 2002)

v) With individualistic (as opposed to collective nature of agriculture work) and low paying jobs, it compromises the ability of the extended family to take care of those with impairments.

Thus the overall livelihood scenario plays an important part in outlining the livelihood profiles of the PWDs and in shaping their experiences.

ii) *Impaired access to education: Blocked pathways to employment*

Education is recognized as a major step towards a stable and secure livelihood. However, studies indicate an overall low level of educational participation for children with disabilities (CWDs). Finding of a recent report suggest that only 10% of the CWDs are in school and that one-third of the 77 million (6–11-year-old) children currently out of school have a disability (UNESCO 2007 cited in Miles and Singal 2010). A survey of 89 schools by the National Centre for Promotion of Employment for Disabled People (NCPEDP) reveals that students with impairments comprised approximately 0.5 percent of the total number of students. In the institutes of higher learning, the percentage of students with impairments was dismally low at 0.1 percent (Times of India 2010)\(^1\). Poor access to education for students with impairments implies that, their most important pathway to employment is blocked\(^2\).

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\(^1\) [http://www.timescrest.com/coverstory/no-country-for-disabled-people-2974](http://www.timescrest.com/coverstory/no-country-for-disabled-people-2974)

\(^2\) There are also several disagreements over the exact number of children with disabilities out of school. Miles and Singal (2009) mention that there are wide variations in the number and percentage of children with disabilities studying in schools. It quotes a study undertaken by in 2005 that 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”. However, according to the Ministry of Human Resource Development (MHRD) in 2004, 67.5 percent of children with disabilities were receiving education (Singal and Miles, 2010). The WHO (2011) report on disability also brings together several statistics. It mentions a survey that estimated the number of children with disability not enrolled at more than five times the national rate. In poorer such states as Madhya Pradesh and Assam, more than
Lack of access to education adversely impacts livelihood prospects and significantly restricts mobility out of circumstances of poverty. Chapter 6A on human assets engages in detailed analysis of education and its impact on livelihoods.

iii) Low levels of skill: Outcome of inaccessible and irrelevant vocational training programs

Given the context of impaired access to education, vocational training programs can create useful livelihood generating opportunities for the young persons with disabilities. However, the existing state of vocational training programs leaves much to be desired. Most of the state supported institutional facilities like the Vocational Rehabilitation Centers (VRC) and Industrial Training Institutes for the Physically Handicapped (ITIPH) are located in the cities. This makes it difficult for the YWDs in the rural areas to access them. The existing studies point to the failure of such institution on two accounts 1) in creating access of young persons with disabilities to the courses and 2) in follow up to ascertain if the skills imparted could be used for livelihood generation (World Bank 2007, WHO, 2011). The vocational training programs available in the rural areas, undertaken by both government agencies and Non Government organizations (NGOs), are often focused on imparting specific skills. However, most of these do not create the mechanisms through which these skills can be translated into livelihood options. Often these programs are high on costs, low in terms of creating employment-relevant skills and fail to reach a significant proportion of their target recipients (WHO 2011). All these factors jeopardize their ability to support the YWDs to engage in livelihoods based on the skills acquired.

half of the children with disabilities remain outside the fold of school educations. Comparing it with global statistics it mentions that worldwide, school attendance rates of children with disabilities never exceeded 74% in urban areas or 66% in rural. These disagreements are important as they indicate the extent to seriousness of the matter. It also determines if the government is actually in denial of the issue and thus determines if the matter is accorded the urgency it deserves. Also, while there are various data sets, experience from the field seems to be overwhelmingly supporting a scenario of low access.
iv) **Challenges to Self Enterprise:**

Self-enterprise is often presented as an exit route out of poverty for the disadvantaged sections including the poor and the PWDs. Based on the Micro-Finance (MF) model of development, it is assumed that by creating access to small loans to enable engagement in entrepreneurial activities, PWDs can be supported to initiate self-enterprise. However, experience has demonstrated that despite these claims, PWDs continue to have poor access to financial services as they are not considered ‘creditworthy’. Self-enterprise is also often the last-resort for the PWDs who tend to be risk-averse, given their limited resources (Handicap International 2006). Also, in the recent context failure of the major MFIs in India, the entire idea of micro enterprise led economic transformation remains challenged. There are questions about their viability and the model is criticized for neglecting the question of demand for goods and services. There are also allegations that the model does not sufficiently take into account the issue of business failure, leading to further depletion of resources (Bateman 2012). Given these concerns, self-enterprise cannot be considered an easy or a fool-proof way of creating and establishing sustainable livelihood for YWD.

v) **Poor access to the Rural Works Programs**

Participation of YWDs in the public works programs is often limited due to the physical nature of such jobs. There are also implementation issues that hinder access of the YWDs to such work. The Mahatma Gandhi National Rural Employment Guarantee Scheme (MGNREGS), for example, remains poorly implemented in the area. Also, MGNREGS, like most rural development schemes, target the poor who can undertake particular types of wage labour like building and repairing of roads, construction of canals, excavation of ponds, etc. Young persons with disabilities, especially those with orthopedic and visual impairments are mostly unable to undertake such activities. Prevailing stigma also plays a part in keeping PWDs excluded from such programs. On one hand, this deprives them from direct livelihood creation opportunities through wages. On the other, this also excludes them from participating in planning or decision-making regarding such work (Seeley 2001). Thus, despite provisions, they continue to be excluded from rural works programs.
vi) *Institutional apathy*

Success of the existing institutions and policies in creating conducive conditions for livelihood promotion is questionable. In addition, important institutions like the office of the Commissioner of Disabilities, the nodal institution mandated to protect the rights of those with disabilities has not been able to impact YWDs, especially for those in the rural areas. Chapter 7 on the Role of Structure and Processes illustrates how city centric institutions without any mechanism for rural outreach have resulted in this rural disconnect. In addition to these, several national levels institutions like the National Institute for the Orthopedic Handicapped (NIOH), National Institute for the Hearing Handicapped (NIHH) are mandated to provide rehabilitation services. However, all of these operate out of cities with severely under-developed extension services, making them largely inaccessible to those in the rural areas. Thus, institutions remain ineffective with regard to addressing the concerns of the young persons with disabilities in the rural areas.

Related to this is the issue of lack of mainstreaming of disability in action on livelihoods. A Report on Employment & Unemployment Survey (2010) undertaken by the Ministry of Labour & Employment, Government of India, makes no mention of employment of those with disabilities. Similarly, the National Commission for Enterprises in the Unorganized Sector (NCEUS) in their report: The Challenge of Employment in India: An Informal Economy Perspective (2009) does not engage with the issues and concerns of those with disabilities despite an overwhelming engagement of those with disabilities in the informal sector. In another instance, the District Human Development Report (DHDR 2010) for the district 24 Parganas (S) has a detailed section on livelihood and employment but it remains silent on the issues pertaining to the livelihood of the PWDs. Such omissions indicate a complete lack of integration of disability issues in mainstream thought and action on livelihoods.

vii) *Institutional distrust of those who do not work*

Institutions remain inaccessible and unapproachable not just due to geographical distance but also because of the social distancing that the people who run them exercise, especially with
regard to the poor and the disadvantaged. This issue has also been dealt with in Chapter 7. As Barnes and Mercer (2010) citing Stone (1986) assert that in a ‘work based’ society, those claiming welfare based payments such as disability pension are seen as seeking exemption from work. This is viewed with prejudice and the individuals claiming these are stigmatized. In such cases, the experiences of poverty often intersect the experience of disability as PWDs encounter classist discrimination (Lott, 2002) in trying to access their rightful entitlement like state support.

viii) Poor access to state support

While the PWD Act 1995 has listed a range of state support services for enhancing and promoting livelihoods as well as providing social protection for the PWDs, the access to these remains poor. A study carried out by Mander (2008) on deprivation among the aged, single women and PWDs reveal that access to the state support is characterized by complex bureaucratic procedures and unreasonable delays that eventually deny services to the most vulnerable. Very few of the PWDs entitled to disability pension actually receive them. Many of these and their caregivers have inadequate information about their entitlements and/or application procedures (Mander 2008). In order to avail of any state support with regard to livelihood, PWDs have to produce a set of documents like disability card, income certificate, identity proofs, birth certificates, etc. Often these are difficult to organize for the poor creating administrative barriers to access services. A recent World Bank study indicates that majority of the PWDs cite complex procedures as an important reason for their inability to obtain state support that they are entitled to (Word Bank 2007). Thus, insisting on complicated documentation serves to reproduce unequal relations of power and authority between the people and the officials. By setting complex processes without understanding the challenges to meet administrative requirements and by finally responding only to those who are able to negotiate the processes, institutions perpetuate the existing and established patterns of inequality (Goetz 1996, Kabeer and Subrahmaniam 1996, Narayan 1999 cited in World Bank, PPA dn). These indicate that in examining livelihoods, the role of institutions in terms of creating access to support and avenues needs to be better scrutinized.
Having broadly looked at the issues concerning livelihoods of the PWDs, the relationship of disability with poverty can be summarized by the rather clichéd but nonetheless useful statement ‘disability is both a cause and consequence of poverty’ (DFID 2000: 1). Being poor increases the likelihood of being born with impairment due to poor pre-natal care, delivery related complications and poor access to health services. Given the physical, social and institutional barriers, opportunities to participate in education are reduced. Deprived of education, these children grow up without much employable skills. At work, the PWDs experience differential access because of negative perceptions. Thus, the failure of the society to accommodate the different needs of the PWDs curtails the two exit routes out of poverty – education and engagement in work (Braunholtz 2007 cited in Singal 2011). Further, poor PWDs are likely to pass their poverty to their next generation as their children might not be able to afford education or might need to work to support the family from an early age.  

Rationale of the Study

Engagement with livelihood is important at two levels – instrumental and intrinsic. Instrumentally, livelihood is one of the most important determinants of development- both at the household and at the societal level. The cyclic relationship between poverty and disability has been widely discussed in existing literature (Elwan 1999, DFID 2001, World Bank 2007, Singal 2008). According to United Nations estimates, at least 25% of any population is directly or indirectly affected by the presence of disability in the family (UN Department for Policy Coordination and Sustainable Development 1982 cited in Poorest Areas Civil Society [PACS] nd). Erb and Harris White (2002) based on their study of villages in Tamil Nadu estimate that in case of a man, the loss of earnings consequent on impairment plunges an agricultural labouring household directly into debt, whereas when as the income contribution of a woman under similar circumstances, the average income of such a household declines by one-third. In a rural and economically deprived context, impairment not only impedes the ability of a person to engage in work but also compromises the ability of the caregiver to work. Given the importance of livelihoods, an engagement with the issues for an excluded group such as the YWD is expected.

3 Having said this, it must be noted that development does not automatically reduce disability. Developed nations have higher rates of disability, partly due to better reporting and because in developed countries, people often have increased survival rates from disabling accidents and disease (Singal, 2008).
to improve understanding and also inform future action. Intrinsically, engagement in livelihood is an important marker of identity.

However, YWDs are considered to lead dependent lives- dependent on their families, on the state, on NGOs, etc. A focus on their livelihoods highlight three essential things- 1) it sensitizes about the range and variety of work that they actually engage in that questions their dependent status 2) it highlights their efforts to break the cycle of dependence, an aspect that is not well covered in the existing literature and 3) it demonstrates the failure of the society to respond adequately to these efforts ad in general, to their needs. In the process, it highlights the ways society erects barriers to livelihoods and creates conditions for dependence. Highlighting their work-lives and documenting their experiences, therefore, brings to light their contribution as members of the society.

Also, like all individuals, YWDs have resources (or assets) that remain inadequately understood. At the same time, knowledge about assets is incomplete without an understanding of how these are used. Thus an engagement with the assets helps to describe the existing resources and opportunities and the mechanisms through which these assets are converted (or not converted) into livelihood outcomes.

In addition, there is significant research gap with a limited numbers of academic studies on disability and rural livelihoods in India. A pioneering work on the subject was the anthropological study undertaken by Erb and White in South Indian villages (Erb and White 2001). A more recent book by Klasing (2007) dealt with the impact of disability on rural livelihoods based on study undertaken by Action Aid. In addition, papers by Mitra and Sambamoorthi (2008) based on their study in Tamil Nadu focus on specific issues such as wage differentials and impact of employment policies are help to illustrate areas of livelihood concerns for the PWDs in rural India. These studies make important contributions in highlighting the problems of the PWD with regard to livelihood. However, significant gaps persist in terms of empirical data that has not been subjected to sufficient theorizing. The study by Erb and Harris makes some of the most significant contributions towards understanding disability and rural livelihoods. However, the study was undertaken in the mid 1990s. There has been much action
on the policy front since then with the United Nations Convention of the Rights of the Persons with Disabilities (UNCRPD) and the formulation of the PWD Act 1995 that included measures to enhance livelihoods for the PWDs. Most significantly, the livelihood scenario has undergone significant changes since then. Unlike the present situation, the rural economy was dominated by agriculture and a collective way of work. This had greater possibility to include family members with disabilities. Given the new developments, it is important to examine the issues in the changed context.

The study takes a micro-macro view to present a holistic understanding of the livelihood issues. It looks at livelihood issues from the point of view of the young persons with disabilities. The study also engages with the structures and processes responsible for livelihood promotion. In doing this, it creates a micro-macro linkage essential to identify the fault-lines between the people and the broader institutional and policy framework.

In the Indian context, academic thinking remains largely divorced from mainstream policy making and implementation\(^4\). Programs and schemes emanating from them are inadequately informed by theories weakening their understanding of the social situation. The present study brings the theoretical models closer to the empirical realities, and uses these studies to better understand the complex realities. It also continuously refers to the gamut of policies and practices. Such a back and forth movement allows it to dovetail theory with practice. This gives the study the vantage point to look at the complete picture evaluating the policies from the perspective of the YWDs.

Finally, this study deals with young persons. Youth is considered to be most productive for all life stages and most productive for all kinds of work—physical as well as intellectual. Engagement with this age provides the unique opportunity to maximize capabilities. Also, the study engages with some of the most relevant concerns for the YWDs. It presents a space to record the experiences of these individuals. A focus on capabilities/opportunities and the barriers to actualize these gives it a practical approach.Positing these against the backdrop of the

\(^4\) though arguably there are changes in the recent times and the revised PWD Act 2011 has involved many academicians
models of disability and livelihoods gives it a foundation making it theoretically relevant. Appropriate intervention, based on the study, has the potential to propel a large numbers of young persons with disabilities outside the vicious cycle of exclusion and discrimination.

**YWD and the circle of influence: Self, family, community and society**

For the YWD, exclusion from livelihood starts at an early age and often in the most basic unit—the family. Preparation for work starts from an early age—through education, through interaction with the parents and elders, through discussions with the peer group. Through these mechanisms, a child prepares for an important aspect of adult life—work. However, children with disabilities are often bypassed in such discussions on vocational readiness. It is assumed that they are incapable of engaging in work and would remain dependent throughout their lives. These perceptions shape the way the YWDs find themselves posited not just in the family, but in larger community and finally in society.

As such, YWD can be seen as placed at the centre of three concentric circles represented by family, community and society. The individual with disability, at the middle of the circles receives inputs or stimulus from the family, community (neighbourhood) and the society and responds to these. Unfortunately, these ‘circles of influence’ mainly exert negative forces that put barriers to work participation for the PWD

**Figure I Young persons with disabilities and the circle of influence: self, family, community and society**
At the individual level, these individuals often do not get adequate opportunities to explore and optimize their skill sets, often an outcome of a wide range of factors that are discussed in greater detail in Chapter 6A on human assets. Most significantly, there seems to be little space for choices with regard to the young individual’s own aspirations or ambition.

At the family level, while individual response to disability varies across families, it is usually the first unit through which the aspirations of YWDs get channelized. However, these individuals often find themselves in situations ranging from being overly-protected to being completely abandoned (discussed in Chapter 6E Social Capital). In both situations, their ability to engage in meaningful livelihood gets compromised.

At the community level, the YWDs negotiate with people and institutions outside the family. It is often at this level that the young individuals with disabilities face the greatest challenge of acceptance that challenges their ability to form social relationships outside the family.

At the societal level, YWDs are viewed with a paternalistic approach—dependent individuals in need of protection. As a result, approaches and polices on disability not only fail to take cognizance of existing assets and potentials but also impedes their realization by erecting barriers (described in Chapter 7 Role of Structures and Processes).

What the YWD actually achieves, in terms of livelihoods, is finally the outcomes of the interplay of all the influences across all these levels. The study focuses on producing context dependent knowledge. In doing so, it builds on the Sustainable Livelihood Approach (SLA) that gained currency with the Department for International Development (DFID), UK proposing it as a tool for analyzing livelihood. The approach provides a framework to bring together and understand the factors that affect people’s livelihoods and the relationships between these factors. The present study builds and improvises on this approach to make it more relevant from its standpoint.
The study builds on the essential components and improvises on the framework to:

- Place the YWDs at the centre of the analysis

- Set the vulnerability contexts under which these individuals operate. These include: type and severity of impairment, economic class, rural location, gender and stigma.

- Describe the resources/ assets/ capabilities that these individuals possess and how it impacts the vulnerability context. Describes six assets- Human, Physical, Social, Financial, Natural and Political. These can also be viewed as capabilities or opportunities as they set the base for livelihoods.

- Analyze the mechanism of utilization of these assets with reference to their access and control over these assets that influence the vulnerability context. The barriers in converting assets into livelihood outcomes are also analyzed.
• Examine the gamut of social, institutional and organizational environment- given that these assets influence and are influenced by the prevailing structures and processes (government, laws, policies, culture). In doing so, it creates micro-macro linkage between people and institutions.

The framework has been criticized for not being able to sufficiently capture the power relations within communities. Political assets are considered important as they mediate access to other assets. Including political assets helps to understand how the institutions are manipulated and benefits of programs are usurped by powerful groups. It can also help to create roadmaps to support the disadvantaged groups like the PWDs in enhancing their political assets through rights based approaches (Baumann 2000). However, for the marginalized groups such as the young persons with disabilities, established forms of collective self-representation are yet to be formed (Conway et al 2002). Given the importance of political assets to articulation and actualization of rights, the present study complements the conventional SLA by including political assets.

Structure of the thesis

The present thesis is divided into eight chapters. While the first chapter presents an overview of the issues that the study engages with, Chapter 2, Review of Literature takes a look at the existing body of knowledge relevant for the study taking into account both theoretical and empirical studies on the subject. The study undertakes a qualitative inquiry and the details and rationale for those are explained in Chapter 3 on Methodology. Given the importance of context for the study and the need to locate livelihoods of the young persons with disabilities within this context, Chapter 4 details the Wider Livelihood Scenario provides the profile of the respondents covered under the study. Chapter 6 begins with an introduction to asset and barrier analysis and is then divided into six parts, each part examining one asset in detail while explicating the relationship with other assets. Given the importance of existing structures and processes, i.e., the range of policies and institutions pertaining to disability and livelihood, Chapter 7 examines the Role of Structures and Processes. Finally, Chapter 8, Conclusion and Recommendations synthesizes of the entire study, reiterates the emergent arguments. It also points out the
limitations of the study and indicates areas for future research. It concludes by providing recommendations that can expand opportunities and address barriers.

The following chapter (Chapter 2), presents a review of existing work on the subject presenting both academic engagement as well as empirical studies including reports that can throw light on the issues. The chapter, however, does not only describe but critically examines the existing literature on the subject.