Social and human development outcomes of education for poor people with disabilities in Ghana, India, Kenya and Pakistan

Terms of Reference

Research Objectives

The World Bank estimates indicate that people with disabilities may account for as many as one in five of the world's poorest people (Elwan 1999), suggesting that of the estimated 1.3 billion living on less than $1 per day (Inclusion International 2005), approximately 260 million have a disability (or an estimated 43% of the world's total disabled population). There is a general consensus in the literature that poverty is both a cause and consequence of impairment and disability (Yeo & Moore 2003). Poor people are more at risk of acquiring a disability because of malnutrition and disease. They are also more likely to lack access to quality schooling, health care, sanitation, safe living and working conditions, the absence of which are associated with higher levels of disability. Once this occurs, people with disabilities face further barriers in education, employment and public services, resulting in failure to break the cycle of poverty. These barriers in most cases are the result of inadequate physical infrastructure, discriminating policies, intense social stigma, negative attitudes and low expectation from community and of self.

Research in the area of disability is scarce and the relationship between poverty and disability has largely been overlooked. While it is argued in the literature that this vicious cycle between disability and poverty can be broken through inclusion in education, many questions remain unanswered. For example, how many years of schooling are regarded as essential? What kind of educational arrangements are most suited for the development (personal, social and economic) of the individual? Such questions are crucial when a wide variety of provisions, such as, special schools, NGO run institutions, non formal education centres, community based initiatives, are being established alongside the mainstream system of education. Nevertheless, research in this area is sparse and therefore attempts will be made to address some important gaps in the literature.

This research will have the following objectives:

1) To develop an understanding of the local definitions and perceptions of disability and poverty, and the relationship between them.

2) To examine the present educational arrangements available to and attended by poor people with disabilities and how are these characterised.

3) To explore the local meanings that people with disabilities, and their significant others, attach to education and schooling.

4) To identify the differences in participation, learning and social outcomes for people with disabilities across various locally available educational arrangements in rural and urban settings. [These arrangements could include: state/NGO provision/religious schools/charitable centres; mainstream/special schools; fee paying/non- fee paying; formal provision/non formal provision/no provision/community based initiatives.]

5) To establish enabling factors that people with disabilities need in order to break the cycle of deprivation.

Suggested research approach

A three-stage approach of data collection is envisaged. Figure: 1 (*see attached page) illustrates the different research methods that will be used and the kind of data/information these will elicit. Some of the central issues are briefly discussed below.

Stage 1: An important issue (and challenge) will be to develop an understanding of the local meanings of disability, poverty and education. Of these, disability presents a particular challenge, which needs to be acknowledged and addressed early on. Defining disability has been termed as 'rather problematic' in the literature (Lwanga-Ntale 2003). The term, in most cases, is most likely to be used for those with physical impairment, mostly of upper and lower limbs. Hence there is an increased likelihood of ignoring those with learning difficulties, and those who are blind, deaf, epileptic, etc. In many languages there is no single word that easily translates into the English word 'disability'. This issue of language would also be a challenge in our research. For instance, in Hindi, the word used commonly for 'disability', does not encompass all types of disabilities but is indicative of physical/locomotor disabilities only. In such a scenario, we need to be very clear when framing and translating questions in the household survey and during the community study. Finding children who are not attending school and the reasons for their absence, and identifying adults (esp. males) not involved in income generation tasks and reasons for this, would help locate those who are likely to be 'disabled'. It would also be useful to make contact with teachers in schools and vocational trainers to ask them if they are aware of any individuals with disabilities. Moreover, we would also focus on triangulating our data through various other methods.

One of the ways in which information on those perceived as disabled will be gathered is through the use of the scoping study and the household census. While this will give us household level data, Rapid Rural Appraisal (RRA) will also be adopted as an important technique to explore community perceptions of disability and disablement. RRA is regarded as an efficient and cost-effective way of learning by outsiders (Chambers 1992). The central idea is that researchers (preferably two of them) spend some time in a village and have informal and open dialogues with the population on aspects of their daily life. A series of tools have been developed to facilitate interaction between the researchers and the community members. Most commonly used techniques in RRA are: semi-structured interviews, dialogues with key persons or local experts, transect walks across the village, and group interviews. Information gathered through the scoping study of the community and the RRA would also assist in identifying the types of educational provisions available for and attended by those with disabilities.

In **Stage 2**, a range of qualitative techniques will be used to gather information about the educational experiences of individuals with disabilities. Data would also be gathered on various social and human development indicators (as listed in figure: 1), with an added focus on the identification of pro-poor pathways.

The research methods used would encompass qualitative interviewing styles (individual, paired and/or group interviews) and participant observations. Individual interviews with persons with disabilities could be conducted using a 'time line' approach and/or a 'life line' approach. Individual interviews would also be conducted with key stake holders working in the different educational provisions identified in the community. Focus groups, will be conducted with persons with disabilities and their significant others, to capture information on a range of issues. Personal narratives would also hold a central place in data collection. Kothari and Hume illustrate how life histories can help develop a dynamic understanding of poverty (Kothari & Hulme 2003). Using narratives (also referred to as personal testimonies, or oral history) they recount the life of two members of a family and paint a powerful picture of their slide into poverty, their endurance and explanation of poverty (interestingly, disability and ill-health emerged as significant factors in this process). While the researchers acknowledge the limitations of making generalisations from such accounts, they do successfully challenge many of the existing orthodoxies in poverty studies and argue for the need to adopt a multi-disciplinary and multi-methodological approach to understanding poverty dynamics.

'Visual sharing' is central to participatory research approaches, especially when working with rural and in many cases illiterate population. Such image-based approaches are also important techniques when undertaking research with children and young adults. Lately, within the field of disability research, images generated by disabled people have become an interesting resource for engagement during the research process. In this research we propose the use of photographs taken by disabled people themselves, to identify factors that facilitate or inhibit their social and human development in different spheres of their lives (Miles & Kaplan 2005). Individuals will be encouraged to talk about these photographs to gather their interpretations of the images that they have captured where it is considered to be culturally and ethically appropriate.

Stage 3:

The purpose of this stage is two-fold and will entail- analysis of the data collected; along with reflections from the community. In the initial stages of the analysis process, data will be organised into conceptual

categories and themes. These themes will primarily emerge from the text itself, influenced by the research questions, common sense constructs and characteristics of the phenomena being studied. This task will be carried out using a qualitative software package, to enable efficient storage and retrieval. At this stage only descriptive codes will be given and a low level of abstraction will be used to help flag the themes emerging from the data. Each of these themes (and sub- themes) will be given a code.

Preliminary analysis of findings will be presented to the research participants. Participants will be encouraged to discuss the findings and to reflect on them. Such discussions will also provide participants opportunities to present their own interpretations of the data. Furthermore, the research findings will also be presented to groups comprising of people with disabilities and significant stakeholders in the community. Discussions will be facilitated to develop a contextual and comprehensive understanding of the relationship between disability and poverty, and the particular role that education plays (or does not play) in breaking the cycle of deprivation.

The second pass through the data will be more analytical, where data will be more coherently organised into themes and ideas, and the final step will involve scanning the data and previous codes to organise the overall analysis around several core issues or ideas.

Research Participants

We would be cautious about proposing the number of participants to be included in the study, as this will emerge after the initial phase of identification. However, efforts will be needed to ensure that participants are from a cross section of persons with disabilities (and their carers/ significant others). The following criteria could be used:

1) Individuals with different types of disabilities are included

2) Ensuring that we have a reasonable representation of both men and women

3) Persons with disabilities from across the following age groups would be desirable-

    a. 14-19 years

    b. 19-25 years

    c. 25 and above

This would facilitate cross-age comparisons and provide richer data that would enable us to capture developments at the community level.

In addition to conducting interviews with individuals with disabilities and their care givers, data will also be collected from teachers and other educational professionals. This would be especially important in communities where some kind of formal and/or non formal educational provision is available for individuals with disabilities.

Ethical Issues

In undertaking this research we need to follow the general ethical guidelines (such as, respecting confidentiality, expectations of participants, right of the participant to withdraw from the research at any point), which would be common across the larger research project (see the Discussion Papers that deal with this issue). In addition to these we need to be conscious of the specific ethical issues underpinning poverty research (such as, concerns about stigmatisation, compensation of time, power issues in the research relationship). All these and other issues become even more important when working with people with disabilities, who are likely to be the most marginalised and least powerful in the community.

The right to a 'voice' is thus a fundamental ethical concern when working with people with disabilities. When researching disability issues, there is a common tendency to rely on others to gather information, hence denying the disabled a voice. This might be done because of a range of reasons, such as the perceived inability of persons with disabilities to express themselves, or the inability of researchers to use alternative modes of communication to establish dialogue with those who do not use conventional methods of communication. These issues will be discussed in the training of field officers.

References

Chambers, R. 1992. *Rural Appraisal: Rapid, relaxed and participatory*. **311**.

Elwan, A. 1999. *Poverty and disability: a survey of the literature*. World Bank.

Inclusion International. 2005. *Fact sheet on poverty and disability*. Inclusion International.

Kothari, U. & D. Hulme. 2003. Narratives, stories and tales: Understanding poverty dynamics through life history. Paper presented to the Staying Poor: Chronic Poverty and Development Policy, Chronic Poverty Research Centre, Manchester, 2003.

Lwanga-Ntale, C. 2003. Chronic poverty and disability in Uganda. In *Staying poor: Chronic poverty and Development policy*. Chronic Poverty Research Centre: Manchester.

Miles, S. & I. Kaplan. 2005. Using images to promote reflection: an action research study in Zambia and Tanzania. *Journal of Research in Special Educational Needs* **5**, 77-83.

Yeo, R. & K. Moore. 2003. Including disabled people in poverty reduction work: "Nothing about us, without us". *World Development* **31**, 571-590.

Fig. 1: OVERVIEW OF THE RESEARCH PROCESS

RESEARCH METHODS

PURPOSES

Rapid Rural Appraisal

Household Census / Scoping study

range of approaches

- Individual interviews with persons with disabilities; important stakeholders in the community; important stakeholders working at the various educational arrangements available in the community

- Case studies of existing community based initiatives

- Participant observations

- Visual sharing/ using images generated by persons with disabilities

- Narratives of Educational Success/Failure

- Focus Groups with persons with disabilities and their significant others

Analysis of data

Workshops with Persons with Disabilities

Community Workshops

STAGE 1

Identification of persons with disabilities through a community based approach

Developing an understanding of the local construction of disability. The types of disabilities identified, the language used to describe disability and the experience of disability (or being disabled).

Identification of persons with disabilities through a household level approach

Identification of the different types of educational arrangements attended by/available for those with disabilities

STAGE 2

- Self-efficacy
- Autonomy
- Self-determination
- Self care
- Community, Social and Civic Participation
- Economic Engagement
- Work involvement
- Life Expectations

Identification of Pro Poor Pathways

STAGE 3

Member check of findings

Community Dissemination and Feedback

5