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Counting the invisible: understanding the lives of people with disabilities in Pakistan

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Abstract

Even though people with disabilities are a significant minority and are disproportionately over-represented amongst the poorest population, there continues to be a lack of understanding of their lives. In this paper we discuss the conceptual underpinnings and findings of a household survey conducted in two regions of Pakistan which attempted to address some of these gaps in existing knowledge. While disability was only a small component of the overall focus of this household survey, the emerging findings on disability issues provide some useful reflections on the status of persons with disabilities in these regions. The findings of this survey emphasize the continued marginalization of young people with disabilities in the areas of education, employment and marriage prospects. Additionally, reflections on the research process highlight the many challenges entailed in undertaking research on disability issues.

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Over the past few decades, shaped by discourses of human rights and human capital there has been a greater recognition of the need to focus on people with disabilities. Additionally, there has been a growing realization of the cyclical relationship between poverty and disability, wherein national and international efforts aimed at poverty reduction can no longer overlook the cascading and intergenerational impact that disability has on the economic status and socio-emotional well being of an individual's family (Singal, 2007). While there has been a greater focus on disability related issues Fijiura *et al. (*2005: 295) note that,

> …it is remarkable how little we know about the lives and the worlds occupied by people with disabilities in developing countries.

Pakistan is no exception to this observation. A report published by the Japan International Cooperation Agency (JICA, 2002) profiling disability in Pakistan states that 'persons with disabilities are mostly unseen, unheard and uncounted persons in Pakistan. They are the most marginalised group' (p. 5). Our understanding of disability in Pakistan is largely anecdotal and the lives of people with disabilities largely remain invisible. Similar to other countries of the South[1], there is a lack of reliable data on the prevalence and status of people with disabilities. Even though the government has made efforts to collect information related to disability, various reports submitted by both national and international organisations highlight this as a major stumbling block in sound planning of policy and programmes (UNESCO, 1999; JICA, 2002; UNICEF, 2003).

An important step in this direction is to develop a reliable picture of the number of people with disabilities for greater advocacy, better planning, and effective reform efforts. This paper discusses the conceptual underpinning and findings of a household survey which was conducted in two regions of Pakistan. While disability was only a small component of the overall focus of this household survey (HHS), the emerging findings on disability issues provide some useful reflections on the status of persons with disabilities.

We begin by discussing the current discourses on disability shaping government policies and academic literature in Pakistan. We argue for a need for reconceptualising current understandings of disability and explain the rationale underpinning the questions we asked in a household survey conducted as part of the Research Consortium on Educational Outcomes and Poverty (RECOUP). We then discuss the findings from the household survey; here we particularly focus on noting the overall

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[1] North' and 'South' were concepts introduced in the Brandt Commission Report (1980). These concepts do not refer to geographical divides but in general terms are broadly synonymous with 'rich' and 'poor', 'developed' and 'developing'. Significantly, most of the nations of the South are bound together by their colonial experience. There is a fundamental economic inequality between the two blocs which results in inequalities in the standard of living, resources available and domination of the Northern bloc in international developments. Even though there is an assumed simplicity, which seems to imply that the world can be divided into two camps, there is awareness that great heterogeneity exists within them. While Crossley and Watson (2003) have been critical of these generic terms, we have used them primarily to move away from an era characterised by the transmission of knowledge from so-called developed to developing nations (even though many of these have much more vibrant and evolved cultures) greatly implied in the earlier terms. This approach is in line with the assumptions underpinning the Disability, Education and Poverty Project which is the basis of this paper.

trends emerging from our data in terms of prevalence rates and demographic characteristics of people with disabilities. We then focus specifically on young people with disabilities and examine their participation in the spheres of education and other areas of social well-being. It is important to note here that this paper is an initial step in analysis and primarily draws on descriptive level analysis. Its purpose is to discuss the findings from the survey in light of the existing literature. We suggest that undertaking such an initial analysis is important to begin to understand some of the emerging trends and make sense of these before moving on to a more complex analysis of this data set. We conclude this paper by discussing some implications for policy and planning and reflecting on the limitations of our work, especially with regard to the questions framed in the HHS. We also propose ways in which this work can be strengthened in future efforts.

People with disabilities in Pakistan: current estimates and prevalent discourses

In Pakistan, similar to other countries of the South, there is a significant absence of reliable data on the prevalence and status of people with disabilities. This observation has also been noted in various reports submitted by national and international agencies, such as UNESCO (UNESCO, 1999), JICA (JICA, 2002) and UNICEF (UNCEF, 2003). This situation exists despite efforts undertaken by the Government to collect such information over the past few decades. Data on disability were collected in the Housing, Economic and Demographic Survey (HED) of 1973, and subsequently in the population censuses of 1961,1981 and 1998. However, these attempts have been criticized for lack of clarity in the terms used and also concerns regarding under-reporting due to issues of social stigma.

Perceptions of disability as a rigid and medical condition dominate the definitions and perceptions of disability in Pakistani society. The construction of disability in medical terms is evident in the definitions used by the government and the programmes of rehabilitation and care developed for them. Furthermore, the types of disability covered in population censuses and other available surveys are quite narrow; capturing severe forms of impairments only. For example, in the 1998 Population Census, disability is defined as "the physical or organic handicap of a person due to natural deformity or deficient functioning if any limb resulting from accident, disease etc… it refers to any visible malfunctioning of any organ of the body". The types of disabilities covered in the census include blindness, deafness and muteness, crippling mental retardation and insanity, and, in addition, severe cases of seeing, hearing, locomotive and learning impairments. Thus, the *visibility* and *severity* of an impairment seem to be important factors in making decisions about an individual's disability.

On similar lines, according to Ahmed (1995) the national survey conducted by the Federal Bureau of Statistics (FBS) during the period 1984-1985, focused on household level and 'concentrated on specific physical and intellectual disabilities that could place serious constraints on an individual's mobility for more than six months'. Herein data on seven major types of disability were collected: blindness, deafness, mutism, leprosy, retardation, lameness and "handicaps". However, the categories and definitions of disability used in this 1986 survey were not consistent with those of the 1981 census, thus making it impossible to compare disability-specific rates.

In addition to the lack of definitional clarity and inconsistent use of categories, another issue which makes data collection problematic is the issue of stigma (Ahmed, 1995). Disability in Pakistan, like in many other Southern countries, is regarded as a consequence of some punishment for sins, vices or faults, known and unknown, that have been inflicted by some powerful and moral force. These perceptions are further strengthened by dominant religious discourses prevalent in the larger society. While some interpretations of Islam suggest that disability is regarded as a neutral condition, where it is neither a curse nor a blessing from God:

> Rather, the Qur'an concentrates on the notion of *disadvantage* that is created by society and imposed on those individuals who might not possess the social, economic, or physical attributes that people happen to value at a certain time and place (Bazna and Hatab, 2005: 5).

However, studies which have explored people's perceptions towards disability, in general, highlight that it is primarily regarded as a curse of God and a punishment for the sins of the parents or a test from God (Shahzadi, 1992; Hussain *et. al.*, 2002). The basis for this can be attributed to mistaken customary beliefs and incorrect interpretations of religious injunctions, which have led to denial, stigmatization and the continued invisibility of people with disabilities. Consequently, the focus is either on hiding the disability/disabled person or on minimizing this stigma by framing the 'other' in ways that make them as 'normal' as possible. For instance, a newspaper reporting a school function in which children with disabilities participated in a series of culture events, used the following headline: "special children forget disability on their day[2]". Such an understanding of disability, where the focus is on perceiving disability as something that needs to be forgotten or made invisible does not acknowledge the real barriers that people with disabilities face, resulting in lack of efforts to address these difficulties.

In summing up the problems with large scale data sets Ahmed (1995) notes,

> there are several ways data could be erroneous. There are reporting errors encompassing the respondent's biases, the interviewer's mistakes in coding and recording, his or her fatigue, rapport and interest in data collection as well as biases and manner of presenting questions. Data on disability could also be affected by the interviewer's training and degree of supervision. Census data collection has its own administrative supervision which concentrates mostly on the coverage of households rather than on the quality of data. The census coverage is usually massive. Therefore, the interviewer's fatigue, disinterest and bias could easily cause

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[2] http://www.dawn.com/2007/05/07/local16.htm

the introduction of errors, especially with regard to relatively low ranked priority areas such as the disabled population.

An additional problem pertaining to disability statistics in Pakistan is the confusing and conflicting interpretation of data available from existing surveys. For example, some authors state that the 1998 census recorded 3.3 million people with disabilities (Rukanuddin, 2003), while the UNESCAP *'Disability at a glance'* document notes that the same (1998) census identified 4.01 million people with disabilities (2.5 percent of the total population). This report also quotes a WHO survey done in the 1980s, which reported 11.3 million people with disabilities, that is, 7.0 percent of the population. The prevalence of disability recorded in the 1998 census is largely accepted as being a gross underestimation, unreliable and invalid (Ahmed, 1993; Afzal 1992; Rukanuddin, 2003). It is believed that prevalence rates are likely to be much higher and figures suggested do vary from 2.5 percent t0 10 percent.

The most recent statistical report profiled by the Asia-Pacific Development Centre on Disability (APCD) notes that the Government itself acknowledges that the disability prevalence rates obtained in the 1998 Census are under-estimates and do not represent the true picture[3]. In the Sixth Five year plan (1983-1988), the Government estimated that persons with disabilities comprise approximately 4 to 6 percent of the total population. The Seventh and the Ninth five year plans do not provide any estimates of disability. Nonetheless, the figure of 2.5 percent remains the most widely used estimate in official documentation (Government of Pakistan, Ministry of Women Development Social Welfare and Special Education, 2002).

It is with the intention of addressing some of these aspects and contributing to the existing literature that the Disability, Education and Poverty Project was undertaken in Pakistan. RECOUP HHS attempted to overcome the problems of reporting bias through same sex interviewing and protracted presence of the enumerators in the household where they were able assess and record firsthand the incidence and severity of disability. In addition, the limitations of enumeration were minimized through extensive sensitivity training of enumerators and close field supervision.

Disability Education and Poverty Project (DEPP) in RECOUP

DEPP is part of the larger Research Consortium on Educational Outcomes and Poverty (RECOUP), which is operating in four countries (Ghana, Kenya, India and Pakistan).[4] The research undertaken in RECOUP is focused on examining the impact of education on the lives and livelihoods of people in the four partner countries, particularly those living in poorer areas and from poorer households. Its purpose is to generate new knowledge that will improve education and poverty

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[3] While there is no date given, information on this website was last updated in 2006.

[4] Qualitative research projects on social and human outcomes of education are being conducted in the same geographical areas, allowing a deeper knowledge of the local context than can be provided by each separately. Details of the various projects can be found on the RECOUP website: http://recoup.educ.cam.ac.uk/,

reduction strategies in developing countries, through an enhanced recognition of education's actual and potential role. One of the central projects in RECOUP is the Disability Education and Poverty Project (DEPP[5]), which aims to develop an understanding of the local meanings and perceptions of disability and also to understand the role that education and other enabling factors play in the lives of young people with disabilities.

An important element of DEPP is focused on respecting the centrality of the person with disabilities. Hence the aim is to engage with and listen to the voices of these young people (15-30 years) - a group which tends to get largely overlooked in policies and programmes, with attention being directed either towards children or adults. A UNICEF report noted that, "Adolescents and youth with disabilities are among the neediest and most overlooked of all the world's children" (UNICEF, 1999, p. 1). The Biwako Millennium Framework for Action towards an Inclusive, Barrier- Free and Rights-Based Society for Persons with Disabilities in Asia and the Pacific highlights the gravity of the situation by stating that:

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

This is despite the fact that current demographic trends in many Southern countries indicate a 'youth bulge', which is also likely to increase the number of people with disabilities as there is evidence to suggest that younger people are at a greater risk of acquiring a disability due to work related injuries, tendency for higher risk taking behaviour such as extreme sports, motor accidents, unprotected sex, violence and warfare. While these trends seem currently more established in developed economies, the rising number of affluent young people in developing economies cannot be overlooked. Moreover, in developing economies, the lack of adequate health care, poor immunization and growing numbers of under nourished children might also contribute to a rise in the numbers of young people with disabilities. There is, therefore, a need to focus on the increasing numbers of young people with disabilities—young people who currently remain doubly marginalised from policies and provisions.

In order to fulfill the research aims set out in DEPP we are collecting data through a large scale quantitative household survey, as well as through community based qualitative research projects in each partner country. This mixed method approach is likely to be extremely insightful. This paper

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[5] See Singal (2007) for details regarding the conceptualisation of the Disability Education and Poverty Project.

however focuses only on the findings from the large scale quantitative data on disability gathered using the household survey in Pakistan.

Disability in the RECOUP household survey: moving beyond head counts

The RECOUP household survey (HHS) was a purpose-designed household survey which collected rich information on various individual, family and community-level factors. It was administered to 1094 urban and rural households between November 2006 and March 2007. These households were selected randomly through stratified sampling from 9 districts in two provinces – Punjab and the North West Frontier Province (NWFP)[6].

The HHS had a roster, which captured basic demographic, anthropometric, education and labour market status information on *all* resident household members in the sampled households (around 9000 individuals). In addition detailed individual-level questionnaires were administered only to those aged between 15 and 60 years. Some 4907 individual-level questionnaires were filled. Most of these individuals were also administered tests of literacy, numeracy, health knowledge, English language and the Ravens Progressive Matrices test (to assess innate ability).

Thus, while the survey did not have an exclusive focus on issues of disability, it was an important aspect of the survey. However, the number of questions that could be focused on disability was limited due to issues space and a need to include other competing themes. However, we were of the opinion that questions about disability incorporated in this survey should be consistent with an understanding of disability that underpinned the *interactionist* approach being adopted in DEPP. Therefore rather than simply asking the conventional question, used in most surveys- "Are you disabled", our aim was to move away from an impairment based approach to suggest an activity limitation approach. Our underlying assumptions were that disability needs to be understood in its totality; hence the focus should not only be on bodily issues but also the perceived impact of these on the individual's activity and participation. Thus it is argued that since 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). This allows us not only to move forward in acknowledging the complexities in understanding disability, but it also enables us to develop a cross-national language around disability.

The questions we used were strongly influenced by the WHO's International Classification of Functioning, Disability and Health (or the ICF model) and were based on a review of efforts being undertaken by the UN Statistics Division towards developing a shared language for disability and has recorded, what are considered to be more reliable prevalence rates. For example, the 1991 Brazilian census reported only 1 to 2 percent disability rate, the 2001 census using the improved approach

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[6] In Punjab in the following districts were covered: Rahimyar Khan, Khanewal, Sargodha, Kasur, Attock and Chakwal, while in NWFP the following were chosen: Swat, Charsadda and Haripur were sampled from NWFP.

recorded as 14.5 percent disability rate. Such increases in measured rates of disability were also seen for Turkey (12.3 percent) and Nicaragua (10.1 percent). An important issue that these increased figures highlight is that ability (and disability) distribution in a population lies on a continuum, and this has important implications for policy and provision of services, especially for the health care sector.

Additionally, the framing of questions for the survey was influenced by past experience and research studies in the field, which noted that deconstructing the question of disability was essential in order to overcome issues of stigma and language barriers (Lwanga-Ntale, 2003). The questions we used in our survey are presented in Figure 1[7].

Figure 1: Questions addressing disability in the household survey (RECOUP)

<table>
<tr><th colspan="6">Seeing</th><th>Hearing</th><th>Speaking</th><th>Walking</th><th>Learning</th><th>Personal care (Such as, washing oneself, caring for body parts, toileting, dressing, eating, drinking)</th></tr>
<tr><td rowspan="2">Yes =1
No= 2</td><td rowspan="2">Degree
1= mild
2= moderate
3= severe</td><td rowspan="2">Since what age?</td><td colspan="3">Does this reduce the amount or kind of activity --- can do</td><td rowspan="2"></td><td rowspan="2"></td><td rowspan="2"></td><td rowspan="2"></td><td rowspan="2"></td></tr>
<tr><td>At home?
Yes sometimes
Yes, often
No</td><td>At work or at school?
Yes sometimes
Yes, often
No</td><td>In other areas, for example, transport or leisure?
Yes sometimes
Yes, often
No</td></tr>
<tr><td colspan="6"></td><td></td><td></td><td></td><td></td><td></td></tr>
</table>

The sub-sections in the Seeing column would be repeated in each of the types of disabilities

Findings from the RECOUP household survey

We begin by providing an overview of disability prevalence, its degree, variation in location and gender composition across the entire sample (ages 15-60 years). This snapshot of the sample highlights some interesting trends. Subsequently, keeping in mind the specific focus of DEPP we direct our attention to a detailed analysis of the socio-economic attributes of young people (ages 15-30 years) with disabilities.

The sample

The data, of which a snapshot is presented, was collected from a stratified, random sample of 1094 households in 9 districts of Punjab (6) and NWFP (3) and represents roughly around 9000 individuals.

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[7] These questions were individually asked from all respondents aged 15-60. In the case of any disability, which would not allow people with disability(ies) to answer the questions, the questionnaire was filled with the help of a family member. These cases usually include severe difficulties with learning, hearing, speaking and personal care.

The detailed information on disability was collected from individuals between ages 15-60 which make up about around 53percent (4633 individuals) of the sample.

Villages and enumeration blocks in rural and urban areas respectively were taken as primary sampling units (PSUs). The PSUs were one urban area and two rural areas in each of the districts. Households within the PSUs were taken as secondary sampling units (SSUs). Every n^{th} household (or the secondary sampling unit) was randomly selected from within the primary sampling units (villages in rural areas and urban blocks in urban areas). Depending on the number of expected households in a village or urban block, a suitable sampling interval was chosen to ensure the sample selected was appropriately representative of the community[8].

Table 4.1: Secondary Sampling Units in each district

	Sample SSUs		
	Rural	**Urban**	**Total**
Sargodha	107	67	174
Kasur	128	45	173
Attock	77	29	106
Chakwal	63	15	78
Rahim Yar Khan	138	54	192
Khanewal	94	24	118
Haripur	58	16	74
Swat	61	28	89
Charsadda	65	25	90

A household was described for the purposes of the questionnaire as all individuals who met the following criteria:

1. They lived under the same roof or within the same compound/homestead at least 15 days out of the year past.
2. They shared food from a common source when they were together.
3. They contribute to or share a common resource pool.

With regards to incidence of poverty, 30 per cent of the individuals in the sample were estimated to be below the poverty line. More than one fourth of the households sampled in Sargodha and Chakwal in Punjab and Swat and Haripur in NWFP fell in the quintile with high per capita consumption expenditure. Conversely, more than half of the households in Charsadda in NWFP and Kasur, Rahim Yar Khan and Khanewal made up the bottom 40 per cent of the economic ladder.

We now move on to the discussion of disability in the sample. In our discussion of these findings we draw on the limited research available in the field and highlight the kind of contribution that our analysis can make in furthering our understanding of the lives of young people with disabilities. We are conscious of the small nature of our disability sample, therefore as noted earlier, the analysis

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[8] Although the households (SSUs) were selected randomly, the sample as a whole is poverty based as those districts and within them those PSUs were selected that represented the socio-economic conditions of the majority of the province and not wealthy outlying regions. Further details on the sampling framework can be found in forthcoming report on the findings of RECOUP HHS in Pakistan.

undertaken is primarily descriptive level analysis. Within these limitations we are hopeful that our findings contribute to knowledge building and allow us to provide important reflections for future research.

Overall trends (15-60 years)

As stated earlier, the HHS inquired about the disability prevalence among all household members between the ages 15-60[9]. Respondents, who had reported having at least one type of difficulty, were then asked about the (perceived) degree of their difficulty/difficulties, at what age the impairment had been acquired, and its impact on the amount or kind of activity that they undertook at home, at work (school) or other areas such as traveling or leisure time. Table 1 presents the results for the disability prevalence by types, severity of disability and sex of the respondents. Results indicate that one in every five respondents (21 percent) reported having at least one type of difficulty. Around three percent of all respondents had also reported having more than one difficulty.

Table 1. Prevalence, types and severity of difficulty (percent of respondents aged 15-60)

	Reported difficulty	Multiple difficulty	Seeing	Hearing	Speaking	Walking	Learning	Personal care
All	21	3	17	1	1	3	1	1
Male	17	2	11	1	1	4	1	1
Females	24	3	22	2	0.5	2	1	1
			Degree of difficulty (percent of people with specific difficulty)					
Mild			69	63	44	38	37	30
Moderate			26	24	24	34	26	33
Severe			5	13	32	28	37	36

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[9] The question was whether the individual has any disability which interferes with his/her walking, seeing, hearing, speaking, learning or personal care. The respondents were probed on whether they had any problem in seeing, walking etc. Seeing disability includes blindness in one or both eyes, or visual acuity problem; hearing disability includes complete or partial deafness in one or both ears; speaking disability includes inability to speak at all as well as stutter/stammer; walking disability includes absence of any part of the limb, deformity of limbs and multiple locomotive deformities; learning disability includes difficulties in attention, memory, thinking processes and mental retardation; and personal care disability includes problems in performing personal care such as washing oneself, caring for body parts, toileting, dressing, eating, drinking etc.

Type of difficulty

Difficulties in seeing was the most commonly reported difficulty (17 percent), followed by difficulty in walking (3.0 percent) and difficulty in hearing (1.4 percent). The prevalence rate of learning, speaking and personal care difficulties was low: less than one percent of the sample reported as having one of these difficulties.

It is important to note that majority of the difficulties reported in seeing and hearing were primarily mild in nature. It could be argued that these were difficulties which were either being (or indeed could have been) supported by the use of assistive devices, such as spectacles or hearing aids. Whereas more than one-third of the people with learning (37 percent) or personal care (36 percent) difficulties reported these as being severe in nature.

While it is easy to be dismissive of the high numbers of certain types of difficulties on account of their mild nature, it needs to be acknowledged that there is no indication of the availability of such assistive devices to this section of the population. Even though the Government of Pakistan is committed to providing free access to prostheses, orthoses and hearing aids for children, through national or provincial rehabilitation centres, there is no information about the total outreach of these services. The availability of such services is of particular concern in rural areas where access to healthcare services is already low. Estimates indicate that in 2001, only 18 percent of the villages had a basic health unit. Thus, the proportion of people with disabilities who have access to assistive devices though unknown, is likely to be low. According to ESCAP (1997) there were more than 500,000 people who were treated as blind as they did not have any access to glasses or low vision aids in 1995. Thus, data on the degree of an individual's perceived difficulty is vital for designing policies and programmes that can identify and address the needs of people with disabilities efficaciously.

Disparities in the reported degree of difficulty by type might be explained by the level of stigma associated with certain types of difficulties. It is therefore plausible that people are more ready to report minor difficulties in seeing and hearing- both of which are socially acceptable as common signs of old age, rather than difficulties associated with learning and personal care. Such an inference is further corroborated by our findings which indicate a strong positive correlation between type of disability prevalence and age, particularly for difficulties in seeing, hearing, walking and personal care (See Table: 2).

Also one could argue that the stigma attached with both seeing and hearing is being overcome to some extent by the portrayal of such people in a more 'able' framework by the media. For instance, newspaper reports on the success of a young woman with visual impairment, Naveed Anjum, who is a Masters student and is running an institution for the education of visually impaired children, are frequently covered by the newspapers (Iqbal, 2008), as are stories recounting the success of the Pakistan's blind cricket team, which won the 2006 Blind Cricket World Cup.

Table 2. Prevalence of difficulty by type among age groups, %

	Ages 15-30 (n=2568)	Ages 31-40 (n=895)	Ages 41-50 (n=605)	Ages 51-60 (n=379)
Seeing	6	17	42	50
Hearing	1	2	2	3
Speaking	1	1	1	1
Walking	2	3	5	8
Learning	1	1	2	0.5
Personal care	1	1	1	2

Table 2 shows that reported prevalence rate of difficulties in seeing, hearing, walking and personal care is lowest among the youngest group (ages 15-30) and increases gradually by age. The differences in reported disability by age groups are more robust in the case of seeing difficulties; among young people (15-30) only 6 percent reported having a difficulty in seeing while its prevalence increases gradually and reaches to 50 percent among the oldest age group (51-60).

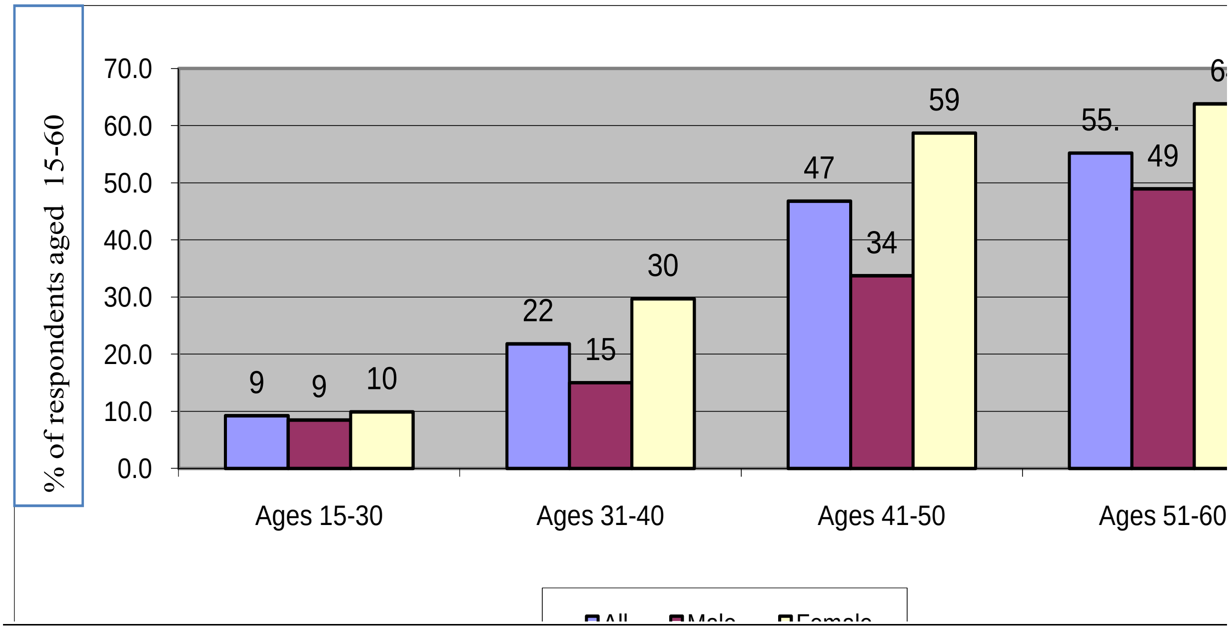
<u>Gender</u>

Women in the sample reported more impairments than men in Pakistan ($\chi^2(1)=35.497$, $p\approx0.000$). The prevalence of women reporting greater difficulties was significantly higher (24 percent) than it was for men (17 percent). Gender variability was also evident according to the types of difficulty reported. For example, women were around twice as likely to report difficulties in seeing or hearing as compared to men. By contrast, men were significantly more likely to report difficulties in walking. These findings of seem consistent with the general findings across other parts of the world, where some disabilities are found significantly more often in girls and women (e.g., blindness, multiple sclerosis); others affect them substantially less frequently than boys and men (traffic, sports and gunshot injuries, autism); while still others are the provenance of women (osteoporosis) (World Bank, 2008).

For the case of Pakistan, the greater number of women reporting various difficulties could be explained by reasons such as intra household discrimination in nutrition amongst families. There is substantial evidence indicating girls and women in Pakistan are discriminated against in intra-household food consumption (MHHDC, 2000; 2005; Bhalotra and Attfield, 1998) and do have inferior nutrition indicators as compared to men (Nazli and Hamid, 1999). Research also indicates that girls and women have lower access to healthcare services (as cited in Haddad *et al*., 1996) and as compared to boys/men they are less likely to receive treatment when they are sick (MHHDC, 2000, 2004; Nazli and Hamid, 1999), thus increasing their vulnerability.

This discrimination against women starts from childhood and continues through child bearing years as women are put at greater risks during pregnancy and child birth, especially in the absence of adequate health care facilities and high prevalence of nutritional and micro-nutrient deficiencies among lactating women (PIDE, UNICEF and Planning Commission, 2004). White (2001) reports that maternal and perinatal mortality ranks second only to communicable diseases in the overall burden of mortality faced in the country. The report also lists low status of women as one of the major factors associated with the poor health status of Pakistan[10]. This assertion is further supported by the Asian Development Bank (2008) which notes that while some 30,000 women die each year due to complications of pregnancy, 10 times as many developed lifelong pregnancy related disability. This rationale draws strong support from our data which indicates that the gender gap increases after 30 years of age (as indicated in figure 2). Findings indicate that the gender difference is small for ages 15-30 and then increases for ages 31-40 and 41-50, then the gap decreases for ages 51-60 years.

Figure 2: Prevalence of difficulty by age categories and sex



Location

According to 1998 Population Census the rural- urban gap in disability prevalence rates are almost non-existent: 2.52 percent in rural areas and 2.59 percent in urban areas.

In examining the data according to location, i.e. (rural/urban) the picture, as shown in Figure: 3 is less clear. While the prevalence rates are higher in urban settings, the difference between the rural (20 percent) and urban (23 percent) numbers are small and only statistically significant at the 0.05 level ($\chi^2(1)=4.672$, $p=0.031$).

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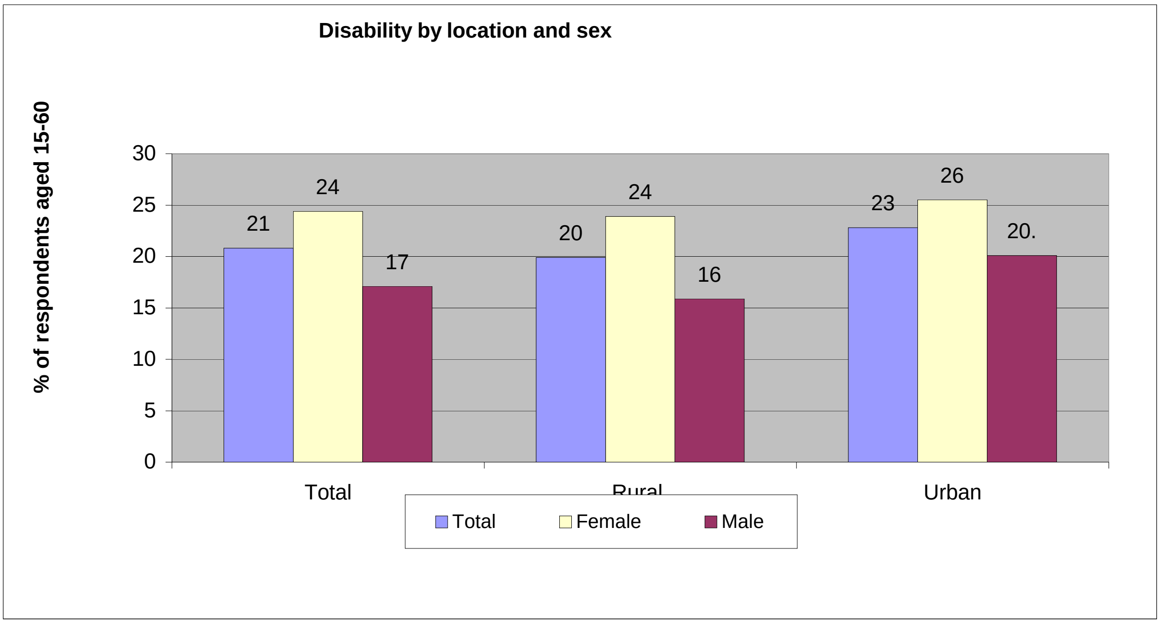
[10] Other factors being- poverty, low educational level, inadequate sanitation and water supplies and poor quality of health services.

Figure 3: Prevalence of difficulty by location and sex



<u>Impact on activity</u>

The degree of difficulty reported had a direct relation with the kind of impact it had on the amount and type of activities that the individual was able to undertake. Difficulties in learning and personal care had the most significant and encompassing impact on the daily lives of people. In such cases, reduced amount and kind of activity was reported across the area of home, work and other areas, irrespective of the individual's gender.

Findings (as noted in Table 3) also indicate that females reported a higher negative impact of their difficulty, this was especially evident in the home sphere where significant differences are noted for women reporting difficulties in seeing, hearing and walking. Interestingly, these trends also hold true in the area of work for those women reporting difficulties in seeing and speaking. While men were more likely to indicate that the kind and amount of activity that they were able to undertake has been negatively impacted 'in other areas'. These differences could be attributed to the gender roles ascribed to women and men, where women are primarily defined as 'homemaker', and have almost solely responsible for carrying out household chores. Most of the time, they are also required to take responsibility for carrying out activities related to livestock management, which are usually based around the house. In the absence of any support (especially from their male counterparts) it is not surprising that many of them noted greater impact on their day-to-day activities.

Table 3: Impact of difficulty on the kind and amount of activities

	Seeing	Hearing	Speaking	Walking	Learning	Personal care
Total (#)	**17**	**1**	**1**	**3**	**1**	**1**
Does disability reduce amount or kind of activity (percent of ppl reported disability)						
At home	79	89	74	82	97	100
**At work*	74	73	78	81	83	100
In other areas	62	79	68	86	87	94
Males (#)	**11**	**1**	**1**	**4**	**1**	**1**
Does disability reduce amount or kind of activity (percent of males reported disability)						
At home	63	76	70	77	95	100
**At work*	74	74	74	81	82	100
In other areas	67	81	70	82	95	91
Females (#)	**22**	**2**	**0.5**	**2**	**1**	**1**
Does disability reduce amount or kind of activity (percent of females reported disability)						
At home	88	95	82	95	100	100
**At work*	74	71	100	78	86	100
In other areas	60	78	64	95	77	95

* If working

Expectedly, there is a positive relationship between the degree of difficulty and its reported impact on home, work or other areas. For example, in the case of visual impairments, 74.6 percent of those who have reported their impairment as mild said that their disability reduced the amount/kind if any activity they did at home while this proportion was around 90 percent for those who had reported their degree of disability as moderate or severe. The fact that such a high proportion of people with mild disabilities stated that this had an impact on their daily activities is indeed significant. It could be hypothesized that in the absence of assistive devices this mild difficulty became problematic and impinged upon the person's ability to work. However in the absence of any additional data one cannot make an strong claims.

Summing up:

Analysis of data from the RECOUP household survey for the age group 15-60 years supports the debates highlighting the continued underestimation of disability prevalence rates in Pakistan. The survey by including information on the degree of difficulty and its impact on an individual's activities provides a more detailed picture of the prevalence and the demographic characteristics of people with disabilities in Pakistan. Our data highlights the following key points:

- One in five Pakistanis has a disability (21 percent of total sample); two thirds of these are mild cases, 28 percent are moderate and 10 percent severe cases.
- Disability is closely associated with age; the prevalence of disability increases as the age of the respondent increases.
- Disability prevalence rate is higher among females than males for ages 15-60; the gender gap deteriorates as the age increases.

We now focus our attention to a more detailed analysis of the 15-30 years age group- the young people with disabilities- who, as discussed previously, are the main focus of DEPP. We will be analyzing data on age of onset, poverty levels and education levels.

2. Young people with disabilities (ages 15-30 years)

Overall trends

Our findings indicate that young people (ages 15-30) constitutes one-quarter of the total sample reporting one or more kind of difficulties in the areas identified in our HHS. As shown in Table: 4, 9 percent of the youth sample reported having at least one type of difficulty. The prevalence rates were higher in urban areas, as compared to rural settings (as was the case in the larger sample), and reporting also suggested a gender tilt, with young women reporting more difficulties than young men, though the difference between sexes are not statistically significant ($\chi^2(1)=1.558$, p=0.212).

Table 4: Reported difficulty (as percent of respondents aged 15-30)

	Total	Rural	Urban
Total	9	9	10
Female	10	9	11
Male	9	8	9

Type and degree of difficulties

The majority of the respondents in this age group reported difficulties in seeing, while other difficulties were much less likely to be reported (see Table: 5). Not surprisingly, most of the respondents categorized their difficulties in seeing as being mild in nature. The degree of severity reported as mild was also significantly higher for those reporting a difficulty in hearing. Thus, similar to trends reported in the larger sample- respondents seemed more willing to report mild seeing and hearing difficulties. Whereas when reporting difficulties in personal care and learning, there was a greater tendency to report these when the severity of the difficulty experienced was more profound.

Table 5: Type and degree disability (percent of people aged 15-30 who reported one or more difficulties)

	Seeing	**Hearing**	**Speaking**	**Walking**	**Learning**	**Personal care**
Total #	**148**	**20**	**18**	**43**	**18**	**14**
Mild	71	60	33	33	28	29
Moderate	23	30	28	33	28	21
Severe	6	10	39	35	44	50

Age of onset

As indicated in Table 6, amongst the youth- the types of disabilities, which are more likely to be reported as being severe (personal care, learning and speaking), are also more likely to be from birth or acquired during the early years of life. This could possibly reflect an important association between the impairment and issues around maternal health and early child care. The severity and the early onset of difficulties related to personal care and learning also draws attention to the issue of consanguineous marriages. Gustavson (2005), based on 12 year follow up of children born in four different areas of Lahore, noted that amongst other factors, such as poverty, malnutrition and birth trauma, consanguineous marriage was also a significant factor which lead to infant mortality and learning disabilities in children. Furthermore, evidence from the UK where research has been carried out with Pakistani and Bangladeshi immigrants suggests that there is a greater likelihood of certain impairments due to a greater incidence of genetic factors related to consanguinity (Lindsay *et. al.,* 2006). Unfortunately, both the number and the coverage of studies exploring this link are very limited in Pakistan. In the absence of a larger evidence base there is a need for caution in overly attributing causation to consanguinity only.

Patterns suggesting an early onset of disability necessitate a need to establish more preventive measures (such as, improving mother's health and nutrition as well as increasing the effectiveness of services provided for early childhood care such as immunization- as argued previously). It also requires investments from the government in early childhood education for children with disabilities- an area which remains underdeveloped in current provision.

Table 6: Age of onset (percent of people aged 15-30 who reported one or more difficulties)

	Seeing	**Hearing**	**Speaking**	**Walking**	**Learning**	**Personal care**
Total #	**148**	**20**	**18**	**43**	**18**	**14**
From birth	8	35	78	20	72	86
Ages 0-9	4	5	11	12	28	14
Ages 10-20	52	35	11	46	…	…
Ages 21-30	38	25	…	22	…	…

Having discussed the nature, type and severity of difficulty amongst the young people in our sample, we now turn our attention to the impact that having a difficulty has on their educational prospects, and socio- economic aspects of their lives.

Education

Despite substantive improvements in education related indicators over the last decade, Pakistan still lags behind in providing education for all. As compared to other countries in the region, educational attainment levels of young people, particularly those of girls, have been low. Government of Pakistan, as a signatory to various international commitments, including the Education for All (UNESCO, 1990) commitment and the Millennium Development Goals (UN, 2000), has increased its efforts in provision of education services to its citizens. The National Education Policy 2008 (Government of Pakistan 2008) envisions:

> Education is a categorical imperative for individual, social and national development that should enable all individuals to reach their maximum human potential. The system should produce responsible, enlightened citizens to integrate Pakistan in the global framework of human centered development. (p. 20)

Nonetheless, a high number of children remain out of the education system. Official figures state that in 2005-06, one-third of primary school going age children were out of school and only around 25 percent of secondary school going age children were enrolled in schools in Pakistan. Children living rural areas and females were less advantageous in being a part of education system (Government of Pakistan, 2008). It is commonly accepted that children with disabilities are over-represented in this category of children who remain excluded from the education system. Fontana and Lari state that 'the education of children with special needs in Pakistan is an area which is grossly neglected and in need of urgent attention' (Fontana and Lari, 2002, p.1) . According to a UNESCAP[11] (undated) document 'only 4 percent of the total number of school going age (approximately 25,000) students with disabilities are enrolled in various schools/centres of the country'. While this seems a

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[11] UNESCAP published a report titled, ' Disability at a glance: a profile of 28 countries and areas in Asia and the Pacific'.

rather low number, it is an over-estimation when compared to figures suggested by some international organisations which state that less than 1-2 percent of children with disabilities are in the education systems in many countries of the South.

Historically, education of children with special needs was mainly in the hands of religious institutions. At the time of independence, only a few schools were functioning for the education of children and adults with disabilities. Following independence, some private institutions became active in providing educational opportunities to children with special needs. The National Commission on Education in 1959 placed the education of children with disabilities on the government agenda for the first time. It recommended the provision of vocational education for children and adults with mental retardation, and training of teachers for the education of children with disabilities. The Education Policy of 1972 provided funds for special education. In the 1980s and 1990s, the UN asked member states to pay special attention to the problems of people with disabilities, a time that coincided with the Presidential rule of the late General Zia ul Haq (1977-1988), which was particularly significant as the General was a parent of a girl with disability making him very aware of disability issues.

The 1980s saw a significant increase in budgetary allocations for newly established special education centres and other institutions for the education and rehabilitation of children with disabilities. Government initiatives resulted in more than 200 special education institutions with more than 20,000 enrolments. However, the National Education Census, 2005 noted that the number of children enrolled in special schools was 13,122 (0.04 percent of the total numbers enrolled), suggesting a lack of increased enrolments even over a period of over two decades. However, neither of these figures are very illuminating as special schools in developing economies are not as wide spread as in other parts of the world and hence the share of the population that they are likely to cover is minimal.

The RECOUP HHS also indicates that likelihood of acquiring some schooling is significantly lower for youth with disabilities as compared to their non-disabled counterparts ($\chi^2(1)=4.861$, $p=0.027$). More than one-third of these young people were ‘never enrolled’ while this was 10 percentage points lower i.e. 26 percent among the youth without disabilities.

Not only are children with disabilities more likely to be excluded, but there is double discrimination in the case for girls with disabilities, which is reflective of the gender discrimination in girls education at large. In 2005-06, at the primary level there were only 82 females for 100 males enrolled at schools (Government of Pakistan, 2008). The enrolment rates also decline significantly for girls as the education level increases. Our data indicates that girls/women with disabilities are less likely to get an education as compared to boys/men with disabilities. Thus, it is plausible that gender is more significant than the disability dimension in the continued exclusion of girls from the education system. The difference between disabled and able-bodied females is around five percentage points and insignificant ($\chi^2(1)=0.512$, $p=0.474$). However, girls/women with disabilities are less likely to complete grade 12 and above than their male counterparts.

On the other hand, for males not receiving any education can be explained by their disability status; the percentage of young men with disabilities who have received no education (29 percent) is significantly higher than that of non-disabled males (12 percent). But the ones who seem to make it into the education system are likely to have the same educational attainment levels as their non-disabled male peers.

Therefore we can conclude that young women with disabilities are less likely to enroll in school as compared to men with disabilities, additionally, even if they do acquire some education, they are less likely to complete high school as compared to men with disabilities and indeed their able- bodied female counterparts. On the other hand, while young men with disabilities are more likely to get education when compared to young women with disabilities, they are less likely to get education then their non-disabled male counterparts. However, if they (young men with disabilities) do mange to attend school, their progression through the system is more stable, and they are similarly likely to complete high school or above.

Table 7: Educational attainment levels of people with disabilities as compared without disabilities (15-30 years)

	Total			**Male**			**Female**		
	Mild	Moderately and severely disabled	Non-disabled	Mild	Moderately and severely disabled	Non-disabled	Mild	Moderately and severely disabled	Non-disabled
N	**138**	**98**	**2332**	**49**	**55**	**1127**	**89**	**43**	**1205**
None	26	36	26	10	29	12	35	44	39
Less than primary	10	6	7	4	7	7	14	5	8
Primary	15	17	18	23	18	20	10	16	16
Middle	16	20	18	29	26	26	9	14	11
Matric	14	11	18	23	7	23	9	16	13
FA/FSc	12	6	8	8	9	8	15	2	7
BA/BSc or more	7	3	5	4	4	4	9	2	5

Even though we are not working with very large numbers, data indicates that the earlier the onset of a difficulty, the less likely is the person to get some education, especially in the case of those with difficulties in learning or personal care, and in some extent to physical difficulty. However it is difficult to draw firm conclusions from the very small numbers present in our survey.

Type of school attended

Over the past few decades, there have been ongoing debates about the types of school most suitable for children with disabilities. Our survey data provides information on the types of schools attended by young people with disabilities, including their participation in Quranic education. The government has primarily encouraged a two-pronged approach towards the education of children with disabilities. Since the 1980s it has actively propagated the development of special education[12], but more recently inclusive education has been noted as an 'emerging trend in Pakistan' (Hameed, 2003). Even though the government has encouraged special education, special schools are largely an urban phenomenon and have not spread across the country. Additionally, there is empirical evidence to suggest that in many rural areas children with disabilities are more likely to attend a regular school. Miles (1997) refers to this as 'casual integration', highlighting a phenomenon where in many rural areas there is just one school and all the children attend it. Our data also suggests that the greatest majority of young people with disabilities, who did attend school, attended a mainstream setting (97 percent). Only one young person in our sample had attended a special school and that too at the secondary level. This raises an important issue which highlights the need to focus our attention to issues of access and quality being offered to children with disabilities in the regular system.

Public or private schooling

A recent World Bank report on public-private schooling in Pakistan notes that every one in three children are enrolled in a private school. Recent years have seen a sharp increase in the number of private schools. A LEAPS survey noted that between the years 2000 and 2005 the number of private schools had increased from 32,000 to 47,000 (Andrabi *et. al.,* 2007). This increase in private schooling has expanded the choices of parents for their children's education both in urban and rural settings. With the advent of low fee paying private schools, even parents in rural Punjab usually have 7-8 schools in the village to choose from (Andrabi *et. al.,* 2007). Such low costs private schools provide an opportunity even to the poorest households to send their child to a private school, which is perceived as being better in quality and easily accessible in terms of distance (Alderman *et. al.,* 2001).

Private schooling, particularly by eliminating the issue of distance to school, could provide an opportunity to children with disabilities to be a part of the education system. Results from our data indicate that young people with disabilities (19 percent) are more likely to attend private schools as compared to their able-bodied peers (11 percent), as shown in Figure 4. This while indicating the

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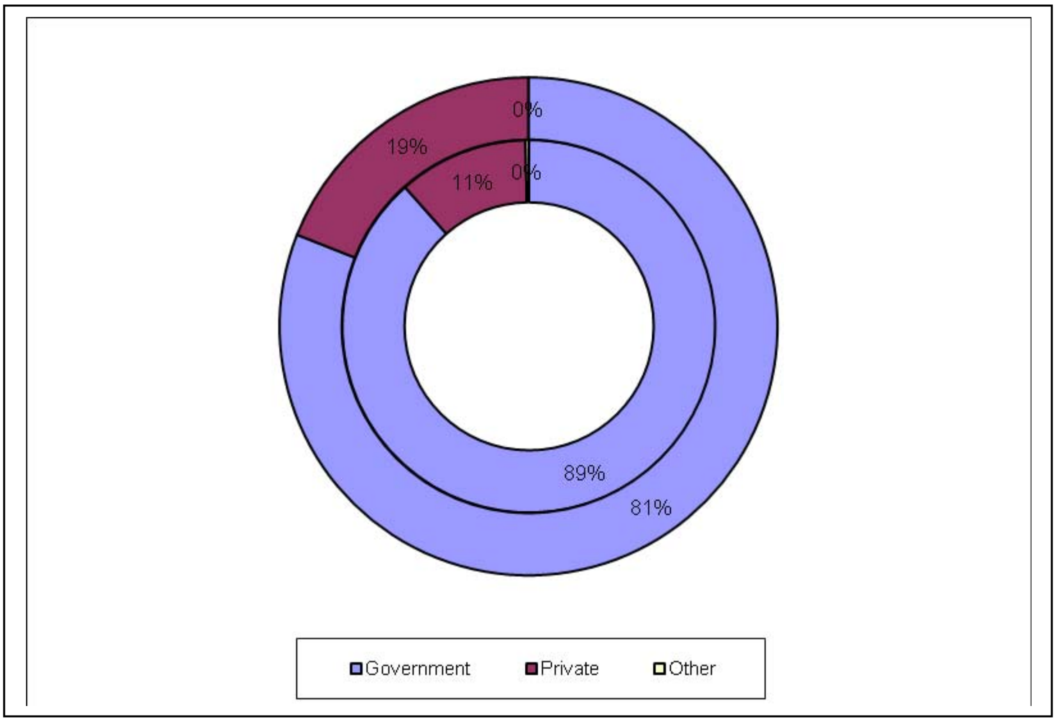
[12] The Directorate General of Special Education has established 46 special education centers, and the National Trust for the Disabled has set up 3 special education centers. Assessment, diagnostic and special education services are provided, personal aids and devices are distributed, curricula are developed and sports and recreational activities are planned. The Directorate General of Special Education runs 11 centers for persons with visual impairment, 12 for those with intellectual disabilities, 12 for those with hearing impairments and 11 for those with physical disability. Provincial governments have also set up special education institutions. The National Institute for Special Education (NISE) was established in 1986 to develop expert training programs, long-term and short-term certification courses, build partnerships with universities, research centers and international organizations as well as develop and publish instructive materials. Special education faculties have been established within the Universities of Karachi and Punjab.

possible inadequacy of the public school system in catering to the needs of children with disabilities also indicates the readiness of families to take the financial responsibility of educating their child with disabilities in the absence of viable options provided by the public sector. While these inferences require further investigations, the availability of low fee paying private schools in close vicinity, with a perception of providing quality education, seemingly helps overcome barriers to the educational participation of children with disabilities.

Figure 4: Management of basic schooling (Outer circle is for the disabled and inner for the non-disabled youth)



More interestingly, even though only one-third (33.3 percent) of young people with moderate and severe disabilities attended secondary schooling (as compared to 40 percent of non-disabled peers); the role of private schooling becomes more significant at the secondary level. Of the young people with disabilities who attended secondary school, 31.4 percent went to a mainstream private school as compared to 12.7 percent of non-disabled youth. In Pakistan almost every village has a public primary school but not necessarily a secondary school. Therefore, at this level distance from school is likely to become a barrier for people with disabilities and private schools might be the only options for those families who want to send their child with disabilities' to school and cannot/do not wish to travel a long distance.

Analysing our data on the basis of type of school attended by young people with disabilities and poverty status of household indicates that while poverty decreases the chances of receiving private schooling for all groups, private schools are almost equally preferred by young people with moderate and severe disabilities and their able-bodied counterparts at the basic education level. At the secondary level, young people with moderate and severe disabilities from poorest households (10 percent) are more likely to receive private schooling as compared to their able-bodied peers from poorest households (6 percent). While this finding might draw support from the argument in favour of access, it also highlights, to some extent, a certain faith in the returns to education being professed by parents who are ready to financially invest some of their already meager resources into the education of the child with disabilities.

Table 8: Percentage distribution of youth attended private schools by disability and poverty status

	Basic (Gr 1-8)			**Secondary (Gr 9-12)**		
	Mild disability	Moderate and severe disability	Non-disabled	Mild disability	Moderate and severe disability	Non-disabled
1st Quintile (richest)	50	25	39	21	40	40
2nd Quintile	13	17	25	14	20	27
3rd Quintile	25	33	16	36	10	16
4th Quintile	6	17	11	29	20	11
5th Quintile (poorest)	6	8	9	…	10	6

Private tuition

Another dominant trend in the current educational climate in Pakistan is that of private tuitions. Even though their numbers are unknown, private tuition, also called coaching centres, are increasingly becoming very common. The breakdown of the state education system is largely held responsible for the rise of this unorganised private sector. Table 9 shows the percentage of young people with moderate and severe disabilities who reported receiving private tuition during their basic schooling is almost double as compared to the percentage of young people without disabilities. Findings indicate that two-thirds of these tuitions are taken voluntarily by the young people.

Table 9: Percentage of youth who received private tuition by disability status

	Disabled (Moderate and severe cases)	**Non-disabled**
Private tuition (% of ppl ever acquired grades 1-8)	***63***	***1852***
Taken private tuition	29	15
Voluntary	67	65
Teacher expected	33	35

It is interesting to note that, unlike private schooling, when we look at the disability and poverty status of the people who had taken tuition at the basic schooling level, we observe significant gaps by poverty and disability status. Table 10 clearly shows that young people from richer households are more likely to receive private tuition particularly if they are moderate or severe difficulties as compared to their peers from poorest households.

Table 10: Percentage who have taken tuition by disability status and wealth

	Mild disability	**Moderate and severe disability**	**Non-disabled**
1st Quintile (richest)	24	47	21
2nd Quintile	45	39	18
3rd Quintile	14	29	13
4th Quintile	14	10	14
5th Quintile (poorest)	3	0	10

Quranic education[13]

An interesting trend evident in our findings was the families' preference towards Quranic education for young people with disabilities- young people with disabilities are twice more likely (5 percent) to trained to become a Hafiz-I Quran[14] as compared to their non-disabled counterparts (2 percent). Such a finding is supported by observations made by Pasha (2003), who notes that,

> if a disabled child is born in a family normally parents persuade the child to take up Islamic education. This is done more as a sympathetic gesture. If the child is brilliant, parents plan to make him a doctor or engineer not an Islamic scholar.

In this regard, our data also highlights an interesting gender dimension- all young adults who trained as hafiz were men who reported, or were reported as having moderate and severe difficulties. Thus, it would be plausible that becoming a Hafiz increases the young man's chances and opportunities for social participation and gives him a better social status. However, because figures can only tell us part

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[13] Quaranic education is mostly imparted in madrassahs, most of which are non-state institutions associated with local mosques and funded through charity. There is no cost of studying in a madrassah and some of these are also residential - they provide children with food and shelter.

[14] Hafiz's are people who memorize the whole Quran. The schooling for becoming a Hafiz is usually provided at madrassas without any cost. Becoming a Hafiz has several advantages including "higher status in society" and receiving some benefits (additional marks in board exams, higher ranking in scholarships etc). In Pakistan it is increasingly becoming common that every family wants to see at least one of their children as a hafiz. Encouraging a child in the family to become a hafiz also means that "the soul of the parents is protected", which makes it a valuable religious duty.

of the story it would be interesting to explore this dimension further through more in-depth interviews with the young people and their parents about the rationale underpinning and the expected outcomes of such decisions.

Marital status

Even though marriage is an important marker of adulthood in many South Asian societies, people with disabilities are considered asexual and their sexual and reproductive rights tend to be overlooked. Mainstream sexual and reproductive health programmes do not consider their needs in the information provided and/or in the training of health workers. Groce notes that often health professionals refuse to provide reproductive health information to young people with disabilities because it is felt that they do not need it (Groce, 2004). Across many South Asian countries, discrimination against people with disabilities in terms of marital status is anecdotally recorded (Singal, 2008).

In Pakistan the legal age for marriage is 18 years for males and 16 years for females. Thus the data has been calculated for males aged 18-30 and females 16-30 in three categories- a) severely and moderately disabled; b) mild disabilities; and c) non-disabled. However, it is important to note that birth registration systems are very weak in Pakistan, which makes the prevention of underage marriages difficult, while early marriages are quite common and socially accepted.

Table 12 suggests that youth with moderate and severe disabilities are less likely to marry as compared to their non-disabled and even mildly disabled counterparts.

Table 12: Marital status of young men (18-30 years) and women (16-30 years)

Young men	Mild disability	Moderate & severe disability	Non-disabled
# of respondents	***43***	***43***	***928***
Never married	67	74	62
Currently married	33	23	36
Widowed		2	0.3
Divorced			0.1
Separated			0.3
Nikkah but no rukhsati			1
Young women	Mild disability	Moderate & severe disability	Non-disabled
# of respondents	***86***	***40***	***1147***
Never married	34	55	44
Currently married	61	43	55
Widowed	4		1
Divorced	1		0
Separated	1	3	0
Nikkah but no rukhsati			0.4

Data also suggests that both young men and women are less likely to marry if they have moderate or severe disability as compared to their non-disabled counterparts ($\chi^2(1)=13.471$, $p\approx0.000$).

Employment

The ability and the opportunity to earn a livelihood – whether in a formal job or through some kind of self-employment– is an important determinant for an individual's well-being. Work is a defining feature of human existence- it is not only a means for sustaining life, but is an important way of affirming one's identity. However, people with disabilities face many barriers and discrimination not only in entering the labour market but also once they are employed. Evidence from across the globe suggests that people with disabilities are less likely to participate in the labour market, more likely to be unemployed and earn less than their counterparts-even after controlling for educational attainment and job related differences (Jones, 2005).

Our data also suggests that young people with disabilities are less likely to be economically active as compared to their able-bodied peers, particularly depending on the severity of their disability. As table 13 shows, 76 percent of the youth with moderate and severe disabilities did not work during the survey reference period (last 1 week) as compared to 67 percent of the non-disabled. Young people with mild disabilities were more likely to be part of the labour force as compared to moderately and severely or able-bodied peers. The difference was more prominent among males: 62 percent of the young men with disabilities were economically inactive as compared to 44 percent of the able-bodied males ($\chi^2(1)=7.308$, $p=0.007$).

Analysis of data by type of economic activities that young people are engaged in provides some interesting results. It is difficult for young people with moderate or severe disabilities, particularly men, to get wage employment: 20 percent of the moderately or severely disabled men were wage employees as compared to 37.2 percent of the non-disabled young men. Both young men and women with mild disabilities, on the other hand, were more likely to be in wage employment as compared to other young people.

Table 13: *Type of employment* of young people with and without disabilities*

	Total			Male			Female		
	Mildly disabled	Moderately or severely disabled	Non-disabled	Mildly disabled	Moderately or severely disabled	Non-disabled	Mildly disabled	Moderately or severely disabled	Non-disabled
Number of respondents	138	98	2329	49	55	1125	89	43	1204
Employed	***31***	***24***	***33***	***53***	***38***	***56***	***19***	***7***	***11***
Wage	20	12	21	41	20	37	9	2	6
Self	11	12	12	12	18	19	10	5	5
Not worked during past one week	***69***	***76***	***68***	***47***	***62***	***44***	***81***	***93***	***90***

*Those who have worked for any pay, profit or gain even for one hour during one week prior to the survey

Conclusions

In this paper we have discussed some preliminary findings related to people with disabilities based on the data gathered from a household survey conducted in 9 districts in two provinces of Pakistan. As we have noted previously, the survey had an encompassing focus and disability was only one small, but important, dimension. We wanted to use this opportunity to not only develop and test an alternative conceptualisation of disability in survey work, but also gather data that would provide us with a better understanding of the kind of lives that young people with disabilities live in this region. In this concluding section we take an opportunity to reflect upon both these aspects of our work.

In attempting to move beyond simply asking people if they were or knew of someone disabled, as is the case in most traditional survey questions, we attempted to take account of issues of stigma and language barriers by deconstructing the very notion of disability. Thus, the focus was on outlining varied aspects of human functioning and then asking people to assess their level of difficulty. Additionally, we not only wanted to capture issues of impairments in bodily structures but also how these impact on an individual's participation in different spheres of their lives. On reflection we would argue that deconstructing the very notion of disability was a very useful strategy as people were more likely to engage with and respond to the question. Also, it helped move away from what could possibly be perceived as a stigmatizing language of disability. By elaborating on the notion of functioning, people seemed more willing to reflect on their perceived difficulties. This is evident from the very high rates of disabilities that we have captured when compared with the official statistics available on disability prevalence rates in Pakistan. It is important however to point out here that a large proportion of the population reported difficulties which were classified as 'mild' in nature- the impact of these on an individual's participation in different spheres of their life was varied. In many cases the mild nature of a difficulty could be accounted for with the use of spectacles or hearing aids. However questions in the survey fail to provide information about how many of these individuals were using and/or had access to various aids, appliances and other assistive devices. This information would be useful as it would not only help in assessing the outreach of current health care programmes but also assist in future planning. Thus, on reflection the survey should have incorporated questions that collected information on the use of such aids and assistive devices by people reporting any kind of difficulty.

Despite the aim of the HHS was to capture individuals' own perceived difficulties, the barriers encountered in interviewing people with severe hearing, speaking, learning and personal care compelled enumerators to receive and trust the information given by their caregivers or other family members. In these cases, sections related to subjective well-being were not asked and the tests were not administered.

It is also believed that individual same sex interviews with every household member aged 15-60 minimized the underreporting of people with disabilities as well. There were only a couple of cases in which the disability of an individual was not revealed or the people with disabilities (mainly children) were not recorded as a member of the family while roster was being filled. These cases were identified and recorded during the individual interviews. The survey with its attempts at mainstreaming data collection in relation to people with disabilities not only provides a very useful snapshot of their profiles in relation to the general population, but also provides an indication of how their lives have unfolded. While our numbers are very small for any complex statistical scrutiny, our basic analysis highlights the marginalized lives that people with disabilities continue to live despite various national and international proclamations. The differences between youth with and without disabilities in education and employment patterns and marriage prospects, as shown in this paper, are some of main reflections of this marginalisation. Similarly, gender differences in prevalence of disability also indicate the need for a more tailored approach towards women, with particular attention aimed at improving health services and nutritional intake of women and girls.

The data also highlights some interesting trends which need to be explored further. For instance, there is evidence to suggest that families, even those from low income households are willing to spend money on the education of their child with disability- this is an interesting finding and is contrary to commonly accepted beliefs. Additionally, there is evidence to suggest that Quranic education is the more preferred type of education for young men with disabilities. Therefore it would be useful to move beyond mere quantitative collection of data to a deeper exploration of issues of *why* and *how* people make or are forced to make decisions about their lives. By using a community based qualitative study we aim to report the voices of people with disabilities, how they negotiate their multiple identities (of being classified as women/men; young/old; type of impairment etc). We attempt to capture narratives that will attempt to be ‘life full’ (Kothari and Hulme 2003) to provide greater insights into policy and planning. Thus while the survey data, though limiting in many respects, has provided a useful overview, the findings can be further enhanced through a closer examination of the lives of young people with disabilities- an insight which is essential in helping us frame enabling policies and effective programmes.

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