

**THE LEVEL OF COMMUNITY PARTICIPATION AND THE PLIGHT OF PERSONS  
WITH DISABILITY IN BUNGATIRA  
SUB – COUNTY IN GULU DISTRICT**

**BY**

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## APPROVAL

This is to certify that the following research of Amito Grace, which has been carried out under the title 'The level of Community Participation and the Plight of children with disability in Bungatira Sub-County in Gulu District' has been under my supervision, is now ready for submission to the board of examiners of Kampala International University with my approval.

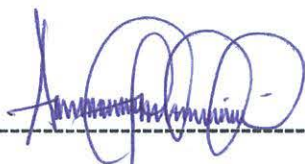
Signed -----

MR ETYANG KEZIRON.

Date 13/09/2010-----

## DECLARATION

Confirm that this research project 'The level of community participation and the plight of children with disability in Bungatira Sub-County in Gulu District', has not been done and presented by any person for the award of a Diploma/Degree or Master in any university except by me.



Amito Grace

date 13/09/2010

## ABBREVIATION

OVC. (Other Vulnerable Children)  
IDP. (Internally displaced Person)  
IDPC. (Internally displaced Person's Camp)  
CDO (Community Development Officer)  
UNICEF. (United Nations International children's Educations Fund)  
UN. (United Nation)  
SCORE (Support to Community Oriented Rehabilitation)  
USDC. (Uganda society for disabled children)  
PSG. (Parent support groups)  
CWD. (Children with disability)  
NGO's. (Non Governmental Organization)  
CBR (Community-Based Rehabilitation)  
PRDP-Peace Recovery and Development Plan for northern Uganda  
PWDs-Persons with disability

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## ABSTRACT

This research assessed the level of community participation in addressing the needs of the Persons with Disability in Bungarita Sub-County in Gulu District. Community Participation was assumed to take place in activities that included needs assessment, mobilization, planning especially during goal setting, trainings, project implementation, monitoring and evaluation of community development projects.

The objectives of the research were; to assess the level of community participation in addressing the plight of People with Disability and to examine the future of the Persons with Disability in Bungarita Sub-County in Gulu District. Therefore the research questions were; what is the level of community participation in addressing the problems of Disabled persons and what is the Future of the Persons with Disability in the Post – Conflict era?

The research methods used included; a cross sectional survey using questionnaire, and key informant interview were used.

According to the 2002 Population and Housing Census, at least 4 out of every 25, or 16 per cent of the population, are disabled. Applying this estimate to today's Ugandan population (approximately 30 million) would indicate that they may be some 5 million disabled people in the country. Disabled people in Uganda, as in most developing countries in the world, face extreme conditions of poverty, have limited opportunities for accessing education, health, and suitable housing and employment opportunities.

The major findings of this research were that the community was aware of the existence and vulnerability of the PWDs in the community (95.4 percent), and 97.3 percent were suffering from conditions of physical impairment. However the community has not taken significant initiatives to address the plight of the PWDs.

There community ranked basic social needs as the priority needs of the PWDS, the quality of services provided to the PWDs was deemed to be poor by the community, the future

vement of the current living conditions of the PWDs seem to be in balance as the community thinks this improvement is dependent on NGOs whose number has seriously declined.

major recommendations included; the high level of community aware of the existence of the disability of the PWD's be translated to community initiatives, the concerns of PWD's be addressed in all the government programmes aimed at attaining the PRDP goals and the participation of the PWD's in development projects be made mandatory.

During Community needs assessment, the level of community participation of the PWD's is during needs assessment. However the community identified Basic Social needs such as education, health, water, involvement in decision making, good sanitation and social protection as protection against social stigma, child labor, sex abuse and other forms of discrimination as priority needs of the PWD's. However, the economic needs such as employment and income generation were ranked as the least needs of the persons with disability, therefore there is need to enforce the law covering persons with disability bearing in mind the societal cultural and economic environment while trying to assure the safety of the rights of persons with disability.

According to the research, Women and men with disabilities can and want to be productive members of society. Employment opportunities for people with disabilities requires improved access to basic education, vocational training relevant to labor market needs and jobs suited to their abilities, interests and abilities, with adaptations as needed.

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## CHAPTER ONE

### 1.0 Introduction

#### 1.1 Background to the study

In Uganda the Minister of State for Education, Mr. Peter Lokeris, once said hostile school environment, lack of instructional materials and capacity of the existing teachers to address individual learning needs of disabled children in the classroom, is largely contributing to the high dropout rate of pupils with disabilities. He said that although the government was doing its best to address the plight of children and students with disabilities. The number of children with physical handicap, visual and hearing impairment, and mental retardation enrolled in schools had increased from 20,000 in 1992 to 218,380 in 2004; the number had continued to fluctuate<sup>1</sup>. Children with disability fall among the category of Orphans and Other Vulnerable Children, in order to address the plights OVC, the Ministry of Gender Labour and Social development developed the policy and the implementation guide lines of mainstreaming the services being provided, but there is negative attitude of some community members in handling children with disability.

This situation is exacerbated by the fact that since 1986 the districts of Northern Uganda have experienced violence characterized by cruel massacres; killings of innocent people; abductions of children; mutilations of body parts such as lips, legs, ears and nose. The rebels also carried out tortures and rapes of women. All these led to the displacement of people from their homes into Internally Displaced Persons camps, between 1996-2006

Gulu district lies 332km north of the capital of Uganda Kampala. Gulu is the original historical home land of the Acholi ethnic group. The 2002 census puts the population of the district at 479,496. Most people are peasant farmers who were displaced by Lord Resistance Army insurgency and living in the IDP camp though they are now returning to their homes.

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<sup>1</sup> See the New Vision paper April 23, 2006 at <http://allafrica.com/stories/200607270178.html>

## 1.2. Statement of the Problem

The global problem of people with disability is huge. The main problems are physical barriers and negative attitudes that lead to segregation of Persons with disability. Their opportunities are also limited because of some other social obstacles that restrict their access to environmental and institutional amenities such as communication systems, education, and access to shelter, health care facilities and other opportunities. It is therefore important to understand the true nature of the opportunities and challenges children with disabilities face. This situation is even worst among the relatively uninformed rural communities in Gulu district who have less insight into strategies that should be available to help their children with special needs. The communities are also less inclined to lobby for or even demand services and relevant interventions for disabled children. This is delaying the treatment of young children with disabilities and is diminishing the eventual outcome of intervention programmes. If no attention is given to the plights of disabled children in Gulu district, then they will fail to develop socially, economically and their political potentials will be ruined.

This research is interested in gaining deeper understanding of the physical and institutional services available to children with disability in Gulu district<sup>2</sup>. Stressed are the following principles: rehabilitation in response to a locally felt need; acceptance of the concept of simplified rehabilitation; partnership with family members; community involvement; an appropriate infrastructure; and recruitment of volunteers from the community. CBR[Community-Based Rehabilitation] effectiveness is discussed showing that the greatest gains came when mothers worked with community volunteers. Recommendations cover: methods of introducing the innovation; ingredients to help establish sound programs; the need for ongoing training; the role of the home visitor and of professionals; curriculum elements; establishment of parent associations; and the relationship between CBR and institutional-based rehabilitation services.

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<sup>2</sup> See Brian John O'Toole 1991. Guide to community –based rehabilitation services. UNESCO Georgetown, Guyana page 32-33. O'toole explains that there are ultimate factors defining who is disabled and who is not in a particular society. It recognizes that while some people have physical, sensory, intellectual or psychological variations, which may sometimes cause problems. O'toole describes these factors as functional limitation or impairments, these do not have to lead to disability, unless society fails to take account of and include people regardless of their individual differences. <http://allafrica.com/stories/200607270178.html>

## **Objectives of the Study**

### **General Objective**

The broad objective of this research was to gain a deeper understanding of the level of community participation addressing the plight of the People With Disability with special attention to Children with Disability who are among the Extremely Vulnerable Individuals in the community.

### **Specific Objectives;**

The specific objectives of the Research were;

- To assess the level of community participation in addressing the plight of People with Disability with special interest in Children with Disability.
- To examine the future of the Persons with Disability with special focus on Children with Disability

## **Research Questions**

Research questions were;

- a) What is the level of community participation in addressing the problems of Disabled persons?
- b) What is the Future of the Persons with Disability in the Post – Conflict era?

## **Significance of the Study**

The knowledge acquired from the research will help Agencies concerned with rebuilding the Post – Conflict Northern Uganda and Gulu District in Particular in their efforts in mainstreaming Persons with Disability community Development Projects.

The research findings also will provide additional insight into the field of Community Participation as a means of identifying the most relevant needs of the community and effective Development Project implementation.

Therefore this research offered an opportunity for the Agencies which implemented several programmes in evaluating the extent to which the People with Disability participated in terms of planning, training and project management in the conflict ravaged Gulu District.

### **Scope of the study :**

research was conducted in Bungatira Sub – County in Gulu District. It covered the parishes Phoo-Pil, Agonga, Mede and Lagwiny. Gulu is part of a region described as Northern Uganda; it is 360 km north of the capital of Kampala. The District is one of the 39 Districts of Northern Uganda that has suffered from the Lords Resistance Army Rebellion for more than 20 years, leaving its infrastructure, Institutions, Social Structures and systems destroyed. However Bungatira was randomly selected from the six Sub – Counties of the District. In terms of content the research examined the level of community participation in terms of needs assessment, planning, community mobilization, training and Community Project implementation.

## CHAPTER TWO

## LITERATURE REVIEW

### Introduction

This literature review discusses diverse views on the participation, rights of children with disabilities, and their educational settings, the political institutions that protect their rights and employment as livelihood strategies for children with disabilities. It begins with analysis of the global situation of children with disability. The overview is followed by analysis of disabled children's livelihood strategies in Northern Uganda and Gulu district in particular. The review is an in-depth discussion of the recent researches on the opportunities and challenges to recovery and reintegration of disabled children in Amuru district.

### Overview of the current situation of Children with disability

The global situation of children with disabilities is grim. For instance Li R., (1987), studied the situation of children with disabilities in China using 41 questions to screen for children <14 years with disabilities<sup>3</sup>. Li studied visual, mental, hearing and speech, Psychotic and those with profound disabilities. A total of 1,57,316 children in 369,448 households were studied. The results showed that:

"40-50% of all disabled needed hospital care or outpatient treatment including cataract extraction, orthopedic assistance, hearing, speech and therapy. Education is the basis of self-support for disabled children. Special education schools and facilities need to be improved in order to comply with the compulsory education law".

In Russia as well, the situations of disabled children have not improved for several decades. Sergey Koloskov, (2001), studied the situation of children with disabilities and found out that "Thirty thousand mentally disabled children stay in Russia's state institutions, where Russian laws have proved ineffective for over ten years"<sup>4</sup>. Koloskov, (2001), reiterates that children born with various disability face discrimination on a daily basis. For instance he notes that:

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Li R., (1987), a study of the current situation regarding disabled children in China and its countermeasure Chinese Journal of Population, 1991;3(1):17-26. Abstract.

Sergey Koloskov (2001). The Desperate Situation of Children with Disabilities in Russian Institutions. *International Children's Monitor*, Volume 14 No 2; at [http://www.disabilityworld.org/01-03\\_02/children/russia.shtml](http://www.disabilityworld.org/01-03_02/children/russia.shtml)

In 1989, I became a father of a disabled child. My wife gave birth to a beautiful girl with Down's syndrome. Already in the maternity ward we encountered discrimination against such children when the doctors strongly suggested that we should immediately place the child in an orphanage as a ward of the state. When we did not agree to do so and brought our daughter home, our family was left to face its problems without any help from the state.

This situation is consistent with UNICEF findings in Russia in 1991 when the UN body found out that "in many cases, we identified children with disabilities who were reportedly left for hours or days in physical restraints (strait jackets that prevent the movement of arms). In practice, these children may live their whole lives in restraints<sup>5</sup>"

Tony Newsman and Michael Wates look at the situation differently by noting that disabled children should be considered against a back drop of the environment where they live especially those who stay with disabled parents need to be studied differently.

The authors argue that:

When we consider disability and its impact on children, we often confine our thinking to disabled children and to the support they and their families need. However, there is a much larger group of children, who may or may not be disabled themselves, who live in households containing a disabled parent. Attention has rightly been given to the ways in which disabled children are socially excluded both through inadequate resources and social attitudes. However, rather less attention has been paid to children who experience social exclusion as a result of their disabled parent's restricted access to employment, housing, transport, hospitals, primary health care and their children's schools. In challenging the social exclusion of children, we need to consider the impact of disadvantage and discrimination on disabled adults with parenting responsibilities<sup>6</sup>.

The current study concentrated on children with various disabilities by considering their livelihood situation and opportunities for reintegration in the normal societal environment.

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See Findings and Recommendations of a UNICEF Sponsored Fact-finding, 1999. Mission to the Russian Federation by Mental Disability Rights International.

This is potentially an important area of research. Tony Newman and Michele Wates 2005. Disabled Parents And Their Children: Building A Better Future. Discussion Paper on Barnardos Policy and Research Unit. at [http://www.leeds.ac.uk/disability-studies/archiveuk/newman/parent\\_disability\\_summary.pdf](http://www.leeds.ac.uk/disability-studies/archiveuk/newman/parent_disability_summary.pdf)



the situation in Africa is even worst as noted by Mohamed Semei Adel 2009 when he said that; people with disabilities in developing countries in Africa face many limitations, despite the proclamation of the African Decade of Disabled Persons (1999-2009).<sup>7</sup>

Parents of children with communication difficulties have difficulties of identifying the right school for the children with specific problems. "For example children with autism are moved from so many schools at very early age and end up being frustrated. Yet they need specific institutions to address their problems. Some of the children are in rural areas and have problems accessing the right institutions. They also lack specialized personnel.

Majid Tumusani (2005 pg 3) argues that "the impact of having impairment does not only affect disabled persons themselves but also their surrounding environment. For instance the presence of a disabled child affects the whole life of a family as well as the life of local community at large". The author argues further that an approach based on community participation, must deal not only with rehabilitation but has the potential to respond to the socio economic, cultural and political needs of society where this group of people live<sup>8</sup>.

Tumusani (2005 pg 3) shows that modern trends in rehabilitation emphasize the value of involving service users and their family in their own care in line with human rights ideals promoted by UN's standard rules, unfortunately such involvement has in fact been neglected in Uganda. This is one of the areas in which this research is interested.

Community participation is hindered by the ever increasing numbers of disabled children, lack of facilities at the rehabilitation centers, inefficient transportation system and over expectation of children and their parents, Tumusani (2005 pg 5) for instance observes that "the majority of community workers reported unrealistic expectations by parents and children who demanded too much care from workers already burdened by many tasks". This problem is expounded by the

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Quoted in Mohamed Semei Adel 2009 page 1; *Rights of Disabled Persons In Egypt* The author adds that human rights of disabled persons receive little or no respect, the general development programs do not take into account their needs or their participation in programs, disabled people have little access to services offered to other citizens, they are unable to make decisions concerning their future, and they are generally living at the bottom of the social scale.

Majid Tumusani (2005) explains that Community Based Approach to care or what came to be known as Community Based Rehabilitation (CBR) in this context involves the provision of services to certain target groups within a local community in a manner that users find accessible, appropriate to their needs, and utilizes local skills and resources.

ted physical mobility caused by impairment, as well as the inaccessible environment at e<sup>9</sup>.

s research is interested in assessing the opportunities for the implementation of user friendly lities which are peculiar to Northern Uganda and Gulu District specifically.

management of disabilities has been generally not easy on the ground in the whole country. The sons usually given include community perception and conservativeness, inadequate resources man, material and funds). In Uganda in particular, there are very few trained teachers that can dle children with communication difficulties. In Apac district, the problems have been cerbated by the poverty and insecurity in some parts of the district contributing to poor dards of living. The World Bank report (1993) shows that 81% of the population in the North nd less than Ug.shs 6,000/= per month whereas 42% do spend less than Uganda shs 3000 per nth. (Apac district, 1997).

imilarly, the New Vision news paper (April 2006) reports that the Minister of State for eication, Honorable Peter Lokeris, said hostile school environment is largely contributing to high dropout rate of pupils with disabilities.

e paper reports further that apart from the hostile school environment, the high rate of dropout also due to various challenges including lack of instructional materials and capacity of the sting teachers to address individual learning needs of these children in the classroom, (New ion 2006 page 3); the number of children with physical handicap, visual and hearing airment, and mental retardation enrolled in schools had increased from 20,000 in 1992 to 3,380 in 2004. Although, the government was reported as doing its best to address the plight children and students with disabilities no mention is made of what is happening in Gulu rict. This research is interested in getting a deeper understanding of the factors peculiar to rthern Uganda and Gulu specifically.

## **Community Participation**

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d notes that all actors have agreed that access to community services were quite poor and disabled people continue to be excluded from stream activities. The exclusion from integrated education for disabled children was perceived as a priority issue for action with focus on secondary teacher / professional training programs including physiotherapy training amongst others. 2005 - Disabled Peoples International

Community Participation can be loosely defined as the involvement of people in a community project to solve their own problems. People cannot be forced to participate in projects which affect their life but should be given the opportunity where possible. This is held to be the basic human right and fundamental principle of democracy. Community Participation takes place in any of the following activities

- Needs assessment – expressing opinions about the desirable improvements, prioritizing goals, and negotiating with agencies
- Planning – formulating objectives, setting goals and critiquing plans
- Mobilizing – raising awareness in community about needs, establishing and supporting organizational structure within the community.
- Training – participating in formal training activities to enhance communication, construction, maintenance and financial management skills.
- Implementing – engaging in management activities, contributing directly to construction, operation and maintenance with labour and materials, contributing cash towards costs, paying of service or membership fee of community organizations.
- Monitoring and evaluation – participation in the appraisal of work done, recognizing improvements that can be made and redefining needs.

### 3.3 Incentive to Community Participation

Goyet, 1999 identified four Initiatives to participation in community projects;

- Community participation motivate people- people feel a sense of community and recognize the benefit of their involvement
- Social, religious or traditional obligations for mutual help
- Genuine community participation – people see a genuine opportunity to better their own lives and for the community as a whole
- Remuneration in cash or kind

Similarly, the same author identified three disincentives to community participation which included the following;

- An unfair distribution of work and benefits among members of the community
- A highly Individualistic society where there is little or no sense of community
- Agency treatment of community members, if people are looked at as helpless people, they are more likely to act as if they are helpless.

**The opportunities for the implementation of intervention suitable to disabled children**

The SCORE (Support to Community Oriented Rehabilitation) project looked at all persons with disability in term of providing anti epilepsy and training community volunteers to form community-based rehabilitation Network. It also provided facilitation for refresher courses for health workers whenever need would arise. The project had also the element of equipping the habilitation units, namely orthopedic workshop, physiotherapy, and occupational unit with the basic equipments. Under the component of training, two local artisans were trained in the production of wheel chairs, AVSI et al (2003 – 2006).

Uganda society for disabled children (USDC) which is still operating up to now is running a community Based rehabilitation program. Its target is children with disability who are below 18 years of age, and handle all types of disabilities. It looks at the child's development holistically in terms of education, health, socially and economy of the parents of the children or the caregivers. Therefore, their activities are geared towards helping a disabled child to live an independent life in future. These NGOs worked together at all levels with emphasis on community of parent support groups (PSG). All these NGOs were either coordinated through district health office, district education office, district community development office, or were facilitated to implement accordingly.

Uganda society for disabled children annual review 2003/04 the establishment and strengthening of parent support groups as they are very important parties in the fight against exclusion of children with disabilities

Parent support groups (PSG's) "enable families to cope more effectively with disability. They seek to raise consciousness of the community about disability and help in generating public awareness and social change. However this research is interested in assessing available interventions to address the plights of children with disabilities in Gulu district. Specifically, the research will assess facilities in educational and health settings in Bungatira Sub County.

## **2.5 Improving the livelihood recovery and reintegration process of disabled children**

The treatment nowadays focuses on developing the person's participation in every life activities (ADL, Activities for daily living) but not fixing their impairments. The severity of the brain damage varies widely and cerebral Palsy is ranked among the most costly conditions to be managed, (Finnie N.L, Scherzer et al 2001, Peacock J et al 2000). However, this condition can be alleviated by advocacy to eliminate discrimination of people with disabilities. For instance PSGs fight against exclusion of children with disabilities. This is done through provision of information leaflets, creating links with other PSGs and logistical support for running of planned activities.

USDC facilitates capacity building within parents support groups in areas like lobbying and advocacy and group dynamics. These parents are empowered to speak up for their children to ensure that children with disabilities are given equal opportunities.

USDC works with PSGs in mobilization of communities. Since parents are usually the care takers of their children, it is easier through them, to register and ensure that children get assistance and also complete the rehabilitation process. Parents also inform people within communities of planned activities, up coming radio programmes on disability and of the existence of opportunities for children with disabilities to take advantage of like surgical camps and outreach clinics". PSGs show how initiatives can be taken to harness resources from promotion of disability understanding and providing, lives of children with disabilities.

Similarly, parents support groups in Chegerere Sub-county in Apac district have come up with ways of overcoming difficulties associated with disability and creating a basis through which their children can attain their needs and opportunities in the community. There has been regular collection of epilepsy drugs on behalf of the group from Apac hospital which has reduced individual transport costs. There have also been lobby meetings with sub-county officials to influence adequate allocation of resources of CWD, home visits and counseling, mobilization of CWD for assessment and corrective surgeries as compared to local leaders and in charges at health units because parents directly reach the children. They change the attitudes of community and augmented acceptance of disability.

The community members have been referring the parent of disabled children to hospitals with physiotherapists, occupational therapists and other medical personnel.

The community has formed village disability committees that have raised funds among themselves to support families of children with disabilities. Sometimes the money is used to transport the child to the main hospital or start an income generating activities to help handle the cost of rehabilitation for the child. An example of a case in Luwero shows how community council at sub-county level passed a budget for disability activities to be included in district plans.

Pupils at different school have also been known to inform special need education coordinators about the presence of a disabled child in the community who does not go to school. Communities have also pointed out to USDC cases of disabled children who were being mistreated in their homes.

The rates of behavior problems among young disabled children, and especially children with learning difficulties<sup>11</sup> are three to four times higher than among non-disabled children. These behavior problems typically continue to persist into later childhood and adolescence (Emerson, 2003) and, as the child increases in size, strength and speed, become more severe. This puts the child at increased risk of harm and also means they become more and more difficult for parents and schools to manage. Challenging behaviour is the main reason why children are placed in 38 or 52 week placements in residential schools (Abbott *et al.*, 2000), and is also a key factor for families being unable to access short breaks (or respite care), and/or the child being unable to access educational, therapeutic and/or community or social activities (Kahng and DeLeon, 2008). High levels of unmet need in skills to manage their child's behaviour are reported by parents, and severity of the child's behaviour problem has been found to be associated with levels of maternal stress (for example, Baker *et al.*, 2003; Quine and Pahl, 1989).

Over many years, behavioral theory and behaviour modification principles have been used to inform and determine interventions to address problem behaviour.

In essence, behavioral theory argues that whether or not behaviors (desired or undesired) are maintained (or continue to be exhibited) is dependent on what happens (in terms of changes in the situation, demands on the individual, and/or other people's reactions) when that behavior is

displayed. These are known as '*reinforcers*'. Reinforcers are conceived as positive or negative. Positive reinforcement is the *presentation of something* to the individual following a behavior which makes it more likely that the behavior will happen again (for example, attention from an adult). Negative reinforcement is *the removal of something* in the individual's environment following a behavior that results in strengthening that behavior (for example, removing a plate of food once a spoonful of a disliked vegetable has been eaten). A number of different phrases can be used to describe children with impaired cognitive and learning abilities. Different countries use different phrases and, across time, the terms used have changed. Learning difficulties is the term chosen for use in this report and is the same as 'developmental delay', 'intellectual disabilities', 'mental retardation' and 'learning disabilities'.

<sup>11</sup> A number of different phrases can be used to describe children with impaired cognitive and learning abilities. Different countries use different phrases and, across time, the terms used have changed. Learning difficulties is the term chosen for use in this report and is the same as 'developmental delay', 'intellectual disabilities', 'mental retardation' and 'learning disabilities'.

## **CHAPTER THREE**

### **RESEARCH METHODOLOGY**

#### **3.0 Introduction**

This study was designed to examine the level of community participation in addressing the plights of children with disability, protection and participation rights of people with disability which enhance their reintegration into the societies where they live. The study assessed the challenges and opportunities to societal change in environmental and institutional settings that impact on the livelihoods of people with disability in Gulu district. The study investigated whether these settings are barriers that impact negatively on children with disability in Gulu district or not.

#### **3.1. Research Design**

The researcher collected data using the survey methods [design] where the collection of data was done by gathering the opinion of people with disability, local leaders and parents to investigate the problem at stake. This involved the use of questionnaires, interviews and observation.

#### **3.2. Area of the study**

This study was conducted in one sub-county in Gulu district. The sub-county was Bungatira. The sub-county was selected through tossing of paper with the names this was to avoid biasness in selection.

#### **3.3. Population of the Study**

The study population was mainly the heads of households. They also included community leaders like the area local councilors, the parents of children with disability, the Community Development workers and particularly the Community Development Officer in Charge of Rehabilitation.



### **The method of selection of the household and other respondents**

The households were selected using systematic sampling technique. Household register was obtained from the Sub-County. From each parish register a total of 9 households were selected at the interval 10. Using this system, a total of 36 household heads were selected. The secretary for gender and special interest group of the respective Parishes were selected. This was because they were better placed to give information on the situation of Disabled Persons in their parish. The other key informants were the area community development workers of the Local Government and the NGOs working in the area.

### **3.4. Sample size**

A total of 43 respondents were interviewed (18 males and 25 female). The reason of having more respondents was that they were the ones who were available as heads of the household. This may be partly because women play key role at the household level as regards caring for the family. As a result the researcher concluded that the information given was more authentic. Three other key informants were interviewed and three Focused Group Discussions were carried out. Each Focused Group consisted of five members of the same age group

### **3.5 Data Collection Methods**

The data was collected both from primary and secondary sources. Primary data was collected using three principle techniques namely by administering a questionnaire on respondents who were unable to read and write and self administered for the respondents who were able to read and write. The questionnaire was both open ended and closed ended to provide both qualitative and quantitative data respectively.

In-depth face to face interviews with key informants who included local councilors and the community development workers of the Local Government and the NGOs of the study area was conducted.

Focused Group Discussion was conducted for three focused group who were randomly selected but of the same age group. The findings of the key informants and the Focused Group Discussion provided the qualitative explanations of this research finding.

Secondary data was collected using desk review of existing documents from NGO report, workshop reports and write ups. They provide information used in the discussion of the results.

#### **Instrumentation;**

The questionnaire for the cross-sectional survey was designed by the researchers in line with the research objectives and the research questions. The four data collectors were familiarized with the objectives of this research, the questionnaire were discussed and attempts were made to translate it into the local language. There was a mock pre-testing of the questionnaire. The results of the pre-testing were used to revise and harmonize the questionnaire ready for field work.

The Focused Group Guide was developed in relation to the research objectives. This was also discussed and a mock exercise was also by the data collectors and the research. This was done together with the Key- Informant interview guide. The believe was that such instruments can not be developed singly without the input of the people involved in the data collection and without seeking the opinion of others.

#### **3.6. Methods for Data Analysis**

Data was analyzed using SPSS (Scientific Package for Social Scientists) computer package using descriptive statistics. This was made possible because of the well coded questionnaire. The open-ended responses were summarized taking into consideration the common responses. These coded questions were able to give the quantitative data required while the opened ended questions offered the qualitative explanation.

For easy interpretation some of the results were translated into Charts and Bar Graphs using the Micro-Soft Excel Package

## CHAPTER IV

### PRESENTATION OF RESULTS AND DISCUSSIONS

#### 1. The Characteristics of the respondents

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	male	18	41.9	41.9	41.9
	Female	25	58.1	58.1	100.0
	Total	43	100.0	100.0	

The respondents were mainly female representing 58.1 percent and the males were 41.9 percent.  
 The respondents were also randomly selected. However this is good since women are seen to be  
 responsible for the care of Children, the sick and are to a greater degree in charge of most  
 household activities

#### 1. The Age Distribution of the respondents

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	less than 20	2	4.7	4.7	4.7
	20-30 years	15	34.9	34.9	39.5
	30-40 years	18	41.9	41.9	81.4
	40 +	8	18.6	18.6	100.0
	Total	43	100.0	100.0	

Most of the respondents are in the age bracket 30 to 40 years representing 41.9 percent. This was  
 followed by the age bracket 20 to 30 years of age. While less than 20 years formed the least. This  
 decreased the level of reliability of the research finding since majority of the members who take  
 in community activities lies within these age bracket (20 to 40 years of age).

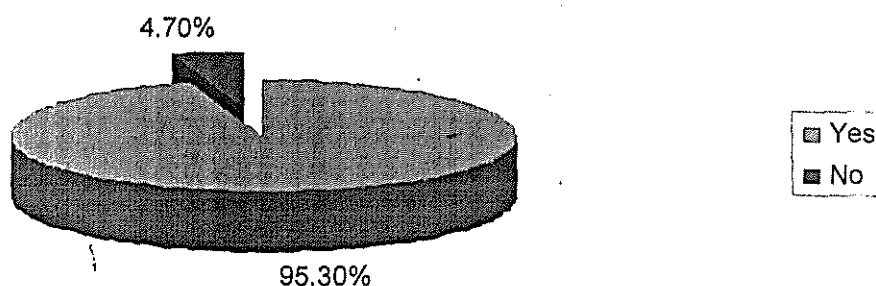
#### 1. Distribution of respondents by level of education

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Primary Education	24	55.8	58.5	58.5
	O' level education	13	30.2	31.7	90.2
	A' Level Education	2	4.7	4.9	95.1
	Other Tertiary Education	2	4.7	4.9	100.0
	Total	41	95.3	100.0	
Missing	System	2	4.7		
Total		43	100.0		

Majority of the respondents attained primary education representing 55.5 percent. This is followed by Ordinary level education. This may be partly because of the high level of literacy in the northern part of Uganda.

#### 2. Level of awareness of the existence of Persons with Disability in the community

Level of awareness of PWD in the community



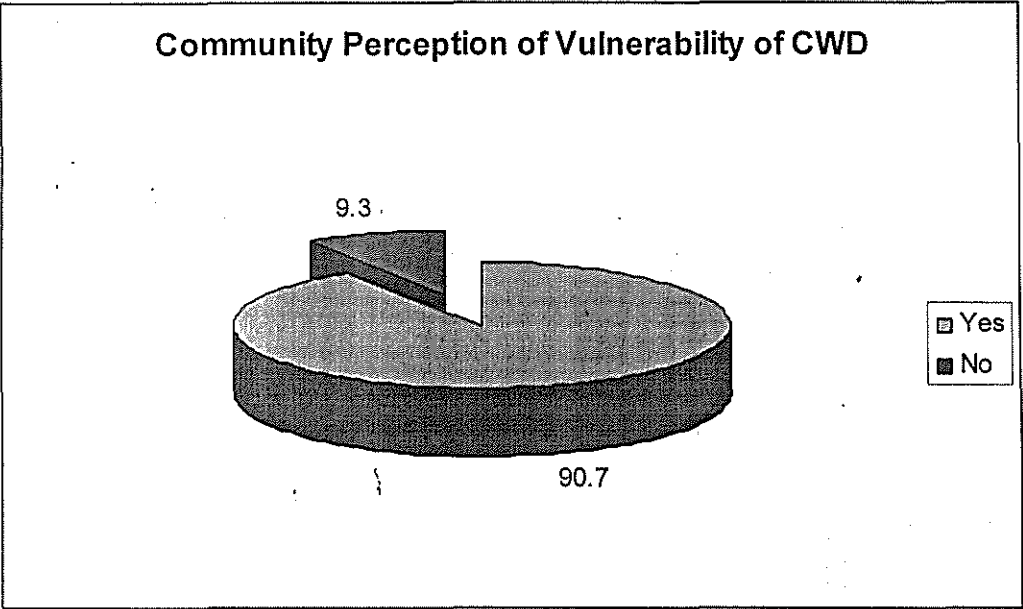
Higher proportion (95.3 percent) of the community was aware of the existence of people with disability in their community. This offers opportunity for community initiative to address the needs of the Persons with Disability especially Children with Disability. This level of awareness too, offers good social environment for the success of programme aimed at addressing the plight of the persons with disability especially the children with disability.

### 4.3 The most common type of Disability in the community

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Impairment	13	30.2	35.1	35.1
	Physical Disability	23	53.5	62.2	97.3
	Total	37	86.0	100.0	
Missing	System	6	14.0		
Total		43	100.0		

The most common category of Disability in the community is physical disability. 62.2 percent reported physical disability as the type of disability they have commonly witnessed in the community. This could be partly attributed to the long period of insurgence in the region where there have been massive landmines planted in the area and other atrocities caused by the insurgents like cutting of ears, mouth, ears and so on. This type of disability is easier to rehabilitate compared to the impairments arising from natural causes.

4.4 Vulnerability perception of Children with Disability by community



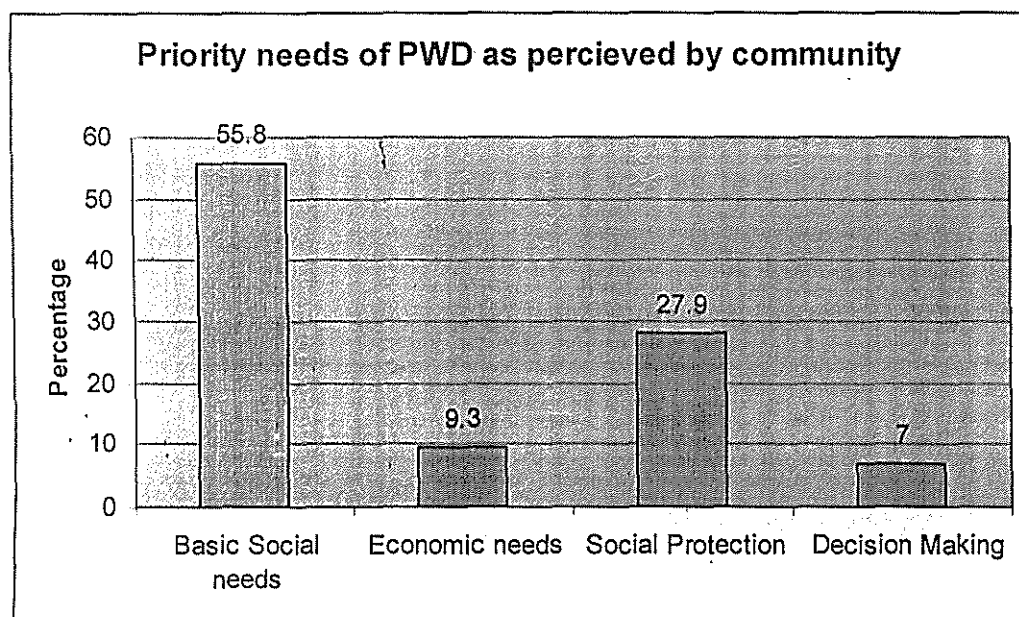
A question was asked whether the respondents consider the Disabled Child most affected and a high percentage of 90.7 percent of the respondents reported that disabled children were the most affected. The reasons included; reduced productivity due to physical disability, difficulty livelihood, and limited access to basic services like education and health, social discrimination, and ineffective laws to promote and protect the rights of disabled children. This community perception was hoped to provide good environment in developing and designing of community development that is based on participatory needs assessment. F

4.5 Any individual and community initiatives to address problems of the Children with Disability

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	14	32.6	33.3	33.3
	No	28	65.1	66.7	100.0
	Total	42	97.7	100.0	
Missing	System	1	2.3		
Total		43	100.0		

The respondents were asked if there had been initiative to address the plight of the persons with disability especially children with disability either at individual level or community level? Only 33.3 percent reported having taken initiative at individual or community level to address the plight of persons with disability. This implied that there was a wide variance between awareness of the problems of the persons with disability and actually taking the initiative to address the problem. The reasons cited for lack of initiatives have been irresponsiveness of the stakeholders in charge of community planning and many of the respondents feel it's not their responsibility to do so.

#### 4.6 The community perceived priority needs of Children with Disability



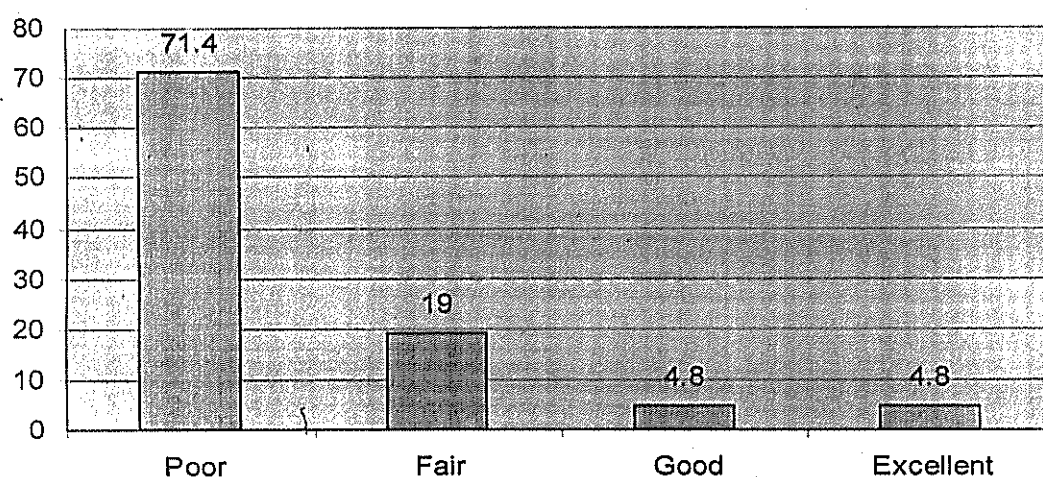
The first priority need of the Children with Disability was identified by the respondents as social protection. This included; protection against social stigma, domestic violence, sex abuse, child labor and any other form of abuse.

The community ranked economic needs (mainly income which is a major determinant of livelihood) as the second priority needs of the persons with disability especially the children with disability. These basic social needs included education, health, safe water and good sanitation. However, the need to participate in decision making processes has been rated as the least need at 7 percent). This is a serious obstacle to addressing the needs of the persons with disability in

era of Community- Driven development approach. The participation of the persons with ability or their representatives is primary in the process of designing programs for community opment

## Perceived provision of services to persons with Disability in the munity

**Community Perception of service provision to PWDs**

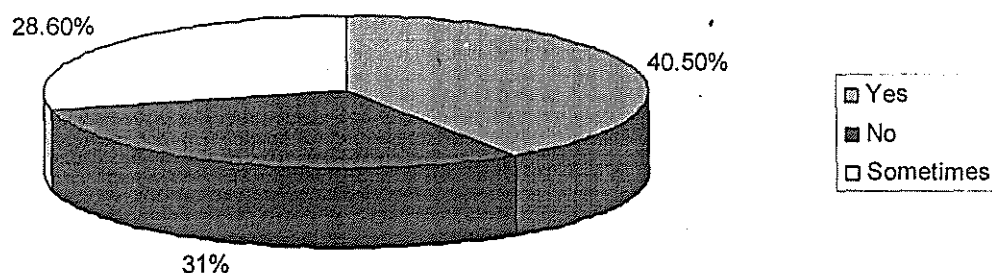


respondents were asked how they rate the provision of services to Children with disability in community. This provision of services was in terms of availability and quality of the services provided. A greater percentage of the respondents (71.4 percent) reported poor provision of services. This could be partly attributed to the limited community initiative to address the problems of disabled persons arising from the limited involvement of the Persons with Disability in the decision making processes. However, this finding could have been due to the general state of service provision in the community as a whole.



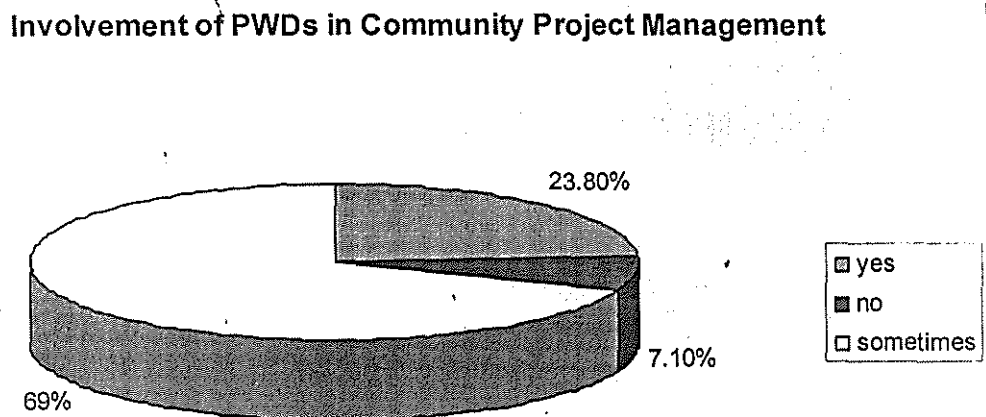
### 3 Availability of People who speak for the PWDs during Community Planning Meeting

Presence of People who speak for CWD during Community Planning meeting



Participation in community planning meetings is important in ensuring that the needs of the children with Disability are mainstreamed in development plans and projects. This finding indicated that there is low level of representation of the PWDs who are voiceless. There were limited agencies like civil society organizations, Parent support groups, the Local Councils and other community leaders who could speak on behalf of the persons with disability. However, the civil society organizations to larger degree speak on behalf of the CWD (46.9 percent) compared to Local Government staff (15.6 percent) and the local councils (12.5 percent) and the wider community (25 percent).

## Involvement of People with Disability in Community Project Management



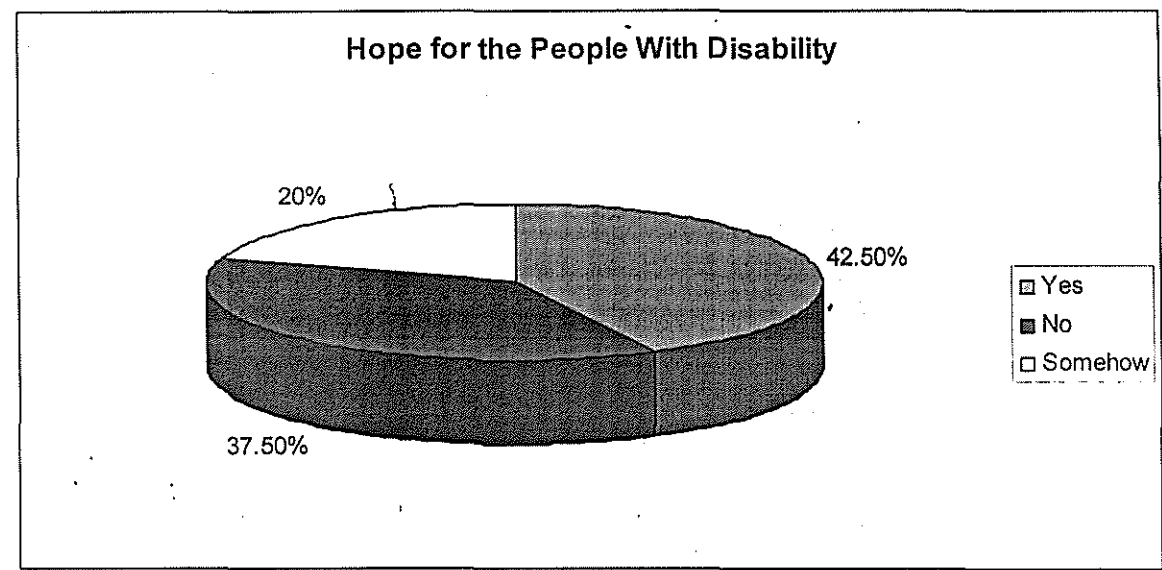
Community participation includes community involvement in community project management.

The research therefore investigated the level of involvement of people with disability in the management of community projects in terms of their election on the community project management committee and other existing community management committees of community facilities such as the Schools management committees (SMCs), Health Unit Management Committees (HUMC), Water Point Management Committees and so on. This involvement undermines the mainstreaming of Disability concerns in project implementation and access of service by the Persons with Disability in the use of community facilities.

The research found that only 23.8 percent of the People with Disability are involved in community Project management while a big percentage (69 percent) said sometimes (occasionally) the PWD are involved. The finding also indicated that where they are involved they are mostly involved only as Members of the committee other than at executive committee level.

This means the involvement of the PWD is not mandatory in most community projects. The implication here is that there is inadequate mainstreaming of Disability Concerns in community projects implementation. This scenario also impinge on the access of services such as Education, Health and Water by the People with Disability.

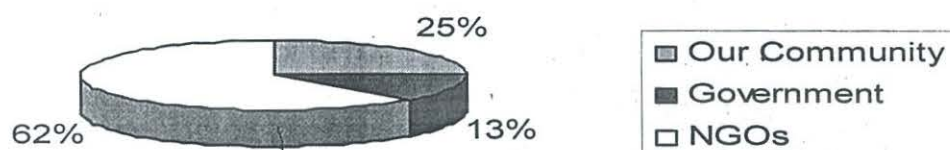
## 5.0 Community perception of Hope for the People with Disability



In prospecting the future of prospects of the people with Disability, the community were asked of whether they see hope for the Persons with Disability especially Children with Disability. Less than half of the respondents 42.5 percent reported that the PWDs have hope for good future improvement in living conditions while 37.5 say there is no hope for improvement of the living conditions of the PWDs. This is a relatively large percentage. While 20 percent think in one or the other there is hope for the improvement in the living conditions of the PWDs. This is because there are vast intentions to improve the living conditions of the PWDs

## The role of the Different Institutions in the improvement of the Living conditions of PWDs

### The role of institutions in improving the living conditions of PWDs



respondents think the future improvement of the PWDs depends greatly on the activities of the Non Governmental Organizations (NGOs) and least on the community and the government. This attitude may be due to the fact that in the last more than two decades there has been an increasing number and activities of the Non Governmental organizations in addressing the problems of the war affected communities of Gulu and other LRA affected Districts of Northern Uganda. The community thinks they can not do much to improve the lives of the PWDs without support from Government and other NGO partners. This means the down play the role they should play in helping the PWDs, during community needs assessment, mobilization, planning, implementation, monitoring and evaluation of community projects to ensure that the needs of the PWDs are addressed. How this reliance on the NGOs to improve the lives of the PWDs may hit a snag due to the fact that the number of NGOs operating in the District has decreased since the Uganda Government and the LRA Peace talks in 2007 in Juba. This is because of the return of IDPs to their homes due to the peace that now prevails in the region.

## **CHAPTER V**

### **SUMMARY, CONCLUSIONS AND RECOMMENDATIONS**

#### **5.0 Introduction;**

This chapter presents the summary of the finding and the conclusions there contained and the recommendations made in a logical manner.

#### **5.1 The Characteristic of the Respondents**

Majority of the respondents were females. Most of the respondents lie within the age of 20 to 40 years and above. Mostly the respondents attained some form of primary and secondary education. The conclusion here is that this kind of respondent was able to give more reliable information in their own community.

#### **5.2 An assessment of the level of community participation in addressing the needs of the Persons with Disability.**

The level of community participation takes place through such activities as needs assessment, mobilization, community planning, project implementation, monitoring and evaluation.

- In terms of mobilization and community awareness, 95.3 percent of the respondents were aware of the existence of PWDs in their community mostly (97.3 of the PWDs) facing conditions of physical impairment. Most of the respondents (90.7 percent) reported that the Children with Disability were the most Vulnerable category. Therefore this presents an opportunity for carrying out interventions to address the problems of the PWDs.
- Regarding Community needs assessment, the level of community participation of the PWDs is low during needs assessment. However the community identified Basic Social needs such as education, health, water and good sanitation and social protection such as protection against social stigma, child labor, sex abuse and other forms of discrimination as the priority needs of the PWDs. However, the economic needs such as employment and income and involvement in decision making were ranked as the least needs of the persons with disability. The conclusion is that the community is concerned with the



symptoms of the problem other than the needs that empowers the community like income opportunities and involvement in decision making.

- 71.4 percent of the respondents think the quality of the services received by the PWDs is of poor quality.
- The level of PWDs participation particularly in project management is low. 69 percent of the respondents reported that the PWDs sometimes (occasionally) involved in project management using election to project management committees as a proxy. Were they are involved in the management committee; they are involved mainly as members other than the executive position.
- There are very limited voicing of the concerns of the PWDs during community planning meetings. At least over 40 percent of the respondents reported that there are people during the community planning meetings who raises the concerns of the PWDs and such concerns were perceived well by the members of the community.

### **5.3 The future prospects of the Persons with Disability**

- 42.5 percent of the respondents think there are more prospects of improving the living conditions of the PWDS, 37.5 sees no prospects of improving the current living conditions of the PWDs (this is a relatively higher percentage in relation to conventional efforts put to improving the current conditions of the PWDS). 20 percent were uncertain of the future of the PWDs.
- The improvement of the current living conditions of the PWDs was envisaged to be largely dependent on Non Governmental Organizations (62 percent), and 25 percent on the community and 13 percent on Government. Its concluded that the long run activities of the NGOs in the area of study due to the more than two decades of the LRA insurgency has created a believe that the community needs can be provided by the Non Governmental Organizations. Secondly, the Community underscored their role to improving the current living conditions of the PWDs through community planning especially in needs assessment, goal setting and community action plans.

### 5.3 major recommendations

- The high level of community awareness about the existence of the PWDs in the community, their level of vulnerability should be able to be translated into community actions to address the plight of the PWDs
- The proper needs identification and prioritization of the needs of the PWDs should be undertaken through participation so as realistic needs are identified that if provided they address the root cause of the problems of the PWDs
- When planning for community intervention both access to basic Socio-Economic Services and the Quality of the Socio- Economic services should be given due attention
- There should be meaningful and effective mainstreaming of Disability in most programmes aimed at achieving the objectives of the Post conflict, Recovery and Development Plan such as Northern Uganda Social Action Fund (NUSAF 2), Northern Uganda Rehabilitation Programme. The participation of the PWDs should be mandatory within the implementation framework. This can mitigate the negative effects on the living conditions of the PWDs as the Number of NGOs kept declining in the area.



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Majid Tumasani (2005) explains that Community Based Approach to care or what came to be known as Community Based Rehabilitation

*Emerson* completed fiscal year 2003 with positive momentum across the company, led by rising sales and earnings and outstanding operational performance. ...

[www.emerson.com/en.../EmersonDocuments/.../chairmansletter.html](http://www.emerson.com/en.../EmersonDocuments/.../chairmansletter.html) -

## APPENDIX B

### QUESTIONNAIRE

#### SECTION A:

#### BACKGROUND INFORMATION

Name (Optional).....

Age ☐ Sex: Male ☐ Female ☐

#### Educational background (Tick where appropriate):

Degree ☐ Diploma ☐ Secondary ☐ Primary ☐  
Never went to school ☐

Profession.....

Current residence

Sub county.....Parish.....Village.....

#### SECTION B

#### Community support to children with disability

1. List the types of disability most common in your community

- (a) .....
- (b) .....
- (c) .....
- (d) .....

2. In terms of gender, who among the disabled children is the most affected by disability?

Why?

- (a) .....
- (b) .....
- (c) .....

- (b) .....
- (c) .....
- (d) .....

9. How were these needs identified?

- (a) .....
- (b) .....
- (c) .....
- (a) .....

### **Social integration and access to employment opportunities**

10. How do disabled children get basic needs requirements in their communities?

- (a) .....
- (b) .....
- (c) .....
- (d) .....

11. Are those needs the children with disability get of quality?

- (a) .....
- (b) .....

If NO why?

- (a) .....
- (b) .....
- (c) .....
- (d) .....
- (e) .....

12. In what ways have the provisions of services/infrastructures to disabled children helped them attain better standard of life in the communities where they live?

- (e) .....

- (f) .....
- (g) .....
- (h) .....

13. What factors have enabled disabled children access available facilities in the communities where they live?

- (a) .....
- (b) .....
- (c) .....
- (d) .....

14. What are the specific challenges that disabled children face as a result of their disability?

- (a) .....
- (b) .....
- (c) .....
- (d) .....

### **Improving recovery and reintegration of disabled children**

15. How can quality of services for the disabled children be addressed by the communities where they live?

- (a) .....
- (b) .....
- (c) .....
- (d) .....

16. The general social status ( eg educational ) of disabled children could be improved in the following ways

- (a) .....
- (b) .....
- (c) .....
- (d) .....



17. How do disabled children participate in decision making processes within their community

(a) .....

(b) .....

(c) .....

**For Questions 17-23 please indicate your best choice and knowledge of the statement by ticking the appropriate box**

Question /Statement		Levels of acceptance		
		Agree	Strongly Agree	Disagree
18. There are disabled children not attending school because structures to help them are lacking.				
19. Lack of tuition fee is a reason for school dropout among disabled children in the district				
21. The disabled children are still left behind due to community perception on disabilities.				
22. The contributions of NGOs have led to improved quality of life of disabled children in the district				
23. The surrounding community support disabled children's activities whenever they are called.				
24. Disparity between government and NGO's support is great and is hurting provision of basic needs of disabled children				

## **APPENDIX C**

### **INTERVIEW GUIDE**

**Topic: Community participation and the plights of children with disability in Gulu district [case study Bungatira Sub County]**

1. What are the environmental and institutional barriers that hinder the attainment disabled children's survival needs in Gulu district?
2. What community mechanisms are available which promote livelihood recovery of disabled children in Gulu district?
3. What are existing structures that try to address the plights of children with disability in Gulu district?
4. Who is responsible for putting these structures in place for example in schools?
5. How are the structures used, for example schools by the nearby community?
6. What are the prospects of improving the livelihood recovery and reintegration process of disabled children in the near future in Gulu district?

## **APPENDIX D**

### **ABBREVIATION**

**OVC.**Other Vulnerable Children

**IDP.** Internally displaced Person

**IDPC.** Internally displaced Person's Camp

**CDO** Community Development Officer

**UNICEF.**United Nations International children's Educations Fund

**UN.** United Nation

**SCORE** Support to Community Oriented Rehabilitation

**USDC.**Uganda society for disabled children

**PSG.**Parent support groups

**CWD.** Children with disability

**NGO's .**Non Governmental Organization

**CBR** Community-Based Rehabilitation



Disabled children have a moment to share among themselves



Okello James looks after home while his abled brothers goes to school



**INSTITUTE OF OPEN AND DISTANCE LEARNING  
OFFICE OF THE DIRECTOR**

Date: 06th September, 2010

**TO WHOM IT MAY CONCERN**

**Re: Recommendation for data collection**

This is to introduce **Amito Grace** Reg. No. **BCR/13134/61/DU** a student pursuing a Bachelors Degree in Conflict Resolution of Kampala International University from **September 2006** in the Institute of Open and Distance Learning Programme. She is writing her research on '**The plight of disabled children in Northern Uganda: A case study of Bungatira Sub- county, Gulu District in Uganda**'. She is at the data collection stage and your Institution/ Organization has been chosen for his research study.

It will be appreciated if you can accord her the necessary assistance.

