Disability as a form of child vulnerability in Uganda

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Abstract

Disability is one of the forms of vulnerability that countries need to address. It is estimated that

there are 500-650 million persons with disabilities in the world, 10% of the world population,

150 million of whom are children. This paper uses the 2002 Uganda Census to compare disabled

and non disabled children in relation to vulnerability among children. According to the 2002

Uganda Census, 2% (over 250,000) of all the children were reported to have disability. The

proportion of children with disability was less than that reported in the general population as

disability increases with length of exposure of an individual. The main types of disability were

hearing difficulty (21%), limited use of legs (20%), sight difficulty (13%), limited use of arms

(6%), deafness (5%), loss of legs (2.1%), blindness (1%) and loss of arms (1%). In general, most

of the disability (85%) was physical. There was evidence that infanticide has been practiced

among the nomadic ethnic groups of Uganda on disabled children. Disabled children have also

benefitted less from the Universal Primary Education as discrimination still exists.

**Keywords:** Uganda, disability, Vulnerability

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#### 1. Introduction

Disability is both a cause and consequence of poverty. Eradicating world poverty is unlikely to be achieved unless the rights and needs of people with disabilities (PWD) are taken into account. It is estimated that there are 500-650 million persons with disabilities in the world, approximately 10% of the world population, 150 million of whom are children. More than 80% live in developing countries with little or no access to services. The majority of children with disabilities in developing countries remain out of school and are completely illiterate. The problems identified and addressed have varied from exclusion from decision making to the severe discrimination and actual killing of children with disabilities. Poverty is both a cause and a consequence of disability. Children with disabilities and their families have the right to an adequate standard of living, including adequate food, clothing and housing and to the continuous improvement of living conditions.

Family science frameworks and research findings for families who have children with disabilities reflect societal changes. Previous research revealed four major indicators of family distress including early out-of-home placement, divorce, social isolation, and child neglect or abuse (Singer & Irvin 1989). However, there was considerable variation in family responses (Taanila et al. 1996). Although families with disabled children may live 'between joy and sorrow' (Kearney & Griffin 2001), increasing evidence points to positive, adaptive coping by families with disabled children mirroring that found in families without disabilities (Trute & Hauch 1988, Singer & Irvin 1989, Van Riper et al. 1992, Seligman & Darling 1997, Ferguson et al. 2000). Over the past 20 years, both research findings and parental narratives (e.g. Featherstone 1980, Mullins 1987, Summers et al. 1989, Wright & Wright 1993) suggest that the quality of life for families with disabled children resembles that of families in general (Ferguson et al. 2000).

Despite the positive improvements in the way orphans are being cared for and being heard, children with disabilities are among those who are discriminated against (World Vision Uganda 2007). In Uganda, there has been a lot of effort to help people with disability including special admission to university and representation at various levels of administration.

### 2. Defining disability

Defining disability is complex and controversial. Though arising from physical or intellectual impairment, disability has social implications as well as health ones. A full understanding of disability recognizes that it has a powerful human rights dimension and is often associated with social exclusion, and increased exposure and vulnerability to poverty. Disability is the outcome of complex interactions between the functional limitations arising from a person's physical, intellectual, or mental condition and the social and physical environment. It has multiple dimensions and is far more than an individual health or medical problem. There are various definitions of disability (DFID, 2000). According to the compendium prepared by the Uganda Bureau of Statistics, it uses three terms to describe disability namely disability, impairment and handicap

Disability is defined as "Loss or limitation of opportunities to take part in everyday life on equal level with others due to impairment"

Impairment "any loss or abnormality of psychological or anatomical structure of a function"

While handicap is "a disadvantage for a given individual, resulting from an impairment or a disability" (UBOS, 2006)

Other agencies have defined a person with disability as

A person who is limited in the kind or amount of activities that he or she can do because of ongoing difficulties due to a long-term physical condition, psychological, anatomical, mental condition or health problem (United Nations, 1998 as cited in Colon Robson)

The World Bank Disability Group's Web site http://wbln0018.worldbank.org provides a section on defining disability thus, the World Bank defines disability as:

more than a description of a specific health issue; rather it is affected by people's cultures, social institutions, and physical environments.

The above definitions may not seem to be fully explanatory, as such, World Health Organization has a guide called the International Classification of Functioning, Disability and Health (ICF). ICF presents a framework which encompasses the complex multifaceted interaction between health conditions and personal and environmental factors that determine the extent of disablement in any given situation (cited in Colon Robson). It is, therefore, recommended that we adopt the definition used by disabled peoples' organization as recommended by Zinkin and McConachie (1995 cited in Treloar 2002) that:

"impairment" is an individual limitation, whereas "disability" is restriction imposed by the current organization of society. "Impairment" is defined by WHO (1980a) as "any loss or abnormality of psychological, physiological, or anatomical structure or function."

Making descriptions at the level of the impairment allows focus on the individual child and her/his needs as an individual. However this study assumes the definition of UBOS for the disabled child since the source of data for this analysis is the 2002 Uganda Population and Housing Census which was conducted by UBOS

### 3. Objectives of the paper

The major objective of this paper was to find out if disabled children were more vulnerable than non disabled children in Uganda. The paper specifically presents: the Prevalence of disabled among children, disability by selected socio economic status and Educational outcomes of disabled children

### 4. Methodology

The source of data for this paper is the 2002 Uganda population and Housing Census. The analysis compared disabled and non disabled children by different socio economic characteristics of the children.

### Findings of the study

## **5.1 Prevalence of disability**

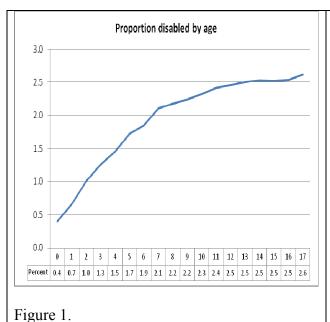
Based on the 2002 Uganda Census, 2 percent of all the children were reported to have disability. The proportion of children with disability is less than that reported in the general population as disability increases with length of exposure of an individual. As a proportion, this may seem small but in absolute figures, over 250,000 children based on the 2002 Census had some form of disability. This level of disability is high for this age and as such, these children may require special attention in regard to provision of different services. Secondly in a poor economy like Uganda, these children will be more vulnerable if disability is combined with poverty.

Table 1: Proportion of disabled children in Uganda

| Has the child got the disability | No        | Percent |
|----------------------------------|-----------|---------|
| Has disability                   | 25,177    | 1.8     |
| No disability                    | 1,347,332 | 98.2    |
| Total                            | 1,372,509 | 100.0   |

## 5.2 Disability with age

A plot of proportion disabled by age (Figure 1) shows that disability increases with increasing age.



Apart from those born with disability who may have high mortality than those born without disability, this is so because the older one becomes, the higher to the length of exposure to conditions that cause disability. At age zero, less than one percent of the children are disabled. By age 17years, 2.6 percent of the children are disabled.

## 5.3 Cause of disability

Figure 1 showed that the proportion disabled increased with increasing age. This meant that the causes of disability were related to the exposure factors. Thus, an analysis of the occurrence of disability among children with disability shows that one in three was born disabled. The rest became disabled after they were born (later in life), with the major cause of disability being disease (56%). Accidents (transport, occupational, others accidents not specified) accounted for one in ten among the disabled children and 0.3 percent of the children became disabled due to war.

### **5.4** Types of disability

The importance of identifying type of disability helps to put in place the right correction / rehabilitation measures and opportunities. The main types of disability were hearing difficulty (21%), followed by limited use of legs (20%), sight difficulty (13%), limited use of arms (6%). Related to these four is deafness (5%), loss of legs (2.1%), blindness (1%) and loss of arms (1%).

In general, most of the disability (85%) is physical. Non physical disability (mental retardation, mental illness, epileptic rheumatism) accounted for just over 15 percent.

Table 2: Proportion of disabled children by cause of disability, main form of disability

| Cause of disability                        | Number   | Percent |
|--|----------|---------|
| Born with a disability                     | 7,504    | 29.8    |
| Disease/illness                            | 14,136   | 58.2    |
| Transport accident                         | 526      | 2.1     |
| Occupational injury                        | 276      | 1.1     |
| Other accident                             | 1,407    | 5.6     |
| War  | 65       | 0.3     |
| Other                                      | 1,263    | 5.0     |
| Total                                      | 25,177   | 100     |
| Main form of disability among the disabled | children | ·       |
| Main disability                            | No       | Percent |
| Limited use of legs                        | 5,085    | 20.2    |
| Loss of legs                               | 524      | 2.1     |
| Limited use of arms                        | 1,484    | 5.9     |
| Loss of arms                               | 179      | 0.7     |
| Serious problem with back spine            | 702      | 2.8     |
| Hearing difficulty                         | 5,287    | 21.0    |
| Unable to hear (Deafness)                  | 1,152    | 4.6     |
| Sight difficulty                           | 3,250    | 12.9    |
| Blindness                                  | 315      | 1.3     |
| Speech impairment                          | 1,065    | 4.2     |
| Unable to speak (mute)                     | 840      | 3.3     |
| Mental retardation                         | 1,257    | 5.0     |
| Mental illness (strange behaviour)         | 1,056    | 4.2     |
| Epileptic                                  | 1,126    | 4.5     |
| Rheumatism                                 | 430      | 1.7     |
| Others                                     | 1,425    | 5.7     |
| Total                                      | 25,177   | 100.0   |

## 6 Disability by selected socio economic characteristics

Sometimes socio economic and demographic factors determine the survival status of the disabled person. For example, in countries with good economies, usually the survival rate of disabled children is higher than that within poor economies. It was therefore important to find the

distribution of disabled children by the different demographic and socio economic characteristics in Uganda.

### 6.1 Sex of the child and disability

Among the children enumerated in the 2002 Population and Housing Census, the proportion of disabled male children (2.0%) was slightly higher than the proportion of female disabled (1.6%). This is also true within the general population there were more disabled males than females.

### 6.2 Religion

Religious belief systems, apart from formalized religious practice, may promote acceptance and assist families to give meaning to the disability (Paterson 1975; Weisner et al. 1991, Wrigley & LaGory 1994, Bennett et al. 1995, Rehm 1999 cited in Treloar 2002). However, while there are more positive than negative functions of religiousness in families with disabled members (Rogers-Dulan & Blacher 1995 cited Treloar 2002), parents may experience increased stress, including the perception of religious failure or punishment for wrongdoing. Few attempts have been made to determine if different spiritual belief systems ascribe meaning differently to disability. Although some early studies suggest possible religious denominational differences with family adjustment to a child with disability (Zuk et al. 1961 cited in Treloar 2002), more recent studies have not supported this (Weisner et al.1991, Rogers-Dulan & Blacher 1995 cited in Treloar 2002). Religion as a personal coping resource used by parents of infants and toddlers with disabilities has received some attention in recent literature (Tess Bennett, -2005). Tess Bennett explains the ways in which religion can be used as a coping resource across the lifecycle of parents who have children with disabilities (CWD). Prayer, church attendance, and specific religious beliefs were identified as sources of support which helped some parents feel a growing sense of hope and strength. However, some beliefs and rituals may promote infanticide.

It is also possible for parents with disabled children to change their religion as individuals might prefer to belong to groups that give them comfort. In the 2002 Uganda Population and Housing Census, a question included on religion showed that small variations occurred in the levels of disability by religious faith. The Christians namely Catholics 2.0 percent, Pentecostal 1.9 percent and Anglican 1.8 percent had the highest proportion of disabled children in that order. On the other hand, Muslims, and other religions like the Bahai Hindus had a lower proportion of disabled children at 1.5%.

Table 3: Proportion of disabled children by gender

|                     | Number    | Proportion disabled |
|---------------------|-----------|---------------------|
| Sex                 |           |                     |
| Male                | 687,231   | 2.0                 |
| Female              | 685,278   | 1.6                 |
| Religion            |           |                     |
| Catholic            | 562,383   | 2.0                 |
| Anglican/Protestant | 493,137   | 1.8                 |
| Pentecostal         | 63,649    | 1.9                 |
| Moslem              | 175,899   | 1.5                 |
| Others              | 77,441    | 1.5                 |
| Rural-urban         |           |                     |
| Urban               | 147,257   | 1.4                 |
| Rural               | 1,225,252 | 1.9                 |
| Region              |           |                     |
| Central             | 360,202   | 1.6                 |
| Eastern             | 355,118   | 1.8                 |
| Northern            | 301,269   | 2.4                 |
| Western             | 355,920   | 1.6                 |
| Total               | 1,372,509 | 1.8                 |

## 6.3 Residence of child by disability

Residence presented here is by rural-urban and region. The proportion of disabled children was higher in rural areas (1.9%) compared to urban areas (1.4%). Based on the region of enumeration, areas with higher proportions of the population experiencing insurgencies had the

highest proportion of disabled children. It is therefore not a surprise that Northern region which has had more insurgencies over a very long period of time (1986-todate here refers to 2002 the time the census was conducted) has the highest proportion of disabled children. It was followed by Eastern at 1.8 percent of the children in this region being disabled. Central and Western regions had the least proportion of disabled children that was less than the national average of 1.6 percent.

## 6.4 Disability by district

The findings and interpretation made based on district of enumeration was similar to that for the region of enumeration (Table 4). The districts of Acholi region which had experienced the highest levels of insurgencies had the highest proportion of children with disabilities. These were Kitgum with the highest of 4.4 percent, Pader 3.5 percent, and Gulu 3.1 percent. In the same way, the neighbouring districts of Lango (Lira-3.2% and Apac 3.2%) were the next. Two districts from the central region namely Nakasongora (2.8%) and Kiboga (2.4%) also had a high proportion of disabled children due to insurgencies that were prevalent in these areas in the early 80s (1980-1986). These were followed by districts of the Teso region; Kaberamaido (2.4%) and Katakwi (2.4%). These two districts have a common border with Karamoja region, and suffered from a lot of cattle rustling. Surprisingly, the districts of Karamoja region had the lowest levels of disabled children. These are Kotido (0.7%), Nakapirit (0.9%) and Moroto (0.9 percent). This needs further investigations whether there is no infanticide of the disabled children in Karamoja region as was the case with the Bahima (sub ethnic group among the Banyankore) since both ethnic groups are cattle keepers. The next district with lowest disabled children was Kampala, but this also needs to be investigated to check whether Kampala people had not deliberately pushed their disabled children to the village homes or to the grandparents (due to high cost of living and affordable services to PWD).

Table 4: Proportion of disabled children by district

|               |        | Percent  |
|---------------|--------|----------|
| District      | Number | disabled |
| Kotido        | 33,670 | 0.7      |
| Nakapiripirit | 8,811  | 0.9      |
| Moroto        | 9,617  | 0.9      |
| Kampala       | 54,197 | 0.9      |
| Kisoro        | 12,890 | 1.0      |
| Wakiso        | 47,804 | 1.2      |
| Kapchorwa     | 10,764 | 1.2      |
| Ntungamo      | 21,058 | 1.3      |
| Mayuge        | 19,203 | 1.3      |
| Rukungiri     | 16,148 | 1.3      |
| Kabarole      | 19,755 | 1.4      |
| Bushenyi      | 41,753 | 1.4      |
| Sironko       | 15,748 | 1.4      |
| Yumbe         | 14,838 | 1.4      |
| Mbarara       | 59,769 | 1.4      |
| Kamwenge      | 15,399 | 1.4      |
| Jinja         | 21,743 | 1.5      |
| Kabale        | 25,591 | 1.5      |
| Kasese        | 29,842 | 1.5      |
| Kanungu       | 11,604 | 1.5      |
| Mpigi         | 24,576 | 1.6      |
| Mbale         | 39,442 | 1.6      |
| Kyenjojo      | 21,642 | 1.6      |
| Mubende       | 39,984 | 1.6      |
| Mukono        | 44,950 | 1.6      |
| Rakai         | 26,675 | 1.7      |
| Kayunga       | 17,488 | 1.7      |
| Kamuli        | 41,810 | 1.8      |
| Moyo          | 10,793 | 1.8      |
| Masaka        | 44,728 | 1.8      |
| Bundibugyo    | 11,620 | 1.9      |

**Table 4: continued** 

|             |           | Percent  |
|-------------|-----------|----------|
| District    | Number    | disabled |
| Arua        | 46,233    | 1.9      |
| Busia       | 12,597    | 1.9      |
| Luwero      | 28,040    | 1.9      |
| Soroti      | 20,960    | 1.9      |
| Kumi        | 21,951    | 2.0      |
| Pallisa     | 30,199    | 2.0      |
| Bugiri      | 24,157    | 2.0      |
| Adjumani    | 11,516    | 2.0      |
| Sembabule   | 10,237    | 2.1      |
| Iganga      | 42,113    | 2.1      |
| Masindi     | 25,717    | 2.1      |
| Tororo      | 30,251    | 2.2      |
| Hoima       | 19,263    | 2.2      |
| Kibaale     | 23,869    | 2.3      |
| Kalangala   | 1,215     | 2.3      |
| Kaberamaido | 7,605     | 2.4      |
| Katakwi     | 16,575    | 2.4      |
| Kiboga      | 12,955    | 2.5      |
| Nakasongola | 7,353     | 2.8      |
| Nebbi       | 24,847    | 3.0      |
| Gulu        | 25,775    | 3.1      |
| Apac        | 39,588    | 3.2      |
| Lira        | 42,015    | 3.2      |
| Pader       | 18,000    | 3.5      |
| Kitgum      | 15,566    | 4.4      |
|             |           |          |
| Total       | 1,372,509 | 1.8      |

# 6.5 Ethnicity and disability

The lives of people with disabilities are shaped by their racial and ethnic status, their religion and their first language. Yet, little research has been done on these intersections. Research that has been done is primarily from the vantage point of service providers and the need to provide culturally appropriate services. Much research is still required to understand the unique situations

of ethnicity in relation to people with disabilities. In Uganda though not well documented, some ethnicities have higher levels of PWD while in others, they are almost nonexistent. For example as indicated above among the Bahima, children born with disabilities where killed at birth. This might be true also for the Karimojong tribes in North Eastern Uganda. The similarity between these two ethnic groups is that until recently, they have been nomadic and are still cattle keepers (Expert conversation with).

The Karamojong ethnic groups include the Pokot who had the lowest levels of disability (0.2 %), Napore (0.3%), Dodoth, So, Nyagia, all with proportion of 0.4 percent each, the Jie, 0.7 percent and the main stream Karimojong 1.1 percent. It was not possible to isolate Bahima from the Banyankore otherwise same levels would have been registered among them. Also the Batagwenda with similar culture in many aspects to the Bahima and Banyankore have lower levels of disability. The Basongora are next in having low levels of disability. This is despite the fact that the Basongora are in an area with a lot of insurgency and also stay near and within the game park. It is, therefore worthwhile to find out if the Basongora also practice the infanticide of the disabled newborn.

The ethnic groups the districts with a lot of insurgencies had the highest levels of disabled children. These were the Acholi (3.4%, who are predominant in Pader, Kitgum and Gulu); the Langi (3.2%) who predominant in Lira and Apac; and the Jonam (3.0%). The Bamba followed and are found in Bundibugyo district which also had a lot of disturbances around the time of the 2002 Uganda Census. Since the district proportions are not equivalent to the ethnic proportions, this implies that most forms of man-made disability are preventable by being in an area in which the lives of the individuals is not in danger.

Table 5: Proportion of disabled children by ethnicity

| Table 3. 110portion of disabled en |         | Proportion |
|------------------------------------|---------|------------|
|                                    | Number  | disabled   |
| Pokot                              | 4,092   | 0.2        |
| Napore                             | 1,745   | 0.3        |
| Dodoth                             | 18,932  | 0.4        |
| So(Tepeth)                         | 1,114   | 0.4        |
| Nyangia                            | 936     | 0.4        |
| IK(Teuso)                          | 805     | 0.6        |
| Lendu                              | 541     | 0.7        |
| Jie                                | 8,233   | 0.8        |
| Kuku                               | 1,866   | 0.9        |
| Batagwenda                         | 2,644   | 1.1        |
| Karimojong                         | 13,740  | 1.1        |
| Basongora                          | 599     | 1.2        |
| Bahororo                           | 10,079  | 1.2        |
| Sabiny                             | 10,273  | 1.3        |
| Bafumbira                          | 25,215  | 1.3        |
| Nubi                               | 1,391   | 1.3        |
| Banyakole                          | 126,554 | 1.4        |
| Bakhonzo                           | 34,981  | 1.5        |
| Kakwa                              | 7,327   | 1.5        |
| Bagisu                             | 60,883  | 1.5        |
| Batoro                             | 33,656  | 1.5        |
| Baganda                            | 235,273 | 1.6        |
| Bakiga                             | 93,597  | 1.6        |
| Lugbara                            | 57,276  | 1.7        |
| Banyarwanda                        | 16,220  | 1.7        |
| Basoga                             | 121,444 | 1.8        |
| Other Ugandans                     | 5,162   | 1.8        |
| Basamia                            | 16,014  | 1.8        |
| Banyole                            | 19,884  | 1.8        |
| Banyabindi                         | 776     | 1.9        |
| Bagwe                              | 4,374   | 1.9        |
| Bagwere                            | 23,271  | 2.0        |
| Iteso                              | 87,776  | 2.0        |

**Table 5: continued** 

|                | Number    | Proportion disabled |
|----------------|-----------|---------------------|
| Babwisi        | 3,779     | 2.0                 |
| Babukusu       | 889       | 2.0                 |
| Kebu(okebu)    | 1,878     | 2.0                 |
| Batuku         | 1,269     | 2.1                 |
| Kumam          | 9,830     | 2.1                 |
| Madi           | 16,388    | 2.1                 |
| Banyoro        | 38,278    | 2.2                 |
| Bakenyi        | 3,725     | 2.4                 |
| Ethur          | 3,021     | 2.5                 |
| Jopadhola      | 20,327    | 2.5                 |
| Banyara        | 1,333     | 2.5                 |
| Alur           | 29,208    | 2.5                 |
| Baruli         | 8,806     | 2.6                 |
| Chope          | 1,188     | 2.7                 |
| Baamba         | 1,881     | 2.7                 |
| Bagungu        | 2,776     | 2.7                 |
| Jonam          | 5,126     | 2.8                 |
| Langi          | 84,785    | 3.2                 |
| Acholi         | 63,490    | 3.4                 |
| Kenya          | 1,484     | 0.9                 |
| Tanzania       | 2,905     | 1.8                 |
| Rwanda         | 5,247     | 1.7                 |
| Burundi        | 4,395     | 2.1                 |
| Sudan          | 8,821     | 1.6                 |
| Dr of CONGO    | 3,490     | 1.5                 |
| Other Ugandans | 652       | 2.3                 |
| None Ugandans  | 865       | 1.0                 |
| Total          | 1,372,509 | 1.8                 |

# 7. How vulnerable are disabled children?

In to access how vulnerable disabled children were in Uganda, the paper looks specific outcome and other forms of vulnerability namely, school attendance, marital status and child mothers and type and characteristics of housing vulnerable children live in ( Table 6 and Table 7).

### 7.1 School attendance and disability

The relationship between disability and schooling among the school-age children aged 6 to 17 shows that the percentage of children that are currently in school disaggregated between primary (6 to 11) and secondary (12 to 17) school age. Children with disability are always substantially less likely to be in school than those without. The deficit among children aged 6 to 11 varies across countries; from a shortfall of 15 percentage points in Mozambique to 59 percentage points in Indonesia. In Indonesia, for example, whereas 89 percent of children 6 to 11 without a disability are in school, only 29 percent of those with disability are in school. In Uganda, a lot of campaign for Universal Primary Education (UPE) has been done but it still falls short of its universality. Whereas 77 percent of children without disability attended school in 2002, only 67 percent among children with disability attended school in 2002. It was also observed that more disabled children have never been to school, one in four children compared to one in six among those without disability. It is further noted that the dropout rates for children with disability is higher among those with disability than those without disability.

## 7.2 Literacy and disability

One in three (35%) among children with disability are illiterate (cannot read and write) while it is slightly less than one in four (22.7%) among children without disability. Overall, disabled children are still left behind when it comes to education achievements

### 7.4 Marital status of children with disability

It was also important to examine the sexuality of disabled children. This was measured by the proportion of those who were married. About 3.5 percent of disabled children (among those aged 10 years and above) were either currently married or ever married. This is still high though lower than that of children without disability at 4.5 percent.

# 7.5 Disability and child mothers

Among children aged 12 -17 years, 6.4 percent of them had given birth which is about the same among those without any disability at 6.9 percent. One would therefore conclude that disability will not reduce child mothers. Therefore, policies on early child marriage should also include the protection of disabled children not to be exposed to early child bearing.

Table 6: Proportion of disabled children by school attendance and literacy

|                          | Disabled | Not disabled | Total   |
|--------------------------|----------|--------------|---------|
| <b>School Attendance</b> |          |              |         |
| Number                   | 20,874   | 897,024      | 917,898 |
| Attended in 2002         | 67.4     | 76.8         | 76.6    |
| Left school in 2002      | 1.3      | 0.9          | 0.9     |
| Left school before 2002  | 7.4      | 6.4          | 6.5     |
| Never been to school     | 23.9     | 15.8         | 16.0    |
| Literacy                 |          |              |         |
| Number                   | 12,835   | 504,728      | 517,563 |
| Literate                 | 65.0     | 77.3         | 77.0    |
| Illiterate               | 35.0     | 22.7         | 23.0    |
| Marital status           |          |              |         |
| Number                   | 12,835   | 504,728      | 517,563 |
| Currently/ever married   | 3.5      | 4.53         | 4.5     |
| Never married            | 96.5     | 95.47        | 95.5    |
| Total                    | 100      | 100          | 100     |
| Child mother             |          |              |         |
|                          | 4,268    | 182,346      | 186,614 |
| Birth                    | 6.35     | 6.91         | 6.9     |
| No birth                 | 93.65    | 93.09        | 93.1    |
| Total                    | 100      | 100          | 100     |

### 8. Characteristics of households with disabled children

The characteristics of the household head that have been considered include gender of the head, broad age group of the household head and relationship to the head.

Considering **sex of household head**, the analysis indicated that the proportion of disabled children live more in female-headed households than male headed households. This difference may be results of some men separate/divorce their wives when they have a disabled child. However, this is subject to further discussion and research.

In relation to the **broad age-groups of the household head**, households headed by the elderly (60+ years) have a higher proportion of disabled children above the national average at 2.1 percent. The probable explanation may be either those children born to the elderly are born with disability or the younger parents usually take their children who are disabled to their parents. To confirm this there is need to look at the relation to the head controlling for the broad age group of the household head.

The **relationship to the head** shows very peculiar findings. Child headed households have the highest proportion of children with disability at 2.2 percent. This is followed by households in which the children are step children at 2.1 percent. Furthermore, the proportion of disabled children staying with other relatives is 1.9 percent higher than that of households in which the child is son or daughter at 1.8 percent. The conclusion from this may be that usually, parents who get disabled children do not want to stay with them. This confirms what has been mentioned on having low proportion of disabled children in Kampala district. Also observed was that 1.1 percent of the disabled children were staying with spouses implying there are married.

### Housing conditions for disabled children

The infrastructure in which children stay is of paramount importance to their survival and living a decent life. This paper, therefore, looked at the promotion of disabled children by type of housing. High proportions of disabled children stay in houses made of temporary materials (2.0)

percent) and the proportion decreases as one looks at more permanent materials at 1.3 percent. However, the proportion of those who stay in huts is lower than those who stay in non huts.

Table 7: Proportion of disabled children by characteristics of the household head

|                                   | Number    | Proportion disabled |
|-----------------------------------|-----------|---------------------|
| Gender of household head          |           |                     |
| Male head                         | 1,086,752 | 1.8                 |
| Female head                       | 275,206   | 2.0                 |
| Total                             | 1,361,958 | 1.8                 |
| Broad age of household head       |           |                     |
| Child headed                      | 8,857     | 1.6                 |
| An adult headed                   | 1,173,101 | 1.8                 |
| Elder headed                      | 180,000   | 2.1                 |
| Relationship to household head    |           |                     |
| Head                              | 4,183     | 2.2                 |
| Spouse                            | 8,071     | 1.1                 |
| Child                             | 1,035,064 | 1.8                 |
| Step Child                        | 55,068    | 2.1                 |
| Brother/Sister of Head            | 34,953    | 1.7                 |
| Other Relative                    | 211,808   | 1.9                 |
| Non Relative                      | 12,811    | 1.6                 |
| Type of housing                   |           |                     |
| Temporary building materials      | 975,441   | 2.0                 |
| Semi-permanent building materials | 174,552   | 1.8                 |
| Permanent building material       | 211,965   | 1.3                 |
|                                   |           |                     |
| Hut                               | 282,977   | 1.7                 |
| Non-hut                           | 1,078,981 | 1.9                 |
| Total                             | 1,361,958 | 1.8                 |

## 9. Discussion

Disability is not a phenomenon that can be easily described with a binary classification yes/no. It is rather an experience that needs to be measured in a continuum to consider several issues such as intensity, duration, and environment. It is important that the instruments used should be able to capture (as much as possible) the different points on this continuum. In this context the design

of the question(s) used as a screener to identify the target population with disability should be carefully studied to be sure they do not exclude part of that population. To measure the complexity of this continuum, multiple questions to set context, clarify terminology, and define multiple domains are required. This aspect is particularly difficult in a census where the number of questions asked is restricted. This is more so with survey data like the UDHS and UNHS so as to supplement the census.

Major cause of disability among children born normal was 56 percent disease. This meant that the Uganda Health system is poor. Improving the health system should not stop on paper but need practical steps if it is to be appreciated.

Specific steps are still required, not only for prevention, but also to ensure that children with disabilities are able to participate fully in the development process, obtain a fair share of the benefits, and claim their rights in full as equal members of the society. Therefore, more is needed to create the necessary political will and a real commitment to investigate and put into practice the most effective actions to prevent disabilities with the participation of all levels of society. In summary, politicians and policy makers should walk the talk.

There is growing evidence that in Uganda, infanticide is practiced in some societies to get rid of the disabled children especially among the cattle keepers like those from Karamajong Region and Western Uganda within the Ankole region. Based on religion, Moslem households had the least proportion of disabled children.

Universal Primary Education (UPE) by the year 2015 is one of the Millennium Development Goals. With estimates that 40 million of the 115 million children (37.8%) out of school have disabilities. This implies that UPE cannot be fully achieved or realized without including

children with disabilities (Susan, 2003). It is further noted that disability may be the single most important factor excluding children with disabilities from schooling. This means that the goal of Education For All (EFA) cannot be achieved simply by doing more of what we are already doing. Among all children, the disabled children are most disadvantaged children in terms of accessing school, many live in households headed by females, and the elderly households.

Being disabled could not stop these children into early sexual activity and to early child bearing. This may be positive depending of from which school of thought. Those who are disabled will urge that even disabled children have conjugal rights and feelings like non disabled children. However in broad sense, this shows that they are not neglected on this aspect. It should also be noted that early pregnancy for disabled children may expose them to other forms of vulnerability. Also there is need to find out if there have been consent on by the disabled children themselves.

#### 10. Recommendation

Disability-disaggregated data are needed in order to define and locate all children with disability, and to provide appropriate educational services. These data must encompass never gone to school, school drop-outs and street children, many of whom may be suffering from unrecorded and undiagnosed disabilities.

Although difference seemed to be small based on religious affiliation, further qualitative studies need to be done within Uganda on religion and disability.

In order to provide data to compare persons with disabilities and persons without disabilities, every census should collect data on living arrangements, employment, and education. Census offices should then produce (as part of their analytical report) tabulated forms for persons with

and without disabilities; different levels of participation related for example to education and work and employment can be easily measured.

A large proportion of disability is preventable. Achieving the international millennium development goals (MDGs) targets for economic, social and human development will undoubtedly reduce the levels of disability in many poor countries Uganda inclusive. However, general improvements in living conditions will not be enough. This will be possible using a multi-policy approach to achieve putting into consideration differences in the socio-economic settings of the different parts of the country.

#### References

- Colin R. (Year), Educating Children with Disabilities in Developing Countries: The Role of Data Sets, The University of Huddersfield with Peter Evans, The OECD Secretariat; <a href="http://siteresources.worldbank.org/DISABILITY/Resources/280658-1172610312075">http://siteresources.worldbank.org/DISABILITY/Resources/280658-1172610312075</a> /EducatingChildRobson.pdf
- Department for International development, DFID (2002) Disability, Poverty and Development (http://www/unicef/disability-unicef.pdf May 14<sup>th</sup> 2008)
- Featherstone H. (1980) A Difference in the Family: Life with a Disabled Child. Basic Books, New York.
- Ferguson P.M., Gartner A. & Lipsky D.K. (2000) The experience of disability in families: A
- Helander, E.A.S. (1993). Prejudice and Dignity: An introduction of community-based rehabilitation. New York: United Nations Development Program.
- Kearney P.M. & Griffin T. (2001) Between joy and sorrow: being a parent of a child with developmental disability. Journal of Advanced Nursing 34, 582–592.
- Molley D. Tim Knight and Woodfield Kandy (2003) Diversity in disability: Exploring the interactions between disability, ethnicity, age, gender, and sexuality. <a href="https://www.dwp.gov.uk/asd/">www.dwp.gov.uk/asd/</a>
- Mullins J.B. (1987) Authentic voices from parents of exceptional children. Family Relations 36, 30–33.

- Seligman M. & Darling R.B. (1997) Ordinary Families, Special Children: A Systems Approach to Childhood Disability, 2nd edition Guilford Press, New York.
- Summers J.A., Behr S.K. & Turnbull A.P. (1989) Positive adaptation and coping strengths of families who have children with disabilities. In Support for Caregiving Families: Enabling Positive Adaptation to Disability (Singer G.H.S. & Irvin L.K. eds), Paul H.Brooke, Baltimore, pp. 27–40.
- Susan (2003) <a href="http://siteresources.worldbank.org/DISABILITY/Resources/280658-1172610312075/EFAIncluding.pdf">http://siteresources.worldbank.org/DISABILITY/Resources/280658-1172610312075/EFAIncluding.pdf</a> 12th May, 2008
- synthesis of research and parent narratives. In Prenatal Testing and Disability Rights (Parens E. & Asch A.eds), Washington: D.C. Georgetown University Press, pp. 72–94.
- Taanila A., Kokkonen J. & Jarvelin M.-R. (1996) The long-term effects of children's early-onset disability on marital relationships. Developmental Medicine and Child Neurology 38, 567–577.
- Tess Bennett, Deborah A. Deluca and Robin W. Allen, (2005) Journal of religion and health, page 301-312, November 2005, Springer Netherlands
- Treloar L.L.(2002) Disability, spiritual beliefs and the church: the experiences of adults with disabilities and family members Journal of Advanced Nursing 40(5), 594–603
- Trute B. & Hauch C. (1988) Building on family strength: a study of families with positive adjustment to the birth of a developmentally disabled child. Journal of Marital and Family Therapy 14, 185–193.
- Uganda Bureau of Statistics, (2006) Compendium of Statistical Concepts and Definitions used in the Uganda Statistical System and Services, volume iii Kampala Uganda.
- Van Riper M., Ryff C. & Pridham K. (1992) Parental and family well-being in families of children with Down syndrome: a comparative study. Research in Nursing and Health 15, 227–235.
- World Vision Uganda (2007) Kamuda Area Development Project baseline survey report, (Unpublished) Uganda, Kampala
- Wright N. & Wright J. (1993) I'll Love You Forever: Accepting Your Child When Your Expectations Are Unfulfilled. Focus on the Family Publishing, Colorado Springs, CO.