

CHRONIC POVERTY AND DISABILITY IN UGANDA

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Abstract

The study of poverty - situation, dynamics, and impact - has received much impetus in the last 10 years in Uganda. Evidence from the country's Household Surveys and the recently concluded Participatory Poverty Assessment (PPA) has yielded much needed policy-relevant information. Emerging evidence from the studies confirms an intrinsic and mutually reinforcing link between poverty and disability. Chronic poverty studies, however, are much more recent. Spurred by a growing need to understand which categories of the population live in perpetual poverty and the reasons behind their "missing out" on the benefits of current development interventions the studies have recently focused attention on specific themes and/or categories of the poor. This study focuses on the relationship between chronic poverty and disability in the country, and it argues that disabled people are not only among the poorest of the poor in the country, but that they remain poor for very long periods of time, and from generation to generation.

The study highlights some of the methodological challenges that still exist with respect to isolating chronically poor from episodically poor people, one of these being the lack of longitudinal studies that devote attention to "tracking" poor people's situations, behaviour and characteristics over time. Yet in the case of disabled people anecdotal information is overwhelming in recognising that the two - long duration poverty and disability are in the majority of cases interchangeable.

The purpose of this study, therefore, is to gain a deeper understanding of the relationship between long-duration poverty and disability. The Study is based on a review of existing literature and actual fieldwork carried out in four districts of Uganda. It seeks to: (a) summarise the current state of knowledge about disability and chronic poverty in Uganda; (b) discuss the factors that disabled people in "perpetual poverty"; (c) describe the efforts that are presently being made to address long-duration poverty among disabled persons in the country; and (d) propose policy interventions aimed at greater inclusion of disabled people in the country's development processes.

The study adopts Hulme and Shepherd's definition, taking chronic poverty to be that poverty where individuals or households are trapped in severe and multi-dimensional poverty for an extended period of time, and where poverty is linked with the intergenerational transmission, so people who are born in poverty, live in poverty and pass that poverty onto their children (Hulme and Shepherd, 2001).

Evidence from the study confirms that disabled people, as individuals, or the households in which they live, face a kind of poverty condition that carries on for a long period of time - beyond five (5) years, during which period, and regardless of different macro and micro interventions, affected households or individuals are unable to sustain themselves or to improve on their livelihoods.

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1. Introduction and background

Chronic poverty and disability in Uganda are inextricably linked. Despite impressive economic gains made by the country in the last 10 - 15 years, current evidence suggests that at least 2.4 million disabled people remain poor². Disability feeds on poverty, and poverty on disability. Because of poverty many people become disabled. Such people have very limited access to health care and facilities (including immunisation); they have very rudimentary feeding and nutrition; they are exposed to a number of disabling conditions, etc. As a consequence chronically poor people are more likely to become disabled. On the other hand, many disabled people lack education and skills training. Hence they cannot easily access employment. The physically demanding nature of unskilled labour (a hallmark of most African economies) also makes it difficult for disabled people to be involved in labour intensive activities. This situation is made worse by outright social exclusion of disabled people that constrains disabled people's participation in the job market.

Understanding the processes that underpin the poverty-disability dynamic, and the reasons that prevent disabled people from participating in, or benefiting from, development opportunities is, therefore, a pre-requisite for suggesting pro-disabled people's policy interventions, hence this research.

Disability statistics: The most recent Census put Uganda's total population at 24.6 million. Using the WHO-recommended ten percent (10%) of this figure to estimate the number of disabled people one arrives at a crude figure of 2.4 million disabled persons in the country. But estimates of people with specific disabilities suggest even larger numbers. The Ugandan **Ministry of Health and Action on Disability and Development (ADD)**³, for example, estimate that there are anywhere between 500,000 and 1,000,000 mentally ill adults in Uganda (Ministry of Health/ADD, 1999). Baingana's (Ministry of Health) estimate of persons with "mental disability" is 766,898 of whom 183,389 are estimated to be with "severe mental retardation" (Baingana, 1996).

On the other hand the Education Assessment Resources Programme (EARS) of the Ministry of Education estimates the prevalence of learning difficulties at 16.9% of all disabilities. Similarly, epilepsy is estimated at 2% of the population, Schizophrenia at 1%, and manic depression at 3%. Meanwhile "common mental disorders" account for 20-30% of all out patient attendances⁴. When these figures are compared with statistics on deafness, blindness and other disabilities, a picture begins to emerge. Bearing all these factors and evidence in mind, an estimate of at least three million Ugandans, or just over 10 percent of the current population would not be an overestimate by any account. If approximately 80 percent of this population live in conditions of long-term poverty, as is being suggested in this study, then up to a staggering 2.4 million disabled people may be classified as chronically poor disabled persons - a considerable number by any account.

² For some the poverty situation has become worse over the last few years.

³ A Non-Governmental Organisation working with organisations formed and run by disabled people themselves.

⁴ Draft Ministry of Health Policy 2000-2005, MoH, Kampala.

2. Objectives of the study

The overall objective of the study is to gain a better understanding of the relationship between disability and chronic poverty and to explore opportunities for suggesting policies that are aimed at chronic poor disabled persons.

Specific objectives of the study include:

- (a) Gaining a better understanding of the local definitions and perceptions of disability and chronic poverty.
- (b) Examining and analysing the socio-economic situation of disabled persons in selected districts of Uganda with respect to depth, duration, and “recurrence” of poverty;
- (c) Identifying disabled people’s coping mechanisms in the light of “persistent poverty”;
- (d) Assessing the role that is played by institutions in addressing the needs and aspirations of disabled people;
- (e) Ascertaining the responsiveness of key policy instruments in Uganda to disabled people’s needs, and identifying gaps in key poverty reduction policies and programmes with respect to disability.
- (f) Making policy recommendations for addressing chronic poverty among disabled persons.

3. Rationale for the study

This research on chronically poor disabled is borne out of three key considerations. First, anecdotal information suggests that disabled people are “borne into poverty” and that both poverty and disability are mutually reinforcing. Secondly, a number of well-intentioned development programmes in Uganda today exclude most disabled people either due to design faults or inappropriate inherent assumptions. Thirdly, not much is known about the key factors that limit the participation of disabled people in poverty reduction initiatives.

Regrettably, also, efforts made so far to involve disabled people in local governance through their representation at various local council levels, have not translated themselves into institutional, organisational or practical gains for individual disabled people or their families, thus necessitating an assessment and understanding of “the missing link” between policy and practice. Further, no explicit disability policy exists in the country. This makes it difficult for definite programmes to be developed and implemented bearing in mind the needs of disabled people.

4. Methodology

4.1. Process: A three-stage process was followed in the study, namely literature review, field consultations, and internal review, analysis and synthesis. **Stage 1** involved a comprehensive review of both published and grey literature on disability and poverty in Uganda. On the basis of this review key issues relating to disability and poverty in the country were identified. These were then used in the construction of a semi-structured interview guide that was used in the actual field work **Stage 2** was the actual fieldwork. This was conducted in four randomly-selected districts representing the country's geographical regions of East (Iganga District), West (Mbarara District) and Central (Mukono District). A fifth district, Arua, that had been selected to represent Northern Uganda was later dropped due to both budget and security limitations. To the extent possible, therefore, the study areas were selected to broadly represent regional diversity and to capture rural and urban dimensions. **Stage 3** was a detailed analysis of the findings from the study through a series of internal workshops, discussion and synthesis.

Each round of visits to a given site was preceded by a pre-visit to make appointments, agree meeting places, and to sound out potential respondents. Subsequently, the first meeting in each village (or site) was a community meeting to which all members of the community were invited. The purpose of the initial community meeting was to introduce the study, its objectives, expected outputs and outcomes, and to explore broad issues relating to the community, poverty and disability. More focused meetings were held subsequently, delving further into the situation of disabled people, but taking care at appropriate moments to separate men from women, youth from elderly disabled, and people of different categories of disability.

4.2. Sampling frame and unit of investigation: The specific unit of investigation was the village, or site. Actual selection of sites was from the same sampling frame used by the Uganda Bureau of Statistics (UBoS) in their most recently concluded Household Survey. The sampling frame comprised of a list of panel sub-counties and sites, and the team aimed at selecting two sites from each district. Where only two panel sub-counties existed, such as in Kampala, selection of the panel sites was automatic. Elsewhere, however, selection was done in consultation with the respective District Planning Officers. The objective in such cases was to maximise diversity.

In using the same sampling frame as UBoS, the study team aimed at deriving as much qualitative information as possible to complement or compare with data obtained from the Household Survey itself. Similar sites were used by the team that studied chronic poverty among elderly persons, again providing another opportunity for comparability.

In addition to the selected sites, the research team made a detailed examination of the poverty situation and circumstances of disabled people who live in institutions. In Mbarara the team visited Ibanda Deaf School and Tukore "Invalids' Salvation Stream". Elsewhere, in Mukono, Nkokonjeru Providence Home for the Disabled and Elderly and Nalukolongo Bakateyamba (in Kampala) were also visited. Given that earlier interventions to addressing disability in Uganda were focused on

institutionalisation, the study wanted to “get a feel” of what the current position of institutions is, who ends up in an institution, and what this meant for future policy, especially on social protection for disabled people.

Four supplementary groups of disabled persons and key informants were also visited by the research team in Kansanga, Kalerwe and Nakulabye to augment information and analysis that is relevant to the study.

In all a total of twenty-four (24) community and focus group discussions were carried out using a semi-structured interview schedule⁵. Dialogue sessions were also held with representatives of disabled people (Councillors) at Village (LC1), Parish (LC2) and Sub-County (LC3) levels. Further, key informant interviews (KII) were held with a wide cross-section of disabled people and carers of persons with disability. Deliberate effort was made to seek out both men and women, young and old, and people with different types of disabilities: those that are blind, deaf, epileptic, challenged by mobility, etc.

4.3. Methods used: Qualitative research methods were used, mostly drawing on PRA/PLA methodology. Using a semi-structured dialogue guide, the researchers spent at least five days in each location (village or site), interacting with communities, conducting interviews with both disabled and non-disabled people, cross-checking emerging information (triangulating) and jointly analysing information with local communities. Dialogue sessions were also held with representatives of disabled persons (Councillors) at Village (LC1), Parish (LC2) and Sub-County (LC3) levels. Further, key informant interviews (KII) were held with a wide cross-section of disabled people as well as professionals and community development personnel who work with them.

5. Study limitations

Methodologically, the first limitation relates to **conceptualising and defining disability**. Two observations are relevant here. First, in adopting the social model that is proposed by Yeo (2001), the study team encountered some difficulty in identifying who is disabled “on the basis of social exclusion”. Both disabled individuals and institutions (of and for disabled people) frequently referred to disability as pertaining to “particular people” and not as a “condition” that disables and/or excludes such people. Secondly, the term “disability” was very widely used by respondents to refer to those with physical impairment, mostly of upper or lower limbs. The likelihood to ignore those with learning difficulties, blind, deaf, epileptic, etc was quite high. In most local dialects, indeed, there was no single word that translated into the English word “disabled”.

Another limitation in the study relates to **inadequacies in literature and data**. Findings that are based on rigorous research were extremely difficult to come by. Similarly, while a large volume of qualitative information does exist on disability per se, there is little information that links poverty to disability⁶. On the other hand

⁵ Details of this appear in the Appendix.

⁶ Fortunately, the recently concluded National Population Census had a question on disability and as soon as processing of this data has been accomplished, the information will be analysed and incorporated into this study.

resource constraints (time, human, financial, etc.) limited the extent and depth of study.

Finally, owing to the current insecurity situation in Northern Uganda, **geographical coverage of the study was limited** to the southern and eastern districts. Given the now well documented economic marginalisation of the northern districts, a long and debilitating war, and significant reduction in levels of immunisation against disabling conditions, there is a strong likelihood that the research missed out on a key source of knowledge and analysis on links between disability and chronic poverty.

6. Key findings

6.1. What is disability? Who is a “disabled person”?

Evidence from the field revealed different, but complementary, types of definitions and conceptualisation of poverty. Different respondents defined disability in the following ways:

“You are disabled if you are missing any one of your limbs or body parts, or if one of your limbs is deformed”

- Group of disabled persons in Ibanda.

“A disabled person is one who cannot look after himself or herself due to physical or mental limitation”.

- Disabled women in Iganga.

“A person is considered disabled if any one of the senses that were given by God are missing. These may include lack of sight, hearing, touch or reasoning”

- Group of Youth Kalerwe

“Disability is when your life is not in your hands - when your physical or mental state is such that other people have to decide for you what to do, where to go, what to eat and who to associate with. You are just an object of pity, and whatever opinion that you give can never be taken seriously. Some people will treat you as if you are a child, even when you are well over 30 years”.

- Disabled Cobbler, Kansanga, Kampala.

The above definitions marry two important aspects: physical limitation and powerlessness (attitudinal). First they bring out the stereotypic view among some people that disability is the absence of a limb or that it is defined by a person missing “any part of the (normal) body”. It is a view that begins from a supposition that there is such a thing as a “normal physical outlay of a person”, and that any form that differs from this “norm” is disability.

On the other hand, the definitions from Iganga and from Kampala (Kalerwe), of a disabled person being one who is not able to look after himself or herself, was echoed in Mukono and Mbarara. It emphasises the helplessness of people with disabilities with respect to livelihood and their dependence on others for survival. In one response in Kalerwe, one disabled person summed up this challenge by pointing out

that “... if you are disabled, and you are looked after by people who are poor themselves, there is no way you can break out of that poverty yourself, even if you had the will to”.

The definitions that were obtained seemed to focus on the medical model of disability, glaringly leaving out the social model that looks at disability as a condition in the environment and among society that impedes particular categories of people from accessing basic facilities and resources.

6.2. What is chronic poverty?

The concept of chronic poverty among disabled people was easily understood by all respondents that the research team interviewed. Various examples were given to illustrate this. The overriding concept was one of **poverty that stays with disabled people for a very long time**. Some groups of respondents argued that the period sometimes extended for up to 15 or 20 years or more. In Kamwokya and Mulago (Kampala) groups of disabled people observed that their (disabled people’s) failure to acquire education in their earlier years meant that they could neither build skills nor obtain formal employment opportunities. This, they argued, in turn “condemned them to perpetual income poverty”. Similarly, because of its menial nature, most informal sector employment was unsuitable for severely disabled persons or for particular categories of the disabled, such as the blind. As such disabled people were obvious candidates for being edged out of both formal and informal employment.

Elsewhere, in Iganga, Kampala and Mbarara disabled women respondents observed that they, as disabled people, were often unable to care for themselves and their children (when they had them), often resulting into disablement for the children as well. This was particularly the case for disabled women that lived off begging but who also bore children “on the street”. The result for such offspring was deprivation of social amenities, proper parenthood, psychosocial support and hence poverty.

Definitions and concepts of chronic poverty that were derived from various respondents are best summarised by the following quote from Nkokonjeru in Mukono District:

Obwavu obw’olutentezi (Chronic Poverty)

Obwavu obwolutentezi bwe bwaavu obutavaawo. Ekyalo kyammwe kyonna bwekiba nga kyaavu, nammwe muba baavu ebbanga lyonna. Obwaavu obumu buba buzaale. Abaana babuyonka ku bazadde baabwe, ate nabo nebabugabira ku baana. Ate bwoba nga tewasikira ttaka, oba nga toil mukulembeze oba mukulu wa kika, ate nga tewasoma, era nga n’ekika tekikwenyumirizaamu, okwo bwogattako obutakola, awo obwavu buba butuuse okukuluma emirembe nemirembe nti amiina.

Kati nno jjukira nti omulema tasikira ttaka. Waakiri basisa omwana wa mugandawo mu kifo kyokusisa omulema. Ate era omulema taweebwa bukulembeze. Ate ekirala abalema tebasoma. Kati obunkuseere n’obwavu kakongoliro obusingako awo obusanga wa?

- Group of disabled people in Nkokonjeru Providence Home, Mukono.

Chronic Poverty: Chronic poverty is that poverty that is ever present and never ceases. If the whole of your village (community) is poor, then all its residents will be perpetually poor. Some poverty passes from one generation to another. (It is as if) offspring suck it from the mother's breast (inherited), and they in turn pass it on to their children.

IF you did not inherit land;
 And you are not a political leader;
 And you did not go to school (no education);
 And your relations do not feel proud of you;
 THEN poverty will bite you for ever and ever - amen

Now remember that a disabled person cannot inherit land. A brother's child may even be preferred in inheritance if he is not disabled. Similarly disabled people do not get to leadership positions, and most are not even educated. Where else can you find this dire poverty and pauperism?

- Group of Disabled Women in Nkokonjeru Providence Home, Mukono

The above conceptualisation brings to light the issue of multi-dimensionality and compounding factors in determining the poverty circumstances and status of disabled people. Seen from the point of view of the "key capitals" - natural (land?), human (education/skills?), social (networks and confidence of family members in disabled person), and political (opportunity to lead others), one may argue that it is the depletion of all the capitals that further entrenches disabled people into poverty.

6.3. The relationship between chronic poverty and disability

Having defined disability and chronic poverty, respondents were asked to describe the relationship, if any, between chronic poverty and disability. A clear relationship was established by groups of disabled people in Mbarara, Kampala and Mukono, between disability and chronic poverty. Most argued that the two are mutually reinforcing, as captured in the following quote from a disabled youth from Kansanga in Kampala:

Obwavu n'obulema kyekimu, era bikolagana. Bwoba omulema oteekwa okuba omwavu, kuba tewali kyosobola kwekolera ate era n'embeera tekuganya. Abo abalema abasobola okubaako kyebakola beebatono ddala, ate mpozzi nga bali mu bitundu bya bibuga. Omulema tosobola kulima kuba tolina busobozi, ate tosobola kukola mirimu gya kkalaamu kuba

tewasoma. Bwoba omwavu kyenkana olemala mu byonna - omubiri n'omwoyo. Tosobola kweriisa, era bwoba n'abaana bagongobala bugongobazi olwendyambi. Ekivaamu nga nvunza mu bigere ne ku ngalo. Ekiddirira kufuuka masikini na bulema.

- Ahmed Kimbugwe and family , Kansanga.

English Translation:

“Poverty and disability are similar and mutual. If you are disabled you must be poor, because you are incapacitated and cannot look after yourself, yet the conditions around you (environment) may not be favourable. You cannot grow crops because you are physically weak to cultivate. You also cannot do skilled work because you did not go to school. If you are poor, it is similar to being disabled in many ways - body and soul. You cannot feed yourself, and if you have children, they all become disfigured and physically disabled due to bad feeding (malnutrition and under-nutrition). The next thing you see are jiggers in one’s feet and fingers, followed by pauperism”.

- Ahmed Kimbugwe and family , Kansanga.

In Ibanda (Mbarara) and Gamba (Mukono) disabled people pointed out the very limited range of opportunities that are open to them, either because of discrimination, or lack of skills, or simply absence of an enabling environment. At the Ibanda School for the Deaf, for example, it was pointed out that many deaf children were unable to get to schools simply because there were no teachers of deaf children. Similarly physically disabled children who lacked assistive devices could not access schools, and even when they did the attention that was given to them was not adequate enough to keep them in school. As a consequence, many disabled children grew into illiteracy, absence of skills and totally alienated from the socio-economic development of other peoples. This, they argued, was a clear recipe for perennial poverty.

6.4. What are the “drivers” of chronic poverty among disabled people?

6.4.1. Activities do disabled people carry out: Overall, the respondents that the research team talked to in Kampala and the rural districts observed that the type of activities that disabled people carry out in pursuit of their livelihoods differ for urban and rural areas and between men and women. They also differ depending on the nature of disability that a person faces. In the majority of cases, however, the activities were closely related to what able-bodied persons do in similar geographical areas, although it should be added that involvement often tended to be at the marginal ends of the activities in question. In some communities where the growing of grains was pronounced, such as in Iganga for example, disabled people were sometimes confined to “keep birds away from eating seeds put out for drying”. Similarly, in urban areas a number of “disabled entrepreneurs” stopped at repairing shoes at street corners. Table 1 below summarises the activities that disabled persons carry out, as recorded by the research team.

Table 1: Activities carried out by disabled persons

| Nature of Disability | Urban (Kampala) | | Rural (Mbarara, Mukono & Iganga) | |
|------------------------|--|---|----------------------------------|--|
| | Male | Female | Male | Female |
| Blind | - Begging - Switch-board operators | -Petty trade -Hand outs | -Agriculture - Crafts making | - Agriculture - Handouts |
| Deaf | - Carpentry - | Left at home | - Casual labour | Left at home |
| Physically handicapped | -Petty trade - Shoe making/ repair - Welding - Carpentry -Begging | -Tailoring - Home / roadside selling - Hand crafts | -Agriculture | -Agriculture - Petty trade - Hand crafts |

6.4.2. Exclusion, isolation, fear and neglect: Exclusion, isolation and neglect were observed to be among the leading causes of marginalisation, failure to access resources, and hence chronic poverty among disabled people. There is fundamental ignorance around disability at all levels of society. In Mukono and Iganga witchcraft was blamed, especially if mental illness was involved, in which case individuals and their families were likely to be rejected by both their families and by communities. Widespread fear of disability, especially of mentally ill individuals, is based on a common perception that disability and mental illness are contagious. The perception is even more deep-rooted for epilepsy. Evidence from Mulago in Kampala revealed that even within the medical profession, disability is given little time in training and negligible allocation of resources hence ignorance is very widespread outside of the tiny number of people that are trained specifically in this area. Approaches that are used by traditional practitioners in dealing with disability follow the “curative medical model”, but often lend themselves to physical and sexual abuse in “treatment”. Awareness raising appears to be an urgent need for all community members and professionals.

(a) Attitude-based exclusion: Exclusion was noted to happen in three different ways: economic, social and political. **Economically**, exclusion centred around obstacles to participation in livelihood activities, especially those of an income generation nature. Access to financial resources was noted to be a major factor in this regard. While there was no evidence of official policy by financial institutions to exclude disabled people from accessing loans, most disabled were on record for having been denied credit facilities in nearly all such financial institutions “simply because managers thought they had no ability to pay back”. People with disabilities were excluded from joining credit groups by able-bodied group members. In such instances members of the groups feared that if allowed disabled people would never be able to pay back their loans. In one instance, in Iganga, this left only the specifically designed ADD-IDIWA Income Generation programme to serve disabled persons. But income generation opportunities were not the only challenge. The majority of disabled people interviewed by the research team in rural areas themselves seemed to prefer being given grants to obtaining loans. The preference is in conformity with the age-old practice of seeking for handouts.

At the community level, also, attitude-based exclusion remains a major problem. In Bwaise a disabled food vendor who moves on her fours revealed that she could not

compete with other women as some customers referred to her as “dirty” (because she has to crawl on the ground to move from one place to another.).

There were, however, other challenges too. Disabled people meet high levels of overheads whenever they try to engage in income generating activities.

“The physical facilities in markets are not conducive to disabled people’s work. In order, for example, to be able to make bulk purchases from the market a disabled person needs to take along with him/her an assistant, which increases the operating costs for disabled persons”.

- Disabled workers, Bwaise-Mulago, Kampala

“When I need to travel, I will have to put into consideration the cost of transporting my wheelchair. Often taxi drivers will reject this, citing lack of space”.

- Disabled person in Iganga

“We work in direct competition with able-bodied colleagues who are also involved in informal trade activities. Whenever, however, Law Enforcement Officers make a raid on informal sector workers, everyone else runs off and saves their wares, except disabled persons who are unable to run”.

- Disabled informal sector workers from Bwaise-Mulago.

But negative attitudes are not confined to simple exclusion of disabled people from participating in economic activities. In certain instances it was clear that able-bodied community members “sympathised with the condition of disabled persons” to the extent that they “pitifully excluded” them. Evidence from Nkokonjeru Providence Home in Mukono revealed that community members who live around the home complained of disabled children being involved in agriculture as part of their routine schedules. To the majority of such people disabled children should never, in the first place, have been “subjected to hard tasks” such as agriculture. The story from the disabled children themselves was however quite different:

“By participating in agriculture we have shown the world that we are able to do things by ourselves”

- Disabled Children at Nkokonjeru Providence Home

“Growing crops and doing work towards personal livelihood has been an empowering process for us.

- Disabled Children at Nkokonjeru Providence Home

A common problem expressed by respondents in nearly all districts was the inappropriateness and lack of access of information on agriculture, especially that which comes via radio waves. Disabled farmers in Mbarara complained about not getting information on agricultural development projects, such as that on availability of clonal coffee seedlings. First, certain categories of disabled people, specifically deaf persons, simply cannot access such information. Yet even in instances where information is available the content of the messages assumes that users (the farmers themselves) are all able-bodied and hence the examples given can only be used by able-bodied persons. Other disabled persons are themselves so poor that they cannot afford a radio, and hence cannot benefit from radio messages. It was further remarked that agricultural extension services only go to those that can afford them,

completely leaving out disabled farmers who are often struggling to get started. Further, there were complaints about agricultural practices not being adapted so as to fit the needs of particular people with disabilities. Similarly, disabled people in Gamba, Mukono wondered why no Government agency had ever conceived a type of agriculture that is suitable for people with disabilities, and which took account of the different disabilities.

(b) Social exclusion Evidence on this took different forms. Disabled children, it was noted, were rarely given an opportunity to go to school, hence their socialisation was limited at an early stage. Reasons for this varied considerably. In a few instances, such as in Namulesa, Mukono, some parents “felt ashamed” to show their disabled children. In other instances children taken to schools also found little or nothing to do there as schools lacked trained teachers, appropriate equipment or the disabled children even met with outright negative reactions from other children. This discouraged them (the disabled children) from participating in school activities.

In Ibanda and Iganga children with disabilities could not easily access education because schools were at least 5km away from home and parents were unable to pay the requisite transport money. Some children also lacked mobility appliances.

However another limitation were the unusually high fees at special needs schools, such as Mbarara, which charges Shs. 40,000/- per term in fees, 38 kg of maize flour and 8kg of beans as opposed to between 8000/- and 21000/= in UPE schools. In Ntinda school of disabled school fees is 80000/= per term. Failure to benefit from educational opportunities condemned disabled children to perpetual poverty. To many parents of disabled children, therefore, their children’s disability was quite expensive.

The architecture in most schools continues to be a major physical barrier to participation of disabled children in education. In Wandegeya Muslim School, for example, disabled children supported by Salvation Army cannot be promoted to higher forms simply because upper classes are physically located “upstairs”. Similarly, deaf and blind children are sometimes excluded from enrolling in UPE Schools because teachers lack the necessary skills to teach. In all districts visited, these children are not enrolled at all.

Involuntary exclusion was also noted with some special categories of children. In Ibanda (Mbarara), Nalukolongo (Kampala) and Nkokonjeru (Mukono) children suffering from *Ostomolisis* and epilepsy were kept at home “to avoid them getting problems while at school”. Regrettably, when such children are kept away from school no compensatory lessons are held for them.

Other types of exclusion are not so easy to note. Children with motor neuron challenges, children that are blind or those that are deaf cannot sit the same types of examinations as do other children. Similarly, in instances where concepts have to be translated into sign language the mode in which such translation is done, including time that is allocated to perform tasks, need to vary. But perhaps the greatest obstacle to further education of disabled children is the stereotyping of children with disabilities as best only for “vocational skills” - shoe making, carpentry, tailoring, etc.

Disabled teenagers on the other hand, especially as they explore and discover their sexuality, find it extremely difficult to find boyfriends or girlfriends, which in turn makes them vulnerable to “any willing sexual partners”, sometimes carrying with them the risk of HIV/AIDS. Several reports, however, also mentioned men who only want to “explore” the sexuality of a disabled person but have no intention of entering into long-term relationships. Adult disabled persons, also, neither had genuine friendships nor fully participated in social activities.

Exclusion from health services was noted to be a widespread problem in nearly all the research districts. While overall disabled people believed that the quality of health service delivery to disabled persons had generally improved in the last 10 years, cases of alienation from the service were still many. In Iganga a case was mentioned of blind persons being skipped “because they had not come with proper guides” (apparent reference to corruption money). Distance was also a critical factor, with journeys being as long as 2-5 kms. This problem aside disabled people even when they turned up at local dispensaries with certain ailments were automatically referred to bigger hospitals as at the lower levels staff were unsure how to handle disabled persons.

On the other hand the research team observed that most health facilities lacked specialised health personnel such as ENT clinical officers or psychiatric nurses (Kamwokya) which sometimes led to aggravation of the disability conditions of some people. The priority given to specialist psychiatric drugs was also noted to be very low with only drugs for well-known illnesses such as Malaria being put on the purchase list of essential drugs. As a consequence many children with disabilities in Mukono and Ibanda were either being given local herbs, or taken to traditional healers.

Most disabled women were observed to be particularly vulnerable because:

- They lack permanent marriage partners
- They are unable to defend themselves in case they are attacked sometimes raped.
- They may themselves be seeking to have a child at any cost and with anybody able and willing to father the child.
- They are unable to make firm decisions on matters of sexuality due to powerlessness resulting from various forms of social discrimination
- Many are made to believe that they are “simply being helped to satisfy their sexual desires”.
- Communication materials that are prepared on important health messages such as HIV/AIDS are either inaccessible or the mode in which they are transmitted unfriendly.
- They lack sensitisation on reproductive issues

The implications of social exclusion ranged from missed opportunities in education, to seclusion and non-participation in development activities. Many disabled persons also missed out on development-oriented information in health, governance, etc. which further marginalized them from participation in mainstream activities.

Case Study 1: Thrown out of marriage for having a disabled child.

Jaliya Namwanje is 35 years old, a mother of two sons. She was happily married to her husband (name not disclosed) when at five years one of their sons, Isma, suffered from a bout of Malaria, which later turned into cerebral malaria. For two years the family struggled with Isma

“We were admitted to Mulago for two years, but all was in vain. Despite some improvement, Isma became disabled, unable to talk or even hear. After being discharged from Hospital my routine changed since Isma needed much attention all the time. I was unable to continue working the same way I had done in the past. But my failure to work was resented by my husband who started insulting me and tormenting me with the words: *“Move out of my house, have you ever seen a disabled person in our family? Take your child where it belongs.”*

“I did not believe that my husband was serious, though he kept on insisting and threatening to kill me. In the end he chased me out of our marital home, and asked me to take “my” son with me. But I was 6 months pregnant when all this happened. My husband did not care at all about my condition, or the condition of our disabled son.. So I went back to my parents in Luwero where I stayed until the baby was delivered. After delivery I returned to Bwaise, Kampala to try and earn a living. I rent a small and carry out petty trade business, selling roasted bananas and charcoal”.

“I now take care of my two children without any assistance from their father. Isma is now in Ntinda School for the deaf where I have to foot Shs.80,000/= per term for fees. My other son, Isaac, is at Bat Valley Primary School”.

“Ntinda School for the deaf has offered to teach us (parents and care givers) sign language so that we can ably communicate with our children, but I am unable to attend as missing work for long means there will not be food for us”.

- Jaliya, Namwanje, Bwaise Disabled and Elderly Association

6.4.3. Feminisation of disability:

(a) Disability a “curse” to the family: Among some people in three out of four districts (Mbarara, Mukono and Iganga) disability was considered to be “a curse” brought to the family through the woman (mother of the disabled child). Thus it was evident in these districts that if disabled children are borne to a family, not only does the burden of care fall on the shoulders of the woman, but she too is often blamed for bringing “kisirani” (a curse) to the family. In Mbarara and Iganga disability was believed to be “transmitted” by a mother, who was sometimes blamed for failing to perform some marital rites or simply “looking at the wrong people” during the course of pregnancy. The common remedy when a woman, therefore, produces a disabled child, is for the man to *“find another wife (woman) who does not produce disabled children”*.

(b) Disability diminishes a woman’s chances to marry: Disability for female children, it was observed, created additional challenges. Communities’ expectation that girl children will be married off at puberty to start their own life - working for their husbands and bringing forth babies - was noted not to hold for disabled girls. Having a disability often meant that one was unable to cultivate, prepare food for self and others, do household chores or even have personal care. This tended to “reduce

the value of disabled girls” which further condemned them to exclusion and poverty. For such young women no marriage meant no livelihood and hence very marginal survival. Since access to prime resources for survival, such as land, are through a husband or male relative, being a disabled girl meant at the outset that there would be no access at all to any important resources.

(c) Disabled co-wives more resented than other women: In Iganga District it was revealed that disabled women who are married as second or third wives faced particular resentment from “first wives” who could not come to terms with a disabled person being their co-wife. Such disabled women, once they came to the household, faced intra-household exclusion and were at times discriminated against. The situation was not, however, the same for all disabled co-wives, especially those who were successful in business.

6.4.4. Disabled persons in politics: situation, dynamics and challenges

Issues of **political exclusion** took on a slightly different dimension during the research. Disabled respondents from Bwaise, Mbarara and Iganga complained that they are rarely invited to community meetings, and on a few occasions when they are invited, their views are not taken into consideration. But there was also insufficient organisation of disabled people at Village, Parish and Sub-County levels, with the consequence that no discussed agenda were ever developed in a bottom-up manner. Indeed many of the disabled people that the research team talked to bemoaned the top-heavy nature of the National Union for Disabled Persons of Uganda (NUDIPU), arguing that its much acclaimed national profile was not matched with results on the ground.

Intra-disability politics was noted to be the other factor leading to confusion and hence exclusion of particular categories of disabled from the mainstream of disability politics. Many disability unions, especially at district level, were led by physically disabled persons. Most of these were themselves people with very minor disabilities. This relegated people of other disabilities to second rate consideration in the activities and programmes developed by the unions. As a result many disabled people who are not physically disabled generally feel that there is marginalisation even within the disability movement itself.

Given the now much acclaimed affirmative action for disabled people it was assumed that articulation of disabled people’s needs in existing governance structures through disabled people’s representatives had now taken root, and was beginning to yield positive results. The reality on the ground was rather different. In nearly all sites that the study team visited disabled councillors were unclear about the role that they were supposed to play. For many preoccupation was with what appeared like “peripheral issues” in disability, such as obtaining some mobility appliances for members (Gamba, Mukono and Ibanda, Mbarara), or having some money voted for supporting disabled persons in undertaking their livelihood (income generation) activities (Iganga). Once a vote was created in the Local Council’s budget, any disabled councillor trying to raise an issue regarding the welfare of their constituents would be quickly rebuffed with such words as: “your budget already exists - use that”. Sadly, too, even when votes have been created there is little evidence to suggest that such monies are ever realised.

The limited focus by disabled people's councillors, has led to budgeting for resources at the local level to continue to be carried out in traditional fashion. Focus has been on the same old priorities, the only difference now being that some monies are voted for disability. In addition the monies voted for disability have not only consistently been negligible but their expenditure focus has also been peripheral. Popular expenditure items include "celebrating the day for the disabled" and awareness-raising workshops for disabled people. The missed opportunity at the political level is for issues of disabled people to be mainstreamed into all aspects of planning and budgeting, regardless of whether a vote on disability exists or not.

An important aspect of exclusion for disabled people was noted to be in the justice system. While the law does not deliberately exclude disabled people, in practice many are excluded from having a fair hearing. The research team observed that in nearly all lower courts there were no sign language interpreters, which rendered such courts inaccessible to deaf persons.

6.4.5. Stereotyping disability

A recurrent finding in all districts that the research team went to was that disabled people were not only being lumped together as one homogeneous group that needed similar assistance, but that most were also stereotyped as helpless, unworthy and "lacking in substance". First, the homogeneous lumping together of all disabled people envisioned physical disability, mostly of those challenged by mobility, walking with crutches or in a wheelchair, as the central definition of disability. This perception completely ignored the diversity of disability and the variety of needs experienced by people with different types of disability. Even disabled people's organisations at both grassroots and national level tended to downplay or even be unaware of the diversities that exist among people with disabilities. Similarly some categories of disabled people experienced greater exclusion. People with different disabilities faced different levels of exclusion. This had implications not only for how disabled people organise themselves or seek services, but also for specific targeting. Categories of disabled people that faced greater exclusion among others include:

- Women with disabilities
- Children with disabilities
- People with severe mental and intellectual disabilities
- People who are disabled by epilepsy
- Elderly people with disabilities
- Youth with disabilities
- People with multiple disabilities

6.4.6. Women with Disabilities:

Ugandan society is still very patriarchal and discriminatory. Although attitudes are changing, women's social role is primarily defined through motherhood and homemaking. With little or no opportunity to live up to the demanding ideals of womanhood that are imposed by society, disabled women experience more discrimination than other women. As a result of exclusion, disabled women are more likely to be poor or destitute and also have a lesser chance of founding a family or benefiting from social capital and protection that are often associated with family relationships. Asked for an opinion, disabled men in Namulesa, Mukono asserted that

“one sure way of entrenching poverty in your household, particularly if you are a disabled man yourself is to marry a disabled woman”. Thus the stigma of disability, its myths and fears are likely to increase women’s social isolation in society, and hence poverty.

But women with disabilities, especially widows, are also more vulnerable to poverty because in addition to having to look after their children single-handedly, such children have fewer opportunities for inheriting properties since they would be considered to have been borne out of wedlock.

6.4.7. Children and adolescents with Disabilities:

Most Ugandan society regards children with disabilities as “unfortunate”, in need of a health cure, incapable of performing all activities that other children are able to perform, and a burden on society, representing a ‘problem’ to be dealt with separately from other children’s issues.

The example of community frustration with the management of Nkokonjeru Providence Home in Mukono which encourages disabled children to grow their own food and to participate in activities that promote their livelihood is a case in point.

Because many disabled children are borne into chronically poor families, such children grow up believing that their disabilities are simply an economic and social curse and burden on their families. Evidence from studies carried out by the Uganda Society for Disabled Children (USDC) reveal that disabled children are unable to defend themselves, are often alone at home, and are often undervalued by those around them makes them particularly vulnerable to physical, sexual and emotional abuse. Such children are also less likely than their siblings to attend school, to go on outings, or to experience situations where they have to solve problems or to contribute to household chores. As a result, they grow to be disempowered adults, unable to take decisions, solve problems or take the initiative. As a consequence many disabled children lack self-esteem and confidence which, in later adult years, contributes to high unemployment figures, and consequently to poverty.

Disabled children in particular are a vulnerable group in Uganda because the population’s attitude to disability is influenced by, among other things, ignorance and superstition. The official strategy for addressing disability among children is to educate the disabled in the formal education system and integrate them into local communities. The programme comprises two components: training specialised teachers and developing a nationwide network of district centres to assess children’s disabilities to ensure appropriate education and adequate support systems. However, funding for these activities is extremely limited.

Evidence from the field (Ibanda, Mukono and Iganga) indeed confirms that dependency, social isolation, rejection, vulnerability and powerlessness characterise the experience of disabled children. Many disabled children, especially adolescents, are exploited (including sexual abuse) and are discriminated, denied access to social economic activities. Confirming findings from Penny’s study on school access (2000), the current study also observed that children without disabilities are sometimes cruel to their disabled counterparts, nicknaming, punching, slapping, beating, teasing and bullying.

6.4.8. People with Severe Intellectual or Mental Disabilities:

The study revealed did not come across any organisations working on the specific needs of people with severe mental/intellectual disabilities. Discussions with various professionals working with disabled people in the four districts revealed also that policy was unclear on how this category of disabled persons should be handled.

People with severe mental or intellectual disabilities are particularly vulnerable either when they are not able to access professional institutions, or during the period of transition from institutionalisation towards community-based services. Anecdotal information suggests that gross human rights violations exist both in and outside institutions for people with mental and/or intellectual disabilities, and yet for those housed in institutions a move from institutionalisation often results in people with severe intellectual or mental disabilities becoming homeless and living on the streets, with little or no community support. Chances are also very high that people with intellectual disabilities or mental illnesses are vulnerable when confronted with the justice system. Their testimony is often not taken seriously, they are not regarded as reliable witnesses and they seldom have access to advocates through whom they can speak.

7. The Policy, Legal and Institutional Framework⁷

7.1. Legislation is “ineffective”:

All respondents were asked to comment on the extent to which they believed that national legislation protects disabled people. Kampala respondents complained outright about the absence of laws that protect them. Some argued that the absence of effective legislation that supports disabled people has contributed to the social exclusion of people with disabilities in the country. Despite having a very pro-disabled National Constitution⁸ and affirmative action for people with disabilities (for example the Local Government Act (1997) and the Tertiary Institutions Act), many of the existing laws in the country still failed to protect the rights of people with disabilities. Worse still, through legislation, some barriers were said to be created that prevent people with disabilities from accessing equal opportunities. An example of this was said to be provisions in the Traffic Act. Although there has, since enactment of the national constitution in 1995, been some effort to include people with disabilities in mainstream political activity, only a few real attempts have been made to identify and eliminate discriminatory legislation from the country’s statute books. Many aspects of past discriminatory legislation remain. In addition, some new laws and amendments contain sections, which directly or indirectly lead to discrimination against people with disabilities. As a result, large sections of the legislative framework in Uganda still fail to meet international human rights standards and principles with regard to the rights of people with disabilities. One reason why legislative discrimination continues to take place is that discrimination is not always obvious merely from reading a statute. Problems often arise when the law or statute is applied. Such problems may include:

⁷ A considerable amount of the discussion in this section derives from a review of existing literature.

⁸ The rights of people with disabilities are enshrined in the constitution, but there is, as yet, no disability specific legislation.

- the way regulations governing specific Acts are drawn up;
- the way Acts and/or their regulations are administered;
- inappropriate and or ignorant interpretation of the law and
- poor monitoring of the law.

7.2. The Uganda Constitution is ideal but its provisions are not translated to practical reality:

Uganda is one of the few countries in the region that boast of comprehensive legal provisions for inclusion of people with disabilities in the country's development process. The main framework for this is the 1995 Uganda Constitution which enshrined in it specific provisions on disability. The Constitution emphasises achievement of:

- (a) Fair representation of marginalised groups (including disabled persons), and
- (b) Recognition of the rights and dignity of persons with disabilities.

These aspirations are further articulated by article 35 where it is specified that persons with disabilities have a right to respect and human dignity and that the state and society shall take appropriate measures to ensure that they realise their full mental and physical potential. Similarly, Parliament was charged with the responsibility of enacting laws appropriate for the protection of persons with disabilities.

According to Article 21 of the Constitution, all persons are equal before and under the law in all spheres of political, economic, social and cultural life in every other aspect and shall enjoy equal rights. The Constitution further stipulates that a person shall not be discriminated against on the ground of sex, race, colour, ethnic origin, tribe, birth, creed or religion, or social economic standing, political opinion or disability. Discrimination is interpreted to mean giving different treatment to different persons attributable only or mainly to their respective descriptions by sex, race, colour, ethnic origin, tribe birth, creed or religion, or social or economic standing, political option or disability.

On the other hand Article 32 further stipulates that the state shall take affirmative action in favour of groups marginalised on the basis of gender, age, disability or any other reason created by history, tradition or custom, for the purpose of redressing imbalances which exist against them, and that Parliament shall make relevant laws, including laws for the establishment of an equal opportunities commission, for the purpose of giving full effect to the above objective.

With respect to language, the Constitution dedicates itself to promotion and development of sign language for the deaf.

7.3. The Local Government Act:

The Local Government Act provides the major institutional legal framework that is supposed to facilitate the participation of disabled people in their own governance, and in local and regional decision-making. It provides for the representation of disabled people at the various Local Council levels. At the practical level this, for

example, meant the election of 46,218 councillors in the whole country (LC1-LC5 levels) in the election year 1998.

Table 1: Disabled Councillors at different Local Council levels, 1998.

| Administrative | Local Councils | Number of units | Number of PWDs at each level |
|----------------|----------------|-----------------|------------------------------|
| Village | LC I | 39668 | 39668 |
| Parish | LC II | 4507 | 4507 |
| Sub-county | LC III | 893 | 1786 |
| County | LC VI | 167 | 167 |
| District | LC V | 45 | 90 |
| Total | | 45,280 | 46,218 |

The Local Council structure on which local governance revolves has representation of disabled people. Regrettably the disabled councillors on most councils are not well inducted in the business of the councils. Neither do the councils possess adequate funds to implement their priority programmes. This makes it particularly difficult for disabled people to benefit from the process of decentralisation, especially given that they are still excluded from the other funding frameworks, such as the PMA. Evidence from Namulesa in Mukono also revealed that below the district disabled councillors, little is known about what councillors are supposed to do, and how. Thus the large numbers of representatives of disabled people have had little or no effect on the livelihoods of disabled persons themselves.

7.4. The Poverty Eradication Action Plan (PEAP):

The PEAP is the overall planning framework for poverty eradication in Uganda. It aims to make policy more focused on reducing poverty, and also strongly relates with other sector plans (e.g. district and lower local council plans). In doing so, it adopts a multi-sectoral approach, recognizing the multi-dimensional nature of poverty and the inter-linkages between influencing factors. In spite of the importance attached to this framework, it does not specifically mention disability as a key target, or social protection for marginalized categories of the population such as disabled.

7.5. The Poverty Action Fund (PAF):

The Poverty Action Fund was set up in 1998/9 as a mechanism to demonstrate that resources from Highly Indebted Poor Countries (HIPC) debt relief and additional donor funds were being channelled, in full, to key sectors in the PEAP. PAF resources are channelled to district level only, as conditional grants. Greater discretion has now been given to the districts for the prioritisation of development plans through participatory planning. Regrettably, however, disabled people are not visible in the utilisation of the PAF funds.

7.6. Plan for Modernization of Agriculture (PMA) and the National Agricultural Advisory Services (NAADS):

The Plan for Modernization of Agriculture (PMA) is a strategic framework for eradicating poverty through various sectoral interventions enabling the people to improve their livelihoods in a sustainable manner. It builds on and complements available opportunities, such as strong social networks existing within the lives of poor people. By its own admission, the PMA realizes that *there is a category of the poor who have no assets and are unlikely to benefit directly from PMA interventions*. Disabled are disproportionately represented in this category, hence they are generally excluded from participating in the PMA. By extension disabled people who are unable to benefit from PMA are most unlikely to benefit in any way from the National Agricultural Advisory Services (NAADS), a “demand-driven client oriented and farmer-led agricultural service delivery system”.

7.7. The Land Act:

In 1998, a new Land Act was passed. Legislation also provides for security of tenure for the tenant and establishes a land fund used to: compensate people who are being evicted from government-owned land; enable people to register land; enable tenants to buy out owners; and to enable the poor landless to buy land. The objective is to create an enabling environment for the participation of all stakeholders in effective planning management and use of Uganda’s land resources.

The key issues to be addressed by the national land policy, as recommended by the Land Act Implementation Study (1999) are:

- i. Redressing historical injustices and providing more equitable access to land.
- ii. Providing livelihood security through employment or access to land for more intensive use.
- iii. Facilitating appropriate development, delivering land-use services and protecting the fragile environment.
- iv. Registering formal and customary rights to land and fixed property.
- v. Generating revenue from land and property tax.
- vi. Providing effective land administration
- vii. Phasing and targeting priorities in the implementation of tenure reform.

While the intentions of the Act are all so good, its implementation is already facing a serious challenge especially given that the cost of implementation is unrealistically

high for Central Government to afford. Similarly many have already expressed a fear that it is mostly local elite who own a large proportion of land and who are likely to make critical decisions even when the Land Act is implemented. Again the prospects for disabled people here can at best only be remote.

7.8. Other policies and programmes:

Other policies and programmes that have a close bearing on the lives of people with disabilities are the Local Government Development Programme (LGDP), Universal Primary Education, the Health Sector Strategy Plan.

The Local Government Development Programme is a mechanism through which resource transfers are made from the centre to the districts. Allocation of funds among the various sectors and within the sectors it is mainly based on conditionalities that are determined at central level. In the main, the priorities follow the country's Priority Planning Areas (PPAs), including education, health, infrastructure, agriculture, etc.

Thus the policy, legal and institutional frameworks while being supportive of disabled people in Uganda, have not been operationalised to be of practical benefit to disabled people.

8. Obstacles to participation

It may be argued from the foregoing findings and discussion that there are no deliberate efforts to frustrate the participation of disabled people in social, political and economic activities. Yet instances of institutional and cultural exclusion appear to be pervasive. The most vivid exposure of obstacles to participation is evident from an examination of key development sectors. In the table below we attempt to outline these obstacles for each sector:

Table 2: A summary of obstacles to the participation of disabled people

| NATURE OF DISABILITY | Obstacles to participation | | | | |
|----------------------|---|---|--|--|--|
| | Education | Health | Agriculture | Socialisation | |
| Blind | <ul style="list-style-type: none"> No schools for blind (all sites visited). Education for blind children not integrated in present educational system Equipment and facilities for training of blind children lacking. Functional adult literacy programme | <ul style="list-style-type: none"> Services are not friendly to blind people (directions to patients are on posters). Often not attended to in health units if coming without a guide. Rarely know "what is going on" when nurses just call out "... the next person in line". | <ul style="list-style-type: none"> Improper training leads to low adaptability in agriculture (for example cases reported of blind farmers uprooting produce instead of weeds). Depend on expensive hired labour, but have to rely on the word (honesty) of the hired as they cannot | <ul style="list-style-type: none"> Cannot participate in social events that have sight focus. | |

| | | | | | |
|----------|---|--|--|--|--|
| | has no component for blind persons. | <ul style="list-style-type: none"> • Harassed by nurses when they go for ante-natal care (“Why do you ever get pregnant?”). • Sometimes raped by those who pretend to be assisting them. | <p>assess the work done themselves.</p> <ul style="list-style-type: none"> • Depend on honesty of employees or family members in harvesting. • Easily vulnerable to dangerous animals such as snakes | | |
| Deafness | <ul style="list-style-type: none"> • Very few schools use sign language for training or offer sign language training itself. • Existing schools for the deaf are more expensive than other average schools (Children in Ibanda school for the deaf pay shs 40,000/=, 8kgs of beans & 38 kgs of maize flour; Ntinda school for the deaf children charge 80000/= a term compared to 24000/= paid by children in UPE schools in Kampala). • Trained teachers for deaf children absent in most schools ; some only improvise in their teaching (Tukore Salvation Stream School in Mbarara district has some untrained teachers but who teach “some” sign language. | <ul style="list-style-type: none"> • Without training in sign language health workers are unable to understand the nature of ailments being expressed to them - illnesses are subsequently only treated on assumptions. • Vulnerable to sexual harassment and rape, which sometimes leads to STIs and HIV/AIDS, and to low self-esteem | <ul style="list-style-type: none"> • Unable to bargain for fair prices with produce buyers due to communication problems - leads to exploitation. • Information on agricultural extension does not reach deaf persons as extension staff cannot communicate, no materials are available in print, and many deaf persons cannot read. | <ul style="list-style-type: none"> • Absence of a common communication medium makes socialisation a major challenge. • Deaf persons unable to share ideas and experience with peers. • Stigmatised and “left alone”. • Exploited by employers who know that deaf persons would find it extremely difficult to report them. | |

| | | | | |
|---|--|--|--|---|
| <p>Physically disabled (mostly due to paralysis of limbs)</p> | <ul style="list-style-type: none"> • Excluded from classrooms that have narrow entrances, and are physically inaccessible (e.g. steps). • Distance to the school may prohibit some, especially when it rains. • Lack of mobility appliances (due to cost or availability). • Inaccessible and poor sanitary facilities in schools a prohibiting factor. | <ul style="list-style-type: none"> • Vulnerable to infections due to the hazardous environments in which some live - especially if crawling • Access to health units problematic especially in rural areas where most facilities are located in distances of over 2-3 kms. | <ul style="list-style-type: none"> • Challenged by labour intensive requirements in most agricultural production. | |
| <p>Mental disability</p> | <ul style="list-style-type: none"> • Majority are not taken to schools as this is considered a “waste of time”. • Those that are taken to schools are often ignored by the teachers as they “cannot slow down the progress of all others for the sake of one or two slow learners”. • Existing schools focus on livelihood skills only - no academic pursuits. • Epileptic children are often excluded from schooling or severely stigmatised. | <ul style="list-style-type: none"> • Psychiatric drugs are not available in Government hospitals where the majority community members seek medical care (they are not considered to be a priority). • First resort for the treatment of mentally ill persons is to traditional healers, and proper diagnosis is usually lacking. • Workers at local health units are not trained to respond to cases of depression or early signs of mental illness leading to a worsening of the disability. | | <ul style="list-style-type: none"> • Discriminated by both able bodied and fellow disabled people. |

9. Concluding note

A number of key issues emerge from the study so far. We summarise them into four main ones:

- The number of disabled people in both rural and urban areas is considerable, though detailed knowledge of specific proportions of the different disabilities is still lacking;
- Disabled people are facing various forms of exclusion, isolation and neglect and this condemns them to perpetual (chronic) poverty.
- Different categories of disabled people have different needs and are differently affected by poverty.
- Existing poverty-focused policies and programmes, in their present form, are inadequate in addressing the needs of disabled people with respect to poverty eradication.

Available evidence from Uganda so far confirms that disability has a close relationship with chronic poverty, but that the detailed nature of this relationship needs to be further explored. It is also evident that insufficient understanding exists regarding the specific nature of relationships between different categories of disability and poverty, given that different kinds of disabilities lead to very different social needs and problems. Further, evidence suggests that current policies and programmes aimed at poverty eradication in the country are inadequate in addressing matters of chronic poverty among people with disabilities. In the first place the need for disabled people to “survive within structures that assume that people are able-bodied” Secondly, it is discrimination, rather than disability itself, which is at the heart of the exclusion experienced by disabled people thereby leading to a greater risk of poverty. The need to gain a better understanding of the intricate relationships between chronic poverty and disability thus makes the current study a vital one.

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Appendix 1: Research Instruments

Key Research questions

(a) *Broad questions:*

Deeper analysis will be made with respect to the following questions:

- *What are the different forms of exclusion, isolation and neglect that lead to chronic poverty among disabled poor people?*
- *What processes enable some other poor people to move out of poverty while many disabled poor are not? Why?*
- *How do chronic poverty issues differ from one category of disabled people to another? What specifically determines the difference?*
- *What factors determine “chronicity” of poverty among disabled persons? How have these factors been changing over time? How do they differently affect people with different disabilities? How do they differently affect disabled men and women?*

(b) *Specific questions*

(1) What are the basic activities in which disabled people are involved on a daily basis?

Examples:

- (a) survival and health promotion.
- (b) Mobility and physical independence.
- (c) Orientation.
- (d) Communication and access to information.
- (e) Social integration and participation,
- (f) Self-determination, and the right to choose one’s own lifestyle.

| Obstacles | Disabled people who may face barriers and experience coping problems | Selected examples of requirements and services |
|---|---|--|
| Mobility and Physical Independence | People with physical or sensory impairments; People with invisible disabilities . People without accessible means for transportation | - Accessibility -Reachability -Functional Home design -Functional appliances and tools Services: * Mobility aids * Other assistive devices * Personal social services/personal assistance |
| Orientation | People who have sensory impairments; people who have | Clarity of design and clear indications of directions; easy language; universal |

| | | |
|--|---|---|
| | learning difficulties. | symbols and markings (including Standard Braille). Services * Guides |
| Communication and Access to Information | People who have seeing, hearing, or speech difficulties; people who have learning difficulties. | - Appropriate formats for communication; - Clear messages Services - Large print; Braille; - Interpretation services; - Personal assistance |
| Social Integration and Participation | In particular people who have mental or psychological disabilities; people who have sensory impairments. | - Non-discriminatory practices; - Public education (Positive awareness and sensitisation); Services - Counselling; peer support. |
| Economic Security | All people with disabilities. | - Equalization of economic opportunities; - Adaptation of the workplace; - Self-employment and home-employment options. Services - (Re)training, including vocational rehabilitation; - Job accommodation (e.g. provision of assistive devices, modification of work schedules and adaptation of equipment). |
| Self-Determination | In particular people who have communication and cognitive difficulties and people who have mobility difficulties. | - Diversity and flexibility of opportunities for self-determination. Services - Personal assistance; - Interpretation; - Advocacy; |

(2) What kinds of obstacles, and consequent coping problems, might people face while engaged in these basic activities?

Issues to consider: *The environment contains numerous obstacles that may limit or prevent people with disabilities from undertaking the above-mentioned activities. In many cases these obstacles may also pose difficulty and risk to non-disabled people. In turn these may lead to chronic poverty.*

(3) What—if any—changes are required in current policy and planning practice to ensure that obstacles are not created?

Issues to consider: *Access and voice?*

(4) What kinds of additional support measures might be required to ensure that specific disability categories are able to participate on the basis of equality in mainstream development?

Issues to consider: *Despite a positive legal and policy framework, certain obstacles to full and effective participation by all still exist. The extent to which use of specific support measures e.g. assistive devices and personal attendants, may improve disabled people's situation should be examined.*

Appendix 2: Research Process

A three-step process was followed, thus:

Step 1: A comprehensive review of literature was undertaken using both published and unpublished materials. Extensive use will be made of information that exists with Non-Governmental Organisations.

Step 2: Fieldwork: This was undertaken in five purposively selected sites, namely:

- Kampala District (Central - Urban)
- Mbarara District (Western - Rural)
- Mukono District (Central - Rural)
- Iganga District (Eastern - Rural)

The sites were selected to give broad representation to regional diversity from the four major regions in the country, to capture rural and urban dimensions, and to provide comparative information with a similar study on chronically poor elderly persons.

Supplementary research was conducted in Kalerwe, Nakulabye and Kansanga to augment information already generated on Kampala.

Focus group discussions :

Approximately twenty (20) focus group discussions were carried out using a semi-structured interview schedule, as follows:

- 4 Interviews with village representatives of People with Disabilities in selected parishes (LC2) - 1 for each district;
- 4 Interviews with Disabled People's Councils of selected Sub-Counties (LC3);
- 4 Interviews with disabled people's groups and/or associations⁹.
- 4 Interviews with the leadership of Disabled People's District Unions¹⁰.

Key informant interviews

Key informant interviews were held with a wide cross-section of disabled people and carers of persons with disability. The following specific categories of people will be targeted:

- Blind persons (male and female)
- Deaf persons (male and female)
- Mentally ill persons or their carers (male and female)
- Epileptic persons (male and female)
- Physically disabled (male and female).
- Disabled persons' carers

⁹ To be identified.

¹⁰ Information to be obtained from the National Union of Disabled Persons of Uganda - NUDIPU.

- Managers of disabled people's institutions.

Site selection

Actual sites for the study were selected from the UBoS-generated list (also similar to one used for elderly study):

| District | Sub-County | Parish | Enumeration Area |
|----------|-----------------|------------------|--------------------|
| Kampala | Central Kampala | Kamwokya II | Contafrica Zone C |
| | Kawempe | Bwaise I | Kiyindi Zone B |
| | | Mulago II | Kafeero Zone E |
| | Makindye | Kibuli | Market Zone B |
| Mukono | Mukono TC | Zone B | Gunga Village |
| | | Kikwayi/Namulesa | Lugonjo/Kikuba |
| | | Namulesa | Gamba |
| Iganga | Imanyiro | Lwanika | Lwanika A |
| | Kigandalo | Bugoto | Bugumya |
| | Malongo | Namadhi | Namadhi B |
| Arua | Beleafe | Orivu | Ejomi A |
| | Omugo | Bura | Godia B |
| | Yivu | Tara | Ojapi B |
| Mbarara | Bisheshe | Kashangura | Kyarutaga I/II |
| | Ishongoro | Nyamarembe | Itabyama & Rwabiju |
| | Rukiri | Nyarukika | Ihoma/Kashari |

APPENDIX 3:

KEY CONCEPTS

Chronic poverty: The most important feature of ‘chronic poverty’ is its extended duration. While noting that severe and multi-dimensional poverty does not necessarily become chronic if it doesn’t last a long time, the study argues that duration, multi-dimensionality and severity of poverty build upon each other¹¹. Thus the study will focus on those who are frequently poor as well as those that are severely poor. The emerging consensus so far is that the study would concentrate on two groups:

- people who are chronically poor in terms of both duration and severity – i.e. whose average incomes are well below the poverty line for an extended period;
- people whose incomes (or capabilities or multiple dimensions of deprivation) have been below a ‘poverty line’ over an extended period of time¹².

Inter-generational poverty, the transfer of poverty across generations, as both a cause and effect of chronic poverty will be examined. In particular the extent to which such transfer is affected by investment in education, health and nutrition, income, gender, etc. will be detailed.

The key concepts in disability derive from a variety of sources, but the main one is The United Nations Standard Rules on Equalisation of Opportunities for People with Disabilities (United Nations, 1994). They are:

Impairment: Any loss or “abnormality” of psychological, physiological or anatomical structure or function.

Disability: Any restriction or lack of ability (resulting from an impairment) to perform an activity in the manner or within the range considered normal for a human being. Disability may thus be considered to be functional limitations, occurring in any population, and people may be disabled by physical, intellectual, or sensory impairment, medical conditions or mental illness. Such impairments, conditions or illness may be permanent or transitory in nature.

Handicap: Means loss or limitation of opportunities to take part in the life of the community on an equal level with others. It describes the encounter between the person with disability and the environment. The purpose of the term is to emphasise the focus on the shortcomings in the environment and in many organised activities in society’ for example information, communication and education, which prevents disabled people from participating on equal terms.

With respect to the different models with which disability issues have been addressed in the past, three main ones come to attention, namely the medical model, the charity model and the social model.

¹¹ Ibid.

¹² Ibid.

In the **medical model**, disabled people are defined by their impairment and medical/technical solutions offered to alleviate their impairment. This is an individualistic approach that does not look at social barriers to people with disabilities.

On the other hand in the **charity model** disabled people are pitied and helped by welfare approaches. In this approach there is no recognition of equal rights or the role that discrimination plays in the livelihoods of disabled people.

The **social model**, the rights based model, sees disability as the social consequence of having an impairment and realises that the inequalities faced by disabled people can only be overcome if society becomes inclusive. There are three major types of social discrimination (based on the social model), namely institutional (this exists where no legal or other provision is made to ensure that people with disability do not partake in local political, social and other structures) environmental (this is where a person with disability is unable to participate due to physical barrier e.g. inaccessible public transport or inappropriately designed buildings) or attitudinal – often expressed through fear and embarrassment on the part of non-disabled person when confronted with a person with a disability and how expectations of people with disability are discriminatory and undermine the confidence and aspirations of PWDs themselves.

APPENDIX 4

SEMI-STRUCTURED INTERVIEW GUIDE

(a) Focus Group Discussions

1. How do you define disability? What constitutes disability? How do you define chronic poverty? Describe the different types of disabled people that live in this community?
2. What do you perceive to be the poverty situation of people with disabilities that live in this community? How has that situation been changing over the last 10 - 20 years?
3. What categories of disabled people are more prone to chronic poverty than others, and why? What is it that makes such disabled people chronically poor?
4. In the last 10-20 years:
 - What has changed for the better for poor disabled people, and why?
 - What has changed for the worse, and why?
5. Which government policies and programmes are you aware of that address poverty issues?
6. Which of the policies listed in (5) above:
 - Target people with disabilities?
 - Miss people with disabilities?
 In instances where PWDs are missed by the policies and programmes, what is the explanation?
7. Which NGO or Private Sector programmes are in place that support PWDs? Which of these “miss” PWDs, and why?
8. What suggestions do you have for improving disabled people’s livelihoods OR getting PWDs out of chronic poverty? What can be/should be done by:
 - authorities at the village and parish levels
 - local Governments (LC3 & LC5 levels)?
 - Disabled People’s institutions (associations, groups, etc)?

(b) Disabled People’s Institutions

1. Background information on the institution (When did it start? How did it start, why and by who? What affiliation?)
2. Who is admitted to the institution (criteria for selection)? Who is excluded from coming to the institution? (Probe for reasons why)

3. Where did the inmates come from (District, Village, Home?)
4. What are the reasons given by resident disabled people themselves for coming to the institution?
5. How do inmates compare themselves with their contemporaries where they came from in terms of poverty levels and duration of poverty:
 - o before coming to the institution?
 - o after coming to the institution?
6. What are the perceptions of the inmates with respect to poverty trends:
 - o for themselves?
 - o for other disabled people who do not live in institutions?
 - o for other people generally?

(c) Key informants

1. *What are the personal particulars of the informant/respondent? (Name, Age, Sex, Marital Status, Profession, Occupation, Education, position in family, etc). Probe for the respondent's life history: his/her background, where born, circumstances of birth, order of birth, type of family to which born, etc.*
2. *When and how did you get your disability? For how long have you had the disability?*
3. *How would you describe your situation as a disabled person? (Probe for social status, self-esteem, poverty, participation in social, political and economic activities, etc).*
4. *How has your situation been changing over the last 10-20 years? If it has been changing for the better, what do you attribute the positive changes to? If it has been getting worse, what are the reasons?*
5. *What do you perceive to be the situation of other disabled people?*
6. *What differences in poverty levels (depth), duration of poverty and characteristics of poverty exist:*
 - i. *Between disabled poor and other poor persons?*
 - ii. *Among different categories of disabled persons (e.g. physically disabled, deaf, blind, etc)? What are the reasons for these differences, if any?*
7. *What Government policies and programmes are you aware of that are meant to address poverty among all people? To what extent are these programmes specifically targeting poor disabled people? What are the*

constraints to realisation of inclusion of disabled people in such programmes?

8. *What NGO or private sector programmes are in place for addressing poverty among disabled people?*
9. *What suggestions do you have for improving on the livelihoods of poor disabled people? What should be done by:*
 - (a) disabled people themselves*
 - (b) disabled people's organisations*
 - (c) political leaders (at village, parish, sub-county, district and national levels?)*
10. *What other general comments would you like to make on chronic poverty and disabled people in your area? In Uganda?*