BASELINE STUDY OF BUSIA DISTRICT

In Preparation for Implementation of Community Based Rehabilitation Programme

Study team
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Acknowledgment

The team of consultants wish to express their most sincere appreciation to all the people who contributed to the success of this baseline survey. We especially wish to thank the District leaders of Busia at district and sub-county level, the persons with Disabilities who participated in this exercise and their carers.

Special thanks to Beatrice Kaggya and the rest of the staff of the Disability and Elderly Department of the Ministry of Gender, Labour and Social Development for your support and the National CBR steering committee for the confidence put in us.

I believe this report will provide a basis for improving the lives of people with disabilities in Busia and Uganda at large.

Dr. Alice B. Nganwa
On behalf the team

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Table of Abbreviations

ACDO	Assistant community development officer
CBR	Community Based Rehabilitation
CDA	Community development assistant
CDO	Community Development Officer
CWDs	Children with disabilities
DDHS	Director District of Health Services
DEO	District Education Officer
NGO	Non Government Organization
PWDs	Person with disabilities
SNE	Special needs education
SNECO	Special Needs education Coordinator
ADD	Action on Disability and Development
DDP	District Development Plan
PMA	Plan for Modernisation of Agriculture
DRO	District Rehabilitation Officer

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EXECUTIVE SUMMARY

Community Based Rehabilitation (CBR) was introduced in Uganda in 1989 and adopted as a Government strategy 1990. CBR was started in 5 districts by Government with support from the Norwegian Association of the Disabled and in 12 districts by various NGOs. An evaluation in 2000 of Government CBR programme recommended a pilot in one district from which other districts could learn from. Tororo became pilot CBR for Government in 2002. The evaluation of Tororo recommended the expansion of the CBR. Busia and Kayunga were recommended as districts to expand CBR because of the existing district structures and for Busia in particular, the progress the district had made in disability issues. Baseline study was commissioned to guide the planning process for CBR implementation in Busia. This exercise was done together with Busai district though this report covers only Busia district.

The **objectives** of the study were to:
Assess the needs and challenges faced by PWDs and their families in Busia district.
To establish a baseline for monitoring and future evaluation of the programme.
To establish internal and external factors that could impact on CBR implementation.

The **methodology** employed to carry out the study was based on qualitative methods and highly participatory. Some quantitative data was also collected. The study covered all the sub-counties of Busia and the technical and administrative district leadership.

Random sampling of PWDs and carers was done through the sub-county registers. 150 PWDs and 100 carers were interviewed using a questionnaire with closed and open questions. Key informants were interviewed and FGDs held with PWD leadership.

The **key findings** revolve around three issues; poverty, negative attitude towards PWDs and low access to services. Poverty was highly prevalent among PWDs and their families and contributes to inaccessibility to services. Many PWDs did not have the basic necessities of life such as beddings, clothing, and food. Poverty was not only limited to families but to communities and the district as well. The sub-counties and districts could not generate enough revenue to provide services for the people they serve; a situation worsened by the removal of graduated tax.

Access to all services was low. The study found that Children with disabilities were not accessing schools. Those who did manage to go to school did not find a conducive learning environment as they were few SNE teachers (0.3 per child), there was no special school or unit for the sensory impaired, learning and teaching material was not available except where locally made by a keen teacher. The SNECOs were not supervised or facilitated to support teachers and CWDs. The district had potential to have an SNE per primary school within one year as several teachers were in training.

Access to medical services was adequate for prevention and basic curative care to the general public. Though available, access by PWDs was limited due to lack of understanding of health workers on needs of PWDs and language barriers for the deaf. Inaccessibility of reproductive health services was high lighted by both women and men with disabilities. The district had poorly developed rehabilitation services and depended on neighboring districts for services either through outreach such as in the case of epilepsy or by PWDs visiting the services in the districts of Tororo and Mbale. Poverty limited referral and access to the services in the neighboring districts. The district had well developed services for prevention of blindness and had started its own out reach for treatment of epilepsy.

The district has several programmes introduced by Government and NGOs for eradication of poverty for example NAADS and ADD. Most are agricultural oriented, however, few PWDs participate because the implementers do not consider PWDs as needing special mobilization and PWDs lack the confidence to participate. Participation has mainly been through DPOs.

On the social aspect, negative attitude still prevails though the district has taken definitive steps to provide a platform for Equalisation. The disabled persons are still called abusive names and CWDs locked up in homes. The district has on the other hand, made attempts to mainstream issues of the disabled in the development plan. Busia includes interests of PWDs in its budget at district level but few sub-counties follow suit.

At the time of the study, Busia district was still undergoing staffing transition and the position of the DRO or CDO was not concretized. This was the same at sub-county where there was Assistant CDOs and CDAs. The district had however, trained staff and sub-county and district level for the implementation of CBR. The district leadership; both technical and political were aware about the needs of PWDs and ready to participate in the inclusion of PWDs in Busia society.

The voice of the PWDs is weak especially at sub-county and lower levels. This has led to apparent strong action and policy at district level which has not translated into tangible benefits for PWDs in their communities.

The team **recommends**:

Great caution is taken when funding CBR to avoid killing local initiatives and initiatives already under taken by DPOs and ADD.

There is need for CBR to mainstream PWDs into existing poverty eradication programmes mainly from microfinance institutions and agriculture sector.

The gap in medical rehabilitation needs to be addressed probably by lobbying the district of Busia to arrange for regular out reach to the two HSDs using rehabilitation personnel from the neighbouring districts and later advocate for the recruitment of the required personnel by the district. The CBR programme should where possible avoid funding medical service delivery except for provision of assistive devices which are currently too expensive for the district to provide. In- reach within the district to reach all persons with epilepsy needs to be undertaken urgently.

Provision of assistive devices is essential for inclusion of PWDs. The provision of assistive should not be the sole responsibility of CBR programme but the family of the user of the device should make a contribution and the district left with the

responsibility to purchase cheaper appliances such as walking sticks and axillary-crutches.

In the education sector, the section for SNE needs to be revamped. In- service training of SNE teachers and provision of units for deaf and blind will improve education for disabled children. The CBR programme could either play a facilitatory role in strengthening SNE or advocate the district or relevant NGOs to inject resources into SNE. At least one special unit of the deaf and another for the blind will be required to enable the visually impaired and deaf receive better education.

The leadership of PWDs should be strengthened to enable it raise the voices of people they represent. They need skills to advocate for the rights of PWDs especially at sub-county and lower levels as well as to empower the disabled people that they lead to harness the opportunities that surround them. The capacity building of PWDs should be result oriented with indicators the programmes can use to measure performance.

Support to Busia from NAD should be long term (5 to 7 years) with gradual withdrawal as the district takes on more responsibility. As mentioned earlier local initiative needs to be left alone to grow.

CBR should facilitate PWDs to access services (educational, FAL, medical and financial) as well as raise the profile of disability issues at various district points of decision making such as the Village Health teams, Parish Development Committees, Sub-counties committees and District Committees. The rights of PWDs at family level need to be ensured especially that of abandoned disabled mothers. In order for this to happen there is need to build the capacity of sub-county development workers and the community workers

SECTION ONE
INTRODUCTION

Background to CBR in Uganda

Community based rehabilitation approach has been practiced in Uganda by government and non government bodies since 1989. Prior to the establishment of the Tororo Model CBR Programme the government of Uganda, through the Ministry of Gender, Labour and Social Development was implementing CBR programmes with the support of NAD, in 10 districts namely, Bushenyi, Mbarara, Kabale, Ntungamo, Rukungiri, Mukono, Iganga, Kamuli, Mbale and Tororo (MGLSD, 2003). A number of evaluation studies were commissioned by the government through its line Ministry to assess the effectiveness of the programmes. Three major evaluation studies conducted between 1993 and 2000 reported considerable success but also shortcomings and gaps that needed to be addressed. Among the shortcomings identified were:

Low beneficiary coverage

Emphasis on one category of disability, i.e. motor disability, at the expense of the rest.

Lack of reliable data on the prevalence and situation of PWDs
Overload of community development assistants (CDAs)
Limited involvement of PWDs in programme design, planning and implementation (Devoid et al, 1993; O'Toole, 1996; Nordic Consulting Group, 2000)

Cognisant of these loopholes the Tororo Model CBR programme was conceived in order to pilot a more appropriate delivery approach which would as much as possible take care of the pitfalls of the existing programmes. The programme that started in 2002 was subjected to internal and external evaluations to assess the extent to which its set goals and objectives were being met (Nganwa et al, 2004; Nordic Consulting Group, 2005). The findings of the two evaluations indicated that over all the Tororo CBR Model Programme was a big success as it was meeting most of the conditions of good CBR practice in terms of programme design, involvement of various stakeholders including PWDs and their families, existence of an efficient management information system and utilisation of voluntary services, among others. Hence both evaluations recommended the need to replicate the Tororo experience in other districts of Uganda.

It was decided that CBR programmes along the Tororo Model be started in two districts, Busia and Kayunga, selected on the basis of the following criteria:

Proximity to Tororo

Availability of government and NGO referral services

Strong and highly motivated team of CBR workers at district level

CBR workers and resource teams at sub-county level

Strong presence and representation of DPOs

The Ministry of Gender, Labour and Social Development, realising the importance of knowing the existing situation and needs of PWDs, families and community prior to the introduction of the CBR programme, commissioned a baseline survey and needs assessment study relating to PWDs and disability in Busia District.

Rationale

CBR is a strategy within general community development for the rehabilitation, equalisation of opportunities, poverty reduction and social integration of persons with disability (PWDs). CBR is implemented through the combined effort of PWDs themselves, their families and communities and the appropriate health, educational,

vocational and other social services. The efficiency and effectiveness of its implementation depends on the availability of human and material resources as well as other critical factors such as positive beliefs and practices, sufficient infrastructures and political will. Corollary, a baseline survey and needs assessment of Busia District communities, where the programme was to be to be introduced, was deemed imperative.

SECTION TWO
BUSIA DISTRICT PROFILE

Introduction

Busia district, a mainly rural area, was created out of Tororo District in 1997 as means of enhancing service delivery to the people. Located in the south-eastern part of Uganda, it is bordered by Lake Victoria in the south, the Republic of Kenya in the east, and Tororo and Bugiri districts in the north and west, respectively. Busia district is a melting pot of multi-ethnic groups with the commonly spoken languages being: Samia-Lugwe, Ateso, Swahili, Lugisu, Japadhola, Lusoga, Luganda, Lugwere and Ngakarimojong.

Busia District occupies a total area of 743 sq. km., with one county called Samia Bugwe County. There are a total number of 10 sub-counties, namely, Busia T/C, Buhehe, Lumino, Dabani, Lunyo, Busitema, Masafu, Masaba, Buteba and Bulumbi.

Topography

Busia District is mainly made up of undulating plain terrain. But there are also low-lying areas, predominantly valleys of which River Malaba valley to the north and River Lumboka to the west are the most prominent.

Climate, soil and vegetation

Despite its location in the Lake Victoria basin the district receives less rainfall compared to other lake basin areas like Mukono and Jinja. Like other districts located along Lake Victoria rains have always been anticipated in the months of February to May and July to September. However of recent the rainy pattern has become unpredictable with rains not falling in the months it is expected and coming when not expected. Notwithstanding this, however, the condition supports two cropping seasons mainly of cereals, mainly millet and sorghum. The soils are generally poor and no longer able to support high crop yields contributing to the persistent poverty among the people.

The vegetation in the district has undergone considerable degradation as a result of continuous deforestation and poor cultivation methods. The following broad categories of vegetation types exist – grassland and wooded savannah, swamps and forests, the biggest being Busitema Forest Reserve. Forests are the main source of firewood and charcoal for the predominantly rural population as well as being a major source of household income.

Demography

According to the 2002 housing and population census, the district has a total population of 227,561 (male, n=109,960 and female, n=117,601). About 83 percent of the population lives in rural areas with approximately 400 people per square km. The major ethnic groups in the district are Samia, Bagwe and Etesots. The Busia Town Council has several other ethnic groups and a more cosmopolitan mixture.

Administration

The district is governed by the District Local Council under the District Local Council V Chairperson. The council is composed of elected representatives of various constituencies including persons with disability. The District Council has an executive Committee whose role is to initiate and formulate policies for approval by the Council and to oversee implementation of Government and Council policies among others. The council also has standing committees responsible for monitoring and reviewing the performance of their respective sectors and report to Council.

The administrative wing is headed by the Chief Administrative Officer (CAO) who is the head of the district civil service comprising key sectors, namely,
Management Support Services,
Finance and Planning,
Production and Marketing,
Works and Technical Services,
Education and Sports,
Health and Environment,
Natural Resources
Gender and community welfare
Council, committees, Commissions and Boards (See organisational structure below)

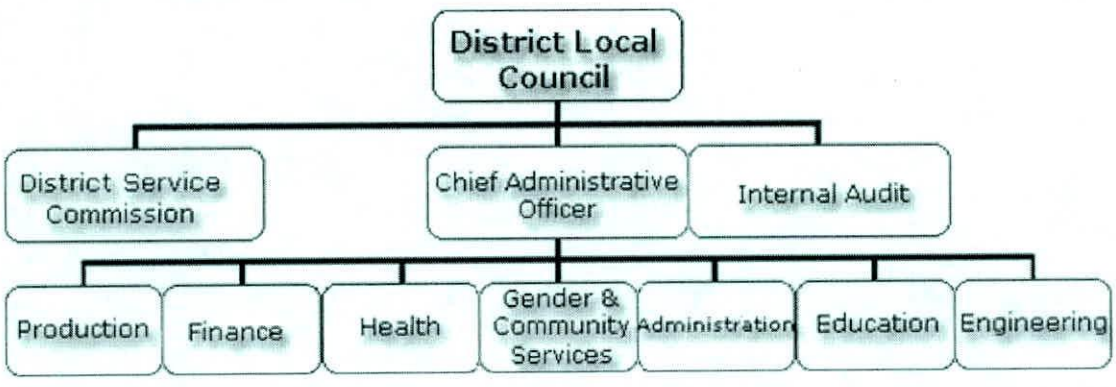


Fig. 1 Busia District Organisational Structure

There are two parliamentary electoral constituencies (Samia Bugwe County North and Samia Bugwe County South) in the district.

Administrative Infrastructure

Although the district, with support from organisations such as EC-MPP, RUWASA NEMA, and DANIDA, constructed office blocks for some departments there is still a shortage of office premises. It rents the premises housing South Eastern private sector

Enterprises Limited and the District Service Commission. Of the 9 rural Sub-counties, only 4 have office building and residential houses, which need repair. The other 5 Sub-counties are currently putting up offices and are at various levels of construction. Nevertheless they operate either in residual houses, community centres or rented premises.

Natural resources

Water sources
Busia District is endowed with plenty of surface and underground water sources. Surface water sources include Lake Victoria and rivers such as Lumboka, Malaba, Sio, Okame, Solo, Namachi, Nasinjekhe, Nabihidwe and Eseka. In addition there are numerous swamps and streams that have enabled the District to have protected springs and boreholes in major areas of the district especially in Busitema, Buteba, Masafu, Dabani and Bulumbi sub-counties. Otherwise the sub-counties of Lunyo, Lumino and Buhehe have no potentials for spring protection leaving the district with no option but to provide deep boreholes and rain water harvesting facilities.

According to the district development plan (DDP) of 2005–2008, 56% of the estimated rural population is within a distance of less than 0.5km and 88% within a distance of 2km from a water source for human consumption. 79% of the urban population is within a distance of 0.5km from a water source.

Mineral Resources
The District has a few gold deposits that the local people extract in small quantities. Some of the gold deposits are found at Tiira and in Lunyo Sub-county. The District has also a high potential for stone quarrying, especially in Buteba Sub-county, and large deposits of sand for construction.

Physical Infrastructure
Transport and communication
The District has a total road network of 730.2 Km composed of trunk roads (125km), district roads (402.4km) and community access roads (200km). The district is also connected with both the digital exchange system and mobile phone services. Postal services also exist Busia town and a few trading centres.

Electricity and water supply
Some parts of the district are connected to hydroelectric power supply from Jinja although this is unreliable due to frequent power cuts. Nevertheless, the largest part of the District is not yet supplied with power. The rural safe water coverage stands at 55.6%.

Banking
There is only one Bank (Stanbic Uganda) offering banking services in the entire District. There are also banking services offered by Post Bank Uganda (at Busia Post

Office), Microfinance Union, Uganda Women Trust and Busia Rural Development Trust.

Livelihood analysis

With the exception of Busia town and trading centres, food crop growing, charcoal burning and fishing are the main sources of livelihood for the people. The district has very few livestock and yet lacks a stable cash crop. This has greatly affected household incomes hence contributing to the rampant poverty in the district. The pattern of livelihood differs among categories of the population. In Busia town many persons including those with disability and children are engaged in cross border trade. Some adolescents and the youth are engaged in odd jobs like working in restaurants. Prostitution is also a major source of livelihood for some young women. The major areas for household expenditure goes to feeding and medical care leaving little resources for education, investment and other needs.

Social and cultural practices

The people subscribe to the three main religions, namely the Roman Catholic Church, the Anglican Church and Islam. There are also a few traditionalists. Owing to the multiplicity of the ethnic groupings there are heterogeneous cultural beliefs and practices although the most dominant are Samia related traditional practices.

The Samia are a male dominated society. Participation of the women in decision making is minimal. For example women have little say in major cultural events. Although more than men women are keen in attending village council meetings the latter dominate the proceedings as well as making decisions.

Health services

Being relatively a new district many service sectors in Busia are still being developed. Health is one such service department which is just taking off. Currently the district does not have a hospital, but a number of sub-county health centres are being upgraded. For example Masafu Health Centre IV is under consideration for upgrading to a hospital status. But of now the district depends on its neighbours (Tororo, Bugiri and Mbale districts) for secondary health care services.

HIV/AIDS is a leading health problem that has negatively impacted on the social and economic fabric of society. Like in other districts the problem takes more of the resources at the expense of other health services. Likewise resources that would go to providing services through other sectors are reduced. Even at the household level resources that would be used to uplift the standard of living are spent on caring for their HIV/AIDS infected member.

According to the Busia DDP (2005 – 2008) malaria and acute respiratory infections especially among children are still rampant. Measles is almost extinct thanks to the vigorous immunisation campaigns.

Challenges experienced

The District experiences a number of challenges, some of which are:

- Poverty is a major obstacle to the social economic development of the district. The majority of the people in the district live below the poverty line.
- Inadequate funding due to little funding from the centre coupled the low local revenue generation as a result of the abolition of the graduated tax.
- Delays caused by the long procurement process.
- Inadequate office accommodation.
- Under staffing
- The capacity of leaders to plan, monitor and evaluate projects/programmes especially at lower levels of Local Government is still low.

SECTION THREE
METHODOLOGY

Aim

This survey aimed at analysing the prevailing situation pertaining to PWDs, their families and the community, the availability of resources (both human and material) which could be harnessed to implement and sustain the programme. In addition, it was envisaged that the survey would help identify gaps and needs within communities in the district and guide Government, other service providers and stakeholders in making informed decisions pertaining to the introduction and implementation of the CBR programme in the district. Finally, the survey was intended to introduce the programme to the people, providing opportunity for them to assess their own needs and resources. This would lead to a cultivation of an attitude of ownership of the programme among the beneficiaries.

Objectives

The objectives of the situation analysis needs assessment survey were:

(i) To assess the demographic situation that has relevance for service provision for persons with disability and other vulnerable groups in the district.

(ii) To examine the physical, social and economic situation and needs of PWDs, their families and the community at large.

(iii) To analyse the social and financial support services, within and outside the district, which affect PWDs and other vulnerable groups.

(iv) To establish strengths, weaknesses, opportunities and threats within the communities in the district that have relevance to CBR programme implementation and sustainability.

(v) To make recommendations that reflect the existing reality of needs and gaps in the district which are to guide the CBR programmes' implementation

Survey design

The survey utilised both qualitative and quantitative methods of investigation. The qualitative investigation adopted the phenomenological approach that aims at understanding peoples' experiences through detailed description of these experiences (Patton, 1990). The specific objectives targeted by this approach were:

- To examine the physical, social and economic situation and needs of PWDs, their families and the community at large.
- To analyse the social and financial support services, within and outside Busia District which affect PWDs and other vulnerable groups.
- To analyse strengths, weaknesses, opportunities and threats within the communities in Busia District that may affect CBR programme implementation and sustainability.

The quantitative method of analysis was confined to frequency counts of attributes of interest to the study. The method was useful in describing the demographic situation that has relevance to service provision for persons with disability and other vulnerable groups in the district.

Location of the survey

The study covered all sub-counties of Busia District, namely, Masafu, Busia Town Council, Lumino, Lunyo, Dabani, Masaba, Busitema, Buteba, Bulumbi and Buhehe. This was to enable maximisation of data collection and enhance its validation.

Target population

Data was solicited from PWDs (male and female, with various disabilities), carers, local leaders, Heads of Government departments (i.e. Chief Administrative Officer, District Education Officers, Director of Community Based Services, Community Based Services Co-ordinator, District Planner, District Director of Health Services), LCV and III Chairmen, Sub-county Chiefs, community development assistants (CDAs), NGOs officials, SNECOs, and non-disabled persons from the community.

Study sample
The sample for the survey was purposively and conveniently sampled from all sub-counties as follows:

(a) Persons with disability and caregivers

- Persons with various disabilities (n=150) were purposively and conveniently sampled from all sub-counties in the two districts. Fifteen (15) PWDs (male and female, of diverse impairments) were selected from each of the 10 sub-counties of Busia District.

- Carers (n=100), 10 from each sub-county, were purposely sampled particularly if the disabled person could not express his/her experiences either because of having a communication/speech difficulty or due to juvenility.

- PWDs holding leadership roles (Local council representatives, male and female (n=10), and executive members of selected DPOs, n=20) were purposively sampled. In selecting the samples there was a deliberate effort to have all major disabilities (i.e. physical, visual, hearing, other impairments) represented.

(b) Community development officers and/or assistants (n=10) were purposively selected from the sub-counties.

(c) District officials (politicians and Heads of Government Dept), namely, LC V chairman and Vice Chairman (n=2); CAOs (n=1), DEO and Inspector of school in charge of SNE (n=2), DDHS (n=1), District Planner (n=1), LC III Chairmen (n=4) and sub-county chiefs (n=5).

(d) Service providers:
- Officials from NGOs (n=2),
- Special needs education co-ordinators (SNECOs) (n=8).

3 Non disabled members from the community (n=5)

Data collection methods
Five methods of data collection were utilised: semi-structured questionnaires, key informant semi-structured interviews, focus group discussions, non-participatory structured observation and document analysis.

Assessment tools
The instruments and the samples for the survey were as in the table below:

Table 1: Assessment tools and participants

Assessment tools	Type of data sought	Participant targeted
Semi-structured questionnaires for PWDs	Qualitative and quantitative data	PWDs
Semi-structured questionnaires for caregivers	Qualitative and quantitative data	Carers
Focus group discussions for PWDs Leaders	Qualitative data	DPOs, Local council representatives
Focus group discussion for CDOs/CDAs	Qualitative data	CDOs, CDAs
Structured interviews for district officials	Qualitative data	LC V chairman and Vice, CAOs, DEO, Inspector of schools in charge of SNE, DDHS, District Planner, LC III Chairmen and sub-county chiefs.
Semi-structured interviews for NGOs	Qualitative data	NGOs and agencies
Semi-structured questionnaire for non-disabled persons	Qualitative data	Non-disabled persons

Development of the instruments

- In developing the instruments for the study the survey team utilised the rich experience of individual members in community based rehabilitation work and needs assessment surveys. Checklists for the instruments were generated through brainstorming among the survey team members. The instruments were further subjected to scrutiny and discussion with Ministry of Gender, Labour and Social Development officials.

- A pilot study was conducted to pre-test the research instruments in Mpigi District one of the districts of Uganda where CBR has not yet been introduced. The instruments and their administration were evaluated and perfected in light of observations made in the pilot study.

Data collection process

- Data collection in the district was conducted in five (5) days. Data collection assistants were identified from among special needs education teachers and CDAs to assist in data gathering data. Ten data collectors, each assigned to a sub-county, were identified. Before deployment the data collectors were given a one day's sensitisation on the nature of disability and challenges PWDs encounter in the community, and given practical training on administering questionnaires.

- A major activity at this stage was translating the questionnaire from English to Lusamia, the local language spoken in the district, and back to English. This was collectively done by all data collectors.

- The data collectors were given four days to gather data from 15 PWDs and 10 carers. Collection of data involved reading the questionnaire items to a study participant and recording the response (in case the study participant was illiterate).

- In-depth interviews with key informants (stakeholders in government and non-government organisations) involved in the service provision in communities were conducted mainly by the assessment team of four. The interviews and FGDs with key informants, CDAs and SNECOs were conducted in the English language while those of PWDs' leaders and DPO officials were in a mixture of Lusamia and English. Fortunately a member on the assessment could speak Lusamia so there was no need for an interpreter.

- Visits to communities (specifically to DPOs, selected sub-county headquarters, health centres and a few homes) were done by members of the team accompanied by officials from MGLSD. Interviews and non-participant observations were recorded in notebooks.

Data analysis

- Data was analysed qualitatively, that is, subjected to thematic analysis. It was recorded, transcribed, and coded, and then patterns identified, displayed and interpreted. Analysis of interview (including focus group discussions) and observation data started immediately its collection was over.
- Triangulation of results yielded by the various methods was carried out. Quantitative data was analysed using the SPSS computer programme.

Validity and reliability

Accuracy in the survey was assured through a number of measures.

- In the first place, during the construction of the research instruments extensive thorough brainstorming and consultation were made.

- Secondly, the instruments were pre-tested (piloted) in a district bearing resemblance to the survey district after which they were perfected in light of observations made.

- Thirdly, multiple methods of data collection (interviews, focus group discussions, etc.) were employed. Each of the research tools was carefully designed to elicit responses from a specific sample in the appropriate context thus maximising chances for validity and reliability. Likewise data was obtained from different samples to achieve rich and diverse data. The use of multiple data collection methods and different study participants ultimately enabled triangulation, by which commonalties in data were understood to be a sign of validity and reliability of research tools, data collection process, and the participants' responses.

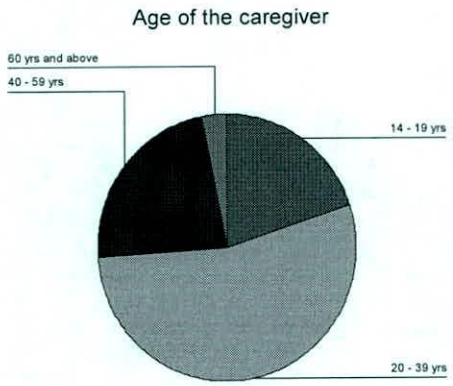
- Triangulation of data from interviews, focus group discussions, questionnaires and observations was carried out to establish validation and reliability. The data were

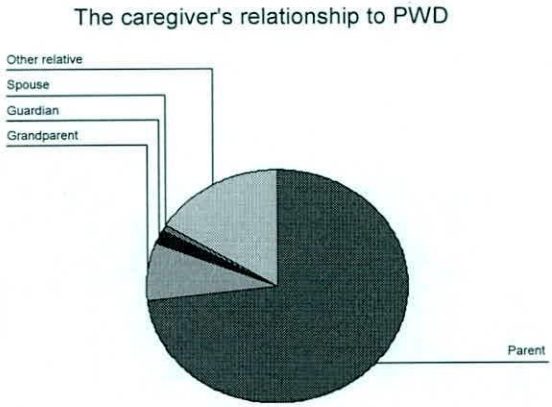
compared and convergence between them noted. Deviant responses and events that appeared not to fit within the general pattern were reported and discussed when this seemed to be significant.

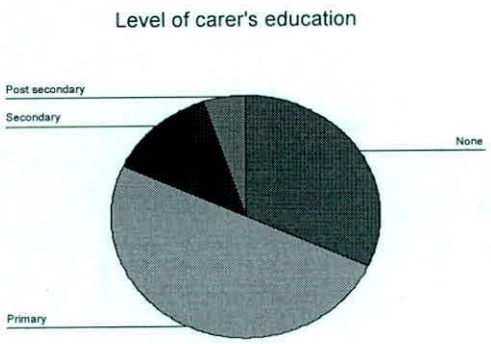
SECTION FOUR
PRESENTATION OF FINDINGS AND DISCUSSION

DEMOGRAPHIC DATA ON DISABILITY AND PWDS

Below is the demographic overview of the sample size.







Documented data on disabilities is generally scanty. The little available was generated by individual departments for specific needs. And this is not necessarily shared among the other sectors and departments. For example the education department had some data on number of children with specific disabilities integrated in different schools. The

production sector had some information on the number of disabled people's organisations that had benefited from the PMA. The result of this information gap makes planning, lobbying and advocacy, and a coordinated implementation of disability related activities difficult.

However the national population estimates for PWDs in Busia is between 8,000 and 9,000 people, representing 3.2% of the total population in the district (The 2002 National Housing and Population Census). This figure however needs to be taken with caution as given the criticism that has been made on the data collection methodology adopted by the UBOS (NUDIPU, Hartley, 2001). It has often been claimed that the figures for PWDs were understated.

The findings of this study indicate that the common disabilities in the district are motor disability (polio and cerebral palsy), visual impairment, hearing impairment, epilepsy, mental retardation, multiple disabilities such as deaf blindness, and leprosy related impairment all at varying degrees of severity.

Incidences of visual impairment were reported to be commonest along River Suwo and the shores of Lake Victoria was attributed to river blindness caused by the parasitic worm called onchocerca volvulus. Epilepsy was reported by a number of service providers to be on the increase particularly among children. This increase could be *apparent* or real. If apparent the trend may be explained by two factors:

- increased access to information on treatment of epilepsy could have led to many people affected by the condition come out for medical service.

- Out reach programmes could have influenced change of attitudes in communities towards the perception of the condition.

On the other hand, it is most probable that the problem of epilepsy is actually on the rise. This could be due to early childhood diseases and infections such as malaria and meningitis; injuries to children due to falling down; drug abuse of both legal and illegal drugs. It was reported that people frequently take against or without the guidance of a medical practitioner e.g. anti malarial drugs. Another factor could be trauma during delivery. According to the DDHS only 20% of expectant mothers in Busia deliver assistance of qualified attendants. Eighty percent of the deliveries are self administered at home, sometimes with the aid of neighbours or close relatives. Although there are a few traditional birth attendants, they are not well trained.

SITUATION AND NEEDS OF PWDs AND THEIR FAMILIES

Data on the social and economic situation and needs of PWDs and their families was obtained from PWDs (n=150) and carers (n=100) through semi-structured interviews. Carers were selected to articulate experiences of PWDs who could not express their views either because they were too young, mentally retarded or had communication difficulties. Additional data was provided by other disability stakeholders and key informants such as DPOs, PWDs councillors, CDOs, SNECOs and heads of sector and

department within the district. Specifically data pertaining to living conditions of disabled and their families, their needs, attitudes, beliefs and practices concerning disabled people, participation, and access to services was sought.

The findings are reported in verbal, tabular and/or graphic forms under the appropriate subtitles.

Challenges and needs of PWDs

The following categories of needs and challenges emerged
Poverty

The challenge of poverty was a common theme in all data obtained from the multiple sources (participants and methods). It was reportedly manifested in PWDs experiencing difficulty in meeting basic necessities like clothing, food, sugar and salt and inability afford to medical services:

> *"There are drugs that I was using before... but I don't have them .... So I experience frequent attacks. Yet I cannot afford to buy more....The tablets are too expensive to buy"* ***(PWDs' data)***
>
> *"I cannot have the wheel chair repaired because there is no money"* ***(PWDs' data)***
>
> *"I cannot manage pay schools fees for my children. So these children are at home" "We cannot afford to buy clothes, sugar and salt"* ***(Carers' data)***

Accessibility challenges

Depending on the nature and degree of disability accessibility challenges experienced differ. The challenges that emerged from data obtained from multiple sources were mostly related to physical accessibility.

b) Physical accessibility challenges

The physical challenges highlighted were those within the home and community. The most expressed accessibility challenges within the home related to difficulties in using the bathroom and the toilet. The table below shows how two disability categories are affected:

Table 2: Physical accessibility challenges experienced by disabled people at home

Disability	Challenges	Coping strategy
Motor disability	<u>Bathroom</u> • Carrying water to the bathroom • Undressing and dressing within the wet bathroom • Difficulty encountered in bathing self • Difficulty in squatting or standing while bathing <u>Toilet</u> • Difficulty squatting on the pit hole • Getting up from the pit hole without any thing to hold on. • Difficulty aiming into the hole while emptying bowels • Dirty toilets and urinals	Relies on others for support: *"they take the water to the bathroom and a stool for me to sit on"* ***(PWDs)*** "She needs to be assisted to bathe. Her hands are too weak and can't scoop water...." **(Parent)** Defecate outside: *"She helps herself anywhere....then I remove later"* **(Parent)** Adapting the latrine: *"We erected support poles for him to hold on".* Wearing sandals on the hands
Visual impairment	<u>Bathroom</u> • Cannot carry water to the bathroom • Tripping and falling while carrying water <u>Toilet</u> • Moving to and from the latrine • Locating the pit hole	Relies on support from others Uses the foot to locate the hole

Using the toilet and bathroom are basic activities of daily that a person of age should be able to do independently. Seeking support from others erodes the person's self-worthy and esteem and compromises his/her privacy. The disabled people have devised various coping strategies. However, some of the strategies are not effective given the hygienic conditions of bathrooms and toilets in poor homes. There are healthy risks involved in using strategies like sitting on latrine holes and in bathrooms. 51% of PWDs interviewed have difficulty in using toilets and bathrooms in their home settings.

c) Accessibility challenges in the community

Persons with different disabilities are affected differently by accessibility challenges in the community as in the table below.

Table 3: PWDs' and carers' perception of the accessibility challenges experienced by different groups in the community

Disability group affected	**Challenges**	**Supporting data**
Motor disability	Long distances;	*"Moving long distances makes me feel tired and weak"* ***(PWD)*** *"Cannot manage to walk long distances"* ***(Carer)*** *"Feels pain in the joints when he walks"* ***(Carer)*** *"He has to be carried...."*
	Difficulty in using public transport	*"Most taxis do not have space for carrying a wheel chair. If there is such space the disabled person is often charged for the wheelchair"* ***(carer)***
	Inaccessibility of roads and pathways	*"It is difficult to reach most disabled people's homes because the tricycle cannot pass through the narrow pathways"* ***(PWD)***
	Inaccessibility of compounds	Compounds of public buildings are rough and uneven and not accessible. The footpaths leading to some buildings are rough and narrow
	Architectural barriers	*"He experiences difficulty in entering buildings"* ***(carer)***
	Physical injury	*"I get bruises when I crawl on stony and thorny places"* ***(PWD)***
Visual impairment	Physical injury, functional limitation, communication difficulty	Bumping into objects **(carer)**
Hearing impairment	Communication difficulty	Not understood by the people **(carer)**
Mental retardation	Negative attitudes; Mistreatment by peers	*"She is abused whenever she goes out"* ***(Carer)***
	Overprotection	*"We fear that she can get lost or beaten by people"* ***(Carer)***
		"He is not allowed to move far alone because of inability to communicate well" ***(carer)***
Epileptic	Fear and anxiety	*"I have epilepsy, therefore I fear moving far lest I get a fit and injure myself"* ***(PWD)***

- People with motor impairment

The perceived accessibility challenges related to long distances separating places and services; difficulty of using public means of transport; and inability to afford the fares. It is common for persons with severe motor disabilities to be left on the way by transport operators on the grounds of their being slow and not having space on their vehicles to carry a wheelchair.

All these difficulties undermine PWDs' mobility, accessibility and participation in social and economic activities. The problem is made worse by the poor conditions of countryside roads and paths which are impassable to tricycles and *boda boda.* Persons who crawl sometimes suffer physical injuries on hands and knees (used for mobility).

- Persons with visual impairment

The survey revealed that visually impaired people's mobility and accessibility are restricted by lack of mobility and orientation skills. As a result of lack of these skills many blind people rely on sighted guides for mobility within the community. Another barrier to participation is in form of difficulty to communicate through print. As lots of information is conveyed through the print media blind persons depend on sighted people to read for them. Even if some information were presented in the Braille format they would not access it since the majority of the blind people are not Braille literate.

- People with hearing impairment

The survey revealed that the communication barriers that exist between the hearing and the deaf persons in the community are reinforced by deep rooted stigma the public generally has towards people with hearing impairment. Difficulty to communicate by deaf people sometimes makes them vulnerable to being misunderstood and even made fun of. Several other negative consequences of the communication barrier experienced by deaf people were identified as follows:

- The affected persons feel insecure on roads as they fear that they could be knocked down by vehicles any time
- Deaf children's learning at school suffers. Many of them have dropped out due to absence of teachers with qualification in special education.
- Some deaf people feel socially lost, inferior and isolated from the rest of the public.

Consequently their integration and participation are undermined.

- Persons with neurological impairments

In this category are persons with intellectual impairments and those with epilepsy. Accessibility difficulties affecting persons with intellectual impairments are mainly social in nature. Findings of the survey indicate that persons intellectual/mental deficits (especially children) are isolated and molested by peers making it difficult for them integrate with their peers. Parents/carers respond to the mistreatment and rejection by

confining the children at home, thus limiting their (disabled children's) social development and participation.

Persons with epilepsy and their carers restrict/limit the range of mobility and activity participation (of the former) for fear that they could suffer seizures/fits in the process. There was no evidence in the data to link existence of the condition of epilepsy to a person's social isolation.

d) Access to other mainstream services

The survey revealed that most PWDs encounter difficulties in accessing other critical services in the community although the degree of difficulty varies with the nature and degree of disability. The study identified the following services as being difficult to access by disabled persons: water sources, medical rehabilitation, educational services, vocational training, and microfinance facilities.

e) Water sources and fuel

A number of challenges relating to accessing water sources emerged:

- Water sources – wells, springs, lake, boreholes – and firewood are generally too far for PWDs to walk.
- The paths to water sources are generally rough and narrow. Persons with motor and visual impairments experience difficulties in accessing them.
- PWDs, especially women with motor disability experience considering difficulty fetching. It was reported that persons with mild to moderate disability carry water in small containers (and small bundles of firewood) which they can carry. Alternatively they are assisted by relatives to fetch the water and bring in firewood. Persons with severe disability rely on carers to have the water and fuel fetched. It emerged that one of the reasons women with disability find difficulties getting married is that they are too weak to carry out domestic chores like digging, fetching water, looking for firewood etc. which responsibilities, among the Samia (dominant ethnic group in Busia District) are culturally associated with women.

f) Educational services

Despite UPE many children with severe motor/sensory impairments are not going to school. The commonly cited reasons for this are inaccessibility of schools (for children with severe motor disability), lack of special teachers and teaching and learning materials (for children with mental and sensory impairments) and inability to meet school dues by parents.

g) Vocational training facilities

Existing vocational facilities in the district are not accessible to PWDs because they neither have the necessary adaptations for easy accessibility by disabled people nor do

they have adapted training kits and vocational rehabilitation trainers. A few lucky disabled youths are placed other districts like Mukono, Mbale and Kampala for vocational training services.

h) Medical rehabilitation services

Difficulties are experienced in accessing appropriate and adequate medical services by the majority of people in rural developing economies. However the problem is worse for PWDs. The survey revealed that PWDs' accessibility to medical services in the district is seriously undermined by the following constraints:

- **Affordability.** The study revealed that many PWDs and their families were not accessing basic medical treatment and rehabilitation services because they are too expensive for them.

- **Distance.** Several PWDs reported that they find difficulties in meeting travel expenses as the medical centres are far from their homes. Some specialist medical services are in neighbouring districts. In case one seeks services there he/she may not be able to make a return journey – implying that he/she must spend on upkeep while there.

- **Information.** The survey observed that some PWDs and caregivers lack information on their medical needs and where they can obtain the services.

- **Absence of rehabilitation services.** The study noted that medical rehabilitation services like physiotherapy, orthopaedic, and occupational therapy do not exist in Busia. These specialist services are available in some district and referral all hospitals, which unfortunately Busia district does not yet have. The nearest districts where some of these essential services could be accessed are Tororo and Mbale, which are very far considering the condition of poverty most PWDs and their families live in.

- **Resignation.** The study found evidence that pointed to the fact that a few PWDs/caregivers give up seeking medical service because they think it not worthy the trouble. For instance one elderly disabled person did not think it necessary to go to hospital because he considered himself too old and his treatment is a waste of money.

- **Communication.** It was reported that some categories of PWDs like the hearing impaired find difficulty in communicating with the medical staff about their problems.

- **Un-adapted medical facilities.** This concern emerged in connection with disabled women in labour however this could affect even other aspects of service delivery. It was reported that disabled women in labour find it difficult to use the high delivery beds in medical centres.

Involvement of PWDs in developmental programmes

Several programmes and projects run by government and non government organisations exist in the district. Among them are: Plan for the Modernisation of Agriculture (PMA), Local Government Development Programme (LGDP), Functional Adult Literacy (FAL) and Community HIV/AIDS Initiative (CHAI). The majority of PWDs and caregivers showed that they were aware of the existence of mainstream developmental programmes aimed at uplifting the economic and social wellbeing of the poor. The most frequently cited programmes in the data are NAADS, FITCA, Farmers Groups, CCF, *'Sweetee'*, FINCA, FAL and African Network 2003. However the majority of disabled respondents reported that they were not involved in the activities of such programmes as shown in the graph below:
PWDs who reported being involved were 47% while those not involved were 63%.
Several reasons for non-involvement were advanced:

- Many PWDs are not aware of the existence of the programmes or projects:

  "We do not get information about these programmes" ***(Disabled person)***
  "We just hear of the programme but do not know what it is about" ***(Disabled person)***

- PWDs are ignorant about their eligibility and rights to participate in the programmes:

  "Most disabled persons are not invited to attend meetings, so they do not know whether they are supposed to attend and participate in the programmes" ***(Caregiver)***

- PWDs think mainstream programmes are for non-disabled people. They wait for programmes that specifically target them.

- For programmes that require some contribution for an individual to benefit, PWDs who cannot afford are left out.

- Fear of risk. Some PWDs fear that they would lose their property or be imprisoned if they fail to pay back the loan and so avoid the risk of taking the loan thus not getting involved in the programme/project at all:

  "Some people have lost their property due to failure to pay back the loan. This scares me." ***(Disabled person)***

  "I do not trust people...some mismanage funds and are corrupt" ***(caregiver)***

- Not being a member of or affiliated to a formal organised group which is often the prerequisite for benefiting from a developmental programme or project.

  "They give those people who are in groups, yet I do not belong to any of those groups because I am a Lugbara and therefore a stranger" ***(Mother of a child with mental retardation)***

- The programmes or projects sometimes do not take into consideration the needs of PWDs:

  "The programmes do not listen to the needs of the disabled".

  "They have nothing to do with my needs and problems"
  "NAADS groups are not conducive for disabled people" ***(Person with severe motor disability)***

- Discrimination by able-bodied administrators of the projects or programmes:

  "We are marginalised, they isolate us ....they feel I cannot do much ...." ***(Blind person)***

Most pressing needs of disabled persons

- Need for assistive devices

The survey revealed that of the PWDs (n=150) contacted by this study only 25% reported that they possessed assistive devices of some kind. As the data was gathered through a questionnaire administered by data collectors (survey assistants) it was not possible to establish if these assistive devices were appropriate and in good condition. It was not possible to establish the proportion of people with disabilities who required assistive devices (need as defined by a health worker) but did not have them.

However, responding to the question seeking to know whether their disability needed to assistive device only 47% showed that they needed one.

The responses indicated in the above figure seem to be at variance with the data indicated that only a few PWDs (25%) possessed assistive devices. Three possible explanations for apparent contradiction are possible. First, most PWDs in the survey sample had impairments did not necessitate the use of assistive devices. Secondly, there is a possibility that PWDs, despite the fact that their condition could be improved by the use an assistive device, were so used to their way of functioning and condition that they saw no need to change this. Finally, some PWDs think they do not need an assistive device because they do not know the benefits of using one that is appropriate to their special need. And, moreover, they may not be aware of negative consequences to their health of not using the assistive device.

Need for financial support

The need for financial support to start income earning projects was widely expressed by both PWDs and carers. Although many of them indicated that they would start some IGA they were barred by lack of investment capital. One reliable source of such capital would be securing loans from microfinance institutions. But unfortunately the survey noted that only a minority (12%) of PWDs were benefiting from the services of these institutions as the data in the pie chart below shows.

Responsibility for Care of PWDs

Analysis of data from a sample of 100 caregivers, selected using the cluster sampling technique (with 10 participants coming from a sub-county) indicated that the majority of disabled people require a carer were children of 0-12 years old (46%), followed by adolescents, 13-19 years, (23%) and adults of 40 years and above (19%) and then age group 20-39 years (12) as in the bar graph below.

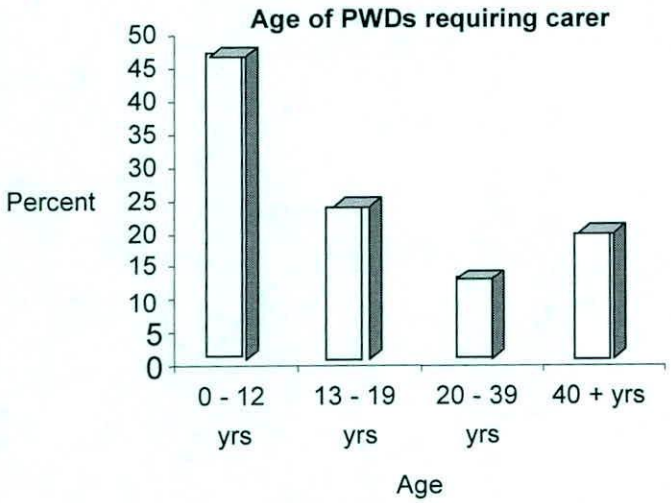


Fig. 7: Age of PWDs under care

The data needs to be interpreted with caution because the proportion of age group 1-12 years are children which is socially expected even among the non-disabled to be more dependant upon adults.

Data obtained from PWDs (n=150) indicated that on the whole the burden of caring for disabled persons is shouldered by different relatives. However, most of the responsibility is borne by the parents or grandparents (45%). Some PWDs, most likely those with mild to moderate impairment and/or have the means, can look after themselves (20%). Other caregivers are wives (12%), disabled persons' children (12%) and other relatives such as aunts, uncles, disabled person's brothers and sisters. See Table 4 below.

Burden of care

(i) The study established that the responsibility for caring for PWDs in the community mainly lies with mothers and grandparents. The study therefore recommends that while focus for training and support should be on these key caregivers effort should be made to encourage fathers and other members of family to be mindful of their responsibilities to the disabled relative.

Table 4: Caregiver for the disabled person

Caregiver	**Percent**
Self	20
Parent/grandparents	45
Husband	6
Wife	12
Offspring	12
Other relatives	5
Total	**100**

The data in the table above seems to suggest that in a family with a disabled person the likelihood of the caregiver to be a parent/grandparent is higher than for any other relative. Given this fact it would be advisable to service providers to work closely with parents and target them for training and other kinds of empowerment.

A significant number of disabled people indicated that they look after themselves. Experience gathered by the survey shows that several disabled persons in Busia district especially those in town have been successfully integrated in the social and economic mainstream where they participate in the lucrative cross border trade. It was reported in focus group discussions of PWD leaders and CDOs/CDAs and in-depth interviews with other stakeholders that PWDs were, in some homes/families, the bread winners. Many of the PWDs were reported to be involved in the cross-border trade. This goes to demonstrate the fact that once an enabling social and economic environment is provided PWDs can lead an independent and dignified life. The CBR programme could understudy the existing cross border trade with a view to finding out on how to build on that experience without involvement in illegal trading such as smuggling.

The data further reveals that children also provide care for their disabled parents/relatives. Reliance on other people for a living is worse if the caregiver is a child. This is so because the child spends his/her life time looking after the relative at the expense of his/her own social, mental, and educational growth. He is deprived of play with peers and schooling. This is especially so where the child is the guide for the blind or helping a disabled mother with the baby.

Challenges and needs of carers of PWDs

The survey, through the Caregivers' Questionnaire, revealed a number of challenges encountered in the course of caring for PWDs. The following were the most outstanding:

Poverty

Most caregivers cited this as one of the most pressing challenges. Participants reported having difficulty in meeting basic needs like food, clothing, medical care etc.:

> *"There is no money for fees, to go to hospital, and to buy food"* ***(Grandmother)***

> *"We cannot afford to take her to Mbale where she can be operated"* ***(Father of a child with hydrocephalous)***

Lack of information

Some caregivers indicated lack of information about what to do to assist their PWDs or where to get help/service they (PWDs) require:

> *"I have not met someone to explain to me the problem"*

> *"I cannot tell when the child is sick" (Mother of a child with mental retardation)*

> *"We do not know what to do for him"*

> *"I do not know where to get the treatment for her"*

Burden of care

The responsibility of looking after persons with certain types of disability was reported to be taxiing. The concern was common among carers of persons with severe physical impairments and those with cognitive impairments (i.e. mental retardation and epilepsy). The following sentiments related to caring emerged:

- the carer has to do everything for the PWDs – no one to assist in caring for the disabled person:

  > *"I get so tired because she likes only me to attend to her and no one else".* ***(Mother of 15 year old girl with severe epilepsy)***

- Family members are kept busy all the time and have no time to do other work. Sometimes the burden of caring means that carers forfeit their social roles:

  > *"I find it difficulty to leave her at home alone in order to attend a burial ceremony"*

  > *"I cannot pay any visit because there is no one I can leave her with"* ***(mother of a child with multiple disabilities)***

"I cannot leave her alone at home. So I am like a prisoner at home"

Stigma and social isolation

The survey recorded experiences that showed that carers are sometimes isolated from social activities due to having a child with disability. One parent of a child with epilepsy lamented that their family had been isolated because of their child's condition.

"Neighbours have isolated us due to my son's condition" ***(Father of an epileptic child)***

Some carers felt concerned that some people do not appreciate the needs and difficulties of disabled people.

"Some people do not understand her problem especially in places where they do not know her difficulties like in schools" ***(Parent of a girl with hearing impairment)***

"Some people, especially children, laugh at and make fun of him because he cannot speak"

Carers' further indicated that they were being deprived of participation in social activities such as funeral and weddings functions because they have to stay at home most of the time to provide care to their disabled relatives.

Access to medical care

A few parents experience difficulty in accessing the much needed medical service for their children because they cannot afford the costs of the treatment and transport to and from the medical facilities. Secondly medical services for certain disability conditions are not available in the district. For example children needing to surgical corrective operations have to be taken to Tororo or Mbale where there are such services.

"W e do not get help from the medical centre because there are no doctors to operate on his leg" ***(Mother of a child with a motor disability)***

Communication difficulties

Some carers of children with communication difficulties, like the deaf and the mentally retarded, experience difficulty in communicating and interacting with other children due to existence of a communication barrier. Communication breakdown sometimes results into irritation and frustration on both sides – on side of caregiver and that of the PWD. The carer may vent her frustration by beating the child; while the child becomes aggressive and destructive.

"Sometimes he just stubbornly continues doing what you tell him not to do. Then I beat him and this makes him mad and more aggressive... he may break anything in front of him."

Worry and feelings of anxiety over PWDs' condition

Isolated data referred to parents concern for the future condition of their children. Two parents stated that they were worried and anxious over the health condition of their children in future.

One grandmother expressed her fear of what would happen to the disabled grandchild after her death.

> *"I fear that the child will lose his sight in future"* ***(Father of a child with low vision)***
>
> *"If I die I do not know what will happen to this child. She is already an orphan – her mother passed away".*

Taking and collecting a disabled child to /from school

A challenge is experienced in taking and returning a child with severe mobility difficulties to school on a daily basis. Some carers expressed the need for a bicycle to minimise the task of transporting their children to and fro school.

Strategies used by carers to cope

The survey identified a number of ways carers were trying to cope with the challenges:

- Some carers seek support from relatives and other good hearted individuals in the community:

  > *"Sometimes neighbours lend us a bicycle when we want to take the child to hospital"*

  The support from community is sometimes in form of counsel and valuable information concerning where help could be obtained.

- In most cases caregivers have no choice but to bear with the situation:

  > *"It is a matter of accepting to live with the situation since there is little to change...you cannot change nature"* **(Mother of a child with severe mental retardation)**

- Working hard to fend for the family and try to meet the needs of the disabled member. A few parents carry out IGAs like petty trading and farming to get income

- Seek advice from SNECOs

- Carers have developed gestures and signs with which to communicate with their deaf relatives

- Praying to God

- Confining the disabled relative at home to avoid accident. Sometimes this is a strategy aimed at hiding the person from the curious public.

Women and youth with disability

Women

The study established that women with disability are doubly disadvantaged in Busia like in other parts of Uganda. They are disadvantaged because they are first of all disabled and then, as women, are culturally and socially oppressed and exploited.

Socially and culturally domestic chores are primarily the responsibility of a woman. Women are expected to work in the garden, fetch water, look for firewood, cook, and generally look after the family. Moderately to severely disabled women experience serious limitations in fulfilling these roles, hence they find it very difficult to get men to marry them.

The key informants and the FGDs with PWDs confirmed findings from else where (Nganwa etal 2004) that unscrupulous men use disabled women to gratify their (the men's) sexual desires. They would not like to be seen with their disabled lovers. Some of these men do not accept paternal responsibility for children borne with disabled women. Rejected children from such relationships are brought up by their disabled mothers single handed or with the assistance of relatives. No legal redress has been possible because the women feel happy they have children and are ready to be secret lovers.

Most disabled women contacted by the survey were unemployed and could not be expected to get easily employed in the formal sector due to lack of education and skills training. It was reported in the FGDs with PWDs that prejudice contributed to low employment rates among PWDs. A few disabled women who try to start IGAs fail due to limited capital and lack of experience and skills.

It was also found that their participation in mainstream economic and social activities was minimal. None of the disabled women met in the survey are in executive positions even in the disability groups. Most of the positions and posts were occupied by men and women only played marginal roles. Disabled women's participation in mainstream groups formed for developmental purposes such as "sweet mutual groups", farmers' clubs, PMA groups and FINDWA are minimal. This could be attributed to feelings of inferiority and low self esteem among disabled women.

Youth

The study revealed that disabled youth experience a number of obstacles and challenges that limit their potential:

Many are not educated. A good number of those who have had the opportunity to go to school have not succeeded beyond primary school due to lack of fees, absence of teachers with special education background in post primary schools, inaccessibility of the physical environment in schools and distance to schools. In the same vein the youth do not possess the minimal admission qualification for vocational institutions, i.e. O-level. Having had no training, the majority of them find it extremely difficult to get employed in the formal sector.

Several youth with mild to moderate motor disability are involved in the cross border trade. However these are the minority who have tricycles. In rural parts of the district disabled young men and women experience the same conditions of unemployment and dependence as their adult counterparts. Women are especially vulnerable as they find ti difficult to leave homesteads.

Beliefs and practices concerning disability and disabled people

Data on attitudes, beliefs and practices relating to disability and PWDs was obtained in both questionnaire responses and focus group discussions (especially of CDAs and CDOs). Focus group discussions and interviews, in spite of in depth probing failed to generate information that implied negative attitudes. The overall impression created is that in Busia communities on the whole have positive attitudes towards PWDs However, there a few exceptional divergent views that emerged and should be noted:

- That PWDs are none performers who need to be helped:

  "PWDs are seen as people who are unable to perform anything" ***(Non disabled caregiver)***

- That disability is contagious:

  "If you eat or share utensils with epileptic persons or those affected by leprosy you can easily contract the disease"

  "Do not skip the urine of an epileptic person, you will get the disease" ***(Non disabled participant, in Busia Town)***

- People believe that disability is inherited from parents

  "Some people believe that if you marry a disabled person you risk producing a disabled child" ***(CDA/CDO FGD)***

- That disability is caused by God as a punishment or curse.

  "PWDs are regarded as God cursed" ***(SNECO)***

- People make fun of the deaf:

  "People think I am stupid and stubborn" ***(Busitema deaf person)***

- The perception that PWDs short tempered is common in the community

Functional limitation and dependence

Many PWDs met during the survey had moderate to severe disabilities that affected their functional abilities. Participants reported that PWDs, owing to their functional limitation relied on other people for support. Disabled people's low activity performance was seen to be compounded by an inaccessible environment and lack of appropriate assistive devices. Some PWDs had assistive devices that they had outgrown or were worn out, limiting independence.

Communication barriers

PWDs encountered difficulty in interacting and participating in social activities due to communication barriers. The most affected disability group was the deaf and to a less extent the blind. Generally it was observed that communication and interaction between the deaf and other people was restricted due to the fact that most people, including the deaf, are not sign language literate. Lack of a medium of communication posed challenges for the deaf:

a) Sometimes gestures are misinterpreted by both the hearing and the deaf

b) People, especially the children, often make fun of them

c) The affected persons feel inferior and may withdraw from social contact

d) The hearing peers may isolate the deaf person

e) The inability to communicate in an understandable way has led to abusive nick-names

Communication challenges for the blind are related to inability to see and read print.

EDUCATION AND SPORTS SECTOR

Four sources were utilised to obtain data on the education and sports sector:

a) Officials in the district education department: the District Education Officer (DEO) and the Inspector of Schools (DIS) in charge of SNE, through an in depth interview jointly held with them.
b) A focus group discussion with Special Needs Education Co-ordinators (SNECOs).
c) Documentary analysis of both Busia and national reports.
d) Interviews with disabled people.

The following findings emerged:

Management of the education and sports sector

The education and sports sector is headed by the District Education Officer. Below him education officers different responsibilities and roles; the district inspectors of schools (who oversee the standard of educational provision and ensure that quality is maintained), the heads of school (who manage the day to day teaching and learning activities in the school), the teachers (who in contact with the pupils facilitate learning) and, in the context of SNE, the SNECOs (who provide specialist support to regular teachers in the area of SNE).

It revealed that the capacity of the District Education Department to adequately and efficiently monitor and supervise educational activities in the district is undermined by the low funding levels from the central government.

Mainstream educational provision in the district

To appraise the efficacy of the educational service delivery for disabled and other disadvantaged children and youth in the district the study deemed it necessary to examine current mainstream educational provision. The universal primary education policy stipulates that education for disabled children should as much as possible be within the mainstream educational provision. Thus massive enrolments registered in schools included unprecedented big numbers of children with diverse disabilities and special needs.

District Education Management Information System

The education department has a management education system that gathers data needed for planning purposes and service delivery. The data generated is on pupil enrolment, number of teachers, and demographic information of children including those with disabilities. However the data, which is basically quantitative, does not give an adequate qualitative analysis of the situation.

Primary school enrolment

The survey could not establish the current enrolment of pupils in primary schools. However the 2001/2002 figures show that 78,069 pupils of the 80,876 school age children (6-17yrs) had been admitted in schools. By 2004 this number had slightly dropped to 74,243 (see Table... below).

Table 5: Primary school enrolment:

	2000	2001	July 2002	Nov. 2003	2004
Boys	32,991	35,821	39,801	40,331	37,790
Girls	34,337	37,284	38,268	37,851	36,453
Sub-Total	**67,328**	**73,105**	**78,069**	**78,182**	**74,243**

Source: Busia District Education Department, 2004.

Educational institutions in the district

The numbers of children admitted in schools following the start of UPE was overwhelmed the existing schools all over the country. However, over the years government has been building capacity and many classroom blocks have been set up. Nevertheless, in spite of this the study established that the existing schools and classrooms are not yet enough.

According to the Busia District Development Plan for the period 2005 – 2008 by 2004 there were 116 government aided primary schools, 18 private primary schools, 10 government-aided secondary schools and 21 private secondary schools in the district as in the table below:

Table 6: The District has the following Educational Institutions:

Institution	Government	Private	Total
Nursery School	0	12	**12**
Primary School	116	18	**134**
Secondary School	10	21	**31**
Primary Teachers College	01	-	**01**
Technical Institutions	01	-	**01**
National agric. Colleges	01	-	**01**
Community Schools	Not applicable	Not applicable	**12**
Technical Schools	01	-	**01**

Source: Busia District Education Department, December 2004

Classroom and desk-pupil ratio

The classroom: pupil ratio in the period 2004/2005 was reported to be 1: 95 (see Table 7 below) which is too high considering that the relevant government guidelines recommend a ratio of 1:54. Currently the district capacity is at 773 classrooms for 73,291 pupils who have been enrolled. The District therefore requires 1,375 more permanent classrooms to cope with the high pupil enrolment. In the same vein the district estimated that an additional number of 14,864 three-seater desks would be needed to accommodate all the enrolled children.

Table 7: Key Education statistics to pupil ratios

Indicator	2001/2002		2002/2003		2003/2004		2004/2005	
	Number	Ratio	Number	Ratio	No.	Ratio	No.	Ratio
Classroom	548	1:128	690	1:113	931	1:80	773	1:95
Desk	10,008	1:8	13,328		14,449	1:5	10900	1:7
School going children	78,069		78,182			74,143	73291	
School age children (Estimate) 6-17yrs	80,876		85,182					
Children out of school (Estimate)	2,347							
Teachers								

(Busia District Education Department, December 2004).

The findings showed that the teacher–pupil ratio in the period 2004 – 2005 was estimated to be between 70 and 90 pupils per teacher (with high numbers registered in lower classes). This is over and above the official 1: 50 figure recommended by government for primary schools.

It should be noted that when the teacher – pupil ratio is too high to effective teaching suffers as it becomes extremely difficult for a teacher to attend to the learning needs of individual learners. In this learners with special learning needs are always the most disadvantaged.

Educational provision for disabled children

Due to the affirmative stance taken toward disabled children in the UPE programme high enrolment rates of children with diverse disabilities and learning needs have been registered in government aided primary schools throughout the district. According to the District Education Management Information System obtained from the district education office, there were 2,430 children with diverse disabilities and educational needs attending mainstream schools in Busia (see Table below).

Table 8: Children with Disabilities/Special needs

	1997	1998	1999	2000	2001	2002	2003	2004	2005
Visual Impairment	21	47	205	342	281	342	634	607	503
Hearing Impairment	17	101	360	514	466	514	743	716	632
Mental Retardation	35	52	107	206	209	206	819	754	680
Physical disability	13	42	71	93	145	93	532	460	453
Others								104	158
Total	**86**	**242**	**743**	**1155**	**1011**	**1155**	**2728**	**2731**	**2430**

(Source: EMIS Busia, 2005)

From the table the highest number of CWDs at school are HI and MR followed by VI. It is worthy noting that of the four major disability categories physical has the lowest number attending. Probably is indicative of the reduced incidence rates in this category which may be attributed to the significant reduction in incidence of disability due to the government programme for eradication of polio. There is a possibility of bundling some children with motor impairment among with mentally retarded such as those with CP.

Secondly there was a sharp increase in the enrolment rates in all disability groups from 1998 to 2000. However a significant decline is noticed in the years 2004-05. Probably this could be due to reluctance on the part parents/carers to take the children to school and/or schools to admit the children. Another explanation for the decline is the high drop out rate.

The study established that many disabled children were dropping out due to a number of reasons. First many children especially those with mobility difficulties could not cope with the long distance to school – a problem aggravated by lack of appropriate assistive mobility aids, and parents/carers not having means and time of/for dropping and picking them from school. Secondly children, especially those with sensory impairments, do not receive appropriate educational service due to absence of teachers with special needs education background and the requisite educational materials like Braille equipment in schools. Big numbers of children in a class makes it difficult for teachers to attend to slow learners. Thirdly inaccessible and un-adapted school environments and infrastructure may have also forced the children out of school.

It was also reported that some parents generally reluctant to take their disabled children to school. Depending on the degree of disability parents think the children will never be of use in future whatever education they acquire. Besides they feel their children are not

being attended to in schools. Hence they think it is not worthy to spend resources on their education.

Findings further indicate that there is a tendency by the district education office to put emphasis on academic standards as a yardstick for judging a school's performance. This has contributed to some head teachers' reluctance to admit children with special learning needs whom they think will lower the general academic standard of the school.

District capacity for implementation of inclusive education

The study established that children with special needs are free to enrol in the neighbourhood school. Even before UPE enforced inclusive education integration of children with motor impairment (without intellectual deficits) and those with mild sensory impairment in mainstream primary schools had been going on in the district. Notwithstanding this, the challenges experienced in meeting the special educational needs of children like the blind, the deaf and children with intellectual deficits (mentally retarded) require special support and resources.

Currently there are 39 teachers in the district with qualification in SNE who, as classroom teachers or SNECOs should be in position to provide educational service. However they are not fairly distributed in the district are not necessarily working directly as classroom teachers. In addition the DEO the DIS in charge of special needs education reported that this was number was not enough.

Disabled children and accessibility challenges

The UPE policy stipulates that children should be admitted in the neighbourhood school. Although it was reported 89% of the children are within a radius of less than 2km from a primary school (DREPS March 2000), this distance is too long for physically disabled children.

The study established that accessibility challenges affecting children with disabilities vary with disability categories as indicated in the table below.

Table 9: Accessibility challenges encountered in schools

Disability category	Theme	Sub-theme
Motor	Physical accessibility	Difficulty experienced in: - entering and moving within classrooms - sitting on the desks - entering and using latrines - moving around the uneven and rough compounds - walking long distances to schools

Hearing	Communication	Experience - Difficulties communicating with teachers and peers - Accidents – sometimes knocked down by cyclists on their way to and fro school.
Visual	Physical accessibility	Difficulty experienced in: - entering and moving within classrooms; - entering and using latrines - mobility and orientation in school compound

Data in the table above suggests that the most obvious difficulties affecting disabled children access to education are related to physical accessibility. The most affected disability groups are those with motor disability and the visually impaired. The deaf experience challenges associated with communication as they can't speak. The use of sign language is limited as both the children and the school community are not sign language literate. The other challenge cited in connection with deaf children was their vulnerability to being knocked down by cyclists.

Sanitary situation in primary schools and accessibility challenges

The number of pit latrines in primary schools had gone up as a result of the school facilitation grant (SFG) released by the central government to support UPE. Notwithstanding this, however, the number is still below what is required. Whereas the recommended ratio of pit latrine to pupil is 1: 25, the statistics show that a pit latrine is shared by 54 boys or 68 girls. (See Table 10 below). Offset the short fall the district requires 1636 more latrines.

Table 10: Number of Pit latrine stances

	2002/03 inclusive of planned		**2003/2004 inclusive planned**		**2004/2005 inclusive planned**	
	Number	Ratio	Number	Ratio	Number	Ratio
Boys	590				688	1:54
Girls	724				535	1:68
Total	1314	1339	1339	79	1223	1:60

(Source: Busia District Education Department, 2004).

Accessibility of pit latrines to children with disabilities

Although the SFG guidelines clearly stipulate that the physical structures constructed using the fund should be disability user friendly, it was revealed that many latrines in schools were not adapted for use by disabled children especially those with severe motor

disabilities and visual impairment. Most pit latrines have ramps for children with severe motor disabilities but they lack support frames within for the users to hold on while squatting or when they want to get off the pit hole. Moreover it was observed that it is difficult for schools to regularly ensure the proper and adequate hygienic conditions.

Special needs education provision

Administration

Special needs education is a section headed by District Inspector of Schools (DIS) in charge of special needs education. The roles of the DIS, on top of the regular schedules assigned by the DEO, are:

- Assessing and carrying out appropriate school placement of children with special needs
- Training and support supervision to SNECOs and teachers in the area of SNE
- Arranging and carrying out outreach and home based programmes
- Planning and laying strategies for implementation of SNE activities
- Evaluating special needs educational activities in the district

The study established that the DIS encountered a number of challenges in executing the roles and responsibilities related to SNE. Prior to the restructuring exercise the above responsibilities were shared by three SNE officers. However the exercise left only one officer (DIS) to shoulder the responsibilities. Secondly the SNE section is under financed making it difficult to implement SNE specific activities such as outreach and home-based programmes.

SNE funding situation

Special needs education activities have been integrated into mainstream education activities. Even then service delivery is undermined by budgetary constraints. The special needs education vote is very minimal. For example in the 2005/06 financial year of the 1.229 billions allocated to the education sector by district only 200,000= was earmarked for SNE activities. Even then this amount was not released. Consequently little was done in the direction of educational service delivery to children with special needs. There is need for the district to give more support to SNE activities.

SNE infrastructure

The SNE section has an office block with an assessment and resource room. Assessment resource is an important facility for special needs education provision – it is for purposes of assessing the children's special educational needs as a prerequisite for appropriate school placement. However the study indicated that the facility is not functional. The assessment equipment is kept away and the room turned into an office space – implying that formal SNE assessment at the district is almost not there. This lack of formal assessment coupled with the limited outreach activities poses a challenge to appropriate school placement.

The section has a vehicle in good running condition but difficulties are experienced in fuelling it; thus undermining further the ability to implement outreach activities.

Special and Integrated schools

There are no special schools in Busia. However, the district has two integrated primary schools: Busia Integrated with a unit for visually impaired children and Bukwekwe Busia Integrated (day) primary school. By the time of the study there were 44 children with special needs (visual impairment =13, hearing impairment =13, physical disability =9, and other conditions =9) and two teachers with diploma qualifications in special needs education. Bukwekwe Primary School on the other hand had 5 children with disabilities (visual impairment =1; hearing impairment =1; physical impairment =3) with only trained SNE teacher. Despite their existence these schools have generally low capacity to provide appropriate and adequate educational service to the children in terms of educational materials, equipment and staffing.

The implication of having no special schools and only a few ill-equipped integrated schools is that the majority of children who absorbed in the integrated schools and cannot benefit from inclusive schooling are out of school.

A few parents have sought appropriate placement for their children in special schools outside the district, namely Ngora School for the Deaf (Kumi District), Madera School for the Blind (Soroti District), Buckley High (for the blind and deafblind), Agururu Primary School (Tororo District) and in schools across the border (in Kenya). It was observed, however, that parents suffer the burden of the high cost of fees, transport and upkeep of their children in the schools. For this reason many of the children have dropped out.

SNE teachers

Currently 39 SNE qualified teachers are serving in the district in various schools in different capacities. The staffing position is expected to improve further when more teachers pursuing studies in the related area with Kyambogo University graduate.

Assuming that all the SNE teachers in the district were equitably distributed among the 116 primary schools, the SNE teacher: school ratio would stand at 0:3 which points to the need to have more SNE teachers trained and deployed throughout the district.

Special Needs Education Coordinators (SNECOs)

As a way of improving SNE service provision to learners with special needs the Ministry of Education and Sports conceived and implemented the idea of special needs education coordinating teachers (SNECOs). Some primary school teachers were selected throughout and equipped basic knowledge and skills in SNE. The role of SNECOs is to

identify children with special needs, make educational and medical referrals for those in need, train regular teachers in schools in their respective clusters, sensitise parents and communities and other stakeholders on special needs and special education on top of executing their normal duty schedules at school.

There are nine SNECOs in the district. However the findings of the survey indicate that they were not performing their roles as expected. The SNECOs attributed this to a number of constraints:

- Their numerically thin on the ground. At the moment one SNECOs is charged with serving a whole sub-county with schools sparsely scattered. Although in the past they were facilitated with bicycles each, they are no longer in running condition due to lack of maintenance.

- Secondly they do not receive enough support supervision from the district education office. This deprives them of the opportunity for feedback and hence get demoralised.

- Officially SNECOs are supposed to given light teaching loads to enable them effectively dispense with their responsibilities. However this is not the case as they are tied down to heavy classroom teaching and often not allowed by their respective head teachers to visit other schools and community on sensitisation campaigns.

- There are no longer regular refreshers courses aimed at strengthening their capacity to execute their roles.

- Schools lack the basic learning and teaching materials and hence SNECOs it difficult to teach and basic assessment of learners with impairments and special needs.

Support personnel

Implementation of special needs education requires the involvement of a number of professionals and support personnel to meet the unique and diverse special needs of the learners. The district does not have support staff such as psychologists. The survey learnt that there were two teachers who are skilled in sign language in the district. However it was not clear from the data as to how these teachers are utilised. Visually impaired children may require the services of sighted guides. These were not available. It was apparent that this service was being offered by either parents/caregivers or the children's peers who did not have the basic skills in offering guiding service.

SNE materials

It was reported that the district is in dire need of educational materials necessary for teaching and learning of children with special needs such as Braille kits, Perkins Braille machine and paper for children with visual impairment. Coupled with lack of SNE teachers this problem has made teaching of science, mathematics and geography subjects very difficult for blind children.

DIRECTORATE OF HEALTH SERVICES

Data on the health sector was solicited through in-depth interviews with key health officials in the district, interviews of disabled leaders, FGDs with disabled persons and document analysis. The following is a summary of the findings.

Health facilities

Currently the district offers preventive and curative health care services to 'in' and 'out' patients, antenatal and post natal, family planning, dental, psychiatric, ENT services and other clinical services. However the capacity of the district to provide health services is still low. A number of factors were cited. These include inadequate funding, an undeveloped infrastructure, low staffing levels, and low staff morale.

Number and distribution of Health units

The district does not have a hospital but has 24 health centres as in the Table 11 below:

Table 11: Health Centres and their Distribution

Sub county	**No. of Health centres**	**Remarks**
1. Busia Town council	1 H/C 4	
2. Bulumbi	4	2 not functioning
3. Busitema	3	
4. Buteba	2	
5. Dabani	2	1 under NGO management
6. Masafu	2	? One is Health Centre 4
7. Masaba	1	
8. Lumino	4	1 not functioning 1 under management of a Catholic NGO
9. Lunyo	3	1 not functioning
10?Buhehe		
Total	**24**	Only 21 Health Centres are functional

Staffing

- Staffing positions are 54% filled
- There are no physiotherapists, occupational therapists, Ear nose and throat clinical officers.
- However the district has one (1) orthopaedic officer and one (1) psychiatric clinical officer both stationed in Masafu Health Centre(HC) IV and one ophthalmic clinical officer(OCO) based in the office of the District Director of Health services.
- The majority of the health workers have not had any training in disability work.
- The deputy DDHS acts as the focal point person for disability.

Common health problems

The District has a high incidence and prevalence of malaria, acute respiratory infections, diarrhoeal diseases, intestinal infections, HIV/AIDS, epilepsy and skin, ear, and eye infections. As a result of the high prevalence of communicable diseases, disability rates from these conditions are high. The focal person suspected that the big numbers of person with epilepsy could be due to the high incidence of malaria.

Medical rehabilitation services

- There are no specialized services for rehabilitation. Services are obtained through referrals to districts with facilities/services and outreach services extended to some parts of the district by rehabilitation programmes in Mbale and Tororo districts.

- Although there are two operation theatres one at Masafu HC IV and another at Dabani HC IV they are only used for minor surgical operations. The district does not have a hospital but depnds on Mbale and Tororo for hospital care.

- There is a psychiatric officer who offers services to epileptic persons at Masafu. There are also private practitioners offering epilepsy related services.

- Two clinical officers trained and equipped by Ministry of Health to do minor ENT services. However they are not active in primary ear care as they are deployed in out patient departments and attend to patients with ear diseases who happen to reach the Out patient department.

Promotive/preventive services

Busia District is highly ranked in promotive/preventive service provision in the country. Home hygiene and sanitation improvement campaigns are conducted door to door. Other promotive services are immunization, health education, school health and HIV/AIDS awareness programs. However, these services do not specifically target PWDs.

Health sector and disability

DDHS is a member on the District Council for Disability. However, by time of this survey the health sector did not have plans specifically addressing service delivery for PWDs. For example there was no budgetary allocation for assistive devices and adapting the physical infrastructure for disabled patients. Notwithstanding, the sector, with support from t he CBR programme, hoped to conduct awareness workshops among the health workers about the needs of PWDs and how to improve service delivery for them.

Challenges

General

- Health services are 'free' but inadequate.
- Low funding. In the 2004/05 financial year the sector was allocated only 170 million shillings for drugs and medical supplies, implying a per capita figure of 700/= for health services!
- Specialized services are expensive and beyond what many PWDs can afford.
- Medical staff too few to effectively provide service.
- Low morale among staff leading due to poor terms and conditions of service leading to high turn over rates.
- Poor and inadequate infrastructure. The roads are generally poor, the district does not have adequate vehicles to support outreach services. The district does not have an ambulance van.

Challenges specific to disability related services

- There are no medical rehabilitation services in the district. PWDs incur high costs accessing referral services in near by districts.
- Health personnel are not Sign language literate, so they encounter difficulties in providing services to deaf patients.
- Infrastructure in health facilities is not designed to meet needs of some PWDs. Some facilities in health centres need to be adapted for PWDs' use. For example the foot paths require levelling, and delivery beds and latrines need to be adapted.

DISABILITY WORK AND PLANNING

Planning in the district is a two-way process: top-down and bottom-up. Under the top-down process the Ministry of Finance and Economic Development issues districts with the government priority areas for the financial year to guide planning at the district and lower levels. It also allocates the resource entitlement. The ministry mentors the districts which in turn mentors their lower local governments.

Bottom-up planning
According to the Local Government Act ... the bottom-up planning is supposed to start at the village level, then to the parish, sub-county and end at the district.

Village level
Community members in the village, including the disabled and their families, identify and discuss their problems and needs of the area and available resources.

Parish level
Proposals from various villages in the parish are presented in the relevant parish council meetings where they are sifted through and prioritized further. New areas for planning can emerge at this stage. The parish council is constituted by all village executives (LC I). People with disability are represented by two councillors on each village executive committee. PWDs councillors at this level are expected to articulate, defend and advance the needs of their constituents.

Sub-county level
The sub-county is the basic power centre in the local government administrative arrangement. As such planning decisions taken at this level stand a better chance for implementation because the resource envelope for the sub-county is located here. Fresh proposals from parishes and other proposals rolled over from the previous financial year; and priorities that may have been conceived at the sub-county level will be scrutinized and passed or shelved for consideration in future depending on the size of the resource envelope. Again at this level PWDs are represented.

District level
Before implementation successful proposals are forwarded to the District Council which is the planning authority in the district. The Planning Council solicits planning ideas and feeds them to the Planning Unit so as to formulate the development plan for the district. The concerns of PWDs are expected to be catered for by two council representatives for PWDs.

Representation of PWDs needs and concerns in planning

(i) In spite of having representatives in all the above planning structures, PWDs' needs and concerns are not always reflected among budgeted priorities especially

from sub-county to lower levels. There is plenty of evidence in the survey data that PWDs' representatives on committees often fail to articulate concerns of their members:

> *"Our representatives do not air our concerns. They mind their personal benefits from the committees. Some of them do not have a strong educational background, so they are easily overwhelmed by the other members of the committees."*

> *"Some PWDs □ouncillors do not possess good communication, lobbying and advocacy skills. They therefore fail to convince others and so they give up."*

(ii) Getting disability issues on the planning agenda is sometimes difficult because they are not considered a priority but rather minority concerns which could be considered in case there are surpluses from funds allocated to other areas. There is also a perception that PWDs are after all part of the community and hence expected to benefit from mainstream services.

(iii) Some participants observed that PWDs sometimes do not receive information pertaining to planning meetings. But even when aware, they are often reluctant to attend citing reasons such lack transport or that the programmes to be for do not specifically target them.

(iv) Sometimes PWDs' deeply felt needs like for assistive devices and poverty do not filter through at parish and higher levels as they are not considered priority areas. People at these levels tend to focus on needs affecting bigger sections of the population. Given the fact that community development officers (CDOs) and their assistants, key service providers in the area of disability, are represented on Technical Planning Committees at sub county and district levels and are in charge of organizing the bottom-up planning one would expect disability issues would feature on the planning agenda. On the contrary findings of this survey indicate that the opposite. Some study participants attributed this shortcoming on the lean resource envelope in the district.

(v) Absence of reliable disability related demographic data in the district does not help matters as the- would- be advocates for disability sensitive planning do not have reasonable grounds for advocacy and lobbying.

Budgetary allocations to disability work

Busia District, at the time of this survey had not developed policies and/or by-laws pertaining to disability service provision. Service delivery for PWDs was reported to be guided by national legislation and policies such as the Uganda Constitution, Local Act, Children Statute, the Disability Policy, the UPE policy, PMA guidelines among others. It was difficult to establish the magnitude of funding targeting disability work because

being part of the mainstream PWDs were reported to receive services like every body else. However the survey findings highlighted the followings:

- Some PWDs and their families are benefiting from developmental programmes such as PMA through training, advisory support, getting agricultural in puts like seedlings besides being helped to start income generating activities like livestock and poultry keeping.
- Educational support to some disabled children and youth disabilities in schools and vocational training centres (within and outside the district) through bursary scheme.
- PWDs are entitled to mainstream programmes and services in community development, health, education, etc.
- Through the production department (Fisheries, Entomology, Agric, Vet,) the district had earmarked 17 million shillings for PWD.
- Officially the district and sub-counties have a vote for disability activities. However it is too meagre and rarely released.

Despite being a relatively new district considerable achievement has been realized in the in the area of disability service delivery. This is attested to by winning the second best National Disability Award in 2000 by the Rotary Club of Kampala which is offered in recognition of exemplary service to PWDs.

GENDER AND COMMUNITY SERVICES

The sector is composed of a number of departments, namely, Community Welfare, Youth and Child Affairs, Social Rehabilitation, Probation Services and Gender. Its overall aim is to improve the wellbeing of women, children, youth, the elderly and the disabled members of community. This is done in conjunction with development partners in the social and economic development.

Staffing

At the managerial level the sector is poorly staffed at the district headquarters. Ideally each of the five sections should have a head. But at the time of this survey only two positions: the Community Development Officer and the Probation and Welfare Officer were filled. The two officers were therefore shouldering the responsibilities of the other sections, which certainly was an overload on them.

Each sub-county has an assistant community development officer whose responsibilities are to mobilize the community for development, coordinate planning at the sub-county and lower levels and to implement CBR programme activities.

Sub-county

At the sub-county level activities and affairs of the departments under gender and community services sector are managed by an ACDO. The thin staffing on the ground causes inefficiency due to an overload. In addition to the low staffing, there is a tendency

for the officer to concentrate on programmes that are well facilitated thus marginalising low funded programmes such as the disability programme.

Transport

Only two ACDOs have motorcycles: the Lumino sub-county and Town council ACDOs. Absence of suitable transport facilitation hinders mobilization work and breeds a tendency to concentrate in nearby areas at the expense of distant places. As a management strategy the ACDOs often rely on sub-county chiefs to carry out mobilization on their behalf.

Training

Only two CDAs in Busia district received training in COMBRA: Lumino and Buhehe sub-county chiefs (Senior Administrative Secretary).

Functional Adult Literacy programme

The Department implements adult literacy programmes in all Sub-Counties. To date 157 FAL classes, run by 150 FAL instructors, have been established. There are currently 3389 Adult learners district wide. The programme has lowered the literacy level and helped to enhance self-esteem for many adult participants.

Analysis of some respondents' views showed that the programme was beset by a number of challenges. When the programme started some people had high expectations such as the programme supporting them to start income generating activities. When this did not happen they were demoralized. Then programme attendants were promised certificates which the programme failed to award.

In addition the survey established that few PWDs are participating in the programme. A number of reasons were given for this. First, the programme does not cater for the training and learning needs of the blind and deaf persons. The instructors are not sign language and Braille literate yet the programme has no provision for hiring services of support personnel like sign language interpreters and sighted guides for the deaf and blind learners, respectively. Secondly all the training materials are in print so the blind do not benefit. Thirdly persons with mobility difficulties find it difficult to travel to training venues. Fourthly some PWDs have low expectations from the programme believing it to benefit able-bodied people mainly. Finally certain categories of PWDs, such as those affected by epilepsy and leprosy, are rejected by able-bodied participants. All these factors combine to work against the involvement of PWDs in the programme.

International agencies, NGOs and/or CBOs

Existence of International agencies, NGOs/CBOs in a district is important for development and service delivery in a district because they close service delivery gaps and lead to improvement in the quality of life. According to the DDP 2005-2008 there are 100 registered NGOs/CBOs (which are mainly indigenous) and a number of international agencies supporting programmes in certain critical development areas. None of these NGOs

specifically tearget disabled people but embrace them as part of the vast vulnerable group which can lead to less attention to their needs.

Among the **international agencies** are the following:

a) UNICEF – targeting education sector
b) DANIDA - rural development through improving access to water and road maintenance
c) European Development Fund (EDF) - community development

The **international NGOs** include:

a) Africa 2000 – Community development
b) Friends of Christ Revival Ministries (FOCREV) – HIV/AIDS, nutrition
c) Christian Children Fund (CCF) – Education, community development, health and sanitation
d) European Development Fund (EDF) – Community Development
e) Compassion International – Educational training and guidance
f) Deed Project (Germany) –
g) Action on Disability and Development

Among the indigenous NGOs/CBOs in Busia District are:

- Uganda Red Cross – Safety, disaster and relief services
- Hope Case Foundation – girl child education, guidance and counselling
- Youth Alive Club -
- Deed Project (Germany) -
- Busia Rural Development Association (BURUDA) – community development
- Busia District Farmers' Association (BUDIFA) – agriculture
- Uganda Youth Development Link (UYDEL) – combating drug and substance abuse
- Child Abuse and Labour Initiative – Child rights and protection
- Busia Women and Youth anti AIDS Club – Health
- Busia Strive Youth Club - Health
- Busia District Union of PWDs (BUDUPD) – Disability work

Constraints

NGO/CBOs are beset by a number of challenges/constraints which limit their capacity to deliver services to the community:

- Indigenous NGOs)'s sources of funding are limited, inadequate and unpredictable
- Their coverage geographical coverage is limited to…

- Apart from disabled people's organizations (DPOs) most of the NGOs/CBOs do not specifically target disability work. However PWDs are free to access the services they offer in the mainstream society.

Disabled People's Organisations (DPOs)

There are four main types of DPOs in Busia: Umbrella (BUDUPD), uni-disability (Busia District Association of the blind and Busia District Association of the Deaf), unisex disability organisation (Busia District Union of Women with Disabilities) and multi-disability organisations.

Busia District Union of Persons with Disabilities

This is the umbrella organisation of PWDs in the district. Being the branch of NUDIPU all DPOs in the district are its affiliates. The organisation has branches in all sub-counties.

At the district BUDUPD has an executive committee, an administrative assistant, a secretary and a rider. The organisation is equipped with a computer, printer, and motor cycle.

The functions of BUDUPD are:

- Mobilisation of PWDs through their respective associations
- Facilitate the formation of PWDs' associations at all levels
- Lobbying and advocacy with local authorities, NGOs/CBOs and other development agencies in and outside the district
- Economic empowerment through training PWDs in saving and IGAs, loan schemes and encouraging members to access mainstream development programmes and services e.g. NAADS.
- Visiting schools to assess the educational provision for disabled children and advise and advocate or lobby for services if necessary.
- Working to mainstream disability issues. For example they succeeded in getting PWDs representation in the Private Sector Promotion Centre.
- Organise training for their members in the areas of health, leadership, group dynamics, IGAs etc.
- Resource mobilisation and fundraising
- Obtain assistive devices for its members from organisations and donor agencies

The district has allocated a plot of land for construction of the organisation's office block within Busia Town.

Challenges

- Low funding. The organisation relies on funding from Action on Disability and Development (ADD), NUDIPU, DED (Deutscher Entwicklungs dienst) and the district local government. However this support is often too little compared to the

needs. Consequently the organisation is able to support only a few of its affiliated DPOs/CBOs members.

- Lack of telephone services and there is no reliable means of transport making it difficult to link up with members in the countryside.

- Being sign language illiterate makes it difficult to communicate and interact with their deaf members.

Single disability organisations

There are two such organisations: Busia District Association for the Deaf and Busia District Association for the Blind, which are the district branches of UNAD and UNAB respectively. Being newly established in the district they had little impact in the district. They have put in executive committees and have embarked on training some of their members.

Busia District Union of Women with Disabilities

This is a newly established disabled women's organisation affiliated to the National Union of Women with Disabilities in Uganda. The organisation has an executive committee. It has carried out training of some of its members in reproductive healthy and HIV/AIDS.

Multi-disability organisations

Membership to these organisations is open to all disability categories and in certain cases a disabled person's caregiver may be included. There are many such organisations spread throughout the district. The main reasons these organisations are formed are to start income generating activities, to gain access to grants and loans and to qualify for support from government and NGOs which require that beneficiaries should be organised in groups before benefiting.

Characteristics

- The majority of multi-disability DPOs have membership that does not exceed 15 PWDs of all ages. The distances between PWDs' homes and lack of transport and suitable mobility aids restricts the membership to only those PWDs near the location of the organisation.

- The majority of DPOs have developmental interests in agriculture (cultivation and poultry keeping). Other organisations depending on the skills of members are involved in other activities such as carpentry and shoe repair. It is common to find DPOs with diverse IGAs.

- The DPOs' activities often depend on funding external to the organisation in order to establish them. Without funds little goes on – and indeed most DPOs' are active when funded.

- Many are not well organised due to illiteracy and lack of organisational skills. None of the two DPOs visited during the survey had records on their programmes and activities. In one of the organisations that appeared better efficiently run the achievements were more of the Chairman's personal effort than the collective membership of the association. In this organisation the chairman doubles also as the secretary.

Challenges

- It is difficult to mobilise members due to distances and inaccessibility of the rural countryside
- Participation of members in group/association activities is often restricted by mobility difficulties.
- Some members are reluctant to attend meetings if no there is no financial or material gain is anticipated
- It was observed that representation of women with disability, the deaf, the blind, and the mentally retarded in the DPOs is very low.
- Due to little funding activities by DPOs often yield little profit and have a short life span.
- The high levels of poverty in the countryside especially among disabled people undermine the associations' ability to invest and sustain their organisations' activities

PWDs representatives

PWDs are represented in all local councils right from the district down to village councils by male and female PWDs. As representatives of PWDs they are expected to voice the needs and concerns of their members so that they are taken care of in planning, budgeting and service delivery.

The survey observed that the effectiveness and impact of PWDs representation decreases as one moves from district down to lower local council structures. This was attributed to the low educational attainment and inability to articulate disabled peoples' concerns at lower levels. LV V and to some extent LCIII councillors representing PWDs had succeeded in getting funding for activities for PWDs such as school bursaries and celebrations of World Disability Day. The team did not find evidence or examples of LC II or I levels representation gaining on the funds allocated to these levels.
The need to lobby at lower levels of the Governance ladder is important because the results will affect many more PWDs and in a way that affects their every day life.

Disability councils

District councils are established at district and sub-county levels. Among their functions are the following:

- To monitor and supervise government programmes to ensure that human rights issues are addressed
- To mainstream disability issues
- To lobby and advocate for PWDs' work

Composition

At district level the Disability Council is made up of the following members: DEO, DDHS, CDO, Chairperson, Social Services Sector, Representatives of NGOs and two PWDs Councillors who are ex-official. At the sub-county level, the council is made up of the Heads of sections, NGO representatives and the two PWDs councils.

Challenges

- Although the councils receive periodic financial allocations from the central government to enable them carry out their functions the funds are too low.
- Confusion of roles between disability councils on one hand and DPOs and PWDs councils on the other. Even some district service providers do not clearly understand the demarcations of the roles.
- In sub-counties they have generally not been received by PWDs who see them as usurpers of the role of the sub-county PWDs union. There is a tendency for PWDs to recognise more the union than the disability council.
-

Mainstreaming of disability issues in the district

The district has put in considerable effort to mainstream disability issues into district development. This has been guided by a number of national and international legislation and policies inform and guide mainstreaming of disability issues in the district. Among the outstanding of the national pronouncements are the Uganda Constitution, the Disability Policy, UPE Policy, Health Sector Policy, and NAADS Implementation Guidelines. In all these disability issues and PWDs' rights and participation are articulated. The survey established that the District Council in compliance with the national policies makes pro-disability resolutions aimed at mainstreaming disability issues and equalising opportunities for PWDs. Indicators of the mainstreaming strategies include the following:

- CBR steering committees have been established at district and sub-county levels. The committees are constituted by heads of sector and department and representatives of various disabled people' organisations. The presence of heads of sectors and department is to ensure that disabled people's needs are taken care of while planning for their sectors/departments.

- PWDs are represented on strategically important committees in terms of service provision, like the District Tender Board, Public Accounts Committee, and District Service Committee.
- Extant data reported that many PWDs, through their DPOs, were benefiting from mainstream development programmes such as PMA and LGDP. For example it was learnt that the PMA programme had provided several PWDs organisations with improved seeds, goats, chicken, pineapple suckers and cassava stems to improve their income generation. Some sub-counties extend financial support to DPOs in their jurisdiction to implement their activities.
- In the education sector mainstreaming has been pursued through promotion of inclusive education, and enforcing the Ministry of Education and Sports policy on accessibility of school structures.
- By policy PWDs or their carers are entitled to services and agricultural in puts offered by the Production Sector. The NAADS Revised Implementation Guidelines 2004/05 require that economically active PWDs are represented on the sub county farmers' forum. Furthermore PWDs, women and youth are represented on procurement committees. Depending on their abilities and interests some PWDs benefit from the sector programmes. For example in the LGDP Financial Year 2004/05 Buhenye PWDs Association received 2 piglets while Majaja PWD Association got 2 bee hives.

  However a number of challenges are encountered by extension workers in providing services to PWDs:

  - Lack of appropriate technology for PWDs; by virtue of their disabilities some PWDs cannot use certain tools and implements un-adapted.
  - The rampant poverty experienced by PWDs makes it impossible for them to implement what they learn in the NAADS training workshops.
  - Some PWDs do not attend meetings either due to long distances or because they lack mobility assistive devices
  - Some homes hide their disabled members even when they are targeted for affirmative action.
  - PWDs' representation at lower levels is weak. Often their needs and concerns are not brought to the attention of the extension workers.
  - Communication with the deaf is a big challenge. Communication through gestures and signs are not always effective.
  - Some PWDs are reluctant to join the non-disabled to benefit from these projects.

  The district is on the right track as far as mainstreaming of disability issues is concerned. This is attributed to the positive political will that has endeavoured to put disability issues on the agenda. The district needs to strengthen this achievement in order to sustain service provision for PWDs.

Vocational training

The district lacks vocational training institutions and facilities for disabled people. However, there are three government aided vocational training institutions (Busitema

National College for Mechanisation, Nalwire Technical School (Polytechnic) and Lumino Technical School) and a few private vocational schools, which not easily accessible to the disabled. Several factors restrict PWDs access to these training centres. First, most PWDs cannot afford the training fees. Secondly, instructors in these facilities are not trained to handle PWDs with specific special needs. Thirdly, the training equipment and physical facilities are not adapted for use by the disabled. Finally many PWDs lack the minimum academic qualifications required for admission into the institutions.

However, every year a few PWDs benefit from the district bursary scheme and the Ministry of Gender, Labour and Social Development arrangement to train in vocational institutions outside the district such as Lweza and Kireka rehabilitation centres. Unfortunately such opportunities are too few to satisfy the demand.

Local artisans

Many local artisans involved in diverse trades exist throughout the district. These include cobblers, carpenters and metal workers. The majority of the artisans were reported to be involved in making and repairing simple assistive devices such as shoes, crutches and walking sticks for PWDs. However, the majority do not specialist skills in designing and making appropriate assistive devices for the disabled.

Financial institutions

The financial institutions existing in the district include banks and micro finance institutions. There are two banks, namely, Stanbic Bank and Uganda Trust Bank. Microfinance institutions offer saving and lending services to individuals and mutual groups. The institutions include: Microfinance Union, FINCA (Uganda), and Rural Microfinance Money Lender.

The survey revealed that although microfinance institutions are open to all people they are reluctant to extend services to PWDs because they fear these may default in paying back. Secondly, PWDs often do not meet the qualification conditions and requirements for the loans. For example for one to secure a loan from some microfinance institutions he/she should be a member of a group where members should stand as surety to the person seeking the loan. Unfortunately many PWDs are reluctant to join mutual groups due to low self-esteem, passivity and discrimination by non disabled members of the groups. Thirdly, individually PWDs lack collateral for loans and others are discouraged to seek loans due to the high interests charged.

BUDUPD Microfinance Initiative

With the support of the Action for Disability and Development (ADD) the Busia District Union of People with Disability started a microfinance programme (of Shs.1.8 million) for its membership to enhance their economic and financial self-reliance. Sixteen groups

PROGRAMME/PROJECT	FOCUS OF PROGRAMME	TITLE OF VOLUNTEERS	VOLUNTEERS' FACILITATION
Africa 2000	Community development	Use volunteers of CCF and FOCREV	
Friends of Christ Revival Ministries (FOCREV)	HIV/AIDS, nutrition	Community volunteers	Given bicycles, T-shirts, meals and transport refund whenever they attend meetings
Christian Children Fund (CCF)	Education, community development, Health and sanitation	CCF volunteers	Transport and lunch allowance whenever they go out in the field, caps, T-shirts, given basic training, given support supervision, allowance, meals whenever they attend meetings
Special Needs Education (SNE)	Special needs education	SNECOs	Given training, given bicycles, supervision by EARS staff during support by DANIDA
Red Cross	Safety, disaster and relief services	Red Cross Coordinators	Caps, T-shirts, transport, receive training, supervised coordinator allowance.
Programme for Modernization of Agriculture (PMA)	Agriculture	Use local council representatives in conjunction with extension officers	Meals, goats, piglets, poultry, seeds and seedlings, fertilizers, given relevant training

PROGRAMME/PROJECT	FOCUS OF PROGRAMME	TITLE OF VOLUNTEERS	VOLUNTEERS' FACILITATION
European Development Fund (EDF)	Community Development	Community Development Committees (PICs)	Given books for record keeping, facilitation allowances, transport and lunch allowance whenever there is a meeting, caps, T-shirts, given basic training, given support supervision.
Disability and Development in communities' (DDC) programmes	Disability and development	Volunteers in disability and development	Given certificate and bicycles

As shown in the table above the fact that some programmes utilize volunteers implies existence of a voluntary spirit in the district which the CBR programme can tap on.

The volunteers, who commonly work with more than one programme/project, are facilitated by in a number of ways ranging from certificate award, allowances, to provision of means of transport. It was however established that the spirit was waning due to a number of reasons. First of all some volunteers were no longer seeing it worthwhile to volunteers while full time programme/project employees with whom they were doing almost similar work were being paid a lot more money. Secondly, some volunteers offer their service hoping that they will eventually be given formal employment by the organization. When this does not happen they give up. Thirdly, some people feel they cannot volunteer because the time available to them would be utilized to fend for their families. Fourthly, it was also reported that due to the numerous developmental programmes in communities each programme coming up with its own implementation committee, there was an apparent 'committee fatigue' among the people. Finally lack of a uniform facilitation system contributes to low morale among some volunteers particularly those in programmes that offer fewer incentives.

Of the programme volunteers mentioned only the Disability and Development in communities' (DDC) programme volunteers focus on directly on disability work. These were identified from among the PWDs leadership and trained by BUDUPD with the support of ADD. At the time of the survey there were 42 trained members.

In light of the above findings the CBR programme needs to exploit the existing voluntary culture in the district. However it should consider the best and sustainable mode of motivating its volunteers to avoid volunteer turn over.

Sustainability of the CBR programme

In the survey instruments there was an item soliciting information on how the district and community will contribute to the implementation of the CBR programme and suggestions on how the CBR programme in Busia could be sustained once co-funding ceases. There was a convergence of views on the following:

- That there is high degree of commitment to the CBR programme among the district administrative staff, political officials and the disabled people's leadership.

- That the CBR programme has an in built system of co-funding from the district and central government. However it is feared that the waiver of graduated tax is likely to be a formidable obstacle to the ability of the district to meet its obligation as alternative ways of raising revenue locally are very few.

- That sustainability should not be envisaged in financial terms only; there are other ways the programme could be sustained, such as:

  - Awareness raising on the needs and potential of disabled people and the CBR programme philosophy and practice in communities. This will contribute to positive attitude change in the public and encourage participation of PWDs in mainstream activities.
  - Capacity building through training staff to internalise the principles of CBR which knowledge and skills could be passed on to others.
  - Empowering PWDs and families with rehabilitation knowledge and skills so that they can be able to carry on with the rehabilitation effort using the available local resources.
  - Empowering PWDs to demand services
  - Mainstreaming disability concerns in all government and NGO programs. This could be done through infusing CBR in the district and sub county plans and budgets right from the out set; and utilising existing structures (e.g. local councils and technocrats). To be effective mainstreaming should start at the Ministry level so as to be emulated by lower administrative levels.

Management information systems

There are a number of management information systems in the district, namely Health Management Information System, Education Management Information System, Water Management Information System, Roads Management Information System, and Production Management Information System. The survey did not carry out an in-depth examination of these management information systems. However the following was observed:

- With the exception of the Education Management Information System the rest of the management information systems do not specifically capture information data on disability and PWDs.
- All the management information systems are run independently of other sector information systems. The nature information collected is specific to the relevant sector.
- The data collected is basically quantitative in nature. It has limited qualitative descriptions of situations.

The proposed CBR programme needs to learn from and utilise the existing systems of information collection. It should also provide a mechanism for feeding information on disability into the existing systems.

STRENGTH, WEAKNESSES, OPPORTUNITIES AND THREATS TO CBR PROGRAMME IMPLEMENTATION

The survey sought to analyse the strengths, weaknesses, opportunities and threats within communities in Busia District that may affect the CBR Programme implementation and sustainability. The data was sought from multiple sources, namely survey participants and document analysis. In the table below are most prominent.

Table 3.13: Strengths, Weaknesses, Opportunities and Threats to CBR Programme implementation

INTERNAL	
Strengths	**Weaknesses**
- Local political support - Administrative structures/implementation framework - Established systems and procedures (e.g. accounting procedures) - Disability councils in place - CBR steering committees established - DPOs with programmes and initiatives in place - Communities' positive attitude towards programme - Existence of voluntary spirit - CDOs/ACDOs trained in CBR strategies - Initiatives aimed at mainstreaming disability issues in community developments, education and production sectors. - Benfited from the early nineties CBR programme when Busia was part of Tororo district	- High levels of poverty in communities - Negative attitudes towards some disability groups - Lack of trained grassroots rehabilitation workers - High expectations among PWDs and carers of the programme - The 'charity mentality' among PWDs and society - Lack of organisational capacity and skills among DPOs - PWDs Councillors at sub-county levels and below not assertive and fail to articulate disability concerns - Weak collaboration, planning and coordination of service between NGOs and government dept and among government Departments. - Poor facilitation of service providers in terms of transport, funding, support supervision. - Inadequate staffing in the relevant sectors - Inadequate infrastructure - Undeveloped referral systems - Referrals places too far for PWDs - Disability not a priority for planning at district and sub-county levels - Lack of disability data - Low revenue base of the district Uncertainty of district to co-fund the CBR programme due to removal of head tax.

Opportunities - Committed donor (NAD). - Disability policy and pro-disability constitutional provisions in place. - MGLSD Dept of disability and the National CBR Secretariat - Existence of the Tororo CBR programme to learn from - Referral and outreach services in neighbouring districts (Mbale and Tororo) - Existence of NGOs and CBOs	**Threats** - Sustainability after NAD withdraws - CBR not being taken as a priority in district development plans - Delay in releasing funds from the centre - Politicising the CBR programme
EXTERNAL	

There is need for the CBR programme to utilise the opportunities to benefit the programmed and to overcome the threats. The strengths need to be built upon and the weaknesses addressed. Special care needs to be taken at the Central Level to avoid weakening what the district is already doing for and with PWDS.

SECTION FIVE

CONCLUSION AND RECOMMENDATIONS

Conclusion

Busia district is a rural district experiencing challenges associated with a rural setting in a developing country. Service delivery is difficult due to an underdeveloped infrastructure and this has a direct impact on the standard of living people. The survey has indicated that the needs of PWDs and their carers by large remain unmet. Most felt needs relate to poverty, rehabilitation, accessibility (physical as well as to information) and social economic integration in the mainstream.

Existing services and opportunity target the general population but do not specifically target PWDs. In addition they are few and inaccessible to most PWDs. Most PWDs are confined in homes where they (especially those with moderate to severe impairment) are cared for by relatives without much support from the community and government and/or NGOs. The PWDs their carers live in dire need of rehabilitation, medical care and other social services including poverty alleviation. It is on this background that the CBR programme comes as desirable relief.

Notwithstanding the numerous challenges experienced in the district, the CBR Programmes is likely to benefit from a number of favourable factors. These include supportive political and administrative officials who are ready to embrace and contribute to the programme, Disability Councils and DPOs with on going programmes and initiatives. The low tax-base may limit sustainability of the programme and limit local financial contribution.

CBR is multi-sectoral in practice and approach. However, at the moment key sectors namely, education, health, and community development are weak with respect to disability related service provision. They will need to be strengthened if CBR activities are to be sustained.

The table below summaries the major findings against the objectives that the team set out to achieve.

Objective	**Findings, Conclusions and implication for CBR programme**
1.To assess the demographic situation that has relevance for service provision for persons with disability and other vulnerable groups in the district.	More urbanisation than most districts and the population per square km is high. This will help in accessing of CBR services. High decency ratio like most of Uganda mainly composed of children. CBR will need to provide services for cerebral palsy and epilepsy as these are the commonest childhood disabilities in populations with high decency childhood ratio. Education services will be an important area of emphasis.
2. To examine the physical, social and economic situation and needs of PWDs, their families and the community at large.	Poverty amongst PWDs and their families is wide spread and was raised as a very important issue at all levels. CBR programme needs to address this concern probably by linking PWDs to relevant microfinance and agricultural programmes. Access to buildings including bathrooms, toilets and water sources at home and in public places is inadequate. CBR will need to address these using local solutions that are cost – effective. Rejection and negative attitude to PWDs is still wide spread and needs to be addressed through sensitising especially at family level. Carers are also isolated due to attitude and burden of care. The CBR programme needs to address their needs.
3 To analyse the social and financial support services, within and outside the district, which affect PWDs and other vulnerable groups.	The frame work of 'prosperity for all,' an important pillar for poverty eradication strategy is available for the CBR programmes to integrate PWDs. Busia has programmes such as NAADS, microfinance institutions, busy cross boarder trade with Kenya all which participation of PWDs has been minimal. The few groups and individuals involved in the above named activities need to be used by the programme to

Objective	Findings, Conclusions and implication for CBR programme
	guide others to be involved rather than recipients from family members. Access to social services is poor due to distance, poverty and negative attitude. Medical referral services are especial inadequate as they are available in Tororo and Mbale districts. The CBR programme will need to advocate for at least the basic referral services such as physiotherapy. The programme will need well trained CBR workers as they will have little support in terms of expertise from professionals. SNE like else where in Uganda is struggling following the end of the DANIDA programme. The frame for SNE from schools to district level is still in place and needs to be utilised by the CBR programme. Social development services and projects are available in the district but are vertical and not accessed by PWDs. Assistant CDOs need to be trained and motivated to integrate PWDs into other programmes they coordinate
4 To establish strengths, weaknesses, opportunities and threats within the communities in the district that has relevance to CBR programme implementation and sustainability.	Busia is one of the few districts that benefited from NAD support in early 90s and the impact in terms of systems and structures at district and sub-county level are still evident. These need to be built upon instead of starting new structures that will support short life-span support. Care needs to be taken that the NAD support does not kill the exemplary district efforts. The weak medical rehabilitation services needs to be addressed. The abolition of graduated tax has reduced local revenue. Discussions on district contribution need to take this into account. The leadership of PWDs at lower level district structures is weak and needs to be strengthened.
5 To make recommendations that reflect the existing reality of needs and gaps in the district which are to guide the CBR programmes' implementation	Key recommendations Great caution when funding CBR to avoid killing local initiatives and initiatives already under taken by DPOs and ADD. Need for CBR to mainstream PWDs into existing poverty eradication programmes mainly from microfinance institutions and agriculture sector. The gap in medical rehabilitation needs to be addressed probably by lobbying the district of Busia to arrange for regular out reach to the two HSDs using rehabilitation personnel from the neighbouring districts and later advocate for the recruitment of the required personnel by the district. The CBR programme should where possible avoid funding medical service delivery except for provision of assistive devices which are currently too expensive for the district to

Objective	Findings, Conclusions and implication for CBR programme
	provide. Provision of assistive devices is essential for inclusion of PWDs. The provision of assistive should not be the sole responsibility of CBR programme but the family of the user of the device should make a contribution and the district left to purchase cheaper appliances such as walking sticks and axillary-crutches. Education sector, the section for SNE needs to be revamped. In- service training of SNE teachers and provision of units for deaf and blind will improve education for disabled children. The CBR programme could either play a facilitatory role in strengthening SNE or advocate the district or relevant NGOs to inject resources into SNE. The leadership of PWDs should be strengthened to enable it raise the voices of people they represent. They need skills to advocate for the rights of PWDs especially at sub-county and lower levels as well as to empower the disabled people that they lead to harness the opportunities that surround them. The capacity building of PWDs should be result oriented with indicators the programmes can use to measure performance. Support to Busia from NAD should be long term (5 to 7 years) with gradual withdrawal as the district takes on more responsibility. As mentioned earlier local initiative needs to be left alone to grow. CBR should facilitate PWDs to access services (educational, FAL, medical and financial) as well as raise the profile of disability issues at various district points of decision making such as the Village Health teams, Parish Development Committees, Sub-counties committees and District Committees. The rights of PWDs at family level need to be ensured especially that of abandoned disabled mothers. In order for this to happen there is need to build the capacity of sub-county development workers and the community workers.

Recommendations

The detailed recommendations are given below and are many in number to enable the programme pick along the menu according to available resources.

Government

1) For sustainability, CBR activities should be mainstreamed in district and sub-county programmes. In addition district and sub-counties should endeavour to meet their co-funding obligation.

2) Women with disability should be specially targeted for social and economic empowerment to enable them cope with the challenges associated with social exploitation and marginalization. They should be taken as a priority group for IGAs and mainstream development initiatives.

3) The existing management information systems in the district should capture information on the disabled; both qualitative and quantitative data on persons with disabilities to enable meaningful planning, lobbying and advocacy effort.

4) Notwithstanding its merits, the inclusive education approach has lasting negative implications for educational provision for children with disability. There is tendency for service providers to ignore the unique needs of the children in terms of planning and allocation of resources, and service delivery in the name of implementing inclusive education. There is need for relevant service providers to consider the needs of the child as an individual first then as a member of the inclusive group next.

5) It is necessary for separate education provision for those children who cannot benefit from inclusive education or education in the mainstream.

   (i) Setting up of at least three special schools each for the deaf, blind and mentally retarded children in the district.

   (ii) ii) Opening more units in regular schools and strengthening the capacity of the existing ones.

6) SNE activities in the district are generally in hibernation. They need to be revived through adequate facilitation of the DIS (SNE) office.

7) The study indicated the role and functioning of SNECOs had been buried with the winding up of the DANIDA support. There is need to revive the services of SNECOs. This will entail retraining, facilitating and offering support supervision to them.

8) The district education office should include SNE educational materials in their educational materials budget. Teachers should be trained in the production of appropriate low cost education materials. In addition the CBR programme in conjunction with the education office should work for the revival of SNE resource centre in the district where teachers can share information on and acquire skills of production and use of educational materials.

9) There is need to sensitize key actors in the planning process on disability issues so as to make them aware and proactive toward the disability cause. Specifically the following need to be targeted owing to their roles in the planning process:

- Local council executives at all levels,
- CDOs and their assistants,
- Parish and sub-county chiefs and

- Technocrats

Busia CBR Programme

1) As the needs PWDs and their carers are multidimensional there is need for the CBR programme to adopt the comprehensive model which is holistic in approach to service provision. The Busia CBR programme need to draw lessons from the Tororo CBR Model Programme, especially with respect to voluntarism, activity based planning and inclusion of PWDs in programme design, planning, implementation and monitoring.

2) Poverty emerged as the main obstacle to participation and empowerment of PWDs. Therefore there is need to take economic empowerment PWDs' households as a key component of the CBR programme. In this the programme may tap on the existing government's poverty alleviation initiatives, e.g. NAADS and *Bona bagaggawale*, to help PWDs to take off.

3) Accessibility difficulties greatly undermine PWDs' activity performance. The survey puts forwards the following recommendations aimed at addressing the accessibility problems experienced by PWDs:

   (i) There is need to assess the mobility and functional accessibility needs of individual PWDs so as to make informed decisions on what they need for assistive devices.

   (ii) Assistive devices are expensive. To sustain their provision the CBR programme apart from buying and distributing assistive devices free of charge to those in need, should consider approaching charitable organisations e.g. Rotary Clubs, Lions Clubs, Wheel Chair Foundations, etc. companies e.g. Mukwano, Nile Breweries etc. to mobilise support from them.

   (iii) PWDs and family members need to be educated on the importance of contributing towards acquiring assistive devices required and on its maintenance.

   (iv) The programme should identify local artisans for training in production of some appropriate assistive devices that they can sell to PWDs at affordable prices.

   (v) One of the findings of this study was that some PWDs are ignorant about their needs concerning assistive devices – they do not know the benefits of using appropriate compensatory aids. It is important that assistive devices and their appropriate use should be one of the components training for PWDs, carers, CBR workers and other persons working with PWDs in the community.

4) It will be necessary for the CBR and DPOs to organise awareness/sensitisation or training workshops for PWDs on their rights and roles concerning government and NGOs mainstream development programmes.

5) The study established that the responsibility of caring for PWDs in the community lies mainly with mothers and grandparents. The study therefore recommends that while focus for training and support should be on these key caregivers effort should be made to encourage fathers and other members of family to be mindful of their responsibilities to their disabled relatives.

6) Lack of information about what to do to assist PWDs was one of the challenges encountered by carers in communities. There is need for awareness raising/sensitisation of caregivers on the needs of their disabled persons and about where services can obtained.

7) There is a communication barrier between the hearing and the deaf community. Even the majority of deaf persons are not sign language literate. The programme should consider sign language training for deaf persons, carers and people working with deaf persons.

8) Vocational training for the disabled youth who have not benefited from formal schooling or have dropped out is highly recommended. The CBR programme should explore training opportunities in existing vocational training institutions in Busia and neighbouring districts for PWDs youth.

9) The CBR programme should seriously consider home based educational programmes for those children who due to the nature and degree of impairment cannot benefit from the formal educational provision.

10) There is need for outreach programmes for purposes of assessment and service provision to PWDs and families.

11) The CBR programme should network with other organisations such as sight savers and USDC that can provide the necessary support so that the materials are acquired education

12) The CBR programme should exploit the home hygiene and sanitation door to door campaigns in Busia District to create disability awareness in the communities.

13) Health workers need to be trained basic Sign language skills so as to interact better with deaf persons.

14) The CBR programme should lobby NGOs and CBOs so as for them to be disability sensitive while providing service. This could be done through awareness raising and including representatives of NGOs on the CBR committees at district and sub-county

levels. Alternatively this may through the civil society organizations coalition in the district whose major purpose is to have a unified voice of lobbying and advocacy.

15) There is need for the different actors in disability work in the district to come up with a framework for collaboration.

16) There is need to build organisational capacity of PWDs so as to effectively articulate their concerns.

17) PWDs should be encouraged to be more assertive so as to influence decision making in farmers' institutions, forums and procurement committees.

18) PWDs need to be enabled to undertake study visits to on going projects within and outside the district. This is not only likely to expose them to new ideas but also motivate them to work harder.

19) CDO should collaborate more closely with service providers in other departments in order to complement each other.

20) On sustainability, PWDs should and their families should be encouraged to contribute to their rehabilitation rather than being passive recipients of service. This helps to build a sense of ownership and ensure sustainability of service provision.

21) On PWDs' inability to use certain implements and tools especially farming tools, the CBR programme should support the designing and trails of adapted farming tools.

22) The CBR programme should consider identifying some local artisans to undergo training in production of disability assistive devices.

23) Given the absence of vocational training institutions in the district the CBR programme could explore the possibility of building capacity of some local artisans who may be willing to train PWDs in artisanship.

24) The CBR programmes should support the existing microfinance initiatives for PWDs. Given the demands of running microfinance schemes the CBR programme should desist from getting directly involved in administration of microfinance schemes. However there is need to consider building capacity and extending financial support to BUDUPD to strengthen its revolving fund scheme. BUDUPD already has the staff, structures, and experience in management of microfinance. On its part BUDUPD should widen its operational scope to all parts of the district. Alternatively the CBR programme could identify one microfinance institution to give funds exclusively for PWDs. There is need to make the conditions (e.g. qualification requirements and rate of interest) for accessing the funds affordable for PWDs. The scheme should be wholly run by the lending institution. However, the CBR programme should oversee its implementation.

25) The CBR programme should establish a management information system that will gather both qualitative and quantitative data pertaining to the situation on disability and PWDs in the district that could be used as basis for planning, advocacy and lobbying.

Disabled Persons' Organisations

1) PWDs should be encouraged to form or join (existing) DPOs which is a prerequisite for support from mainstream development programmes.

2) Women should be encouraged to form or join DPOs and other women groups in order to benefit from a collective voice. Membership in organisations is likely to promote their social and economic integration and improve their self confidence and self-esteem.

3) The CBR programme needs to strengthen DPOs capacity through training of their leadership in IGAs, project planning and management

4) The survey established that there is a high level of illiteracy among PWDs. disabled people's organisations should mobilise their membership to participate in the ongoing Functional Adult Literacy Programmes.

5) PWDs in need of appropriate mobility aids should to assisted to get them. BUDUPD in conjunction with NUDIPU should lobby for assistance from district local funds.

6) There is need for regular and frequent monitoring and supervision of those DPOs that have received financial support.

7) BUDUPD and the CBR programme should mobilise DPOs for microfinance initiatives by government such as *'bonna bagaggawale'*. They should make sure that unregistered DPOs are registered with their respective sub-counties.

8) Although mother National DPOs are already extending some support to their district branches, there is need for more especially in respect with funding, training and mentoring.

9) There is need for the DPOs at district level to have permanent office premises where their membership can meet.

10) The capacity of DPOs to plans and implement activities for their constituents should be enhanced. In view of their central role DPOs should be represented on the CBR steering committees.

11) PWDs councillors need to be trained in skills of lobbying, advocacy, negotiation among others. This is inevitable especially after the recently concluded elections that could have brought in a new set of leaders.

12) There is need to educate disability stakeholders on the specific roles of the DPOs, PWDs leaders and the disability councils.

13) There is need for disability awareness raising among mainstream financial institutions in order to allay their fears concerning the rights and abilities of PWDs.

14) Need to train PWDs in entrepreneurship skills and to motivate them to reach out to existing financial institutions for loan facilities

APPENDIX A

CHECKLIST FOR PWDs' (LEADERS) FGD

1. What problems do disabled people face? What are their most pressing needs?
2. Which disability group is affected most? How? (probe for disability groups, women, youth)
3. How do they cope?
4. What challenges do PWDs face in accessing rehabilitation services?
5. How do they participate in the community?
6. What barriers to participation do PWDs and their caregivers face?
7. What is your role in planning at district and sub-county levels planning?
8. How do disabled people benefit from the government and NGOs development programmes or projects in the district?
9. What do you think can be done to improve the conditions of PWDs and their families?
10. How are PWDs organised? What has been achieved? What are the challenges?
11. What do you think should be the role of PWDs in the CBR programme?

APPENDIX B

QUESTIONNAIRE FOR ADULT DISABLED PERSONS

Dear participant,

The purpose of this needs assessment survey is to generate factual data on what exists and what does not exist in the community. The information provided is to be utilised by the Ministry of Gender, Labour and Social Development in conjunction with the District administration in setting up an efficient, effective and sustainable community based rehabilitation programme in the district. Please try to respond to the items as accurately as possible. Confidentiality and anonymity of the information are assured.

Thank you in advance.

Disability Survey Team

SECTION A: DEMOGRAPHIC DATA

1. **Gender:** **(1) Male** **(2) Female**

2. **Age:** **(1) 14-19 years old** **(2) 20-39 years old** **(3) 40 and above**

3. Level of education: (1) None (2) Primary
   (3) Secondary (4) Post Secondary
   (5) University

4. **District:** **(1) Busia** **(2) Kayunga**
   Sub-county .....

5. Location of residence: (1) Rural (2) Urban
6. What is your occupation? ----------
8. What is the nature of your disability?

   (1) Motor (2) Visual (3) Hearing (4) Multiple disabilities
   (5) Epilepsy (6) Mental retardation (7) Mental illness
   (8) Other disabilities or conditions.....

9. How would you grade your disability?

   (1) Mild (2) Moderate (3) Severe

10. Are there activities of daily for which you need assistance?
    (1) Yes (2) No
11. If yes, who provides the assistance?
    (1) Self (2) Parents/guardians (3) Husband (4) Wife (5) your children
    (6) Other relatives (specify).....(7) None

B: ACCESSIBILITY AND PARTICIPATION NEEDS AND CHALLENGES

12. Does your disability require an assistive device? (1) Yes (2) No

    (a) If yes, do you have it? (1) Yes (2) No

    (b) If yes, how did you get it?

(b) If no, why? ----------

13. Do you have any difficulty moving beyond your neighbourhood? (***Probe for mobility, sight, hearing, communication difficulties, entering buildings***)
(1) Yes (2) No

(a) If yes, which difficulties?

(b) How do you cope?

---

14. Do you encounter any difficulty using the latrines or bathrooms? (1) Yes (2) No
(a) If yes, what difficulties? ----------

(b) How do you manage?

(c) If you are deaf or blind, what communication challenges do you encounter?

---

15. What challenges do you encounter in using the public transport system?

---

16. What is the source water in your community? ----------

17. How far is the water source from your home? ----------

18. What difficulties do you experience in accessing the water source? ----------
---

---

17. (a) What difficulties do you encounter in accessing rehabilitation services? (*Probe for medical, vocational, and educational services*)

(b) How affordable are these services

---

18. What do you see as your most pressing need(s)?

---

19. What difficulties do you face in meeting these needs?

---

20. Which community activities do you participate in?

---

21. What activities don't you participate in and why?

---

22. In your community, are there cultural beliefs and practices that discourage disabled persons from participating in certain activities? **Yes/No**

If yes, mention the belief or practice and the activity affected.

---

23. What developmental programmes (that aim at uplifting the economic and social welfare of people) in your community are you aware of?

---

24. Are you involved in one or more of these programmes? **Yes/No**

(a) If yes, which ones?

(b) If no, why?

---

25. How do you think the quality of life of PWDs and their families could be improved in your community?

APPENDIX C

SEMI-STRUCTURED QUESTIONNAIRES FOR (PWDs') CAREGIVERS (OF PWDs BELO AGE 14 YRS AND OTHERS NOT ABLE TO EXPRESS THEMSELVES)

Dear participant

The purpose of this needs assessment survey is to generate factual data on what exists and what does not exist in the community. The information provided is to be utilised by the Ministry of Gender, Labour and Social Development in conjunction with the District administration in setting up an efficient, effective and sustainable community based rehabilitation programme in the district. Please try to respond to the items as accurately as possible. Confidentiality and anonymity of the information are assured.

Thank you

Disability Survey Team

SECTION A: DEMOGRAPHIC DATA

Please put a tick on what applies to you

Gender: (1) Male (2) Female

Age: (1) 14-19 years old (2) 20-39 years old (3) 40 – 59 years old (4) 60 years and above

Level of education: (1) None (2) Primary

(3) Secondary (4) Post secondary

(5) University

5. Relationship to the disabled person

---

6. District: (1) Busia (2) Kayunga
   Sub-county .....

5. Location of residence: (1) Rural (2) Urban

6. What is your occupation? .....
7. What is the age and gender of the person you care for?

---

8. What is his/her disability?

   (1) Motor (2) Visual (3) Hearing (4) Multiple disabilities (5) epilepsy (6) Mental retardation (7) Mental illness (8) other disabilities or conditions..... (Specify)

9. Indicate the degree of the disability.

(1) Mild (2) Moderate (3) Severe

10. How much help does the person you care for require?

(1) Very much help (not able to move, needs help with toileting, bathing feeding)
(2) Much help (some help with toileting, bathing feeding)
(2) Little help (can do most activities of daily living independently)

B: ACCESSIBILITY AND PARTICIPATION NEEDS AND CHALLENGES

11. Does the person's impairment require an assistive device? (1) Yes (2) No

   (a) If yes, does he/she have it? (1) Yes (2) No

   (b) If yes, how did he/she get it?

(b) If no, why? ----------

12. Do he/she have any difficulty moving beyond the neighbourhood? (*Probe for mobility, sight, hearing, communication difficulties, entering buildings*)
(1) Yes (2) No

(a) If yes, which difficulties?

(b) How does he/she cope?

---

13. Do he/she encounter any difficulty using the latrines or bathrooms? (1) Yes (2) No
(d) If yes, what difficulties? ----------

(e) How does he/she manage?

(f) If he/she is deaf or blind, what communication challenges does he/she encounter?

---

14. What challenges does he/she encounter in using the public transport system?

---

15. What difficulties (if any) does the person face in accessing:

(a) The water source? ----------

(b) Fuel e.g. firewood, charcoal, and paraffin? ----------

16. What do you see as the other most pressing needs of the disabled person?

17. How can they be overcome?

18. What are your pressing needs in caring for the disabled person?

19. What do you do to overcome the needs or challenges

20. Who else helps you in caring for the disabled person?

21. What is the nature of the help?

22. What developmental programmes (that aim at uplifting the economic and social welfare of people e.g. micro-finance institutions, PMA, NAADS etc.) in your community are you aware of?

23. Are you, or the disabled person, involved in these programmes?
    (1) Yes (2) No

(a) If yes, which one?

(b) If no, why?

C: REHABILITATION SERVICES

24. What services that address the disability has the disabled person received?

---

25. Who provides the services?

---

26. When was the last time the person received the services?

---

27. Have you ever participated in an awareness or sensitisation workshop on PWDs and disability issues? (1) Yes (2) No

If yes, what did you learn about?

---

28. What suggestions do you have for improving the quality of life of PWDs and their families in your community?

APPENDIX D

Questionnaire checklist for non disabled residents

1. What are the common disabilities in the community?

---

2. What are the causes of these disabilities?

---

3. What are the beliefs and practices concerning disabled persons and their families in the community?

---

4. What problems does the community experience?

---

5. How are disabled people and their families affected by these problems?

---

6. How are disabled people involved in community activities?

---

7. What development projects/programmes by government or NGOs exist in the community?

---

8. How do disabled people and their families participate in these programmes?

---

9. What difficulties do disabled persons experience in the community?

---

10. What programmes are available to develop/support PWDs?

---

11. Are men and women or girls and boys treated differently in the community?
    (1) Yes (2) No

If so, how

---

12. How can the community help PWDs

---

13. The CBR programme has come. How can it best benefit the PWDs?

Thank you

APPENDIX E

STRUCTURED INTERVIEWS FOR DDHS

1. How many hospitals with rehabilitation facilities for PWDs exist in the district?
2. What specialised facilities for disabled persons and those with chronic health conditions exist in hospitals and medical centres?
3. What medical rehabilitation services do you have in the district? *(Govt, NGO)*
4. What preventive/promotive services do PWDs including children access? (health education, HIV, nutrition, immunisation, condoms, ANC. Epilepsy services)
5. What challenges do hospitals and medical face in offering services to PWDs?
6. What challenges PWDs do you face in accessing services to PWDs?
7. How affordable are medical services to PWDs?
8. What is the percentage of field positions according to the staffing norm?
9. What is the staffing position regarding physiotherapists, occupational therapists, orthopaedics, opthamologists, psychiatric nurses, and other specialists?
10. Have any health workers undergone training in disability work?
11. Do you have a focal person for disability?

12. What is the district plan on disability? How much funding went to disability last financial year?
13. How have you been involved in the CBR programme? What would you suggest?

APPENDIX F

INTERVIEW GUIDES FOR DRO AND CDO

1. What is the general situation of PWDs in the district?

2. What are most pressing needs of PWDs? What measures are in place to address these needs?

3. What measures has the government put in place to address the accessibility needs of PWDs in the following service areas?

4. What mainstream development programmes exist in the district? How are PWDs involved?

5. What do you perceive to be the main obstacles to their involvement?

6. What challenges do PWDs face in getting involved?

7. What do you suggest needs to be done in improve their inclusion?

8. How much of the district budget is allocated to disability work? How much is released?
9. Who are the other service providers in the community? How they involve PWDs? What are the possible areas for collaboration with the CBR programme?
10. What are the major referral centres e.g. schools, medical centres, education departments such as EARS, where PWDs or their families can get help or service?
11. What is their capacity: staffing, training, equipment?
12. If the referral centres are not in district, where can such services be obtained?
13. Are disability issues catered for in the district/sub-county programmes?
14. Are there pro-disability policies? In which area?
15. What is the preparedness for the CBR programme? (Human resource, office space, transport, budgetary support, etc.?)

16. What political/administrative organisational structures that facilitate implementation of CBR programme activities exist in the district?
17. How does the district hope to sustain the CBR programme?

18. What is potential of voluntarism? How are volunteers facilitated and motivated?

APPENDIX G

SEMI-STRUCTURED QUESTIONNAIRE FOR SPECIAL EDUCATION TEACHERS AND SNECOS

1. What is the total enrolment of the disabled children in your school/schools that you co-ordinate (if you are a SNECO)?

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2. What difficulties do disabled children face in the learning environment?

---

3. How do disabled children benefit from UPE?

---

4. What can be done to enable the children benefit more?

APPENDIX H

FGD CHECKLIST FOR CDAs

1. What the common disabilities in the sub counties?
2. What does the community think are the causes disability?
3. What problems do disabled people face? What are their most pressing needs?
4. Which disability group is affected most? How?
5. How do they cope?
6. What challenges do PWDs face in accessing the following services (if they exist)?

- Education (schools, colleges and institutions)
- Medical (hospitals, medical centres, clinics, physiotherapy, occupational therapy, orthopaedic, epilepsy clinics, reproductive health, etc.)
- Vocational (workshops, employment places)

- Recreational (entertainment, leisure, sports, etc. facilities)
- Religious (places of worship)

7. Are they adequate? Accessible? Affordable to PWDs?
8. What do you suggest needs to be done?

9. How are disabled people treated in the community?

10. How do they participate in the community?

11. What activities are they excluded from and why?

12. What cultural beliefs, practices and attitudes are harmful to integration of PWDs?

13. What barriers to participation do PWDs and their caregivers face?

14. What are your roles in the sub-county?
(In rehabilitation, in planning, mobilisation, awareness raising, etc.)

15. What are you doing to help PWDs?

16. What mainstream development programmes exist in the district?

17. How are PWDs involved in these programmes?

18. What do you think are the main obstacles to their involvement in mainstream programmes?

19. What do you suggest needs to be done to improve their inclusion?

20. How do you work with government and non-government service providers in your sub-counties?

21. What are the possible areas for collaboration between service providers in the district and the CBR programme?

22. What are the major referral centres e.g. schools, medical centres, education, vocational, departments such as SNE/EARS, where PWDs or their families can get help or service.

23. What is their capacity in terms of staffing, training, equipment?

24. If not in district, where can services be obtained?

25. How can the community be involved in the planning and implementation of the CBR programme? Are there volunteers?

26. What resources within the community could be tapped to promote CBR? (e.g. land, human (artisans, trained rehabilitation assistants etc)?

27. What do you think can be done to improve the conditions of PWDs and their families?

28. What do you, as CDAs, face in working with PWDs and families?

29. What do you comment about your workload Vs disability work?

30. How are you facilitated to do your work?

31. Do you have relevant knowledge and skills on disability and CBR?

32. What needs to be done to enable you effectively implement CBR activities?

APPENDIX I

INTERVIEW SCHEDULE FOR SUB-COUNTY CHIEFS

1. What are the common disabilities in your sub-county?
2. What problems do disabled people face?
3. How is the sub-county addressing these problems?
4. How much of the budget was allocated to the disability programme this financial year?
5. How much has been released?
6. How are disabled people involved in the sub-county planning?
7. How do disabled councillors contribute to the development of the PWDs they represent?
8. How do disabled people benefit from the government and NGOs development programmes or projects in the sub-county?
9. The CBR programme has come to the district. In which way can your sub-county support it?

APPENDIX J
INTERVIEW SCHEDULE FOR CAO

1. What are the common disabilities in the district?
2. What problems do disabled people face?
3. How are PWDs catered for in the district plan?
4. How are disabled people involved in district planning?
5. How much of the budget was allocated to disability work this financial year?
6. How much has been released?
7. Are there specific policies in the district that specifically address mainstreaming of disability issues?
8. How does the district administration address the issue of accessibility for disabled people (the blind, the physically disabled, the deaf etc.)?
9. How will the district contribute to the CBR programme?
10. Which personnel are available to provide specific service do PWDs?
11. How will the CBR programme be sustained when donor support ceases?

APPENDIX K
INTERVIEW SCHEDULE FOR AGRICULTURAL OFFICERS

1. What is your role in community development?
2. Please tell some success you have scored in your work
3. What are the common disabilities in the district?
4. What problems do disabled people face?

5. How do they participate in your programmes? *(The blind, the deaf, the physically disabled, the women, men etc.?)*

6. What challenges do you face in working with PWDs?

7. Suggest your programme can collaborate with the CBR programme

APPENDIX L
INTERVIEW SCHEDULE DISTRICT PLANNER

1. What are the common disabilities in the district?

2. What problems do disabled people face?

3. What is the process of planning in the district? (How is planning in the district generated?)

4. How are disability issues included in district planning programmes?

5. How do PWDs participate in the district planning?

6. What aspects of disability do you plan for?

7. How much of the budget is allocated to disability issues and disabled people?

8. What NGOs and CBOs operate in the district?

9. Which NGOs or CBOs focus on disability?

10. How can the Community Based Rehabilitation programme fit in the district planning framework?

11. How can the CBR programme be sustained once donor funds cease?

12. Do you have any survey reports on disability?

13. How is information collected on PWDs for planning purposes?

14. Which disability group (i.e. motor disability, the visually impaired, the deaf etc.) has the least access to services?

15. Are there differences between men and women with disabilities in accessing services?

16. Are there differences in the challenges between girls/women and boys/men with disabilities?

If yes, what are they?

APPENDIX M
INTERVIEWS GUIDE FOR NGO OFFICIALS

1. What the common disabilities in this area?
2. What problems do disabled people face?
3. What services does your organisation offer in the district/sub-county?
4. What is your service sector?
5. Which sector of the population do you target?
6. What is your scope?
7. How do PWDs benefit?
8. Do you have objectives and policies that focus on disability and service provision for PWDs and other vulnerable persons?

If yes what are they?

9. What are the possible areas for collaboration with the CBR programme?

LIST OF STUDY PARTICIPANT INTERVIEWED IN BUSIA DISTRICT

1. Chief Administrative Officer	Mr. Okello Charles
2. District Extension Coordinator	Mr. Wakapisi Fred
3. District Planner	Mr. Wabwire Patrick
4. Director of Health Services	Dr. Oundo
5. LC V Chairman (formerly)	Mr. Wanyama Steven Oundo
6. District Council Speaker & PWDs LC V Rep.	Mr. Geoffrey Wandera,
7. Chief Administrative Officer	Mr. Charles Okello
8. Community Development Officer	Mr. Titus Ouma
9. District Education Officer	Mr. Charles Wadenya
10. Inspector of Schools (SNE)	Rev. Barnabas Muniala
11. District Residence Commissioner	Lt. Ssebirumbi Kisinziggo
12. Water Officer	Mr. Isaac Natukunda
13. District Engineer	Eng. Isaac Wani

14. Manager, Busia Microfinance — Mr. Godfrey Mangeni
15. Busia Vice Chairperson
16. Chief Finance Officer
17. District Natural Resources Officer
18. Principal Personal Officer

Baseline Survey and Needs Assessment in the District of Busia and Kayunga

Alice Nganwa
Moses Moiza
Ali Baguwemu
Moses Ddamulira

Over view of presentation

- Background
- Aims and methodology
- Demographic information
- Physical, social and economic situation and needs of PWDs and their families
- Social and financial support services
- Strengths, weaknesses, opportunities, threats
- Recommendations

Background and Rationale

- CBR introduced in Uganda in 1989
- Adopted as a Government strategy 1990
- CBR in 5 districts by Govt (supported by NAD) and in 12 districts by various NGOs
- Evaluation in 2000 of Govt CBR programme recommended pilot in one district
- Tororo became pilot CBR for Govt in 2002
- Evaluation of Tororo recommended criteria for expansion
- Busia & Kayunga selected for expansion along Tororo CBR model

Rationale for study

- To ensure relevance of CBR programme to PWDs and their families
- To establish a baseline for monitoring and future evaluation of the programme.
- To establish internal and external factors that could impact on CBR implementation

Methodology

- Quantitative and qualitative designs were used
- Study covered all the sub-counties in the two districts
- The participants were selected using both purposive (FGDs and KI) and random sampling methods (parents and PWDs)
  - PWDs Kayunga, n= 135 Busia, n= 150
  - Carers Kayunga, n= 90 Busia, n= 100

Key informants

- Chief Administrative Officer
- Community Based Services Coordinator
- Director of District Health Service
- Community development officer
- District Education Officers
- District Planner
- LCV or vice
- LCV representing PWDs
- District Inspector of schools (SNE)
- NGO officials
- Opinion leaders
- Community members (non-disabled)

Key informants (cont)

- Heath workers including mental health worker, ENT officers, Ophthalmic clinical officers, clinical officer, orthopedic officers, focal persons for disability, TB/Leprosy supervisors
- Agricultural extension workers
- Probation and welfare officers
- Ass chief administrative officers

Data analysis

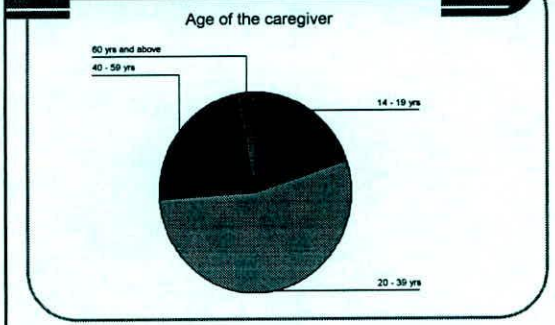
Quantitative

- SPSS computer pkg was used

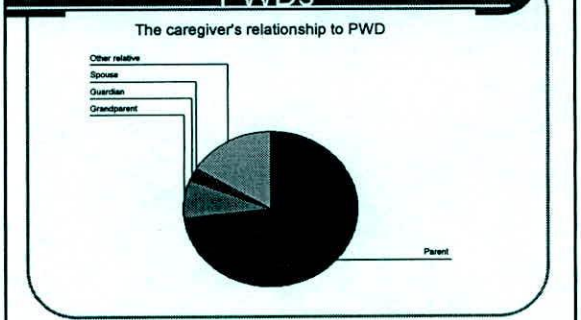
Qualitative

- Thematic analysis manually

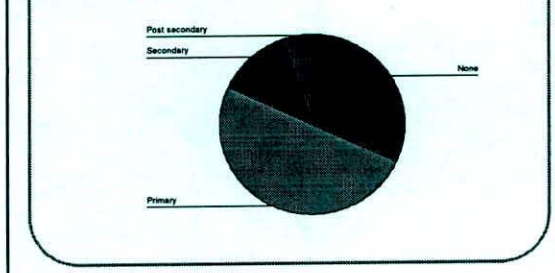
Age of carers Busia



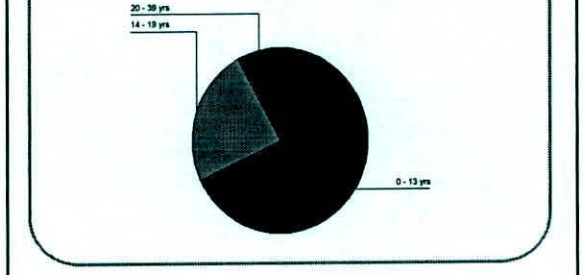
The Carer's relationship to PWDs



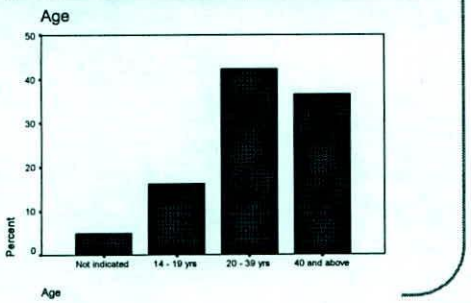
Level of Educ. of carersBusia



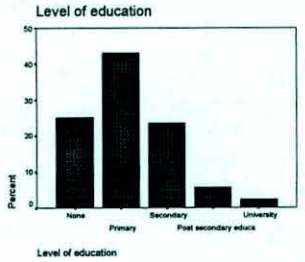
Age of PWDs Under Care



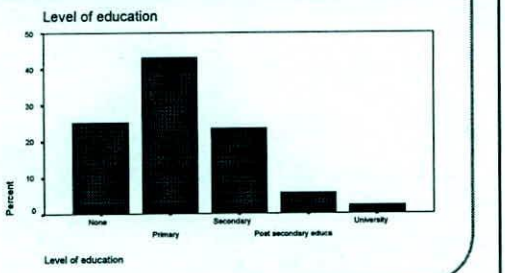
Age of PWDs (Kayunga)



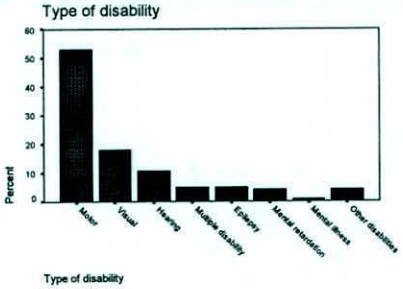
Level of education of PWDs K



Level of Education of PWDs K



Types of Disabilities K



Physical, social and economic situation and needs of PWDs and their families

- Poverty
- Attitude
- Access & communication
- Health & Rehabilitation
- Gender issues
- Youth & children
- Disability category specific needs
- Carers

- Lack of basic necessities was a very significant issues Poor housing, no beddings, clothes and food)
- Poverty is due to low or no education, non-involvement in devt. programmes, lack of capital, lack of assistve devices and guides, search for cure and self-care, time spent in caring for children, low self esteem.

- Labeling-names such as *Kasiru, koloba, butcherman*
- Beliefs- cursed by God, witch craft, disabled children are produced by mothers not fathers
- Prejudice- short tempered, PWDs would be dangerous if not disabled, HIV- free
- Practice-labeling, isolation, over-protection, rejection, denial inheritance, ready to get rid of PWDs
- Effects on PWDs - Low-self esteem, discrimination, sexual abuse and vulnerability to HIV/AIDs

Health & Rehabilitation

- Distance to health units
- Inaccessible reproductive health services (negative attitudes of health workers and inaccessible delivery beds)
- Inaccessibility to medical rehabilitation services
- Lack of assistive devices
- Costs of the medical services high
- Low or no participation in HIV/IADS services

Accessibility & communication

- Inaccessibility within home - bathrooms toilets, latrines, entrances, compound
- In community – long distance, muddy during rains, fatigue, pain and bruises,
- inaccessibility of built environment (Busia Dist. HQTRs buildings accessible, new schools in both dists. Accessible)
- Blind – lack mobility and orientation
- Challenges using public transport – physical disabilities, visual, hearing.
- Deaf – lack of sign language and hearing aids in both districts

Gender issues

- Burden of care on mothers, grandparents
- Disabled boy child favoured over disabled girl child
- Wwd find difficulty getting married
- For the issue is money – disability disappears when money is there
- Girls and women sexually abused
- Men ashamed of disabled lovers
-

Children, Youth & Older Persons

- Children with severe disability & epilepsy isolated & supported
- Children hidden, locked up, even by educated parents
- Youth:
  - many drop out of school
  - Lack sec. sch. & vocational opportunities
  - Wait for progs that target them, hence not mainstreamed in youth prog./projects.
  - Vulnerable to HIV infection
- Older persons – neglected, denied food (K)
- Girl youth not given life skills for the future

Disability category specific needs

- Absence of rehabilitation services for HI, VI
- Physical disability – mobility assistive devices (KB)
- Persons with epilepsy isolated & avoided when they fit (KB)
- Blind burn their houses (B)
- Mentally retarded have no spokespersons, isolated, abused

Carers

- When CWDs get lost, destroy property, not independent, etc carer bears the burden
- Communication barrier btn CWD and carer
- Poverty
- Inaccess to rehabilitation services
- Lack of info disability & services
- No time for social and devt activities
- Disabled children fall sick very frequently
- Education – no fees, no special schools

SOCIAL AND FINANCIAL SUPPORT SERVICES

- Community mobilization & development
- Education
- Health
- DPO
- Volunteering
- Sports & recreation
- Agricultural extension services
- Governance
- CBR
- Financial services

Education

- UPE led to high pupil enrolment in schools
- High teacher – pupil-ratio
- High drop out rates esp. among CWDs (Deaf and blind)
- Inaccessible school environment (both built & natural)
- Poor sanitation
- Long distance to school
- Lack of post-primary school facilities
- Lack of SNE teachers
- SNECOs not facilitated
- Lack of educational materials
- Lack of assistive devices
- SNE activities generally stagnated following cessation of Danida support (K)

Community mobilization & Development

- Structure in transition – DROs vs CDOS, CDAs vs ACDOs vs Chiefs,
- Personnel available and trained for CBR implementation
- Poor central & district support
- Mobilisation:
  - Difficult to mobilise PWDs,
  - PWDs expect vertical progs for them
  - Issues of motivating volunteers

Health

referral hospital in both districts
- Busia lacks a district hospital
- Both lack orthopedic assistive devices workshop, physiotherapy & occupational therapy services, hearing assessment & hearing aids & orientation & mobility
- Both have mental health services but Kayunga more mature.
- Lack of training of front line workers in disability
- Referral services far & not affordable
- Communities not sensitized on the causes of disability and services

Health (contd)

- Little interaction btn health & Community devt programmes
- Epilepsy biggest non communicable disease in the mental health progm.
- Communication difficulties experienced with deaf
- Low participation of men in health programmes
- Busia has more NGOs than Kayunga
- Very many orphans with disability & HIV/Aids
- Lack of staff but also lack of staffing positions in the guidelines
- Increase in new programmes such as disability but budget remains the same
- Sanitation programme been weak over all

Agricultural extension services

- Mainstreaming disability issues and concerns
- PWDs benefiting from PMA programmes depending on their disabilities and interests
- PWDs represented on procurement committees
- Lack of appropriate technology in agric.
- PWDs do not implement what they are taught
- Even when mobilized they do not turn up for meetings
- Parents hiding PWDs therefore not accessing services
- Communicating with deaf a challenge

Governance

- Councilors representing PWDs at LCIII and lower councils reported not achieved much (K) due to:
  - to negative attitudes of other councilors,
  - lack of lobbying skills
  - giving up pressing up for their issues
  - Unclear roles btn disability councils, councilors & DPOs. CBR steering committee added to the confusion

CBR

- CBR not internalized by stakeholders, but no clear plan for implementers to follow (K)
- PWDs want increased representation on CBR steering committees (K)
- Lack of transparency was concern among PWDs "will this money reach the target group?" (K)
- CBR hurriedly launched (K)
- Busia has a more mature disability programme this will affect implementation of CBR

SWOT

- Strengths
- Weaknesses
- Opportunities
- Threats

Threats

- Co-funding not certain due to reduced revenue sources for districts
- Sustainability after NAD withdrawing
- Failure of districts to take CBR as a priority area
- Delay in release of funds

Strengths

- Existence of political will
- Committed donor
- Supportive secretariat
- Administrative & implementation framework in place
- Established systems & procedures e.g. accounting procedures
- Existence of disability councils, steering committee, DPOs to support implementation & monitoring
- Existence of a number of disability initiatives e.g. mobilization and support from DPOs
- Govt & development increasingly becoming disability sensitive in service delivery
- Spirit of voluntarism

Weaknesses

- High levels of poverty
- Negative attitudes towards some disability groups
- Lack of trained grassroots rehabilitation
- Some PWDs & carers expect free things (Charity)
- Inadequate organisational skills among DPOs
- Weak collaboration & coordination btn NGOs & govt programmes & among different govt programmes
- Councilors at sub-county lack lobbying skills
- Lack of data on magnitude of the disability problem
- Suspicion among stakeholders within the districts concerning financial management

Weaknesses (contd)

- Low coverage of rehab. Service in terms of PWDs receiving services
- Poor facilitation of service providers in terms of transport, supervision
- Lack of facilities for teaching with special education needs in schools
- Absence of voc. rehab. Institutions
- At sub-county level planning disability related services not a priority among competing areas
- No management information systems
- Medical referral services inaccessible and not affordable

Opportunities

- The Tororo CBR experience to learn from
- Disability related service initiatives in place e.g. outreach progms from Mbale and Tororo (B)
- Busia referral fairly near e.g. Butiru, Cure, Tororo hosp. Eye Care
- Existence of a number of NGOs and CBOs e.g. Feed the Children, Rubaga Youth Dev. Association, Kitimbwa Child Devt (K), Compassionate Friends, Africa 2000, ADD, (B)

RECOMMENDATIONS

- There is need for capacity building among all stake holders in CBR programme
- Need to lobby and advocate for more support (co-funding) and good political and civic will.
- PWDs activities should be mainstreamed

RECOMMENDATIONS (Contd)

- Sub county staff should be trained as are trainers of other lower staff.
- The chiefs, L.C.III Chairpersons should monitor sub county CBR activities and account to the people.
- Recruit CBR volunteers, train them and motivate them to serve diligently.
- Contribute a co-fund to the CBR activities.
- Own the programme to avoid a feeling of "their programme" as it may be the case in other projects.

RECOMMENDATIONS National Level

- Consider different funding approaches to the two districts: Busia smaller funding over a longer period, Kayunga initial large funds which are trailed off over a long time
- Clarity and systematic approach in the districts with plans and funds known to all stakeholders
- Introduce national CBR implementation guidelines (not PAF guidelines)
- Health sector should include provision for assistive devices and epilepsy drugs in the district planning budgeting guidelines
- Funding should be long term, a minimum of seven to enable sustainability

RECOMMENDATIONS District Level

- Involve sub-county implementers in CBR planning and development
- Provide support to develop referral health services through the office of the DDHS
- Strengthen participation of relevant sectors in the CBR steering committee by expanding the agenda beyond NAD funding and greater transparency
- Need to strike a balance between top-down and bottom-up planning
- Strengthen SNE activities
- Involve volunteers in service delivery at grassroots level

RECOMMENDATIONS District Level (contd)

- CBR programme should avoid direct involvement in micro-finance but could contribute through micro-finance organisations with funding or by referral of PWDs
- Persistent mobilization and empowerment of PWDs to benefit from mainstream poverty and HIV alleviation programmes
- CBR intervention should be holistic to address the needs of PWDs and carers
- Health dept should include provision for assistive devices and epilepsy drugs in the budget

RECOMMENDATIONS District Level (contd)

- Replicate components from the Tororo model such as volunteers, disability and gender specific activities through DPOs, using the sub-county trio (CDO, SNECOs and health assistants)
- Develop advocacy and lobbying skills of PWDs councilors esp. at sub-county
- For sustainability district & sub-county council should continue and gradually increase the disability activities they have been funding
- Busia steering committee needs to include organisation outside Busia District that contributing to referral and outreach e.g. Cure hosp., Butiru outreach programme

APPRECIATION

- To PWDs and their families
- To district officials in Busia and Kayunga
- Ministry of Gender, Labour and Social Development
- NAD
- Research assistants