UGANDA SOCIETY FOR DISABLED CHILDREN (USDC)

REPORT

OF

DISABILITY BASELINE SURVEY IN UGANDA

A USDC COMMISSIONED STUDY

2005-2006

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EXECUTIVE SUMMARY

Uganda Society for Disabled Children (USDC) is a local CSO in Uganda involved in the medical and social rehabilitation of children with disabilities in Uganda. The Society's mission is ***to help children with disabilities and their families to access resources and opportunities to enable them achieve their full potential.*** USDC's long-term vision is ***a society in which children with disabilities have equal rights and equitable opportunities for growth and development.*** Underpinning this is a belief in the uniqueness of each child, and a people-centred approach to development.

The main thrust of USDC's strategy had been to increase the integration of services for children with disabilities (CWDs) in mainstream planning, budgeting and development processes at all levels of government in Uganda; in other words, trying to remove societal barriers that stop children with disabilities from benefiting from integrated services. USDC implemented this strategy in 13 administrative Districts and two other districts of partnership. USDC was guided by the following four strategic objectives:

- Increased awareness of disability issues among policy makers, professional staff and communities in order to promote more positive attitudes and better understanding of disabled children's needs.
- Increased capacity within the government, local organisations of people with disabilities and empowerment of parents and families was another strategic objective to enable them to participate in the rehabilitation of the disabled children in their care, and encourage others to do likewise.
- Increased policy advocacy and lobbying activities to influence official policies and activities in favour of CWDs.
- Improvement in the collection, management and dissemination of disability information so as to inform policy and planning within USDC and partner organisations.

Purpose of the Survey: The survey assessed the wider programme environment, for purposes of determining the future strategy of the USDC. The Specific objectives were:

- To establish benchmarks against which to measure and assess its future work with disabled children in the country.
- In broad terms to assess the impact of USDC's work over the years in the main programme districts.
- To identify priority needs and strategic gaps in provisions for CWDs to facilitate development of a new Country Strategy for USDC.
- To document best practices and lessons learnt from USDC's work and the work of other actors that will inform the process of strategy development within USDC and other organisations.

In broad sense, the baseline survey aimed at getting a broad picture of the situation within the disability area in Uganda, as a result of the work of the different actors, with special emphasis on CWDs. In that respect, therefore, the survey looked at the whole country triangulated from a small purposive sample on:

- Awareness, knowledge, perceptions, beliefs and attitudes with regard to disability as this, to a large extent determined preventive actions and what could possibly be done for CWDs.

- Rehabilitative health care for P/CWDs as this, to a great extent, determined accessibility of education or skills training for CWDs.
- Education and skills training of CWDs as this was a key determinant of productivity and independence thus social integration in the longer run.

Changes in above three areas included perception and attitude towards children with impairment, and the strengths, weaknesses, opportunities and the challenges, which USDC faced.

Chapter 2 dealt with **Methodology:** ***In terms of Scope and Rationale for Selection of Districts* -** The scope of analysis was mainly ***qualitative*** in nature; with an interest in its intrinsic ***qualitative*** dimensions ***located within particular settings, which provided opportunities for exploring all possible social variables; and set manageable boundaries.*** Being a predominantly qualitative study, the sampling and selection were largely ***purposive.***

Hence, the districts were first and foremost, purposively selected basing on the client's demands to ensure the inclusion of the 15 USDC programme districts. This was very important in as far as they generated results that not only described and assessed USDC's programmes in those districts where it had long term occupancy, but also provided an avenue for a *comparative* analysis of USDC services with those of other stakeholders operating disability related services within the very districts.

Additional 8 non-USDC districts were identified to the 15 USDC above to enable the study provide USDC with an objective picture of its comparative presence in terms of relevance and competitive edge over other stakeholders in the disability movement in the country. However in selecting these 8 control districts, care was taken to ensure that they were regionally balanced to provide socioeconomic and development variability of the study areas. Other criteria included: a) regional representation; b) districts where other organizations were working with CWDs, especially where the government had programmes for CWDs; c) districts that had groups of people with unique and strong cultural practices and livelihood practices having impact on CWDs; d) districts with experiences of conflicts and with regional representation, hence specific effects on areas of disability; e) uniqueness of geographical and development conditions in location; and f) districts without proven disability services.

The bulk of the information required from respondents was more perceptive than statistical. The consultants were keen into unforeseen areas of discovery within the lives of children and other people with disabilities to illuminate and emphasise their 'significance' in the population rather than 'general' characteristics of the population.

***Data Collection* -** Qualitative survey instruments (see Annex 2) and six Forms for quantitative data (see Annex 3) were designed and used specifically to collect qualitative and quantitative data, respectively. Both the survey Forms for quantitative data and qualitative questions addressed the following focus areas:

- Population of the PWDs in respective districts,
- PWD/CWD population desegregated by disability category and degree, as well as, sex, age, literacy and location, e.g. Sub-county,
- In-school and out-of-school numbers of CWDs and also desegregated by welfare, sex, age, and location,

- Access to rehabilitative services of PWDs as predisposed by disability type, age, sex, social conditions and literacy. Additionally, health indicators on CWDs would focus on how they were treated in health units, levels of access to health services, and estimates of those not able to access health services,
- Considerations of interventions focused on P/CWDs by different stakeholders in the districts (public, private and non-governmental partnerships) as well as by their disability specialisation,
- Trends of changing perceptions of the general population towards P/CWD, their rights and welfare outside and in USDC, and of other stakeholders, were assessed.
- Strengths, weaknesses, opportunities and challenges (SWOC) information from USDC branches (and those of other partners) with regard to the a) trengths (how USDC had supported CWDs, for example); b) weaknesses (e.g. problem areas past, present and future, partnerships and networks); c) opportunities (e.g. what they could take advantage of already, mid- and long-term future, in comparison with other partners in the PWD movement); d) challenges (e.g. what challenges lay ahead, presently, in the short- and long-term future? How did this compare with other stakeholders?);
- Resources (e.g. what was the resource base of the disability programme at national, district and lower local government levels? What was the resource base of USDC and other disability organisations? What were the trends in resource development and how had this affected services provided to P/CWDs? Above all, what was the overall proportion of programme versus administration budgets for these different stakeholders and what did this imply for quality and sustainability of CWD support?).

The phases of the survey included **preparatory phase and initial preparatory meetings**. The specific activities on-going included:

1. Preparatory meetings with USDC management,
2. Interpreting the Terms of Reference (TOR),
3. Literature review both internal to USDC and external such as from Ministries of Health, Education and Sports, Gender Labour and Social Development, Finance Planning and Economic Development, etc,
4. Proposal and instruments development,
5. Sharing of ideas and instruments for USDC district offices to collect quantitative data,
6. Checking completion of the forms and sorting them to put together the data gathered, and
7. Reflections to cross-check general information and consult on other issues.

Field based *Qualitative Information Collection*: The fieldwork was focused to emphasise collection of qualitative data along the lines of:

1. *Review of secondary sources* – USDC, stakeholder and other relevant literature on policy and developments aimed at supporting disabled children and the disability movement in general,
2. *Focus group discussions (FGDs)* – to obtain information from discussions with various categories of people,
3. *Key informant's interviews (KIIs)* – to obtain specific and unique areas of information,

4. *Observation* – Observation of disability-friendly infrastructure, conditions in homes, schools and of CWDs together with behaviour and attitudes portrayed were a continuous process.

Gender Considerations - Attempts at gender equality were ensured, by inviting both parents to the FGDs. This was not however, assured due to the very low turn up of fathers. In interviews with KIIs, gender was not deliberately targeted, though key informants included both men and women in almost equal numbers as demonstrated by the list of interviewees (see Annex 5).

Quantitative Data Collection: A questionnaire was designed to specifically collect quantitative data from the USDC programme districts and 8 non-USDC districts, from other disability partner organisations and relevant institutions in the study areas. This was on the understanding that relevant quantitative information was important and necessary, in order to support and establish a linkage with the field information gathered through interview processes and observations. This would give a meaningful broad picture of the situation of disability and have benchmarks.

Ethical Considerations: Permission from interviewers was sought first through explaining the purpose of the interview or focus group discussion. One important ethical consideration was the commitment USDC made to provide feedback to districts on the findings of the study.

A workshop was organised by USDC at the national level to review the findings of the survey. This workshop brought together the key stakeholders at district and national levels to assist in interpretation of the findings, to streamline views, to iron out differences, to build up an agreed picture, fill information gaps, and contribute to conclusions and recommendations. Another presentation was made at the USDC strategic planning workshop for the next programming cycle, at which a general overview of study findings and recommendations was given, in order to guide the strategy planning process.

Interpretation and Analysis of Data: For ***Qualitative Analysis***, the notes made during the day were perused and where possible typed out while in the field or on return from the field. Qualitative data collection became a learning process for both the interviewees and interviewers. It was a movement towards consciousness and knowledge about impairment and social attitudes leading to disability in children and how it was being managed to the benefit or detriment of CWDs. Reflection on each day's interactions helped the consultants to see actively and search for meaning in what they observed and heard.

The team developed Chapters based on the TOR. The raw data was then analysed under the main Chapters and slotted under each thematic area identified. The core of the qualitative report was based on the sub-themes. The key issues and recommendations were based on this analysis.

There was a lot of overlap of data, for example, when a piece of data fell under two Chapters or under two themes, the data was not deleted for repetition, but utilised where it was identified. In some instances, whole thematic areas were transferred to different Chapters to avoid irrelevant repetitions.

In ***Quantitative Analysis*** a combination of statistical packages were used as found appropriate for analysis of the quantitative data. Primarily the aim was to make trend and forecast analyses of the progress being made by the CWDs and in the services of the various stakeholders.

Qualitative data collected by both the USDC staff and other agencies and the qualitative information gathered by the consultants was analysed to establish linkage with the field information gathered through interview processes and observations. The information was used to determine trends and to make comparative analyses.

Challenges during Data Collection **-** Insecurity in Gulu and Moroto districts hindered home visits and visits to internally displaced persons (IDPs) camps. Permission to enter one of the camps near Gulu town was denied by the authorities. In some districts, top officials were not available to be interviewed because they had either travelled to Kampala or to neighbouring districts on official duty. The District budget process limited time spent with district officials as most were involved in last minute preparations of plans and budgets or were attending budget meetings. Important documents, some of which had been quoted by district officials, were not available for verifying information.

The interviews at all levels were time consuming because the intensity of each interview to get qualitative information was determined by the need to probe in-depth in order to get clearer and more informative picture. In non-USDC programme districts, the teams had to draw programmes on arrival, and made approaches at short notice that sometimes resulted in not getting the respondents the first time or missing them completely.

Returns of the six Forms were incomplete or partial from a number of districts of which USDC programme districts included Hoima, Masindi and Arua/Yumbe. Some districts were supplemented later, such as Gulu.

Chapter 3 introduced the **definitions of the concept of disability**. According to the World Health Organisation, health was not merely the absence of disease and infirmity but a total physical, mental and social well-being. The report used disability in its broadest sense covering the three facets of the disability process in order for the reader to appreciate the interplay between the CWD and the environment.

Disability was an umbrella term for impairment and activity limitation in carrying out activities in a manner or to the extent that was expected of people without the impairment. It denoted the negative aspects of the interaction between an individual with impairment and that individual's contextual factors (environment and personal factors). Impairment was a loss or abnormality in body structure or physiological function (including mental functions).

The medical view argued that what needed to be done to handle the problem of disability was changing the individual medical condition through attention of professional medical personnel, assistive devices or appliances or cure in order to adapt to the environment or society. However, the new paradigm focused on the interaction between the individual with activity limitation and their environment which determined the extent he/she participated in society. The person's limitation might be mild but the environment could be negative or with barriers impacting on considerable restriction in participation. The impairment might be severe but the barriers in the environment could be few, so the individual experienced greater participation and was therefore 'less' disabled.

Consequently, rehabilitation ought to address both the impairment and the environment. The social approach emphasised human rights, solidarity, respect for value of the individual impaired, participation and equalisation of opportunities in order to liberate the CWD and give him/her identity, pride, and common cause to rid society of its discriminating barriers.

Yet, the understanding, perceptions and attitudes of society presented impairment as something unfortunate and fearful leading to rejection and social disability. It built resistance to support rehabilitation of a child out of the impairment and disability to let it grow and develop.

The cultural values and norms sought explanations in the mystery of the underlying unknown forces beyond human capacity. This presented causes of impairment and disability as something detached from human responsibility, preventing society from developing in-depth understanding of impairment and disability. Human acts such as mismanagement of pregnancy period or early childhood sickness were not considered. Instead, the society distanced itself from imapirment, perceiving it as far-fetched. These resulted in societal rejection of the valuable life in the CWD (who was like any other human being) to be availed opportunities to be rehabilitated and to develop his/her potential.

The negative explanations of impairment by social beliefs attributed it to parents, specifically mothers, who were made to carry the stigma of having produced children with impairment. Most fathers were negative towards their own CWDs and did not see value in the long and bothersome process and heavy investment in rehabilitation of a CWD. Such attitude tended to make parents consider medical treatment and education of CWDs as the responsibility of government or CSOs. Meanwhile mothers acknowledged and valued CWDs as products of their womb. Hence, the silent pain of the stigma of mothering a mystery child was a motivation to take on rehabilitation activities if supported, and become good agents of change for the better for CWDs.

Disability exposed CWDs to common yet real challenges they faced in their lives. CWDs were conscious of the negativity unleashed on them in denial, rejection and social exclusion by parents, guardians, communities and service providers. These built in the CWDs particular perceptions of, and attitudes towards their environment. They developed deeper inner hindrances of oppression, rejection and denial that lay beneath the relationship between them and others. This bred in them fear, self doubt, self hatred and other deep consequences.

There were parents and families that accepted CWDs and did all that were within their capacities to rehabilitate the children, with extra efforts to ensure integration of the child through such actions as following up performance in school; keeping the home in some form of order for the visually impaired children to find their way around and involving the siblings in supporting the disabled child.

Magnitude of Disability - National and sub-national data on P/CWDs were hard to come by, for presentation of a clear extent of the problem of disability. The National Population and Housing Censuses (NPHCs) conducted centennially had been the only sources of data, especially for 1991 and 2002. At district and lower levels of administration, information on P/CWDs was non-existent, except for scanty data in a few districts where attempts had been made to collect and analyse such information.

In Chapter 4, a review was made of policy and political environment that were at play in determining support programmes in the disability area. Influence of International Conventions, Standards and Frameworks on national Legislation and Policy formulation in support of mainstreaming issues of disability were reviewed. Implementation of legislation and policies were reviewed at national and sub-national tiers of governance and strategic gaps and challenges identified.

International Conventions in Support of P/CWDs - The International Conventions, Standards and Frameworks cited included the United Nations 48th Session Resolution 48/96, adopting 'The 22 Standard Rules on Equalization of Opportunities for Persons with Disabilities, the Alma Ata agreement in 1978 where nations adopted a strategy to improve people's health using primary healthcare (PHC) through promotive, preventive, curative and rehabilitative healthcare, the UN Universal Declaration of Human Rights in reference to Article 26, the 1989 Convention on the Rights of the Child, the World Declaration on Education for All and Framework for Action to meet basic learning needs (Jomtien1990), the Salamanca Statement and Framework for Action on Special Needs Education (Salamanca, 1994), the Dakar Framework for Action (UNESCO 2000) and other frameworks in support of mainstreaming disabled persons in health, education and social rehabilitation processes.

National Laws and Policies and Protection of the Rights of P/CWDs) - The Government of Uganda appropriately adopted and translated some of the International Conventions and Frameworks into national Laws, Policies and Frameworks for implementation. The provisions in Article 34 of the National Constitution (1995), the Children Act (Cap. 57) 1997, the policies of Universal Primary Education (UPE) 1997 and 'Inclusive Education'. The 22 Standard Rules were used by MOH to develop National Standards for PHC in 'Essential Services for Rehabilitative Health Care for Persons with Disabilities in the District' provided the standards. Parliament passed the Law on National Disability Council and a Bill No. 18 of July 2005 (Persons with Disabilities Bill) was introduced in Parliament.

As a basis for implementation of decentralised system of governance the national laws and policies were further translated into the Local Government Act (1997) for districts to formulate and enact Ordinances and By-Laws. Particular references were made to the Constitution 1995, the Children Act Statute that eventually translated into the Children\s Act in 2004, and the Local Government Act in order to enact appropriate provisions in support of P/CWDs.

In the area of socio-economic management policy, the PEAP was the strategic document, based on five main pillars and in particular for the baseline survey, highlighting the Human Development pillar. Sector related strategic plans were curved out of the PEAP, and included HSSP, ESIP and SDIP, which were further reviewed under Chapters 5, 6 and 7, in that order. For comparative purposes reference was made to the historical perspective of the five-year development planning cycles in 1960s and early 1970 against the current three-year rolling budgeting cycles.

In the current planning cycle, the timetable of a typical annual national budgeting procedure started with the preparation of a PRSP as a basis for development support, since a greater proportion of development budget was donor funded. By working through sectors, development priorities were determined and set with earmarked resource requirements. These were consolidated into a Macro-economic Framework Paper (MFP). While appropriate Laws and policies on disability were made, the current budgeting/planning process stifled prioritisation of disability concerns.

Roles for Local Governments in Disability Concerns - At local government (district and lower local governance) levels, the decentralisation law devolved a range of mandates to the local governments including formulation of plans/budgeting in accordance with the MOLG guidelines, rendering the process rather subjective than objective. The DDP was structured on the basis of the PEAP, but adapting its focus on local development situations. However, the local governments depended heavily on subventions from central government in conditional and non-conditional grants (75% to 80%) while locally generated resources were 5-10% of the total annually. The balance of the budget (10-20%) was funded from donor resources. So there was very limited flexibility for local governments to objectively reprioritise spending.

Some of the common features in the prioritisation of disability were that it was not a stand-alone, but merged with other vulnerabilities, such as the elderly, orphans and other vulnerable children (OVC). This rendered CWDs inconspicuous, often overshadowed by activities of other vulnerable children as it was specifically not provided for. The problem associated with negative perception and attitude of society and government officials towards P/CWDs exacerbated the marginalization even further in plans and budgets. Annual budgetary allocations for disability were small and often none or little would be released. There were gaps in budget allocations for disability, by local governments to key sectors (health, education and social services). In the education sector, refresher courses for SNE teachers, construction of ramps, latrines, etc that provided conducive learning environment to CWDs were part of the education grant budget. In the health sector, preventive and curative services, with no specific reference to CWDs, were budgeted for and rehabilitative services were referred to within the general 'rehab package'. In the social services sector, only parents' mobilization and sensitization was budgeted for.

Nonetheless, a number of districts showed commitment and made significant budgetary allocations or planned for P/CWDs. In non-USDC programme districts, Tororo, Gulu and Kasese and in USDC programme districts, Masaka, Sembabule, Hoima and Adjumani made some local budget allocations for disability.

Roles for CSOs in Disability Concerns - Participation of CSOs in the rehabilitation of CWDs was reflected as important, as resources from government tended to be prioritised elsewhere. CSOs targeting disability entered districts to implement their own programmes and the local governments considered the CSO financial and other resources as relief on what they received from central government, donors and those locally generated. The role played by USDC was distinct by involving its partners at district level in reviewing, planning and monitoring its programme. It also participated in the DDP preparation process to pursue implementation of its advocacy and lobbying objectives.

Strategic Gaps and Challenges in Policy - A number of strategic gaps and challenges were observed and featured in the areas of policy, budgeting/planning, representation and disability information/data as follows:
Policy: a) Policy formulation was a major domain of national and district political leadership. While there were national frameworks, policies and Laws to make reference to, districts were unable to translate them into appropriate ordinances, by-laws and policies for local development situations, for lack of appropriate capacity. b) For the budgeting/planning process, it suffered from lack of robust socio-economic planning management framework at national and all subsequent planning levels, which stifled holistic policy development planning and implementation. c) Interpretation of the PEAP at district and lower levels was difficult because of a gap created by lack of needs assessment. The ideal situation was for a plan based on facts and assessed needs on the ground.

Planning/Budgeting Process: a) Government at the respective levels did not see disability as life threatening as Malaria, HIV/AIDS, tuberculosis and budgeting targeted those areas fully. b) The budgeting process was subjective and dependent on availability of resources from central government and local revenue. Disability was not among priority areas. c) CBOs found minimal role for them in the local government budgeting processes, which provided no clear entry points for their respective programmes.

Representation: a) The level of representation of PWDs in terms of numbers was not enough measure for or conducive to supporting the disability cause. The representation lacked capacity to adequately articulate disability issues and largely ornamental (window dressing). b) Programmes of work (work plans) of DPOs, like NUDIPU, national and lower Disability Councils did not reflect any plans for CWDs except perhaps in inordinate procurement of assistive devices and/or appliances.

Disability Information/Data on the magnitude of disability was not supported by accurate data and information. A great deal depended on information collected by CSOs and some government departments, largely in process of their programme implementation.

Chapter 5 examined factors that affected access to promotive, preventive and curative care on the one hand and rehabilitative care on the other. The general health framework for supporting disability existed in all health units, including ordinary facilities, workers and in some cases budgetary resources such as in the PHC funds. However, those inherent attitudes and perceptions explained above made health planners, workers and administrators regard disability as a problem that was out of reach and could only be managed in a special manner, using special facilities, personnel, equipment and programmes. As such the existing health framework was not designed to address rehabilitation of impairment and disability and specifically CWDs.

Very few health workers received training to re-orient them to work with rehabilitation. None of the structures that related more regularly with the community (nurses, clinical officers, nursing aids) were trained, leading to their non-involvement in sensitisation activities and attending to the needs of CWDs. Hence most of the health workers not oriented on rehabilitation were not in position to provide rehabilitative services and display the kind of attitude conducive to draw parents and CWDs away from seeking for traditional health services. They were unmotivated and unsupervised.

Hence, rehabilitation services were not easily available and when they were, they were not accessed on a regular basis for complete child development. When offered, the services were impairment oriented and did not take into consideration the whole spectrum of disability (impairment, difficulty in performing activity, limitations in participation). Health services, especially outreach were poorly coordinated and allowance-oriented, hence 'killing' static services where no allowances were paid..

Although MOH was in the process of developing various specific disability policies to address each disability type, the practical implementation of these policies remained a challenge for the health facilities within the autonomy of decentralisation system. For instance, the directive that provided for 50% of the PHC funds to be spent on drugs; and additionally Credit Line where each HC could order drugs from the NMS within limits for MOH to pay directly, had not been observed. There were several reports from the field about shortage of drugs in the face of growing needs. The training of mental health service providers without sensitising their immediate supervisors to appreciate mental disorders and on the required drugs and sundries that accompanied the new skills resulted in the ultimate target of the training not being reached with the intended service. The health workers and the clients both remained frustrated.

The consultants heard about honesty and commitment among the medical personnel exposed to manage medical rehabilitation of P/CWDs, while others sounded to have minimal regard and commitment for disability. The evident lack of commitment among government staff could be perceived as a manifestation of the fact that government pronouncement on CWDs might not be rooted in in-depth commitment and understanding of the devastating effects of the social rejection on CWDs. The consultants could not find strong evidence of MOH adequately advising the government on the fact that if disability was addressed during early childhood, it was either healed completely or reduced in effect so that a child had opportunities to develop its potentials fully.

In districts where USDC and other CSOs had CWD programmes, disability was regarded as a CSO focus area for them to accommodate. Arrangements such as outreach, provision of epilepsy drugs, and orientation of medical professionals to handling disability, were left to CSOs. Hence, direct assistance to CWDs provided by government employees in health sector were promoted by CSOs which collaborated with the government. USDC adopted collaborative approach of supporting and working with the government service providers/implementing agents in providing social and medical rehabilitative services to CWDs as a practical demonstration. This enhanced capacities of government in addressing issues of CWDs and disability in general.

Challenges and Gaps: a) The directive that provided for 50% of the PHC funds to be spent on drugs; and additionally Credit Line where each HC could order from the NMS within limits for MOH to pay directly was not observed. There were several reports from the field about shortage of drugs in the face of growing needs. b) Training of mental health service providers without sensitising their immediate supervisors to appreciate mental disorders and on the required drugs and sundries that accompanied the new skills resulted in the ultimate target of the training not being matched with the intended service.

c) Health workers and clients remained frustrated hence; rehabilitation services were not easily available. When they were available, they were not accessed on a regular basis for complete child development. d) When offered, the services were impairment oriented and did not take into consideration the whole spectrum of disability (impairment, difficulty in performing activity, limitations in participation). e) There were indications that parents did seek for services but were limited by the lack of services, attitude of health workers and costs of transport. Transport providers were often reluctant to carry mothers with CWDs.

The supply of epileptic drugs was either inadequate or inconsistent. This had maintained the status of epileptics (continuous fits), which eventually led to death. Mental retardation and movement disabilities developed as secondary disabilities.

The service provision for Occupational Therapy remained extremely low leading to CWDs not being trained in activities of daily living or remained dependent on parents and siblings.

Staffing: a) There was poor staffing at Health Units. Very few health workers received training to re-orient them to work with rehabilitation. Hence 90% of medical and paramedical (front line) personnel were not adequately trained and equipped to reorient them to give medical care to P/CWDs in the rehabilitative services which demanded the display the kind of attitude conducive to draw parents and CWDs away from seeking for health services. They were unmotivated and unsupervised. b) Lack of knowledge by frontline workers: None of the structures that related more regularly with the community (Nurses, Clinical Officers, Nursing Aids, etc) had been trained, leading to their non-involvement in sensitisation activities and attending to the needs of CWDs

Coordination of Health services: a) Health services, especially outreach were poorly coordinated and allowance oriented, hence 'killing' static services where no allowances were paid; b) Although MOH was in the processes of developing various specific disability policies to address each disability type, the practical implementation of these policies remained a challenge for the Health Facilities within the autonomy of decentralisation system.

CSOs: a) In districts where USDC and other CSOs had CWD programmes, disability was regarded as a CSO focus area for them to accommodate. Arrangements such as outreach, provision of epilepsy drugs, and orientation of medical professionals to handling disability, were left to CSOs.

Chapter 6 looked at education. When the body organ of a child is damaged moderately or severely, it experiences limitations in learning. Such a child requires special teaching and learning skills, as well as equipment and facilities for effective learning if the impairment is not completely rectified. Although education was a right for all children it was often a difficult process for CWDs without such support. Education rehabilitation therefore addressed both special learning needs for the specific impairment and the environment in which the child lived and where the learning occurred.

The baseline survey examined the provision of rehabilitative services in the education sector in terms of policy and implementation programmes at different levels, namely national, district, institution/school and community/home levels giving attention to specific issues that were pertinent in the education of CWDs.
Education of CWDs improved over the years due to various factors. At policy level, Conventions, Standards, Frameworks, Legislations and Agreements supporting education in general and that of CWDs in particular were in place. For example at international level, the World Declaration on Education for All (Jomtein1990) and the Salamanca Statement and Framework for Action on SNE (Salamanca, 1994) recognised and emphasized among others the right of all children including those with temporary and permanent needs for educational adjustment to attend school.

The 1995 Constitution recognised the rights to education, to respect and human dignity of PWDs. This was translated in the 1992 Government White Paper on Education. The 1997 UPE policy and the MOES pronouncement on special needs education in 2003 all catered for children with barriers to learning and development including CWDs. Special needs education was embedded in the National Orphans and Other Vulnerable Children's Policy (2004) that recognised disability as one of the barriers to access and full participation of children in education.

Enrolment of CWDs in Schools and Institutions - Many CWDs had enrolled in schools in both USDC and non-USDC programme districts due to different factors. Available data indicated that more boys than girls had enrolled. As a result of the above policies and the presence of CWDs in schools, among others, different interventions were being implemented.

Planning and Budgeting for SNE - Government of Uganda through the MOES planned for special needs education through the Department of Special Needs Education /Guidance and Counselling. In 2001/2002, a budget line was created under MTBF to fund some activities in the department of SNE/Guidance and Counselling. A subvention grant was also created to support SNE. Eighty-seven (87) Special Schools and Units catering for SNE nationwuide were receiving subvention grants although the fund was too inadequate to meet the needs of the CWDs. Parents were requested by the schools to contribute to maintenance of the children.

Establishment of Structures to manage SNE - Uganda established a programme of Special Needs Education/Educational Assessment Resource Service (SNE/EARS) with the support of DANIDA. The programme was aimed at providing a comprehensive programme of assistance characterised by equal educational opportunities to learners of the age bracket 0-18 years with special educational needs. DANIDA initiated the EARS/SNE programme in 46 districts. Under the programme, it supported establishment of EARS/SNE resource centres, including construction of staff houses, office block, provision of educational materials, equipment, double cabin pickups to facilitate movement of staff, and other equipment. The structures provided foundation for SNE in those districts.

A fully-fledged Department in MOES (SNE/Guidance and Counselling) was established with the aim of ensuring that facilities for SNE including educational materials and equipment were available for children with special learning needs.

Provision of Learning Centres for CWDs - Government established special schools either for specific impairments or mixed. These schools were few and scattered in different parts of the country. MOES encouraged mainstreaming of children with special learning needs including CWDs in ordinary primary schools. Government supported special units/annexes/resource rooms in a number of schools where extra lessons and special learning and teaching materials or equipment were provided. Some Local Governments, USDC, DANIDA and SSI through CECS supported building and equipment of resource rooms in schools.

Establishment of Institutions for and Training of Teachers in SNE - Government through MOES established a programme for training teachers with support of DANIDA. Uganda National Institute of Special Education (UNISE) at Kyambogo was established and became the only institute for SNE as early as 1989. The Institute later became part of Kyambogo University and was transformed into the Faculty of Special Needs and Rehabilitation Studies. Short-term training programmes in SNE were conducted countrywide by MOES in different districts with support of DANIDA for orientation of teachers in the special needs of children with learning difficulties in accessing education.

Teacher Training Curriculum - Teachers training curriculum was first developed as specialised areas hence produced specialist teachers. This meant that a teacher would be limited to teaching one skill such as sign language. Few teachers were trained and most had trained from abroad. The curriculum later changed to Special Needs Education with the aim of training teachers with general knowledge of a wide range of special learning difficulties, for an inclusive setting. Aspects of special needs education were incorporated in the curriculum of Primary Teacher Training Colleges (PTCs) so that teachers trained from 1998 would have skills in managing children with special learning needs.

Education Standards for Children with Learning Needs - The basic requirements and minimum standards indicators for education institutions (Standards) was produced by Education Standards Agency (ESA) as a guide for monitoring standards in schools. This was used by the agency during annual and district inspections.

Assessment of Learning Outcomes in SNE - Assessment for all children by UNEB was found to be uniform in primary and secondary schools without special consideration for CWDs, except for deaf children for whom extra thirty minutes were allowed during examinations..

District Levels of Provision for Education of CWDs - Some districts were supportive of SNE and made substantial budgetary contributions compared to those that made very minimal or no contributions at all. Government provided a conditional grant to districts to cater for CWDs, in special schools and those with Units or Annexes.

Instructional Materials and Equipment - DANIDA provided materials and equipment (Braille machines, Braille paper, manuals and others) to schools. MOES provided more educational materials and equipment to primary schools for the period 2004-2005 and had already planned to procure more for the period 2005-2006. USDC equipped a number of resource rooms for special needs education, while SSI was in process of furnishing the resource centres it constructed in Masindi and Hoima.

Training in SNE at the District Level - USDC was a major partner in building the capacity of teachers in service in special needs education in its programme districts. It supported 5-day training for teachers in different areas of disability in order to help them to handle CWDs within school environment. SSI through CECS also supported two weeks training for teachers (referred to as Itinerary Teachers) to identify and refer blind children for medical care.

Disability-friendly Structures - Schools were constructed by the central government through school facilities grants and other provisions. Districts were expected to monitor construction of schools and facilities such as ramps and special latrines to aid mobility of CWDs. Schools were expected to improve on old structures to make them disability friendly. However, very few schools adopted or transformed the encironment to suit mobility of CWDs.

Some CWDs had assistive devices such as wheel chairs and white canes. MOES, local governments and CSOs such as USDC, NUDIPU, Rotary Club and others were supportive and provided devices to some CWDs, thus enabling some who would not have been able to access school, to do so.

Provision of/and Monitoring/ Supervision of SNE - District Education offices were coordinating and supervising SNE activities through District Education Inspectors and specifically the SNE/EARS Coordinators. Meanwhile SNE Coordinators (SNECOs) provided SNE supervision and monitoring in schools at sub-county level. USDC provided some support to the SNE Inspectors in its programme districts.

The District SNE Inspectors used a general guideline for inspection of education standards indicators. SNECOs were using a different tool for supervision and monitoring of SNE. These different guidelines needed to be harmonised.

Interventions towards Social Recognition and Social Acceptance of CWDs by Schools and Parents – As a result of the long and entrenched negative attitudes towards children with impairments in became necessary to work on attitudes of the parents, teachers and society as a whole, to recognise and accept these children as equal beings and support their growth and develop. A number of SNE teachers in both USDC and non-USDC districts especially in schools with units/annexes conducted sensitisation about disability among teachers and pupils while others sensitised parents. A few schools were promoting use of sign language and were using total communication during assemblies.

Some parents of CWDs working through PSGs sensitised other parents about disability and encouraged them to support their children while in school and in medical rehabilitation. Some parents anxiously participated in the learning process of their children through visiting them in the schools and sharing ideas with teachers on how to support the children.

USDC initiated child right's clubs (CRCs) in a few schools. The clubs helped children both CWDS and non-disabled to learn about their rights, build confidence, participate more in class and demand for their rights.

Advocacy through outreach programmes for CWDs had been done mainly by CSOs. USDC facilitated outreach programme teams that mobilised and sensitised parents to send CWDs to school and take them for medical treatment. It also sensitised different people including teachers to play a more active role in sensitising the community about disability. It worked with other CSOs in different districts to support the commemoration of special occasions such as the International Disability Day, which enabled the children reach the top leadership in order that they might see their values.

Challenges and Gaps - While the baseline survey established that efforts were being made by different actors in providing special needs education and learning opportunities to CWDs, equally many challenges and gaps existed both at national, district and community/home levels. a) Planning and budgeting for SNE done both at national and district levels was inadequate. Lack of up-to-date data on CWDs denied opportunities for effective planning; b) The number of teachers trained in SNE was too small to cater for the large number of children with different types of disabilities enrolled in school especially in inclusive schools. The number of children in classes was equally so big for CWDs did not get attention; hence inclussive education did not provide quality and adeaquate education for CWD in the absence of requalired facilities and teachers c) There were inadequate teaching and learning materials in all schools visited both primary and secondary schools (in both USDC and non-USDC programme districts).

d) The social attitude towards CWDs was still negative particularly among leaders, parents, pupils and teachers with no training or sensitisation on issues of impairment and disabilities; e) The standards for monitoring/supervising SNE both at national and district levels were inadequate. f) The assessment system was found to be unfavourable, particularly to deaf children and those with severe physical impairment; g) Post-primary institutions catering for CWDs were too few to absorb their growing number completing their primary school cycle at the time of the study. h) Parents whose responsibility it was to provide mobility devices were unable because they were largely too poor to afford.

The challenges and gaps identified above showed that education of CWDs needed more support and action from the government and other sources in order to make them equal to the other children. Unless these issues were addressed holistically and quickly, the education of CWDs would remain inequitable.

In Chapter 7, social rehabilitation services were reviewed as provided by government, CSOs, parents/guardians, local community and PWDs themselves. Such services were either provided using appropriate legislation (legal frameworks), or policies and direct social services delivery by caregivers and CSOs.

Policy Framework for Disability - The national social policy framework for disability was provided by/under the leadership of MGLSD in the SDIP 2003-2008 (December 2003). For plan implementation, the following were put in place: a) Social Sector Policy, b) Disability Policy, c) Orphans and Other Vulnerable Children (OVC) Policy, d) National CBR Programme and other relevant programmes in social rehabilitation of P/CWDs. Recent developments in handling disability preferred integration than separation for the P/CWDs to benefit from integrated rehabilitative service delivery (health, education and social healing).

Social Rehabilitation Services for P/CWDs in practice in areas of the survey included the following:

Awareness, Mobilization, Sensitization and Consciousness Building - Social rehabilitation through awareness and consciousness level building, sensitisation, and mobilisation, were done through the provision of information on causes of impairment, management and prevention, available rehabilitative services and to bring forward CWDs for medical treatment. This process helped to transform negative attitudes towards impairment to positive consciousness and passion to appreciate the potential in CWDs. The main social rehabilitation service providers included USDC, the Norwegian Association of the Disabled (NAD), Parents Support Groups and Parents Associations ((PSGs/PAs).

Care and Support - CWDs needed very close provision of care and support services, needing to be fed, clothed, provided shelter, loved and provided stimulation to acknowledge they were part of the family, society or community. Parents were the closest to the CWDs and were the primary caregivers, siblings, neighbours and the community.

Capacity Building - Capacity building was targeted at a) caregivers, b) PSGs/PAs and c) P/CWDs in acquiring knowledge and skills training and life skills. The main service providers included USDC in strengthening capacities of parents, availing rehabilitative facilities at health units, training health personnel in rehabilitative services, training parents for home-based management, post-operative care and building PSGs. UPACLED built capacity of its members on needs of their children with learning disabilities, trained parents in counselling, supervision and to reach out to other parents in their communities such as through radio programmes, newsletters. SSI through CESC facilitated the community to take responsibility for implementing the *onchocerciasis* programme for their benefit, emphasising community sensitisation on use and management of drugs. Child Care International (CCI) provided a home and support to vulnerable children (OVCs), including some CWDs. It provided basic skills to the children in a home environment including agriculture, animal husbandry, and poultry.

Child-to-Child Activities - Child-to-child activities provided social acceptance, relief and support to CWDs. Siblings of CWDs supported them by washing their clothes, giving them food, going to school together, playing with them and helping with the impairment. Classmates/pupils interacted and played with CWDs, shared desks and they elected some CWDs to responsible class/school positions. Extra-curricula activities like sports debate and drama clubs resulted in total inclusion of CWDs and built confidence in them.

Conscientisation - The appreciation of disability involved deeper understanding, diligent and painstaking response through positive change in attitude to embrace passion, equity and equality towards P/CWDs. Parents and PSGs were key in engaging other parents in this sort of support ofor CWDs.

Counselling and Protection - Disability presented a state of trauma to the sufferer, especially in terms of participatory limitations and access to services, and to the family in perception and attitude, especially isolation and being looked down upon. A number of CSOs provided such services to rehabilitate the children of such hindrances. Among them were TPO in Moyo, Adjumani, Gulu and Soroti, FORDIPOM in Moroto.

Lobbying and Advocacy - At national, district and lower governance levels, social development, health and education personnel needed to view CWDs with positive attitude. USDC used these structures to promote inclusion of disability in budgeting. USDC targeted Sub-county and district officials, opinion leaders, etc to integrate and budget for the children. The commemoration of special occasions, e.g International Child Related Day, were used to reach out and lobby top leadership and show potentials of CWDs. USDC quarterly review and planning meetings were equally used for advocacy and lobbying.

UPACLED sought to alleviate two major problems, which children with learning disabilities experienced, namely a) lack of awareness about their abilities, potentials and value to their families and community and b) the attitudes of parents and families towards children with learning disabilities. Advocacy was therefore the main activity. NUDIPU already formed branches in all districts. Using the structures its branches carried out a number of activities. However, not all the union branches were directly targeting CWDs. Child Rights Clubs (CRCs) in schools provided opportunities for CWDs to participate learn, know and lobby for their rights.

Representation of P/CWDs on different councils - The necessary Laws and policies were put in place at national level and appropriately included in the Local Government Act for implementation at district and lower levels. Other laws and policies had been passed to strengthen the position of disability organizations. Representation at lower level was not effective for lack of competence in articulating disability issues in the councils.

Strategic Gaps/Challenges were observed in implementation as follows: a) There was need for more sensitisation on disability issues among parents, community, government and society to appreciate and be knowledgeable about imapirment and disability; b) Men needed to be brought on board to realise the potentials of CWDs to live meaningful lives; c) The spiritual aspects in rehabilitation had not been captured adequately among parents; d) PSGs faced a problem of sustainability as they relied heavily on USDC and support of other donors. They were not adequately linked to government structures. There was inadequate clarity of direction, content and priorities in development of PSGs; e) The CBSD was weak, did not have clear terms of reference (direction) and lacked budgetary and obligatory support from national and district authorities; f) Due to there was strong emphasis on medical rehabilitation without considerations for social rehabilitation. The challenge was one of conceptualising rehabilitation as social, medical, nutritional, educational and skills acquisition where all sectors must be involved; g) Problems of disability tended to recur due to poor nutrition, negligence, etc. h) Most of the community services staff were not trained in disability. The challenge was to determine the focus while establishing clarity of programmes in health, education and social services to fit in CBSD training or orientation;

i) The district local governments were not adequately taking on responsibility of service provision for rehabilitation of CWDs. Disability services were viewed as special, vertical and expensive and a complicated issue that could best be handled by CSOs such as USDCEach local government needed to acknowledge the importance of matching its resources to those of any donor by providing for it in plan and budget; j) In order for concerns of disability to be adequately provided for in plans and budgets, the challenge was to obtain adequate data on the magnitude of disability.

k) Training of community workers to participate in areas such as early detection of impairments, the provision of primary assistance and referral to appropriate services faced challenges of who should provide for them. Expectations of voluntarism in the face of rampant poverty had become void.

Chapter 8 assessed the character of the **inter-organisational relationships** (different forms of cooperation, coordination, and competition) that emerged among the different actors involved in social and medical rehabilitation of CWDs. The survey looked at inter-sector relationships at ministerial and district levels, and government to CSO relationships that included the coordination role of the government. Another level was the relationships among CSOs. Yet another level concerned itself with the nature of relationship between CSOs and the beneficiaries.

Ministries and departments were observed to engage in collaborative activities, which appeared haphazard in nature. This seemed to demonstrate lack of recognition and appreciation for the underlying holistic character of the different organs of the government. Their engament in rehabilitation of CWDs did not clearly articulate, portray and emphasise the inter-relationship and complementarities among government organs for effective functioning. The MGLSD had not come out clearly on the essence of social and medical rehabilitation of CWDs, and its role of providing strategic leadership to draw and engage the other ministries and departments in multi-sectoral and complementary approach in rehabilitation of CWDs.

While the CAOs were aware that their districts addressed issues of disability through CSOs, most of them or their Assistants in the baseline districts were not entirely aware of their role in coordination of rehabilitation services of CWDs. In general district local governments did not show perception of disability as their responsibility; neither did they see it as priority. There were no by-laws and specific programmes initiated by districts to coordinate and streamline programmes and activities of rehabilitation. There was minimal commitment of local government in managing the growing disability in children and adults through establishing understanding of impairment and disability, strategic plans to guide interventions of other actors, and inject budgetary provisions. The government viewed disability services as special, vertical and expensive; a complicated issue that could best be handled by CSOs such as USDC.

Consquently, the government did not provide good leadership necessary to build a more conducive working environment to enable relationships to emerge and evolve in supporting the rehabilitation process. CSOs and the local government entered into non-binding Memorandum of Undertstanding that did not adequately commit the local government. The CSOs lobbied the government as a manifestation that government pronouncement on CWDs might not have been rooted in in-depth commitment and understanding of the devastating effects of social rejection on CWDs. The inadequacy in leadership further did not lead to sector departments to assume responsibility for initiatives started by CSOs, nor did they match their resources adequately with CSOs for more ownership and responsibility to ensure continuity.

The relationships among CSOs had different characteristics. In some districts CSOs took initiative to create informal networking structures to work together to influence the local government to make purposeful provisions for children. However, in the absence of effective leadership to coordinate, streamline, supervise and monitor, the inter-organisational relationships turned into different forms of unhealthy competition, open conflicts and simmering conflicts and dishonesty among CSOs within districts, and unbecoming dishonest practices by local government staff

Tha above situation was fuelled by the fact that CSOs utilised services of the same government staff. There were overlaps in demand for staff, facilitation and areas of catchments in terms of persons or communities targeted in outreach. It would appear that to a large degree the civil servants promoted and perpetuated the duplication and unhealthy competition. While the local government staff appeared interested and committed in rehabilitation work, they took advantage of the many players demanding their services and exploited it in terms of high allowances from different sources for the same work. They were not willing to disorganise the facility by being straight and honest

While there existed opportunities for organisations providing rehabilitation services to be coordinated by those with network character in specific sectors like education or health or disability movement, they were hampered by suspicion, and probably lack of clarity in shared essence of rehabilitation of disability.

The nature of relationship between CSOs and the beneficiaries to a great deal depended on the motives and commitment of the CSOs, and clarity of conception of the essence of their intervention. The consultants were of the view that the primary purpose of any intervention for the sustenance and development of CWDs needed to adopt approaches that helped the CWDs to be freed of their inner hindrances. Such interventions would enable the disabled become creative and make their own future. The parents, siblings and other family members, and the society equally needed to be freed of their attitudes, guilt and other hindrances in their relationships with CWDs

The survey findings highlighted various types of relationships between CSOs and the beneficiaries. There were relationships of respect for experience, learning and empowerment observed in the relationship of CSOs such as USDC and SSI. Such were exemplified in the respect for the role of parents in order to ensure continuity of rehabilitation process to the children. Parents were facilitated to learn and own the learning and healing (rehabilitation) process of the child. The approach promoted peer engagement in horizontal relationship and learning with mutual understanding among parents. It liberated latent relationship of inter-dependence, self-reliance and generosity with the USDC, with CWDs and among parents. Such were also the relationships where the approach involved facilitating the community in taking up responsibility for decisions on how to implement the *onchocerciasis* programme supported by Sight Savers International through CESC for the benefit of the community.

Some CSOs relationships with beneficiaries were 'sweet coated' as providing genuine support to disabled persons, while fraught with underlying exploitative tendencies. The emphasis was on material benefits but short-lived. Such relationships focused on making impressive, projected and exaggerated impact, by exaggerating the numbers of beneficiaries they worked with to win donor funding and government attention. These relationships did not develop inner abilities, capacities and consciousness about understanding the oppressive hindrances of disability, to enable the CWDs to take responsibility for managing their own situations in the future.

The government-beneficiary relationship was characterised mainly by indifference by its inadequacy in taking responsibility to raise awareness about the existing problems, yet it had structures for information and sensitisation up to grassroots levels. Unfortunately, the interventions in exploitative and indifference were rather linear with limited consideration for the holistic and complex nature of human development. Parents also engaged in relationships of dishonesty by obtaining funds from CSOs for treatment of CWDs, but put them to other usage.

Chapter 9 dwelt on the overview of various presentations on interventions in social and medical rehabilitation of C/PWDs to determine impact of rehabilitation activities, answering the question, **'Are the actions at the intervention level leading to improvements in the lives of children (people) with disabilities at the lower levels?'** In accordance with the TOR, the survey sought to determine the positive changes leading to trends in improvements in the lives of the children from four broad areas of assessment, namely, a) if levels of non-discrimination had been reached; b) if they were in the best interests of CWDs; c) if CWDs could be said to participate in various aspects of life, and d) if all was well for the survival and development of CWDs.

Family life of P/CWDs and Social Acceptance: Chapter 3 presented social rejection and scapegoat attitudes of parents and society at large, because parents experienced frustration at failure to determine how to deal with the situation of impairment in their children. They lacked information, knowledge and support in how to manage impairment and disability. In a few informed and knowledgeable homes CWDs were loved, given proper care and protection and stimulated equally to develop

Considering that information is light, strength and wealth, it was a measure to promote change in negative attitudes towards impairment and the challenges of parenthood of CWDs, especially of girls with disabilities. Mentioned elsewhere, USDC through its Disability Information and Education strategy involved and engaged many actors in multi-disciplinary approach to reach P/CWDs, parents and the public with full information and documentation on impairment and disability, diagnosis of different types of impairment, rights and services available, the value of rehabilitating CWDs in order to develop their potentials to live self reliant life and cease to be dependant.

Information to parents was not discriminatory to the extent that all those who attended outreach clinics listened to and were sensitised on disability. Those who did not attend outreach clinics; those who could not read and those with visual or hearing impairment did not access such information unless provided in appropriate form, due to lack of appropriate technological considerations to access information and documentation.

SSI through CESC sensitised people to understand that some causes of visual impairments could be dealt with by the community, hence the importance of using the drugs continuously and be managed by them.

Impact of Access to Information: Viewing the information and documentation provided against the USDC strategic objective of ***"Increased awareness on disability issues among policy makers, professional staff and communities in order to promote more positive attitudes and better understanding of disabled children's needs"***, it could be said that the strategy contributed to creating awareness and raising levels of consciousness to cause change of attitude where PSGs existed.

Respondents among parents and government officials affirmed that people increasingly became aware of the need and opportunities to develop potentials of CWDs in order to involve them in social processes. Parents received knowledge and skills, which enabled their attitudes to positively, change. The change enabled parents to manage impairment and disability and the healing processes of their children. They began to experience appreciation of the impairment in their children and potentials of the children that could be developed.

USDC support to parents in the formation of PSGs created links among parents to inform and support each other; and among parents or PSG and the wider community to inform them of the existence of opportunities and services for rehabilitation of CWDs.

Children received attention and experienced love, care; and benefited from the parental desire to make them benefit equally with other children. This was a best practice in dealing with rehabilitation of CWDs. Many of them became better or were rehabilitated. They gained social acceptance in both the family as equal participants and within the community. The healing promoted full participation of PWDs in family life. Parents provided opportunities for the children to access education and to learn to write.

As the Director of Kampala School for the Physically Handicapped said, ***'Parents are the first in lives of CWDs. If they love them, they will be loved, but if they reject them, the CWDs will also be rejected by the society. When the parents love their CWDs, they will support their education'***. .

Impact of Interventions in Medical Care was observed in changes in accessibility tomedical rehabilitation services, improved mortality and improved developmental milestones in the children with disabilities.

Changes in Accessibility of Health Service: In Chapter 5, a number of CSOs, particularly, USDC, which focused on children, SSI, CUAMM, AVSI, the Churches and others, supported medical rehabilitation of CWDs in one way or other. USDC supported districts in ensuring availability of services in terms of infrastructure, facilities and equipment, availability of skills and knowledge at all levels of government, families and parents, geared towards attitude change. This contributed to the second strategic objective of USDC, i.e ***'....increased capacities within government, local organisations of PWDs and empowerment of parents and families enable them to participate in the rehabilitation of CWDs and integrate services for children within mainstream planning and development processes".***

The attitude of health providers who were sensitised towards CWDs changed a great deal. The support received by the families and siblings, and health workers led to more spontaneous referrals by parents, community leaders and frontline health workers. This boosted acceptance and confidence of CWDs within families, often with empathy. Many CWDs in USDC districts were medically rehabilitated after receiving rehabilitative medical services through surgery, drugs and care. As more people were conscientised, more CWDs accessed medical services. Many were healed and the severity of some of the impairment reduced

However, due to the mismatch between the quantities of services provided compared to the very large burden, many CWDs did not access adequate services that hindered accessibility to medical services to enhance rehabilitation. Where the health units proved unhelpful, parents in dilemma took the CWDs to be tortured through alternative treatment with traditional healers. Hence, despite what appeared to be some levels of change in consciousness and awareness among the public evidenced in the spontaneous referrals, discrimination still occurred when it came to commitment of funds for tangible health services. The impact of interventions so far had not had deep lasting impact on resource commitment to service delivery.

The change in the attitude and perception of parents had its limitations in social reintegration of CWDs. The dire poverty many families lived in imposed limitations in access to social services that were important for full inclusion of the child.

Mortality and Improved Developmental Milestones: Most of the parents interviewed in the PSG expressed satisfaction and in many instances happiness at the growth and development the child had made since identification and initiation of home-based programmes or surgery.

Provision of rehabilitation services not only improved the quality of life of the CWD (reducing chances of death) but improved the development and chance of survival. This was an indication that when developing child survival programmes based on several initiatives such as immunisation, management of fevers, child nutrition and child health days, it was important that the issues that increase vulnerability of CWDs to early death, poor or no development were addressed. The mainstreaming of CWDs in such programmes would underscore their right to life and promote positive support from the parents

Challenges of Re-thinking Care

The ideal situation for approach to service delivery would be that of providing child focussed services that put the interest of the child and concerns of the parents first. The advances in expansion of CBR had not changed the approaches used in service provision which still rotated around the best interest of the health worker and his/her perception of what was good for the child.

There was need to change the paradigm to service provisions so that a rehabilitation health worker with broad skills could manage the multi-impairments a child with cerebral palsy and refer only what was difficult. This required overhauling of both general and rehabilitation health workers training or creating a new cadre with a different outlook that put the child and parents before their own rehabilitation plan

Impact of Intervention in Education: CWDs were provided opportunities to learn through three major different educational settings *Special Schools* increased in focus, numbers and general attention with adequate teachers, materials, equipment, friendly environment both social and physical, and other facilities. These schools could be considered to be non-discriminative because they demonstrated how positive attitude of care, protection, facilities to enable them learn and move, availability of teachers together with learning and teaching materials served the best interests of CWDs. This promoted quality education and participation among the CWDs and SNE teachers in the learning process.

However, the costs discriminated against the poor particularly those living in rural areas because they could not access the special schools. The isolation denied interaction with 'able' children keeping them from socialisation and being accepted by other normal children for a long time during the essential prime years. This situation was necessary for severe disabilities such as cerebral palsy and mental illness only.

Integrated schools in most cases offered materials and equipment for learning and teaching and enabled them to mix with the other children during some activities. The limited number of teachers who were at the same time full time teachers for the mainstream school posed challenges of over working and inadequate time to teach the CWDs. However, separating them from their peers in different classrooms socially isolated them.

The inclusive/ mainstream settings with facilities for CWDs offered them opportunities to interact with other children, to play together; share learning and other things with the 'able-bodied'. However, the high teacher/pupil ratio and inadequate materials and equipment did not permit the CWDs to receive adequate attention to take them at their own pace of learning. This limited their participation in the learning process.

Social Acceptance within School Environment: Self-esteem of CWDs stemmed from social acceptance which included support given to manage their environment. A sensitised school environment provided mutual acknowledgement of the need to support each other among mixed society of CWDs and 'able children. They were helped with work such as washing, collecting water and reading notes. However, in situations of no sensitisation the teachers shunned CWDs particularly as they had difficulties understanding how to manage them.

The child rights clubs provided opportunities for mainstreaming and integration of children with disabilities and their participation in the same learning environment with non-disabled children. Each non-disabled child took responsibility of ensuring the welfare of his or her friend with impairment and stood up for them.

There was growing interest and anxiety among informed and conscientised parents to monitor progress of development of their CWDs. However, many schools systems did not emphasise or provide for adequate and free interaction between parents and teachers in the educational development of the CWDs.

The provision of assistive devices and equipment to enhance their mobility to achieve the equalization of opportunities was parents' responsibility. This situation discriminated against majority of children with severe physical impairments from poor families, who required assistive devices.

Translation of Policies into Implementation: Although the constitutional and legal provisions for families to provide specific care (basic education, medical treatment, or any social or economic benefit) for CWDs existed. the consultants did not come across any evidence to the effect that the state provided programmes to promote the rights of children to respect and dignity within the families to ensure that there was no discrimination against parenthood of CWDs. The majority of parents had no access to legal provisions on the rights of children and so did not know them in order to advocate for them. The provision of information and documentation for awareness creation among parents and children was basically done by CSOs and on a small scale due to resource limitations of the committed CSOs.

The ***inclusive education policy*** and other legal frameworks mentioned in Chapter 4 acted as a catalyst to interest both parents to send their children to school and for teachers, administrators and SMCs to accept CWDs and provide for their special needs. However, the enforcement of these policies in MOES, District Local Governments and in schools left much to be desired. The laxity left pre-primary education of CWDs outside any provisions for education of CWDs. Hence the children delayed and often started at a late age.

The political window dressing character of the policies, SNE received inadequate budgetary provisions to re-train enough teachers and provide adequate scholastic materials and equipment for CWDs to access equal opportunities for learning and teaching.

The study showed that the environment provided at schools and their learning was knit together. What was further required was allowing for curriculum flexibility, addition and adaptation; providing for quality materials, ongoing teacher training and support to teachers.

Unless the different inadequacies were addressed so that all CWDs learnt in an environment with teachers qualified and sensitised teachers in disability, they were enabled to access and use all the necessary educational materials and equipment, they were enabled to learn using a fair curriculum and were assessed on an assessment system that took into consideration their different disabilities; unless they were availed mobility devices; and were learning in an environment that promoted social acceptance, it would not be possible to speak of no discrimination, best interests, participation, and whether all was well for survival and development of CWDs.

The absence of accurate data on the extent of disability paused challenges in determining the exact numbers of CWDs.

The Chapter did not hide the fact that there were still barriers to equalisation of opportunities for CWDs to contribute to the development of their communities; therefore cease to be treated as dependants. USDC demonstrated efforts to ensure all CWDs had equal opportunities to medical, educational rehabilitation, and acceptance by the communities to enable them participate in community development activities which they were part of.

In **Chapter 10**, the quantitative data determined the progressive support USDC and other organisations supporting CWDs, made in contributing to changes the CWDs were experienced in accessing resources and opportunities to enable them achieve their full potential. It also established a general picture of the different categories of CWDs and by district, general levels of accessibility of services and information. It contributed to establishment of a database, particularly on CWDs, levels of service availability and gaps.

This was probably the first time a comprehensive baseline study of the disability area had been undertaken. There had been sectional studies or reviews undertaken by service providers to P/CWDs (e.g USDC study on Accessibility and Relevance of Education for Children with Disabilities in Uganda – October 2003) and mainly in the process of their respective work programmes. It was generally observed that most, if not all, programmes of services related to disability were prepared and implemented without background statistical information. The main reason for such kind of situation was the supply driven nature of such interventions (programmes). Some programmes implemented by agencies/CSOs such as UNICEF, Save the Children, World Vision, etc, targeted children in general and amongst them there was no indication of targeting CWDs in particular or as a component of such programmes.

In conclusion in **Chapter 11**, the study assessed the levels of perceptions and consciousness or values that engaged different stakeholders in supporting CWDs, which held them (committed or not) together in complementarities or collectively or even apart from each other, giving indications of where strengths or weaknesses existed, and the challenges and gaps were. In terms of context, rehabilitation processes by USDC, Sight Savers International through CESC and the model CBR programme in Tororo, were not limited to addressing impairment, but tackled the social contextual limitations that affected inclusion and participation as well. The motives and commitment demonstrated clarity of conception of the meaning of their intervention hence, relationship of respect for experience, of learning and

empowerment. It liberated latent relationship of inter-dependence, self-reliance and generosity with USDC, with CWDs and among parents.
The consultants were of the view that the primary purpose of any intervention for their sustenance and development needed to adopt approaches that helped the CWDs to be freed of these inner hindrances of oppression, rejection and denial that lay beneath the relationship between them and family members, between them and the society; enable the disabled become creative and make their own future. This bred in them fear, self-doubt, self-hatred and other deep consequences of deprivation, oppression and abuse.

Recommendations: In response to the critical challenges identified in interventions in social and medical rehabilitation of CWDs under each Chapter above, the consultants made the following recommendations

For successful and sustained rehabilitation of CWDs, USDC needed to strategically think about approaches and strategies that send out strong advocacy to engage the government and other development partners with commitment to appreciate issues of disability in children to be addressed at early age and avoid or limit disability in future.

Laws and frameworks were put in place by government to support disability. They need to be beefed up with more definitive legislation and by practice in terms of implementation with appropriate guidelines provided to local governments. .

A framework for capacity building and coordinated and sustainable data collection on P/CWDs, analysis, storage and dissemination was needed to be developed. Impairment/disability should be documented by type/category and the extent of rehabilitation, to be able to make more informed decisions and initiate development in those areas for the central and local governments to embrace. .

In ***health and disability***, the ***recommendations*** emphasised adequate and sustainable medical services that should include provisions for rehabilitation of the impairment and social disability. This entails that the government should prepare medical workers for mainstreaming health services to CWDs, bring the services closer to the people for their easy access so that parents would be encouraged to support medical rehabilitation of the CWds. At community level, engage rehabilitation services as close to the community as possible and provide a resource for advice to parents when outreach teams. It also entails strengthening health rehabilitation services in missionary/ private and government hospitals and lower level health centres. It further entails sensitising health workers and parents to embrace this responsibility understandably. It is argued that such rehabilitation services should be provided for all the different types of disabilities.

The ***recommendations*** on ***education and disability*** called upon the government to make deliberate effort in terms of planning, adequate budgetary provisions and supervision, to embrace practical responsibility of providing quality education for CWDs through provisions for materials, equipment and learning environment to afford them equal opportunities to learn. This includes subvention grants, training more teachers to acquire sufficient knowledge and skills to teach both CWDs and without, monitoring and supervision using SNE focused tools, Favourable

Assessment System for CWDs; post-Primary Institutions for CWDs, provision of educational materials for children with special learning needs; adoption of total communication as a policy in both primary and secondary schools; home care for the very severly impaired; emphasis on Socialisation of CWDs with Other Children, and all other such requirement for equal opportunities.

Social rehabilitation of disability: In general, MOH, MOES and MGLSD to come out clearly on conceptualising the rehabilitation of CWDs as social, medical, nutritional, educational healing and skills acquisition, where all sectors must be involved. The CBSD needed to articulate its role very clearly in steering social rehabilitation across/within the respective sectors and in different areas where it was supposed to be working. The clarity would help to promote consciousness about complementarities and sense of collective responsibility, and recognition for each other's professional contribution to joint efforts to rehabilitate CWDs

Disability needed to be appropriately placed to gain recognition and adequate budgetary provisions and to emphasise social rehabilitation and the cross-cutting nature of rehabilitation. MOES, MGLSD and MOH needed to come out clear on the interconnectedness and inter-linkage within their professional areas and embrace the nature of collaboration, cooperation and complementarities that exist between their ministries through practice. MGLSD should specifically develop concrete guidelines for mainstreaming disability. Dissemination of such guidelines and policies should be education-oriented and not just sensitisation, especially for technocrats (such as DRO, DDHS, DEO and their respective departmental teams),

There was need for a continuous process of reorientation of different structures and processes (both civil society and government) in articulating and mainstreaming issues of disability and of setting up a process of continuous monitoring of the disability issues so that disability was perceived and approached as part and parcel of ordinary life that must be provided for with specific emphasis within the normal activities.

In order for the government and all stakeholders to engage meaningfully with CWDs and disability as a whole it is emphasised that there was need for collecting quality data on disability.

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CHARTS

MATRICES

PANELS

ABBREVIATIONS AND ACRONYMS

AAH	*Afrika A. Hilfe*
ABEK	Alternative Basic Education for Karamoja
ACAO	Assistant Chief Administrative Officer
ADEO	Assistant District Education Officer
AVSI	Association of Volunteer Services Overseas
CAO	Chief Administrative Officer
CBM	*Christofel Blinden* Mission
CBO	Community Based Organization
CBR	Community Based Rehabilitation
CBSD	Community Based Services Department
CCI	Child Care International
CCG	Classroom Completion Grant
CCM	*Comitato di Collaborazione Medica*
CCT	Centre Coordinating Tutor
CDA	Community Development Assistant
CDO	Community Development Officer
CECS	Comprehensive Eye Care Services
CO	Clinical Officer
CSO	Civil Society Organization
CWDs	Children with Disabilities
DDC	District Disability Council
DDHS	Director District Health Services
DDP	District Development Plan
DHMT	District Health Management Team
DPAR	Disability Prevention and Rehabilitation
DPO	Disabled People's Organization
DPU	District Planning Unit
DRO	District Rehabilitation Officer
EMIS	Education Management Information System
ENT	Ear Nose and Throat
ENT CO	Ear Nose and Throat Clinical Officer
ESA	Education Standards Agency
ESC	Education Service Commission
ESIP	Education Sector Investment Plan
FAWE	Forum for African Women Educationalists
FENU	Forum for Educational NGOs in Uganda
FGD	Focus Group Discussion
FORDIPOM	Foundation for Rural Disabled Persons Organization for Moroto
GOVT	Government
HC	Health Centre
HMIS	Health Management Information System
HSC	Health Service Commission
HSD	Health Sub-District
HSSP	Health Sector Strategic Plan
ICF	International Classification of Impairment, Disability and Functioning
IT	Itinerant Teacher
KII	Key Informant's Interview
LAN	Lions Aid Norway

LC	Local Council
LGDF	Local Government Development Fund
MEF	Macro-economic Framework
MFPED	Ministry of Finance Planning and Economic Development
MGLSD	Ministry of Gender Labour and Social Development
MOES	Ministry of Education and Sports
MOH	Ministry of Health
MOLG	Ministry of Local Government
MORAs	Mobility Orientation Rehabilitation Assistants
MOU	Memorandum of Understanding
MS	Medical Superintendent
MTBF	Medium Term Budget Framework
NA	Nursing Assistant
NACWOLA	National Association of Children and Women Living with AIDS
NAD	Norwegian Association of the Disabled
NCC	National Council for Children
NGO	Non Governmental Organization
NPBC	National Prevention of Blindness Committee
NPHC	National Population and Housing Census
NUSAF	Northern Uganda Social Action Fund
OA	Ophthalmic Assistant
OCO	Orthopaedic Clinical Officer
OURS	Organized and Useful Rehabilitation Services
PCO	Psychiatric Clinical Officer
PDC	Parish Development Committee
PEAP	Poverty Eradication Action Plan
PHC	Primary Health Care
PIP	Public Investment Plan
PLE	Primary Leaving Examinations
PNO	Psychiatric Nursing Officer
PRSP	Poverty Reduction Strategy Paper
PS	Primary School
PSC	Public Servise Commission
PSG/PA	Parents Support Group/Parents Association
PTA	Parents Teachers Association
PTC	Primary Teachers College
PTSD	Post-Traumatic Stress Disorder
PWD	Person with Disability
PWE	Persons with Epilepsy
RDC	Resident District Commissioner
SCORE	Scaling up of Community based Rehabilitation. A rehabilitation project in Northern Uganda implemented by MOH, AVSI, CCM and CUAMM
SFG	School Facilities Grant
SMC	School Management Committee
SNE	Special Needs Education
SNECO	Special Needs Education Coordinator
SS	Secondary School
SSI	Sight Savers International
TBAs	Traditional Birth Attendants

TPO	Trans-cultural Psychosocial Organization
UBOS	Uganda Bureau of Statistics
UHRC	Uganda Human Rights Commission
UNAB	Uganda National Association for the Blind
UNAD	Uganda National Association for the Deaf
UNISE	Uganda National Institute for Special Education
UPACLED	Uganda Parents Association of Children with Learning Difficulties
UPE	Universal Primary Education
USDC	Uganda Society for Disabled Children
VHT	Village Health Team
YCC	Young Child Clinic

CHAPTER 1: INTRODUCTION

Uganda Society for Disabled Children (USDC) is a local NGO in Uganda involved in the medical and social rehabilitation of children with disabilities in Uganda. The society's mission is **to help children with disabilities and their families to access resources and opportunities to enable them achieve their full potential.** USDC's long-term vision is **a society in which children with disabilities have equal rights and equitable opportunities for growth and development.** Underpinning this is a belief in the uniqueness of each child, and a people-centred approach to development.

The main thrust of USDC's strategy has been to increase the integration of services for CWDs in mainstream planning, budgeting and development processes at all levels of government in Uganda, in other words, trying to remove societal barriers that stopped CWDs from benefiting from integrated services. USDC implemented this strategy in 13 administrative districts and two districts of partnership. USDC was guided by the following four strategic objectives:

a) The first strategic objective was increased awareness on disability issues among policy makers, professional staff and communities in order to promote more positive attitudes and better understanding of disabled children's needs. Disability information and education activities were carried out at national, district and lower levels, to help give information about disabilities to policy makers and implementers, PWDs and their families and the general public. The aim was, in the long run, to influence perceptions, attitudes, and consequently decisions, plans and policies at different levels in favour of CWDs.

b) The second strategic objective was increased capacities within government, local organisations of PWDs and empowerment of parents and families to enable them to participate in the rehabilitation of CWDs and integrate services for children within mainstream planning and development processes. For this to happen there must be appropriate capacity at different levels to do so. Increased capacity within the government, local organisations of PWDs and empowerment of parents and families was a way to enable them to participate in the rehabilitation of the disabled children in their care, and encourage others to do likewise. Capacity building here encompassed a number of areas among others:

i) Supporting the provision of medical rehabilitation services through training of staff, provision of physical facilities and equipment,
ii) Integrating CWDs into mainstream schools through removing different barriers to their learning, teacher-training, provision of special equipment, improving physical environment within schools to increase accessibility and strengthening support supervision by EARS staff, etc., supporting skills training so as to enable children grow up into productive and independent adults,
iii) At the grassroots level parents and families were empowered through training to assist the CWD in the home, local council representatives were empowered through transfer of knowledge and skills necessary to enable them assist such families with advice or referrals. PSGs and CRCs were formed, encouraged and supported through training as a means of providing mutual support and as a voice for the children, respectively,
iv) Direct support to individual disabled children and their families to enable the children to access essential rehabilitation services.

c) The third strategic objective was increased policy advocacy and lobbying activities to influence official policies and activities in favour of CWDs. The aim here was to encourage policy makers and implementers to take needs of PWDs into consideration in decision-making, drawing plans or formulating policies. This was the only means of achieving true integration of services for CWDs.

d) The fourth strategic objective concerned improvement in the collection, management and dissemination of disability information so as to inform policy and planning within USDC and in partner organisations. The disability information and education activities had been carried out at national, district and lower levels to help give information about disabilities to policy makers and implementers, PWDs and their families, and the general public. The aim was, in the long run, to influence attitudes, decisions, plans and policies at different levels in favour of CWDs.

The USDC programme districts have since been expanded to include another two districts in partnership (consortium) in the area of mental health, thus making them 15 in total.

This particular baseline survey was aimed at establishing a broad picture of the overall situation with regard to the disability area in Uganda and special emphasis on CWDs, to identify gaps and challenges and provide strategies for the next USDC strategic plan.

1.1 Background and Relevance of the Study

USDC began its initial programme by providing small-scale welfare help to disabled children and their families. Later it adopted a community-based rehabilitation (CBR) approach in the 1990s. USDC's 1994 Country Strategy was implemented until April 2000 when another review was carried out, which gave rise to the current country programme enshrined in the Strategic Plan for the period 2000-05. The Country Strategy was based on the achievements of the previous 15 years, as well as on general development in the country, in terms of disability awareness and the potentials offered by new resources flowing into government sectors as a result of the sector wide approach (SWA).

USDC believed that a lot of factors had changed in the wider environment during the five years of implementation of the Country Strategy that had direct effect on the effectiveness, relevance and longer-term impact of its programme. It was, therefore, within this context that USDC planned to scan the wider environment through a baseline survey so that it would be able to relocate itself strategically within the environment and to remain relevant and effective in terms of its Country Programme.

The baseline survey assessed the current status of CWDs in 24 districts of Uganda as a result of the work of the different actors; including government, international agencies, CSOs and the private sector over the years. Specifically the exercise assessed changes in three main areas in answering the following pertinent questions or concerns:

a) Was there higher-level cumulative impact in bringing about social change and greater inclusion of P/CWDs in society?

b) What actions had been taken at the intervention level (policy) to change the situation for P/CWDs as a result of the higher level changes in depth of understanding disability, perceptions and attitudes, while determining who was involved?

c) Had the actions at the intervention level led to improvements in the lives of P/CWDs at the lower level? (Both medical and social healing of the CWDs and the social environment).

1.2 Purpose of the Survey

Overall the survey assessed the wider programme environment, for purposes of determining the future programme strategy of USDC.

1.2.1 Specific Objectives

- To establish benchmarks against which to measure and assess its future work with disabled children in the country.
- In broad terms to assess the impact of USDC's work over the years in the main programme districts.
- To identify priority needs and strategic gaps in provisions for CWDs to facilitate development of a new Country Strategy for USDC.
- To document best practices and lessons learnt from USDC's work and the work of other actors that would inform the process of strategy development within USDC and other organisations.

The survey assessed the current status of CWDs in Uganda as a result of the work of the different actors in the country. It therefore assessed the status in the following three main areas:

- Awareness, knowledge, perceptions, beliefs and attitudes with regard to disability as this, to a large extent, determined preventive actions and what could possibly be done for CWDs,
- Rehabilitative healthcare for P/CWDs as this, to a great extent, determined accessibility of education or skills training for CWDs, and
- Education and skills training of CWDs as this was a key determinant of productivity and independence thus social integration in the longer run.

Changes in the above three areas included perception and attitude towards CWDs, the strengths, weaknesses, opportunities and the challenges, which USDC faced.

The Survey had Five Inter-related Components, namely:

- *Baseline survey* of disability in USDC programme and non-programme districts as well as an audit of other stakeholder activities (qualitative and quantitative) that led to improvements in the lives of CWDs in order to establish a broad picture;
- *Situational analysis* to identify priority needs of and establish strategic gaps in provision for CWDs and determine USDC's comparative advantage;
- *Record good practices* of different organisations in working with CWDs;
- *Determine the effectiveness of approach and methods* of different organisations in working with CWDs; and
- *Assess the impact of USDC* work in broad terms in order to determine how USDC contributed to the current improvement in the status of CWD and establish if USDC was on the right direction. This would help to determine

how the structure of social relations and governance was transforming towarthe CWDs indicating the future direction. The process involved broad assessment of programmes of other stakeholders in order to determine the effectiveness with which issues of CWDs were being addressed.

The survey established understanding of the wider context within which USDC operated and how the environment impacted on USDC work. It provided relevant information on CWDs to facilitate advocacy for mainstreaming disability issues in planning processes at various levels.

1.3 Consultants' Interpretations

The broad picture should bring out both quantitative and qualitative information on CWDs in study areas. Quantitative data collection was to include such information as numbers of CWDs per district, desegregated by disability type; CWDs in school or out of school; health seeking patterns; interventions by numbers, categories and by whom. Meanwhile, qualitative information on changes in the main question areas above included, trends such as in perception and attitude towards CWDs, the invisible driving activity or force underlying the promotion of or hinderance to transformation of the structure of social relations in relation to CWDs; and the strengths, weaknesses, opportunities and challenges, which USDC faced.

SECTION I

METHODOLOGY

CHAPTER 2: STUDY METHODOLOGY

2.1 Scope and Rationale for Selection of Districts

2.1.1 Scope – Theory behind the Study

Being a predominantly qualitative study, the sampling and selection was largely *purposive.* One of the justifications for purposively sampling the 24 districts was based on the theoretical scope of the study. As Fadlalla (1986) observed, given the theory and the methodology used, data collection would vary a great deal depending on the nature of the research problem and the objective of the research itself[1].

In terms of theory, our understanding of disability evolved from a 'normative' medical approach of the disabled population to a 'social model' that took specific interest in difference and socio-economic and cultural outcomes thereof within the disability community. The social model was humanist in that it took economic, cultural, attitudinal, physical and social barriers as the key variables to be *unpacked and re-interpreted* and not to be *counted* per se. Basing on this 'humanist' theory of the study population, the scope of analysis ceased to be *statistical* and became mainly social in nature; and for that matter, also ceased to be based on the *quantities* of the study population but rather an interest in its intrinsic *qualitative* dimensions.

Holliday (2002) described the focus of the qualitative approaches to research as one that described actions within a specific setting and invited rather than tried to control the possibility of a rich array of variables. The key interest was in making sense of human relationships and invoked the need to discover as much about how research subjects felt about the information they provided as about the information itself. Indeed, the people about whom the research was carried out were less 'subjects' than 'participants'. It was these qualitative areas in social life – the backgrounds, interests and broader social perceptions, which defied quantitative research that qualitative research addressed[2].

2.1.2 District Selection - Why Districts were sampled purposively

As Holliday (ibid) further explained, qualitative research located the study within particular settings, which provided opportunities for exploring all possible social variables; and set manageable boundaries. This explained the 15 USDC districts. Hence the second justification was that, by implication therefore, the terms of reference already desired a predominantly qualitative field based approach.

a) The 15 USDC Programme Districts

First and foremost, the districts were purposively selected basing on the client's demands to ensure the inclusion of the 15 USDC programme districts. The purposive inclusion of the USDC programme districts was very important in as far as they generated results that not only described and assessed USDC's programmes in those districts where it had long term occupancy, but also provided an avenue for a *comparative* analysis of USDC services with those of other stakeholders operating

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[1] Fadlalla O.M. Bashir and Kiros G. Fassil (1986) *Research Methods in the Social Sciences: A quest for Relevant Approaches for Africa,* Khartoum: OSSREA.

[2] Holliday Adrian (2002), *Doing and Writing Qualitative Research,* London, SAGE Publications

disability related services within the very districts. This was important since the situational analysis component of the survey intended to build a picture to inform USDC's future strategic plan in view of how they compared with others in terms of comparative advantage.

Statistically, the purposively selected 15 USDC programme districts already constituted more than over 10% of the total districts (56) in Uganda. This in itself rendered it impossible to justify any pretence at probability or random sampling. The latter would assume that all characters in a study population should have equal probability of being included in the sample. Secondly, even if the geographical scope of USDC programme districts was not the parameter, we still bore in mind the fact that much as USDC might interest itself in PWD population of Uganda as a whole, its specific constituency was that of the disabled children in the country.

However, this was a population that was unknown in terms of its proportion within the 'equally' unknown population of PWDs in Uganda. Once ignorant about the overall statistical population it became impossible to justify a scientific sample against no background population data. Thus in selecting the 24 districts, we were here mindful of the fact that neither UBOS nor any other credible research or academic institutions were yet to provide any census or otherwise generaliseable statistics of the disability population of Uganda.

Instead, as researchers, we were still forced to deduce the population of the PWDs from percentages based on either WHO index that the disability population constituted 10% of the world's population or the formula as used in medical circles (that suggested that the PWDs population was 4% of the world's population) none of which provided a credible basis for random statistical sampling.

b) Additional 8 Control Districts for Institutional Triangulation

Additional 8 non-USDC programme districts were added to the 15 USDC because the study also had an institutional dimension to it. Besides the experiences of individuals with disabilities, however, USDC wished to use the study to assess its comparative presence in terms of relevance and comparative advantage over other stakeholders in the disability movement in the country. To obtain an objective picture on this, purely researching USDC programme districts would only provide a one-sided picture – that of how USDC was rated against other organizations in its programme areas. Thus it was useful to have insight in non-USDC programme districts, where views would probably differ in that they might not even know about USDC at all. However, in selecting these 8 control districts (in agreement with USDC), we took care to ensure they were regionally balanced to provide socio-economic and development variability of the study areas.

c) Ethnic Experiences

The other justification for a purposive sample required substantial elaboration that was the fact that the bulk of the information required from respondents was more perceptive than statistical. We were keen into unforeseen areas of discovery within the lives of children and other people with disabilities rather than 'general' characteristics of this population. A mere quantification of numbers of PWDs and the perhaps even smaller population of children in them could only reinforce their 'insignificance' in the general population, which wasn't the point of the study. Our point was to 'magnify' through exploring ethnic glimpses, illuminate them and interpret the lives, conditions and services accessed by PWDs through them.

2.2 Justification of the Study Area

In conclusion, the baseline survey was aimed at getting a broad picture of the situation within the disability area in Uganda, with special emphasis on CWDs. In that respect, therefore, the survey did not limit itself to the USDC programme districts but looked at the whole country triangulated from a small purposive sample. The study was conducted in 24 districts – 15 USDC programme districts out of which two were districts of networking with other CSOs on specific mental programmes and 9 non-USDC programme districts including Kampala.

Other criteria for purposive selection of the study areas *as discussed with USDC* were as follows:

a) regional representation;
b) districts where other organizations were working with CWDs, especially where the government had programmes for CWDs; .
c) districts that had groups of people with unique and strong cultural and livelihood practices having impact on CWDs;
d) districts with experiences of conflicts and with regional representation, hence specific effects on areas of disability;
e) uniqueness of geographical and development conditions in location, and
f) districts without proven disability services.

2.2.1 Districts clustered by Planned Flow of Implementation

The study districts were clustered to ease the implementation of the survey (see list of the selected districts in Matrix I below) together with criteria applied and the work plan.

Matrix I: Sample of Districts Clustered by Planned Flow of Implementation

Cluster One	***Selection Criteria***
Nebbi	USDC District
Arua	USDC District
Yumbe	USDC District
Moyo	USDC District
Adjumani	USDC District
Cluster Two	
Luwero	USDC District
Nakasongola	USDC District
Masindi	USDC District
Hoima	USDC District
Apac	USDC District
Lira	USDC District
Soroti	USDC District/Networking with other Partners
Kotido	Non-USDC District/No Disability Services/Unique Cultural Practices
Gulu	Non-USDC District/District in Conflict Area
Cluster Three	
Kabarole	Non-USDC District/Regional Representation/No Disability Services
Kasese	Non-USDC District/District in Conflict Area, regional representation
Ntungamo	Non-USDC District/Regional Representation/ Govt. Programme to get after effect.
Sembabule	
Masaka	USDC District
Kalangala	USDC District

	Non-USDC District/No Disability Programme/Unique Island Situation
Cluster Four	
Kapchorwa	Non-USDC District/ Govt. Programme/Regional Representation/Unique Cultural Practices
Tororo	Non-USDC District/Govt. Community Based Rehabilitation Programme/Regional Representation
Jinja	USDC District/Networking with other Partners
Kampala	USDC District/Head Office

2.3 Duration and Phasing of the Survey

The survey was originally, scheduled to be implemented in a total of 53 days spread over a period of nine months from the date of commencement. However, it took more time due to the intensity and thoroughness of the work done. It was a four-stage process guided by the external facilitators.

2.3.1 Phase 1: Preparatory Phase and Initial Meetings 6–25th January 2005

Prior to the start of the field exercise, the consultants had preparatory meetings with USDC staff in Kampala (especially the Executive Director and the Field Director) to give the Consultants opportunity to gain a clear understanding of the assignment; to review the existing information; and workout modalities and detailed schedules for the whole survey process. As this was planned to be a participatory process, the consultants maintained contact with USDC staff throughout the survey period to seek clarification, guidance and to validate information. The specific on-going activities included:

a) Consultative meetings with USDC management,
b) Interpreting the Terms of Reference (TOR),
c) Literature review both internal to USDC and external such as from Ministries of Health, Education and Sports, Gender Labour and Social Development, etc,
d) Proposal development,
e) Sharing of ideas and instruments for USDC district offices to collect quantitative data,
f) Checking completion of the forms and sorting them to put together the data gathered, and
g) Reflections to cross-check information gathered and consult on emerging issues.

2.3.2 Phase 2: Field-based Data Collection

This phase involved actual fieldwork in the mentioned 24 districts over a period of 32 work days. It involved data collection from selected respondents at national, district, sub-county and parish levels; communities and children, institutions like schools and health centres; as determined by the consultants and using appropriate methods (see List of Respondents in Annex 5). The survey adopted both a qualitative and quantitative approach to establish a broad picture and benchmarks.

Qualitative Information Collection

The fieldwork was focused to emphasise collection of qualitative data along the following lines:

h) ***Review of secondary sources*** – USDC, stakeholder and other relevant literature on policy and developments aimed at supporting disabled children and the disability movement in genera. This included among other, District

Development plans, USDC plans and reports, reports from government sectors at district level.

i) ***Focus Group Discussions (FGDs)*** – to obtain information from discussions with various categories of people. FGDs were held with children with and without disabilities, parents, mecial professionals; special needs education teachers, PTAs and School Management Committees, DUs, CSOs collectively in some cases, etc.

j) ***Key Informant's Interviews*** – to obtain specific and unique areas of information as in Matrix III below.

k) ***Observation*** – Hard data on observables e.g. disability-friendly infrastructure, conditions in homes, schools and of children with disabilities will be a continuous process.
   - Soft data on power relations, work methods, and others.

In cognizance of the attitudinal barriers leading to social exclusion of CWDs, the Consultants engaged respondents during key informant interviews and focus group discussions in interventions of conversation to challenges negative attitudes and sensitise them to appreciate disability and their roles in promoting development of CWDs.

Many respondents werte met both men and women, young and old; children with disabilities and able-bodied children, in school and out of school, and community members. These people were met at various levels and in various setting and to gather different types of information. The trix II below shows the list of respondents and specific tools that were applied as appended to this report as **Annex 3 for Qualitative Tools and Annex 4 for Quantitative SurveyTools.** (Please refer to the legend at the bottom of the Matrix for meanings of abbreviations used).

Matrix II: List of Proposed Respondents and Intended Tools for Data Collection

List of respondents	**Tools applied**	**Type of Information** ***(caution that in each case, the required information is not dogmatic and could therefore omit additional data requirements that will emerge in the field)***
Children with and without5 disabilities in schools and out of schools (separately) through Child Rights Clubs or independent	FGDs, and KIIs OBS, Questions	Dynamics of welfare, rights and access to equitable social and economic resources allocation in light of family, local, district and national changes in policy, attitudes and practices, perceptions about disability. Roles and relevance of children's associations and clubs, and other actors. To analyse challenges, continuities and changes in KABPs of children without disabilities as kin and peers of CWDs.
Representatives of School Management Committees and PTAs Schools, Head teachers of schools with or without specialised units.	FGD, KIIs,	Assess extent of inclusiveness of primary schools to educational needs of CWDs in sampled districts. Assess the KABP towards the changing role/capacities of the school and linkages among partners in energizing the rights and welfare of CWDs to equitable education, forces driving the changes and continuities. Triangulating child-based concerns about in-school problems with teachers and management. Assessments of disaggregated trends of enrolment and qualitative performance of CWDs in sampled schools.
Parents through: Parents Support Groups Outreach Clinics and Anti-natal clinics	KIIs, FGDs, Gis	To assess the KABP of parents towards CWDs in view of the rising consciousness about children's rights in Uganda and the roles of disability organisations including USDC.
Special Needs Education Co-ordinators (SNECOs) 20 per district. EARS Coordinators, DEOs	KIIs, FGD, OBS Quest Literature review, budgets	Measure forces informing scope of work, opportunities and constraints and how these relate to intrinsic and/or extrinsic factors to USDC and other disability organisations in respective districts. Perception indicators with regard to these variables shall be embedded in the data collection tools.
Medical Professionals during	FGD, KIIs,	Achievements of the medical profession in meeting disability

outreach programmes. (Physiotherapists, Orthopaedics, Ophthalmologists, Mental Health, Occupational Therapists, DDHS, ENT, Clinical Officers together with staff of local health units)	Quest, Lit-rev of plans, budgets and reports.	requirements for equitable health, present and future challenges. As well as, analyses of stakeholder roles and major networks and reforms required for mainstreaming disability needs into medical practice at large.
Local Councillors (1-5)	FGD, KIIs, GIs, Lit-rev of budgets, plans and reports.	Assess role of LC Vice Chairpersons as gate keepers of children's rights at different tiers of governance, challenges and prospects, knowledge of CWD needs and changing policy towards CBR and other disability-friendly reforms, as well as, levels of resource allocations towards the disability cause, especially at district (LC V) and sub-county (LC III) levels.
Disability Councillors. Development Committees Representatives from Sub-counties and parishes in addition to the district committee.	FGD, KIIs, Quest.	Assessment of roles, achievements and challenges. Specific areas of CWD and or disability addressed, partnerships formed and reasons thereof. General SWOT of function of these councillors. Obtain statistical information on the population of different categories of CWDs.
Religious institutions (Clergy/staff)	FGD, KIIs, Gis.	How they integrate dimensions of disability in the institutions they run - in their pastoral duties and in health, education and development programmes.
District Planning Unit (Planner, Economist, Statistician)	FGD, KIIs, Lit-rev.	Rigorous analysis of data banks at district levels in view of how they capture disability issues. Reviews of planning processes, old plans in view of establishing trends in attempts to mainstream CWD issues into district plans. Interviews to analyse changing roles, achievements and challenges. Specific areas of CWD and or disability addressed, partnerships formed and reason thereof. Obtain statistical data on desegregated aspects of CWDs and the PWD population receiving medical and social rehabilitation.
Other Partners such as World Vision, Plan International, Save the Children, UNICEF, AMREF, Action Aid, Sight Savers, CUAMM, AVSI, ADD, NUDIPU, NUSAF, UNAD, UNAB, UNAPD, Epilepsy, Mental Health Uganda, NOWUDU/ DWNRO; District Union of PWDs	FGDs, KIIs, Lit-revs.	Acquire all relevant data on CWDs and disability issues at large. Assessment of roles, interventions, achievements, degree of social change in CWD and the society and challenges. Specific areas of CWD and or disability addressed partnerships, collaborations and networks of disability import formed and reasons thereof. General SWOC of function of these organisations. What is the cumulative impact in bringing about social change? What is the degree of inclusion of CWD in support to PWDs. Assessment of practical networks with the disability movement and outcomes of such synergies. Challenges and prospects for the future.
Ministries of Health, Education and Sports, Local Government, Finance and Planning, Gender, Labour and Social Development, Parliamentarians, NCC	FGD, KIIs, Quest and Lit-revs	Mainly to evaluate policy trends and their role in advancing disability issues in development. E.g. budget lines, projects implemented in that regard, M & E's of such projects and nature of follow-ups. Seeking specific nuances linked to and trends in rights and welfare of CWDs. Assessment of practical networks with the disability movement and outcomes of such synergies. Challenges and prospects for the future.
Specialised Model Schools Ngeta, Nancy, Ntinda, Madera, Kireka for retarded, Mengo, Masaka, Iganga School for the Blind	FGDs, KIIs, Quests.	The changing role of the specialized schools and their partners in energizing the rights and welfare of disabled children to equitable education, forces driving the changes and continuities and triangulating child-based concerns about in-school problems with teachers and management. Statistical assessments of disaggregated trends of enrolment and qualitative performance of CWDs in sampled schools. Basing on trends conduct SWOT analyses, as well.
UHRC,	KIIs,	Acquire all relevant data on legal and human rights of PWDs and roles of human rights groups in enforcing these rights. Assessment of achievements and challenges. Specific areas of CWD addressed, partnerships and networks of disability formed and reasons thereof. General SWOC of function of these organisations.
USDC Field Coordinators and Assistants	KII, FGD, Lit Rev.	Acquire field – based data relevant to the research. Interviews on work-based and other experiences in view of their mandate in districts and lower level tiers of government down to beneficiaries in a trend analysis framework. Measure forces informing scope of work, opportunities and challenges and how these relate to intrinsic and/or extrinsic factors to USDC and other disability organizations in respective districts. Undertake SWOCs of their impacts in areas of operation.
Training Institutions UNISE, NTCs, National	KIIs, Lit-revs	Extent of inclusiveness of PWD-linked training institutions to meet educational needs of PWDs. The changing capacities and roles of these

Curriculum Development Centre, Vocational Training Institutions,		institutions to meet educational needs of CWDs (in terms of policy, equipment, as well as, human resource). Linkages built with disability partners in energizing the rights and welfare of disabled children to equitable education. Specific roles, challenges and perceived future opportunities. A SWOT of selected case studies. Also assess the contribution these institutions have had in mainstreaming PWD policy and curriculum needs.
CAO, CDO, DRO, DDH, Gender Officer, Probation and Welfare	KII, Lit-rev.	Analyse plans, budgets and reports to assess planning and integration of disability issues. General assessment of mandates, achievements and challenges in advancing policy on all-inclusive PWD development issues.

Legend:

FGDs – Focus Group Discussions	OBS – Observation
KIIs – Key Informant Interviews	GIs – General Interviews
Lit-Rev – Literature Review	Quest – Questionnaire

KABP – Knowledge, Attitudes, Beliefs and Practices

Strategy to cover Respective Categories of Respondents

In order to cover the various categories of respondents within the limited time allocated, the consultants identified them into groupings in the FGDs and KIIs as shown in Matrix III below.

Matrix III: Focus Group Discussions (FGDs) and Key Informant Interviews (KIIs) Categories

Respondents	**Method of Data Collection.**
• Children with or without disabilities divided ----------------------	FGD 2 + KIIs
• Youth with disabilities--	FGD 1
• Parents groups--	FGD 1
• Family members (Father, mother, siblings, neighbours individually)	KII 4 x number of families
• SNECOs + EARS + SMC/ PTA + HT + CCTs + ESA----------	FGD 1
• DEO--	KII 1
• Health rehabilitation workers, ------------------------------------	FGD 1
• DDHS or/and MS--	KII 2
• Heads of Department (CDO, DRO, DP&W Gender)------------	KII 2
• Councillors (Disability and Vice Chairperson Levels 3&5)-----	KII 1
• CAO--	KII 1
• District Planner ---	KII 1
• Representatives of Sub-county Development Committees------	KII 1
• NGOs at district level--	KII x no. of sub-county
• Religious leaders---	KII x number of NGOs
• Disabled Persons' Organisations at district level-- ---------------	KII or FGD
• USDC Field Coordinators & Programme Coordinators--------	FGD 1
• Parents in ante-natal clinics--------------------------------------	KII 1
	FGD 1

There were variations in actual FGDs according to arrangements made in the respective districts. Some CWDs not in school were met in KIIs in schools and homes. Some youth with disabilities were met in FGDs. Often more than one group of parents were met for focus discussions. A number of groups of parents were met in ante-natal clinics and some met according to disability types during outreach programmes. Suffice to say that while well prepared diftricts offered opportunities for large numbers of respondents to be met, the Consultants missed to discuss with some categories of respondents in some districts.

Gender Considerations **-** Children with or without disabilities were in some cases divided in groups of males and females to elicit their participation. Attempts at gender equality were ensured, by inviting both parents to the FGDs. This was not however, assured due to the very low turn up of fathers. In interviews with KIIs, gender was not deliberately targeted due to the focus on positions, though key informants included both men and women in almost equal numbers as demonstrated by the list of interviewees. The following was the list of interviews scheduled and undertaken at national level in Kampala:

	Details of National Level Data Collection in Kampala	**Methods**
1.	Commissioner/Disability – Mrs Sylvia Ntegyereize	KII 1
2.	Principal Medical Officer/	KII 1
3.	Principal Medical Officer Mental Health – Dr. Shiela Ndynabangi	KII 1
4.	Senior Orthopaedic Officer – Mr Bashasha	KII 1
5.	Plastic Surgeon /Head Plastic Surgery Unit Mulago – Dr. Rose Alenyo	KII 1
6.	Occupational Therapy Department - Mengo Hospital - Ms. Patti Squire	KII 1
7.	Deputy Director Education Standards Agency – Mr. Moses Otyek	KII 1
8.	National Council for Children - Secretary General - Ms. Joyce Otim	KII 1
9.	Kampala School for Physically Handicapped – Mrs Joy Mwesigwa	KII 1
10.	Uganda School for the Deaf, Ntinda – Jackson Mbuusu	KII 1
11.	Iganga Secondary School	FGD 1
12.	Bishop Willis Demonstration Primary School	KII 1
13.	Buckley High School	KII 1
14.	Kireka Home for Children with Special Needs – Ms. Margaret Biyinzika	KII 1
15.	Chesire Home Katalemwa – Sister Betty Katalemwa	KII 1
16.	Parliamentary Representative of PWDs - Hon. Margaret Babadiri	KII 1
	- Hon. James Mwandha	KII 1
17.	Epilepsy Support Association of Uganda – Mr. Augustine Mugarura	KII 1
18.	Mental Health Uganda – Mr Julius Lutaakome Kayira	KII 1
19.	Uganda National Association of the Blind (UNAB)	KII 1
20.	Uganda National Association for the Deaf (UNAD)	KII 1
21.	National Union of Disabled People's of Uganda (NUDIPU) – Mr. Abdul Busulwa	KII 1
22.	Principal Education Officer SNE/Guidance and Counselling – Mr. Nigris Onen	KII 1
23.	Kyambogo University, Faculty Special Needs and Rehabilitation – Lawrence Eron	KII 1
24.	Minister of State for Disability & Elderly – Hon. Florence Naiga-Sekabira	KII 1
25.	Uganda Human Rights Commission (UHRC) – Mr. Arthur Beingana	KII 1
26.	Uganda National Action for People with Physical Disabilities – Ms. Mary Mukisa	KII1

Partners' workshop for Government, CSOs and DPOs was held and a summary of findings presented to elicit further input into the fundings.

Ethical Considerations

Before each KII and FGDs was conducted, the purpose of the interview was explained and permission sought to proceed with the interview. Where photographs were taken and recordings done permission was further sought to proceed to use these technologies of information collection.

2.3.3 Quantitative Data

For purpose of gathering quantitative data, (which was already more commonly thought about than the qualitative aspect), survey instruments were designed for administering in USDC programme and selected non-programme districts. This was justified by the fact that the consultants would only have 2-3 days for each district and would not have time to administer the instruments themselves. They could only help to clarify on methodology of selecting second stage primary units (Sub-counties) and coverage of schools and health units, SNE teachers and health professionals. They would also help to clarify on the information to be completed, especially in USDC programme districts and survey process management. Nonetheless, the consultants gathered additional quantitative information as part of their review of secondary literature and policy documents and this continued till the end of the fieldwork experience.

2.3.4 Quantitative Data Collection Instruments

As noted in Matrix III above, six Forms (see Annex 4) were designed and used specifically to collect quantitative data from all USDC programme districts and 8 other districts (see list in Matrix I above), other disability partner organisations and relevant institutions in the study areas. Each of the Forms was to be completed for specific areas of study as follows:-

Form 1A:	Enrolment of CWDs in Institutions of Learning (Primary, Secondary and SNE Schools, Vocational Training Centres, etc for 2002, 2003, 2004 and 2005;
Form 1B:	Data on trained SNE Teachers per School/Centre;
Form 1C:	Total Enrolment of CWDs per selected Sub-county during 2002, 2003, 2004 and 2005;
Form 2:	Data on Services provided to Persons/Children with Disabilities by Organizations;
Form 3A:	Data on Services provided to Persons/Children with Disabilities by Health Centre III, IV (Health Sub-districts) and Hospitals during 2002, 2003, 2004 and 2005; and
Form 3B:	Data on Health Workers trained in Disability for Hospitals and Health Centre IV.

The dispensation of the six Forms was on the understanding that relevant quantitative information would be important and necessary in order to establish a meaningful and broad picture of the situation of disability and have benchmarks. USDC already had an extensive databank. However, it was hoped that this additional information would enrich it even further.

The Forms were sent earlier to the USDC programme districts to collect this additional quantitative data through its field staff (see list in Annex 6) who were briefed by the head office and later by the consultants during field visits (no formal training). In the meantime, a day's training programme was arranged for data collectors from non-USDC programme districts at USDC head office and included Gulu, Kabarole, Kalangala, Kapchorwa, Kasese, Moroto, Ntungamo and Tororo, at which the consultants were resource persons. The main objective was to go through the six Forms for quantitative data collection and the procedure for purposive selection of Sub-counties as primary units and coverage of schools and health units. However, the Moroto data collector arrived a day late and was given instructions separately, while data collectors from Kapchorwa could not come to Kampala and were identified and given instructions (see list in Annex 6) on how to complete the Forms by the consultants at the respective district headquarters during the field visits.

The survey Forms for quantitative data and qualitative questions addressed the following focus areas:

- Total population of the PWDs in respective districts,
- PWD/CWD population desegregated by disability category and degree, as well as, sex, age, literacy and location, e.g. Sub-county,
- In-school and out-of-school numbers of CWDs and also desegregated by welfare, sex, age, and location,
- Access to rehabilitative services of PWDs as predisposed by disability type, age, sex, social conditions and literacy. Additionally, health indicators on CWDs

would focus on how they are treated in health units, levels of access to health services, and estimates of those not able to access health services,

- Interventions focused on P/CWDs by different stakeholders in the districts (public, private and non-governmental partnerships) as well as by their disability specialisation,
- Trends of perceived changing perceptions of the general population towards P/CWD rights and welfare out of USDC and other stakeholders, interventions were assessed
- Strengths, weaknesses, opportunities and challenges (SWOC) information from USDC branches (and those of other partners) with regard to the following:

  a) Strengths (how USDC had coped with CWDs, for example);
  b) Weaknesses (e.g. problem areas past, present and future, partnerships and networks);
  c) Opportunities (e.g. what they could take advantage of already, mid- and long-term future, in comparison with other partners in the PWD movement);
  d) Challenges (e.g. what challenges lay ahead, presently and in the short- and long-term future? How did this compare with other stakeholders?);
- Resources (e.g. what was the resource base of the disability programme at national, district and lower local government levels? What was the resource base of USDC and other disability organisations? What were the trends in resource development and how had this affected services provided to P/CWDs? Above all, what was the overall proportion of programme versus administration budgets for these different stakeholders and what did this imply for quality and sustainability of CWD support?).

2.3.5 Work Schedule

The team commenced the survey together in Cluster One as a learning experience strategy, and thereafter broke into two groups for the rest of the Clusters. The proposed overall work schedule showing the specific allocation of fieldwork days by Cluster in the technical proposal proved an underestimation of the intensity of qualitative interviews and time demanded to dig out meaningful information from different categories during planning. The interviews were intense and time consuming determined by the need to probe in-depth in order to get clearer and more informative response. In USDC supported districts, the USDC Field Coordinators made prior appointments for the consultants which eased interview schedules. In non-USDC districts, the teams had to draw programmes on arrival, and approached respondents at short notice (see Matrix IV for Work Schedule).

Matrix IV: Work Schedule

Cluster One Districts:			
Team	***Selection Criteria***	***Number of days***	2 Consultants started joined by 1. This was intensive restless work for the Consultants until a third one arrived.
Nebbi	USDC District	3	
Arua	USDC District	3	
Yumbe	USDC District	2 *	
Moyo	USDC District	3	
Adjumani	USDC District	2 *	
Cluster Two Districts			
Luwero **GROUP1**	USDC District	3	Two Consultants, per sub-team - total number of days per person is 11
Nakasongola	USDC District	2	
Masindi **GROUP2**	USDC District	3	
Hoima	USDC District	3	
Apac **GROUP2**	USDC District	3	}Two Consultant each 6 days.
Lira	USDC District	3	}
Soroti **GROUP1**	USDC District / Specifically for Networking with other partners.	2	}
Moroto **GROUP1**	Non-USDC District/ No Disability services / Unique Cultural Practices	2	} Two Consultants each 6 } days
Gulu	Non-USDC District/ District in Conflict Area	2	}
Cluster Three Districts			
Kabarole **GROUP2**	Non-USDC District/ Regional Representation/ No Disability Services.	2	Two Consultants each 6 days
Kasese	Non-USDC District/ Regional Representation of Districts in Conflict Area.	2	
Ntungamo	Non-USDC District/ Regional Representation/ Government programme to get after effect	2	
Sembabule**GROUP2**	USDC District	2	} Two Consultants each 5
Masaka	USDC District	3	} days.
Kalangala **GROUP1**	Non-USDC District/ No Disability Programme/ Unique Island Situation	2	Two Consultants each 2 days
Cluster Four Districts			
Kapchorwa **GROUP1**	Non-USDC District/ Regional Representation/ Unique Cultural Practices	2	Two Consultants 4 days
Tororo	Non-USDC District/ Govt. Community Based Rehabilitation Programme/Regional Representation.	2	
Jinja **GROUP1**	USDC District / Specifically for Networking with other partners	2	Two Consultants each 2 days
Kampala **3 Consultants**	USDC District/ USDC Head Office/ Seat of Ministries and national NGOs/ Institutions,	3	Each Consultant 3 days

2.3.6 *Interpretation and Analysis of Data*

The notes made during the day were perused and where possible types out while in the field or on return from the field. Qualitative data collection became a learning process for both the interviewees and interviewers. It was a movement towards consciousness about disability in children and how it was being managed to the detriment of CWDs. Reflection on each day's interactions helped the consultants to see actively and search for meaning of what they observed and heard.

The team developed Chapters based on the TOR. The raw data was then analysed under the main Chapters and slotted under each thematic area identified. The core of the qualitative report was based on the sub-themes. The key issues and recommendations were based on this analysis. There was a lot of overlap of data, for example, when a piece of data fell under two Chapters or under two themes, this data was not deleted for repetition, but utilised where it was identified. In some instances, whole thematic areas were transferred to different Chapters to avoid irrelevant repetitions.

Both quantitative data collected by the USDC staff and others and the qualitative information gathered by the consultants was analysed to establish linkage with the field information gathering through interview processes and observations. The information was used to determine trends and make comparative analyses. A combination of statistical packages of SPSS, SAS and Excel were used as found appropriate for the analyses of the quantitative data. Primarily, the aim was to make trend and forecast analyses of the progress being made by the CWDs programmes.

Qualitative data was analysed in the course of FGD processes and then coded by nominal and axial coding approaches in line with the key variables and themes emerging from the study objectives and quantitative analyses. It sought to understand the consciousness or values that engaged and obliged the different stakeholders to support CWDs and hold onto them. It highlighted issues of attitudes, knowledge, perceptions at different levels towards different categories of disabilities; social acceptance and integration of CWDs. The benefit was to provide coherent and logical meaning to the statistics generated by the study, as well as, to enrich it further with case studies of specific experiences of children with disabilities, and useful insights on them as narrated by respondents. It further created an understanding of the institutional arena for support to CWDs.

2.3.7 Phase 3: Workshop for Synthesising Information collected

In Phase 3, a workshop was organised by USDC at the national level to review the findings of the survey. This workshop brought together the key stakeholders at district and national levels to assist in interpretation of the findings, to streamline views, to iron out differences, to build up an agreed picture, fill information gaps, and contribute to conclusions and recommendations. During the workshop the consultants gave an overview of their findings and interpretations and guided the whole review process. Another presentation was made at the USDC Strategic Planning Workshop for the next programming cycle, at which a general overview of study findings and recommendations was given, in order to guide the strategy planning process. Significant contributions were made by participants in both workshops and therefore, considerably enriching the final report.

2.3.8 Phase 4: Report Write-up

This phase of the exercise involved the consultants writing up the full report of the baseline survey exercise, for submission to the Executive Director, USDC.. This was a very tedious exercise because of the bulk of data gathered and the need to highlight as much of the information as possible for extensive use by USDC and eventually other stakeholders. The data entry took a long time due to delay by some districts in submitting adequately completed data, hence repeated references to data collectors. The data entry person was not consistent in sticking to the time schedule initially arranged and agreed with him, hence another had to be hired to complete the work.

2.3.9 Administrative Reporting

The consultants reported to the Executive Director of USDC and worked under the general guidance of the Field Director. To ensure further control over the survey process and while at the same time ensuring that the consultants found less encumbrances in relating with the main thrust of the field work in the 15 USDC programme and the 8 non-USDC programme districts, USDC management assigned Mrs. Suzan Kisitu, Field Director the role of backstopping the consultants. She effectively coordinated the consultancy, especially in the field in USDC programme districts and with other stakeholders, while relating the consultants' needs to respective institutions/offices in the process of facilitating the consultancy. USDC field offices arranged the itineraries and made appointments with district officials and national organisations.

2.4 Study Management

The team of four consultants adopted collective responsibility and worked as a team, understanding the complementarities in between and among the different areas of expertise, under the lead role provided by Ms Salome Kamure Okayi.

2.5 Limitations and Challenges

The following challenges were met during qualitative data collection:

a) Insecurity in Gulu and Moroto districts hindered home visits and visits to internally displaced persons (IDPs) camps in Gulu. Permission to enter one of the camps near Gulu town was denied by the authorities. As a procedural matter, such permission was granted only by either the RDC or the LC V Chairperson,

b) In some districts, top officials were not available to be interviewed because they either travelled to Kampala or to neighbouring districts on official duty,

c) The District budget process limited time spent with district officials as most were involved in last minute preparations of plans and budgets or were attending budget meetings. Important documents, some of which had been quoted by district officials, were not available for verifying information,

d) The interviews at all levels were time consuming because the intensity of each interview to get qualitative information was determined by the need to probe in-depth in order to get clearer and more information. In non-USDC programme districts, the teams had to draw programmes on arrival, and made approaches at short notice that sometimes resulted in not getting the respondents the first time or missing them completely. It should be noted that the commitment of the consultants was maximum, such as undertaking interviews during evening hours in Cluster 1 districts, there was a very broad category of respondents and yet too few consultants, in order to cover the set scope.

The following challenges were met in the process of quantitative data entry among others:

i) The six Forms were made relatively simple so as to be completed quickly and timely by the respective respondents. However, from the record of returns, there were incomplete or partial returns from a number of districts of which USDC programme districts included Hoima, Masindi and Arua/Yumbe.

ii) Among the other category of districts, it was only Gulu where returns were partial and these were supplemented later by deployment of another data collector, who did commendable work and collected data using Form 1A, Form 1B, Form 1C, Form 2 and Form 3A in Gulu Municipality.

SECTION II

FINDINGS AND DISCUSSIONS, CONCLUSIONS AND RECOMMENDATIONS

Annexes

CHAPTER 3: CONCEPT, PERCEPTIONS AND MAGNITUDE OF DISABILITY IN CHILDREN

3.1 Concept of Child Disability

According to the World Health Organization (WHO), health was not merely the absence of disease and infirmity but a total physical, mental and social well being.

3.1.1 Definition of Disability

In this report, disability was used in its broadest sense covering the three facets of the disability process as shown in Diagram I. In order for the reader to appreciate the interplay between the CWDs and their environment, the international definition and common terms used were as given below:

Disability was an umbrella term for impairment, activity limitation and participation restrictions. It denoted the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environment and personal factors).[2]

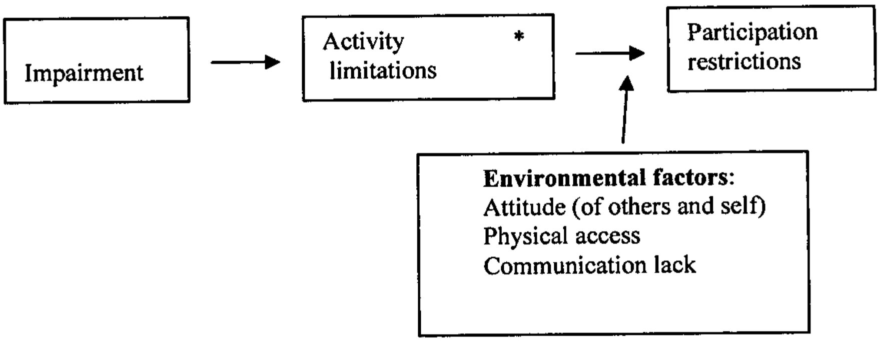
An impairment was a loss or abnormality in body structure or physiological function (including mental functions).[2]

Any disease process progressed into 3 directions as follows:

- Complete healing and restoration of full function of the individual,
- Irreversible damage to a body organ, or
- Death.

When a body organ was damaged moderately or severely the individual would experience limitations in carrying out activities in a manner or to the extent that was expected of people without such impairment. The medical view argued that what needed to be done to handle the problem of disability was changing the individual (rehabilitation) through professionals' help, assistive devices or appliances or cure in order to adapt to the environment or society. However, the interaction between the individual with activity limitation and the environment would determine the extent he/she participated in society. On one hand, the person's limitation could be mild but the environment was negative or with barriers resulting into considerable restriction in participation. On the other hand the impairment could be severe but the barriers in the environment were few, so the individual experienced greater participation and was therefore 'less' disabled. This was aptly put by the CBR Coordinator Matany Hospital, Moroto District, **'If you are rich your disability is gone'** meaning the external/environmental barriers, especially negative attitude, were markedly reduced because of the good financial status. Thus the rich individual experienced less societal exclusion.

Diagram I: The Disability Process



This definition emphasized the restricted participation as a result of interplay between the difficulty experienced due to the impairment and the environment unlike the definition used in Government's CBR Management Information System manual[16] which put the onus on the impairment alone or the definition used in the National CBR strategic plan which put the responsibility upon the environment only.[17]

The social model of disability argued that it was economic and social barriers mentioned above which stopped PWDs from participating fully in society. Alex Ndezi (1999)[3] affirmed this by stating that disability or impairment (loss of limbs, organ, function or sense) had such traumatic physical and psychological effects on a person that they could not ensure a reasonable quality of life for themselves by their own efforts, without special provisions. The society put up such widespread disabling barriers/environment, including the effects of an inaccessible physical environment for a wheelchair user, the effects of society's negative attitude towards supporting P/CWDs to enable them develop to self-sustaining life; a society that was insensitive and hostile to minority rights; a society that did not communicate, e.g. in accepting sign language for the deaf to be adopted by all in order to facilitate smooth communication among the entire people; or the significance of a white cane for visually impaired people. All these factors hindered those with impairment from ensuring a reasonably good quality of life for themselves.

Below in Panel I are examples of activity limitations imposed on the child with impairment by the limitations the environment imposed:

Panel I: Examples of the Disability Process

Disease	**Impairment**	**Limited activity**	**Environmental limitation**	**Restricted participation**
Trachoma	Scar on the Cornea	Difficult Seeing	Lack of Braille Equip. Negative attitude of parents or teachers	Restricted Education
Meningitis	Permanent damage to area of brain controlling movement	Difficulty moving	School far from home No assistive devices eg wheelchair	Restricted Education

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[3] The Disability Movement in Uganda: Progress and Challenges with Constitutional and Legal Provisions on Disability by Alex Ndezi, 1999.

Viral encephalitis Viral infection of the brain	Permanent Damage to area of the brain for cognition	Difficulty in self care eg toileting, behaving appropriately	Negative family and neighbours	Locked up and restricted family activity
Infection of the middle ear	Abnormal middle ear structures	Difficulty hearing or deaf	No sign language available No hearing aid Negative attitude	Restricted learning at school and at home

The consequences of disability, therefore, did not arise from the impairment alone but also from the environment. All the examples given above needed not be negative if the impairment was mild or if the environment had fewer barriers.

Rehabilitation was about reducing the impairment, for example, through surgery or eliminating the limitations imposed through attitude or provision of accessible environment including buildings. Rehabilitation ought not to address the impairment alone, as was the case with the medical model of disability but should, in line with the social model address both the impairment and the environment. The social approach emphasised human rights, solidarity, respect, participation and equalisation of opportunities. Alex Ndezi (1999)[4] considered the social model as liberating because it gave P/CWDs identity, pride, and common cause to rid society of its discriminating barriers.

According to Amartya Sen's[5] definition of people-centred development, social and medical rehabilitation of CWDs ought to be a process of increasing the possibilities for many of the children with impairment and activity limitation to realise their potentials as human beings through the expansion of their capabilities for functioning. This should enrich their lives by increasing their freedom to choose between different ways of living. Allan Kaplan 1999[6] affirmed that people-centred development was about increasing 'choice'. It ought to be about doing things together with P/CWDs and their context, in order to increase their consciousness to understand themselves, expand their own capacity so that they were better able to take responsibility for their own consciously chosen future. This meant guidance towards understanding the patterns and dynamics, which trapped them into unconscious or unhelpful ways of doing things. It meant the facilitation of a growing self-understanding, so that they and their surrounding saw them afresh.

3.2 Community Understanding of how Disability occurred in Children

The communities, specifically parents understood impairment in children as arising out of two ways. First, part of the body was recognised at birth to be not normal and dysfunctional. Talking to mothers in antenatal clinics and in PSGs, they narrated experiences of having delivered children with some form of impairment. These included among others, 'twisted foot' (clubfoot), 'cut lips' (cleft lip or with cleft palate as well), 'deafness' (hearing impairment), 'blindness' (visual impairment) and paralysis of the body.

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[4] ibid

[5] To be inserted

[6] Allan Kaplan in Artists of the invisible –From CDRA Annual Report 1999

Second, disability happened in the life of a child when any part of the body became impaired and dysfunctional either through severe sickness, or accidents. Many parents testified about having delivered normal children, who later developed severe sicknesses often associated with high temperature/malaria, flu, cough, and measles. The sicknesses developed into various conditions of illness resulting into different forms of impairment, such as chronic discharge and blockage of the ears leading to difficulties in hearing or deafness or blindness. Severe untreated sicknesses led to mental retardation, and weakened the body of the child often resulting in paralysis and other damages to the body. Mothers said that when they took a child with malaria or measles or flu for treatment, the conditions got severe because in their view, not adequate treatment was provided. Sometimes the children became paralysed or deformed or epileptic after quinine injection. A respondent in Ruharo Eye Centre said that visual impairment was caused by toys/instruments like stones, knives, steel, and thorns, which children used to play with and thus injured their eyes. Eye problems were also caused by river blindness, particularly in Hoima, Masindi, Kibale and Arua.

The after-birth period when sicknesses started in the life of many children ranged from 4 days to 17 years. This was expressed in some of the statements below.

Parents' confessions in Sembabule and Nebbi Districts:

At 4 years, he became yellow, got back pains, swelling and the arm growing weak' which has remained at 17 years old.
'My son was 7 years when he became lame on one leg.'
At 2 months, we realised that the she could not talk and one eye was not seeing well.
'When my son reached 13 years the leg got swollen and the child could not walk on the leg. He limps up to now'.
'At six years his one leg began to grow small. It has remained small'.
'When our child reached two years she caught fever. Although we tried to treat the sickness it continued and she lost sight. The child remained short and blind'.
'At one year and 8 months, the child got fever which resulted in epilepsy, and one leg is short'.
'At one and half years she caught fever, lost mental ability. Now she is six years'.

The above demonstrated that there was ample knowledge and memory among parents about how children became impaired. Traditional birth attendants and some more enlightened mothers expressed the views that sometimes children were born with impairment as a result of failure to attend regular anti-natal clinics and poor management of the pregnancy period. They admitted that the failure to attend immunisation programmes and poor management of early childhood illnesses exposed the children to serious sicknesses. Some severe sicknesses led to disabilities. In Apac Hospital expectant mothers during ante-natal clinic said that they had never been taught in health education that mismanagement of pregnancy could lead to delivery of a child with impairment or soon after birth. It was like a surprise to them that their own mismanagement led to impairment.

The history of civil wars in different parts of Uganda had added to causes of disabilities. For instance in Gulu District, common disabilities included landmine victims/accidents, shock and mental retardation of children arising from effects of war. There were victims of new cases of gunshots and landmines/accidents, shock and mental retardation in children arising from effects of war, and such similar incidences. Disabilities also arose from people being burnt in fires at IDP camps.

3.3 Most Common Perceptions and Attitudes of Communities/Parents about Impairment

Although the explanations of disability after birth sounded clear, communities perceived abnormality in body impairment as something beyond their comprehension. These confessions were overshadowed by the explanation of mystery once sickness reached the level of impairment, considered as bad omen, and curse. The negative explanations of disabilities by the social beliefs were attributed to parents, specifically mothers, who were made to carry the stigma of having produced CWDs or the strange mystery called 'curse' or witchcraft in the family. For example, mothers said that discharge of the ears was caused by a curse on the mother. The same problem named *'awola'* among the Alur in Nebbi district was believed to be caused by powers of ancestral spirits, and to be healed only by local spiritual remedies. Among the Langi, Banyoro, Baruli, Batoro, Bakonzo and Karimajong, impairment was considered as determined by fate. Some believed it was a curse from God or the Creator, or misfortune, hence, wondered as to why God did it. They lived with the guilt of bearing children with impairment.

'God is unjust because he creates. I am not a bad person but I have to look after a child with disability. Bad people do not face similar fate' a mother said during FGD at Kangole in Moroto.
'God has given me the child in that condition and I accept the condition' said a caring father in Parombo, Nebbi, whose child had CP and had managed to walk after 9 years.
'The child is God given. We accept to play with him and feed him' the siblings in Parombo, Nebbi said.

Among the Lugbara people in Arua and Yumbe districts, and the Alur in Nebbi Districts, CWDs were passively accepted, often referred to as a curse arising from disrespect or as a result of breach of oath. Sometimes they were believed to be an act of the underworld because a pregnant mother went to the well either very early in the morning or very late in the evening; or passed through some valley or ritual tree with some beliefs attached. However, seemingly that victims of gunshots and landmines/accidents, shock and mental retardation of children arising from effects of war, people being burnt in fires at IDP camps, and such similar incidences were not attributed to the above supernatural beliefs.

3.4 Effects of Community and Parents' Negative Perception and Attitudes on CWDs

3.4.1 Social Rejection and Scapegoat

Mothers and CWDs in all the districts visited expressed disappointment that parents, mostly fathers, were negative towards their own CWDs. The father of a blind girl in Maracha in Arua told the SNECO who went to pick her to go to school at Ediofe Girls Primary School said
'I have never seen such blind children go to school and do anything meaningful. If you have too much money to waste take her.'[7].

This was an expression of frustration at failure to determine how to deal with the situation due to lack of knowledge of how to manage disability. The girl sat PLE in

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[7] Reported by the SNECO of Ediofe Girls Primary School and the girl herself.

2004 and passed to join secondary school. However, lack of school fees prevented her from joining secondary level education at Mvara Secondary School in Arua. She was repeating P7 in 2005.

The birth of a child with disability in a family was a traumatic problem in social relationships, or a blessing in a few cases. Most men blamed disability on mothers for bringing misfortune into homes through giving birth to CWDs. A driver in Kibale Local Government was quoted as saying *'I do not give birth to such children'*. Many men divorced or separated from mothers of CWDs and/or abandoned the children with old grandparents. In Kasese, Masereka Maketon, 9 years old, (in picture) was abandoned by the father, a policeman working in Mbarara.

The mother reported him to the local Probation Office and was threatened with arrest. Once or twice he came around to his wife, and already produced another child without impairment with her. However, he had not quite accepted them. Another girl with disabilities called Victoria Odraru Munguleni, 12 years old, was abandoned to similar fate with the maternal grandparents. The mother lived with the siblings in Arua Town. In a number of cases, grandparents of CWDs took care of them in the absence of parents (through separation or just sheer abandonment). Grandparents tended to be loving and caring for their grand children with disabilities. However, they could not provide or take responsibility for medial and social rehabilitation of the children.

Scovia, who lives with the grand parents, had mobility difficulties, but could stand on form or chair or against the wall and anxiously walk slowly around. Through her own struggle she was able to sit on a chair. The consultants' observation was that Scovia was denied opportunities to be trained, given medical treatment and to develop potential which she had. They lived near Offaka Health Centre, where outreach clinics supported by USDC were conducted. Her father, a Prisons Department staff worked in Arua where he could have taken her for medical rehabilitative services. It was sad she missed such an opportunity.

Mr. Nyathi's statement in the Daily Monitor dated 6th September 2005 that ***'attitude towards the disabled was so bad that people who produced disabled children at first used to kill them at birth because it was seen as an embarrassment for a family to have a disabled child'*** was true. 60% of the respondents agreed with Mr. Nyathi that even at the time of the study, CWDs were hidden from the public view because they were considered as dead, embarrassing and shameful, hence the negative practices unleashed on these children. Some parents resorted to tying them on trees or in the house to restrict their movement or just starved them to death. This practice was worse in the case of CWDs in polygamous or broken marriages, where stepparents, especially mothers did not accept responsibility for such children.

In Adjumani, the father and the stepmother of a CWD locked him in a goat house without feeding him so that he could die. The neighbours became curious and concerned when they did not see the child around for two days. Since nobody could tell them of the whereabouts of the child, they called in the LC1. The LC1 together with others mounted search and found the child in a frightening state.

The Odravu PSG in Arua District submitted that parents used to lock children with impairment in their houses. Some did not provide them with proper sleeping places while some did not give them good plates for eating. Generally, the children were neither fed nor dressed well and were denied opportunities to go to school or to church. Parents of able children blocked them from playing with CWDs.

3.4.2 Social Rejection by Communities

Culturally, among the Karimajong and the Bahima, babies would be strangled at birth if they failed to cry because such were considered a manifestation or initial sign of impairment, hence a curse. In Karamoja weak people were viewed as useless or liabilities particularly in view of the nomadic pattern of life where they had no role in the nomadic community. The chronically sick, disabled, HIV/AIDS victims were abandoned or neglected if they were kept in the homes, to die as the rest of the family moved on. There was a very high rate of deaths among the disabled people due to such neglect.

Parents and children in each of the districts testified that patients with epilepsy who got fits would be abandoned by society for fear that it was infectious. Before marriage the family background of a girl or a man would first be investigated to ascertain the presence or absence of history of epilepsy. The belief still existed among many people that touching a person having epilepsy fit or coming in contact with the saliva, urine or flatus would pass on epilepsy. This belief was widespread in districts visited. As a result people with epilepsy were isolated or in some families fed and slept alone.

'I found the child used to stay in a hut alone, eat alone on separate plate and drink in a separate cup' said the Chairperson of Jinja PSG.

In Yumbe, respondents said the disability victims were not properly fed and denied goat's meat, which was believed to contain too much fat that increased attacks. The population of Yumbe District was overwhelmingly Moslem (about 90%), with high illiteracy rates and rampant poverty. These factors promoted traditional beliefs about mental illness, the use of traditional herbs and '*mwalimus*' (traditional healers).

Neighbours said CWDs were cursed and advised them to be taken to traditional healers. They did not want their children to visit homes with CWDs, nor did they understand that all people had potential for becoming disabled. Nyamaata Asumpta in Kabarole said that neighbours' attitudes were much discouraging. She narrated her ordeal with neighbours who said that she was wasting time and her father's money studying, and that she bothered people to take her to school and to places. This made her feel bad.

While the societal stigma tended to make fathers leave CWDs a burden on mothers, most mothers on their part acknowledged and valued CWDs as products of their womb. Mothers were the majority among parents that turned up for the meetings with the consultants. Mothers felt very strongly for CWDs and loved them more. The mother of Sharon Atuhaire said that it was painful to see her own child in that state. Atuhaire, 13 years old, dropped out of school because the mother was no longer able to transport her to school since she lost her job. Mothers cared but because the society lived in a hand to mouth situation, (they were either digging for other people or went to town in search for money) they had no time to socialise and train CWDs. If the fathers did not cooperate, it became hard for a mother to manage the rehabilitation process alone.

3.4.3 CWDs perceived as Government/NGO Responsibility

The negative attitude tended to make parents consider medical treatment and education of CWDs as the responsibility of government or CSOs/NGOs. At Mpondwe Primary School, a school with SNE teachers, the mother of a child who was wasting away gradually, brought him to the consultants in a special hire vehicle while she claimed she did not have money to take the child to Fort Portal or Mbarara for medical treatment. On consulting with Kagando Hospital she had apparently not exhausted opportunities that were available for treatment and rehabilitation of the child's disability from closeby. Her idea was to hand over responsibility to someone else. In Apac one man brought his child when the consultants met the Chegere PSG and said if the consultants wanted they could take over responsibility to provide for the child, while he was not making efforts to rehabilitate her both medically and educationally.

A neighbour of Obeti (with physical disability) at Ediofe in Arua, Katerena Drajo, said that she would wish to have Obeti taken away by an organisation to provide for his up-keep and education. She was concerned that the stumps got aggrevated needing medical attention.

Katerena said, ***'The disabled child should be taken and cared for by somebody and be properly looked after.'***

In a number of cases parents said the children belonged to God and God wanted them to be as they were. They were willing to give up the children by taking them to church missions and leave them there.

In Adjumani Primary School, CWDs expressed the view that government should help them to develop their future since some had poor parents and others' parents did not care for them. In Gulu, communities, parents and local governments thought responsibility for catering for P/CWDs was for NGOs. In Masaka parents thought there were NGOs ready to take care of CWDs. However, they said they were tired of NGOs that did not deliver services. It would appear they used them as a source of income through the sympathy of the society of NGOs.

This negative societal perception was so deeply entrenched in the minds and understanding of people that they carried it along to positions of responsibility in the government or various structures and processes as manifested in their lack of commitment to provide for rehabilitation of the 'abnormality' in body structure or physiological function (impairment) of the child or person. It was this social rejection in the family, among the community and other social positions such as in service provision, which limited the child with impairment and causing serious disability.

3.4.4 Effects on health seeking Behaviour of Parents

The perceptions about disability affected community health seeking patterns, and how they treated the CWDs. Parents, particularly fathers, found it bothersome to take CWDs through the long process of rehabilitation, especially where the disability was severe. They assessed a child with impairment and resented the extra efforts required and difficulties involved, which made rehabilitation efforts, appear a burden. Hence, they refuse to take children with severe disability to school or for medical treatment. During focus greoup disacussions, it was said that many parents believed the CWDs might not survive and said, **'What will this one do? Why waste money on this one?'** A CWD in Hoima reported another incident where the father threw away the medical form that referred him to Mulago Hospital. He did not proceed with the child to Mulago, where the impairment could have been worked on at an early stage.

In many cases parents either sought medical treatment immediately or after some delayed the latter leading to the worsening of conditions. The majority of parents testified that they had often thought of medical treatment as a first reaction to get treatment and to fight the stigma. They reverted to traditional healing because the herbalists showed they cared and provided immediate action sometimes leading to cure. Parents expected an immediate visible recovery or cure from medical care.

Alizuka Edward, 12 years old in Ntungamo, was attacked by pneumonia at two and a half years. At Itojo Hospital the mother found many children with similar conditions and were dying. She said the hospital only administered a tablet through the anus, which did not show evidence of seriousness. The depth of the sickness made her lose hope in the hospital commitment to treat her child. She went back home and consulted a herbalist who she believed helped the child to improve. The resultant cerebral palsy was what she was willing to take up with medical facilities. Again she did not know where to go where she could receive effective treatment. The child was improving and went to school. He was a determined child who said he wanted to become a teacher.

Many times treatment by the herbalists failed and only then did parents go back to medical treatment. Sometimes they gave up for a long time and if the disability persisted or developed complications, they went back to medical treatment. A mother in Parombo in Nebbi said she went back to medical care because she observed that the USDC funded outreach programmes had helped some children. Her son was now very big although with acute conditions of epilepsy.

One traditional healer stationed himself at Yumbe Town Council (only six kilometres from Yumbe Hospital) claiming to heal all types of mental illness. He attracted large numbers of patients, until one died and two were rushed to Yumbe Hospital in critical conditions. The hospital successfully treated the two patients. Their recovery in the hospital was an example to parents and the public that the traditional healer was false and fake in his profession. When discharged the patients went out and campaigned against the traditional healer who had to go into hiding.

Some parents came once, and they did not honour instructions for follow-up visits. Epilepsy was observed to develop into acute complications because victims or parents failed to continue with administration of drugs, either because it was too much of a bother going to hospital for drugs, too expensive or they just did not understand that the drugs could be helpful in reducing attacks and eventual healing. Yet parents found it quite acceptable to take a **child with simple physical disability** through a process of medical, educational and social rehabilitation. This indicated that the degree of disability did sometimes determine willingness to assume responsibility for social and medical rehabilitation.

There was need to engage in processes that eraseed such deeply rooted perceptions embedded in the environmental limitations in order to free the children of activity limitations and focus on developing the potentials in them. The perceptions and beliefs towards disability limited or delayed access to definitive care even when this cure was within geographical and economical reach by the family. This promoted the seeking of less useful interventions from local herbalists and witch doctors.

3.4.5 Attitude of CWDs towards Society and Themselves

Disability exposed CWDs to common yet real challenges they faced in their lives. These included among others, the negative attitudes of parents, communities, teachers, other children and authorities (the local governments did not provide budgets for CWDs) elaborated below. These built into inadequate access to medical care and education services (many CWDs did not have opportunity to attend school, and there were few special provisions in few schools for either the blind or the deaf). In schools they lacked scholastic/learning materials, lacked special needs teachers, facilitation in mobility for the physically handicapped (among the victims of war a number of them needed appliances and service providers were overwhelmed), etc. These were further elaborated under service provisions below.

The negative attitudes and disregard of parents, guardians, the community and service providers built in the CWDs particular perceptions of and attitudes towards their environment. CWDs were conscious of the negativity unleashed on them in denial, rejection and social exclusion. They were conscious of being isolated, denied education, medical treatment, given little attention and were often hindered from moving due to lack of assistive devices. They said that they were abused in reference to their disabilities, despised and teased by other children, adults, neighbours and sometimes, family members. Sometimes they were called ***'imuduku'*** meaning small useless and blind, or ***'pa dulu dulu'*** meaning with short (amputated) legs.

CWDs said some of them were mistreated or ill treated as they were made to dig and carry out heavy household chores especially when their mothers were separated, divorced or died. They said that in school other children feared sitting near them and demanded that CWDs were given separate benches to sit on. Non-disabled children tended to abuse them. They said, ***'When we eat other children run away from us'***. Those were moments they said they felt bad enough to think that they should not bother others to help them. Below a girl with severe physical disabilities gave a testimony about her experiences.

'I was born normal like any child, but when I was just three months, I was attacked by polio, since I was not immunised. It had to spoil all my body both upper and lower parts. Later, I encountered very many problems at school for the first time joining school. At school they refused me saying that I am be-shaming those in the school since I had no wheel chair and therefore was being carried on the back. I also faced the challenge of competing with other students in speed' said Nyamaato Asumpta.

These testimonies showed that negative attitudes towards and rejection of these children had devastating effects on the children, and even the parents themselves. Hence there was need to engage in processes that erased such deeply rooted perceptions that caused environmental limitations in order to free the children of activity limitations and focus on developing the potentials in them. The consultants did observe that there were parents quite positive towards their CWDs and this had tremendous positive impact on their growth and development.

3.4.6 Parents and Leaders with Positive Attitudes towards CWDs

There were parents and families that accepted CWDs and did all that were within their capacities to rehabilitate the children. Several examples were seen where CWDs had been accepted in the family, given emotional support, love and were trained to be independent. The acceptance was with extra efforts to ensure integration of the child through such actions as following up performance in school; keeping the home in some form of order for the visually impaired to find their way around; involving the siblings in supporting the disabled child; giving them equal opportunity in house work; awarding them leadership positions in school, for example blind boys as class monitor and prefect in Ediofe Boys and Kamurasi Demonstration School, respectively. These actions enabled the children grow with a sense of independence, confidence and responsibility and all round good performance.

Ms. Suzan Ocokoru the Guardian/Stepmother of Obeti (whose mother died in 1997 and father in 2002) kept and lived with him. He needed new artificial limbs because he had outgrown the old ones. He wore them for going to school for convenience of walking to school. There was an old wheelchair but in need of repair. Despite these shortcomings, the boy was active and played along with siblings and neighbours' children, because the stepmother treated him like any of her biological children, a neighbour at Ediofe in Arua reported. Similarly, Mr. Michael Obitre a neighbour testified that Obeti's late father initially took him to Yumbe Hospital, later to Ovujo Mission Hospital where the legs were amputated when they started wasting away below the knee. While still alive, the mother and father loved and cared for him and had no disagreement on his condition. Another neighbour Ms. Katerena Drajo said she had not noticed any harassment, abuse or teasing in the family, neighbourhood or among children, whenever she was at home. Obeti was enthusiastic in education as a result of the love and acceptance shown to him at home and at school.

A family in Arua had one blind boy and another visually impaired boy, who were treated equally like the other siblings. Even before USDC came onto the scene the children had been taught how to manage various responsibilities around the house, including cooking. They were given extra support in their education and they felt loved, accepted equally like any other member of the family. This motivated them to study well. In Soroti the CWDs said about their families ***'Generally they look after***

us well and help us when we need help'. A boy in Adjumani Girls P.S said he became disabled at the age of two and a half years. His father loved him and treated him better than the other children for fear that he could curse the able bodied children. His mother died and the stepmother used to abuse him and this caused her to be sent away. His siblings supported him and carried him to school. He felt happy with the love showered on him and developed well in school and among the community.

Comparing the negative effects of negative attitude of parents with the positive parental attitudes, and the social effects of negative attitude on the development of potentials of CWDs, it became important to support the individual CWD to overcome the physical and social impairment. This required sensitising parents with negative attitudes to appreciate the potentials in their children and help them to develop them.

As would be seen later in parts of this report, USDC and other organisations made sizeable efforts in activities to transform negative attitudes and perceptions using different approaches. However, there was still a big challenge of reaching out to the society in general and parents in particular, which acknowledged neither the rehabilitation nor understood what to do about disability in their children.

3.5 Magnitude of Disability

3.5.1 National Demographic Information Situation

There was marked paucity of quantified national and sub-national data on disability, as published information for access to the public. A quick observation seemed to suggest that national and other institutions and organizations responsible for statistical information collection, collation, analysis, publication and dissemination, in particular demographic data, had not adequately targeted the area of disability on regular basis. This meant that national and sub-national data on P/CWDs were hard to come by, for presentation of a clear extent of the problem. The National Population and Housing Censuses conducted centennially had been the only sources of data, especially for 1991 and 2002.

The census results for 1991 indicated 1.1% of persons enumerated were disabled, while for the 2002 Census, the indicator was 4.4% of total population. In comparative terms, the percentage increase within the ten years would be considered abnormal. However, the underlying factor in lower percentage of PWDs in 1991 and almost fourfold increase in ratio of the total population was largely attributed to better coverage and improvements in the method of data collection in 2002. Even then, disability organizations that were service providers (including USDC) still considered the 4.4% to be low. WHO estimated an indicative rate of 10% as the disabled population out of total population (as a world indicator) and this rate had been utilized a great deal in Uganda as a planning figure. For example, NUDIPU estimateed (2003) that there were 2.46 million P/CWDs in Uganda, same as recorded in the recently revised PEAP 2004/05 – 2007/08.

TABLE 3.1: POPULATION OF PERSONS WITH DISABILITIES IN SURVEYED DISTRICTS IN 2002

SURVEY DISTRICT			IMPAIREMENT				
	Physical	**Hearing**	**Sight**	**Speech**	**Mental R**	**Mental**	**Other**
1. Adjumani	2,754	1,434	1,649	195	268	331	668
2. Apac	12,831	7,373	8,107	1,266	1,116	867	3,583
3. Arua	12,962	4,236	5,305	796	1,608	1,846	3,104
4.Gulu	9,507	5,037	5,118	563	591	617	3,624
5. Hoima	4,749	1,764	3,112	584	497	473	1,055
6. Jinja	4,191	1,573	2,639	488	461	466	827
7. Kabarole	4,936	979	1,895	602	444	477	849
8. Kalangala	688	121	293	33	45	29	122
9. Kampala	7,075	2,000	5,898	715	734	893	1,708
10.Kapchorwa	2,571	873	1,353	131	134	148	182
11.Kasese	5,799	2,166	3,215	967	363	378	1,052
12.Lira	15,684	8,501	10,695	1,477	1,293	1,229	4,182
13.Luwero	8,373	2,175	3,858	677	1,011	865	1,764
14.Masaka	13,024	3,525	6,130	1,206	1,581	1,265	3,167
15.Masindi	6,693	2,319	3,525	635	547	475	1,918
16.Moroto	1,279	583	785	77	64	52	90
17.Moyo	2,459	1,143	1,436	155	286	293	778
18.Nakasongola	2,846	967	1,431	254	202	357	542
19.Nebbi	10,685	3,232	5,641	518	827	984	4,128
20.Ntungamo	3,870	1,115	1,441	455	330	341	505
21.Sembabule	2,808	825	1,051	243	287	176	520
22.Soroti	5,835	1,704	3,604	421	353	336	950
23.Tororo	8,369	3,421	5,192	753	475	637	1,806
24.Yumbe	3,127	976	1,348	159	300	307	774

Source: **Uganda Bureau of Statistics – 2002 National Population and Housing Census**

As can be observed from the categorization in the Chart 3.1 below, it was possible that the list of types of disabilities used as indicators to collect census information in 1991 and 2002 might have differed in some respects, such as detail. The last two National Population and Housing Censuses held in January 1991 and September 2002, respectively, incorporated questions in the main household questionnaire for collection of demographic information on PWDs. In the 1991 Census information was collected from households on disability categories that included Blindness, Deaf/Dumb, Amputee, Leper, Epilepsy, Cripple, Mental and Other.

The classification used in the 1991 Census might not have been as detailed such as the classifications used by WHO or USDC and also that there could have been a definite undercount due to insufficient training of enumerators on identification of PWDs in the households. In the 2002 Census, demographic information on disability was collected presumably, from all households, as incorporated in the main household questionnaire and categories covered, included Physical, Hearing, Sight, Speech, Mental Retardation, Mental Illness and Other. This might not have been as detailed as in the International Classification and that used by USDC.

Chart 3.1: Classification of Impairments 1991 and 2002 Population Censuses and by USDC

1991Census	2002 Census	USDC Classification
1. Blind	1. Physical (Limbs, Spine)	1. Physical
2. Deaf/Dumb	2. Hearing	2. Cerebral Palsy
3. Amputee	3. Sight	3. Club Foot
4. Leper	4. Speech	4. Oesteomylities
5. Epileptic	5. Mental Retardation	5. Burn Contractures
6. Cripple/Lame	6. Mental Illness	6. Spina Bifida
7. Mental Disability	7. Other Categories	7. Hydrocephalus
8. Other Categories		8. Microcephalus
		9. Cleft Lip/Palate
		10. Speech Impairment
		11. Visual Impairment
		12. Hearing Impairment
		13. Epilepsy
		14. Mental Retardation
		15. Multiple Disabilities
		16. Others

Indeed, the categories of disabilities were being continuously refined and there were new and emerging types that had been classified. In addition, incidents of some disabilities had generally increased, key among them were cases of epilepsy, which were rapidly growing, or had been hidden and were being identified. There were disabilities whose causes were related to war in northern Uganda, *konzo* (cassava cyanide effect on joints resulting in paralysis) related disability, etc. According to the Uganda Bureau of Statistics (UBOS), by using the International Classification of Disabilities to analyse the 2002 Census results, the percentage of disabled persons out of total population was lower at 3.3%. This suggested that the adoption of the WHO International Classification would have left out a section of the disabled population in the 2002 Census results.

Table 3.2: Population of Persons with Disabilities by Type of Disability in 1991 and 2002

Year	Census 1991			Year	Census 2002		
Disability Type	Age 0-19	Age 20-34	Age 35+	Disability Type	Age 0-17	Age 18-30	Age 31+
1.Blind	3,949	1,981	16,765	1.Physical	79,884	66,862	207,584
2.Deaf/Dumb	11,917	4,146	8,713	2.Deaf/Dumb	62,958	16,539	48,196
3.Amputee	1,613	1,140	2,816	3.Vision	36,554	22,484	129,712
4.Leper	975	959	5,138	4.Speech	18,682	6,736	7,205
5.Epileptic	4,395	1,791	2,239	5.Mental Retardation	12,862	7,971	9,205
6.Cripple/Lame	27,988	13,375	22,440	6.Mental Illness	10,421	8,142	12,073
7.Mentally Retarded	11,478	9,671	10,286	7.Epileptic	11,762	4,891	4,671
8.Other	9,086	5,267	10,666	8.Rheumatism	3,966	2,709	12,254
9.Not Stated	634	272	735	9.Other	13,715	7,999	18,804
TOTAL	72,035	38,602	79,798	TOTAL	250,804	144,333	449,704

Source: Statistics Department/UBOS – 1991 and 2002 National Population and Housing Census

3.5.2 District and Lower Administration Information Situation

At district and lower levels of administration, information on P/CWDs was virtually non-existent, except for scanty data in a few districts where attempts had been made to collect and analyse such information. In Adjumani district, a form was designed for conducting a census of PWDs last financial year (2004/05), but due to inadequate financial resources, this was not done. Even then, the design of the form needed some technical input from UBOS so that other districts that were also planning to undertake future censuses of PWDs could benefit from this initiative. More importantly, the results could also be universally comparable and therefore acceptable.

Attempts were made in other districts (surveyed) to gather information on disability in two ways. First, secondary information from administrative records of disability service providers, i.e access to users of health, education and social services facilities, had been collected, analysed and disseminated, especially by CSOs like USDC, CUAMM, AVSI, etc. Secondly, there were those where attempts had been made to carry out village level counts by District Unions of Disabled Persons, such as in Kasese and Kalangala; CBR programme as in Tororo District Rehabilitation Office, Local Government Departments such as Education, Health and Social Services, in order to come out with district figures. In one way or another, none of them were based on a complete count or report on the extent of disability and numbers of disabled persons.

In the absence of regular and detailed national and sub-national data, in a number of districts visited for the baseline survey, some attempts were made to determine actual numbers of P/CWDs, but none came out with complete and usable data. Even organizations supporting PWDs did not have ready global data, except partial data for the limited programme related areas they supported. For example, USDC had data on its programme areas related to the CWDs that accessed services it provided over the years and similar experiences for CUAMM programme in West Nile, CBR programme in Tororo, AVSI programme in Gulu, etc.

CHAPTER 4: POLICY AND POLITICAL ENVIRONMENT

In this Chapter a review was made of International Conventions, Standards and Frameworks, national Legislation and Policy Frameworks, attitudes and perceptions of Central and Local Governments and how these translated into the degree of mainstreaming issues of disability, particularly of CWDs and how international frameworks influenced national legislation, policy making and programme development, such as by Ministries of Health (MOH), Education (MOES), Finance Planning and Economic Development (MFPED), Gender Labour and Social Development (MGLSD) and Local Government (MOLG).

4.1 International Conventions

A number of International Conventions, Standards and Frameworks related to disability were issued by responsible agencies for observance and/or implementation by member countries and were cited here for this analysis. The United Nations 48th Session, in Resolution 48/96, adopted **'The 22 Standard Rules on Equalization of Opportunities for Persons with Disabilities (PWDs)** to address the impairment and the environment the PWDs lived in. In 1978, at Alma Ata, nations agreed that the strategy to improve people's health was through primary health care (PHC) strategy, which included promotive, preventive, curative and rehabilitative healthcare system.

Uganda was a signatory to **The Universal Declaration of Human Rights.** Article 26 of the Declaration established that every person had a right, among others, to education. Uganda was also a signatory to **The 1989 Convention on the Rights of the Child** that established the rights of every child to primary and secondary education, early identification and health care. **The World Declaration on Education for All and Framework for Action to meet basic learning needs** (Jomtein1990) accorded every person educational opportunities designed to meet their basic learning needs; **The Salamanca Statement and Framework for Action on Special Needs Education** (Salamanca, 1994) which emphasized among others the right of all children including those with temporary and permanent needs for educational adjustment to attend school; **The Dakar Framework for Action** (UNESCO 2000) among others stated that by 2015, all children particularly girls, children in difficult circumstances and those belonging to minorities would have access to completely free and compulsory primary education of good quality.

The background to Community Based Rehabilitation (CBR) had a UN intervention, starting with the year 1981 being declared the **International Year of Disabled Persons (IYDP).** This was followed closely by the adoption of the **World Programme of Action concerning Disabled Persons** in December 1982, to promote effective measures of prevention of disability, rehabilitation and realization of the goals of ''full participation'' of Disabled Persons in social life and development of ''equality''. In further action, the UN declared 1983–1992 **the Decade of Disabled Persons.** In terms of the definition by WHO, **''CBR involves measures taken at the community level to use and build on the resources of the community, their families and their community as a whole''.**

4.2 National Laws and Policies and the Rights of P/CWDs)

The Government of Uganda appropriately translated some of the International Conventions and Frameworks into national Laws, Policies and Frameworks for implementation. First and foremost were the provisions in Article 34 of the National Constitution (1995), then the Children Act (Cap. 57) 1997, the Local Government Act (1997), Parliament recently passed the Law on National Council for Disability (NCD) to promote rights of PWDs through monitoring and this Law had been interpreted and implemented at district and lower levels. A Bill No. 18 of July 2005 ***(Persons with Disabilities Bill)*** introduced in Parliament was guided by The Standard Rules on the Equalization of Opportunities for Persons with Disabilities (UN General Assembly Resolution 48/96) and cited here for purposes of this report.

These national Laws were translated mainly in the Local Government Act (1997) for districts to formulate and enact Ordinances and By-Laws. The Local Government Act recognised the participation of persons with disabilities and in particular Article 11 (d) of the Act stated that two Councillors with disabilities, one of who should be female, should represent persons with disabilities. The Act also provided for Local Governments to plan using bottom-up approach, which should mainstream issues of disability right from the lower levels of the local councils and planning units and such plans would then form the basis for the national plan.

4.2.1 The National Constitution, Children Act, Local Government Act and Other Provisions

a) The Constitution 1995 - Article 34 of the Constitution of the Republic of Uganda 1995 accorded rights to all children. The same Article also accorded parents the responsibility to look after their children and stated in part that

1) Subject to Laws enacted in their best interests, Children shall have the right to know and be cared for by their parents or those entitled by law to bring them up.

2) A child is entitled to have basic education, which shall be the responsibility of the state and parents of the child.

3) No child shall be deprived by any person of medical treatment, education or any other social or economic benefit by reason of religious or other beliefs.

b) Children Act 1997 - outlined the role of Government and other stakeholders, in supporting all children including those with special needs. This Act was promulgated to protect the rights of the child (person 18 years and below), providing for the child's right to live with the parents or guardians. It was their duty to maintain the child and gave such a child the right to education and guidance, immunisation, adequate diet, clothing, shelter and medical attention. In the context of CWDs, Section 9 of the Act specified that ***'Parents of CWDs and the State shall take appropriate steps to see that those children are i) assessed as early as possible as to the extent and nature of their disabilities, ii) offered appropriate treatment, and iii) afforded facilities for their rehabilitation and equal opportunities to education'***. The Law therefore, adequately provided for the rights and privileges that a CWD should enjoy like any other child.

c) The Local Government Act 1997 - recognised the participation of PWDs. Article 11 (d) of the Act stated that two Councillors with disabilities, one of who should be female, should represent PWDs. The Law enabled a good representation of PWDs by number.

d) Poverty Eradication Action Plan (PEAP) - In the area of socio-economic management policy, the Poverty Eradication Action Plan (PEAP) was the strategic document, anchored on five main pillars, including Human Development, which generically provided for a planning process that incorporated requirements, aspirations and sustenance of P/CWDs under the Social Protection for Vulnerable Groups as orphans and other vulnerable children (OVC), the elderly and PWDs. A number of strategic plans have been curved out of the PEAP to support those particular sector programmes, including Health Sector Strategic Plan (HSSP), Education Sector Investment Plan (ESIP) and Social Development Sector Investment Plan (SDIP), among the prominent.

Health Sector Strategic Plan (HSSP) – The overall objective of the Plan was to reduce morbidity and mortality from major causes of ill health and create a system to deliver a minimum package of health services to the population, largely through PHC. The target was to strengthen the district health systems for delivery of the package. Within the context of the 22 Standard Rules cited earlier, MOH developed National Standards for guiding districts to develop and monitor the rehabilitative arm of PHC. A document entitled 'Essential Services for Rehabilitative Health Care for Persons with Disabilities in the District', often called the **'rehab package'** provided the Standards, as discussed in Chapter 5 of this report.

Education Sector Investment Plan (ESIP) 1997, 2003 - The Plan spelt out strategies for ensuring equity of access to all levels of education as one of the major focus of access to basic education, particularly in primary education under Universal Primary Education (UPE) policy 1997 and 'Inclusive Education' policy as discussed in Chapter 6 of this report.

Social Sector Strategic Investment Plan (SDIP) – The national social sector policy was synthesised in the SDIP. This policy framework in summary targeted overall promotion of social protection and transformation, gender equality, social equity, human rights, culture, decent work environment and empowerment for different groups including women, children, unemployed youth, IDPs, the elderly and PWDs. The policy concerns therefore addressed issues of exclusion, inequity, inequality, vulnerability, unemployment and powerlessness of the different groups. The overall objective was 'to create enabling environment for social protection and transformation of communities' and the vision was 'a better standard of living, equity and social cohesion'. A number of legal provisions through legislation and policy frameworks were put in place to meet the main objective of the SDIP including

i) National Disability Policy - The overall concept of a national disability policy was based on a situation of PWDs being accepted, neglected or rejected in society, family or community. Government policy was therefore, aimed at protecting PWDs from negative cultural, societal and family attitudes and actions. In this context such policy was to provide a framework for protection, access to affordable rehabilitative services and creation of equal opportunities for participation of PWDs in all spheres of socio-economic activities.

Part of the framework was first to create and strengthen disability movements through appropriate legislation (National Council for Disability Act 2004, Persons with Disabilities Bill 2005, etc). The second task was to support social sector restructuring to become more relevant to tasks requiring social rehabilitation processes for PWDs and consider disability as a multi-sectoral and multi-disciplinary problem that equally required similar disciplines of approach. Finally, government's intention was to move away from institutionalised rehabilitation to community based rehabilitation (CBR). Thus according to the Guidelines for CBR in Uganda[1], prepared by the Department of Community Development in MGLSD (originally based in the MOLG), government adopted the ideal of moving away from institutionalised (vocational) rehabilitation services, to CBR approach and methods to service provision to Disabled Persons.

ii) National Orphans and Other Vulnerable Children (OVC) Policy (November 2004) - This policy essentially provided the framework for promotion of social protection of poor and vulnerable children (including orphans, victims of HIV/AIDS, street children, child labourers, socially discriminated, marginalized and abused children and children caught in armed conflict situations).

4.3 Disability in the National Planning Process

Background to Development Planning in Uganda

The first post-independence Five Year National Development Plan of 1962/63 to 1966/67 was prepared and launched in FY1962/63. The second Five Year Development Plan was prepared and launched in FY1967/68. These national plans were drawn by technical teams of professionals of the National Planning Commission that worked through sectoral committees. A separate Ministry of Planning and Economic Development (MPED) was the Secretariat of the Commission. Key development policy guidelines were thoroughly discussed as provided by government. Such policy frameworks had national outlook and focus, were robust and well thought out. They were not just mere implementation of direct pronouncements or ad hoc policies issued from time to time by political leaders in government.

The planning process was backed by background information and needs assessment (as in health, trade and industry, infrastructure, community services, education, agriculture, employment, population, etc) and situational information, which were collected and analysed. It would therefore, be the needs that were translated into policy and subsequently plan as a cardinal step. As a result, development was broad-based and well spread throughout Uganda as well as within East Africa. These plans were regularly monitored and reviewed by competent authorities and where targets were not met like mid-stream there would be revised implementation strategies, but not necessarily policy change.

No plan of the nature and magnitude of the two five-year planning cycles were prepared and implemented after 1971, partly as a result of rapid changes in government, through coups. However, since 1986 only one system of governance (Movement) prevailed and there had been no attempt to plan in five-year cycles. Instead, a three-year rolling plan cycle had been implemented, no different from the three-year Recovery Programme prepared in early 1970s and a similar one in early 1980s. This was basically a budgeting process or allocation of available resources to areas considered as priorities.

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[1] Guidelines for Community Based Rehabilitation Services 1992, Republic of Uganda

Government also decided to merge MPED with Ministry of Finance (MF). This merger partly made the original planning role of the former to be subsumed and the result was the existing budgeting process that was assumed to be the planning process by national and district governments. Therefore, mainstream development planning stopped many years ago. It was however, anticipated that when the National Planning Authority (NPA), established by Act of Parliament No. 15 of 2002 as provided for in Article 125 of the National Constitution of 1995, started its mandated work proper, professional and technically oriented development planning would begin.

The Current National Planning Process

The current national budgeting/planning reference document was the Poverty Eradication Action Plan (PEAP), which stated the cardinal goals of government that contributed to poverty eradication (improvement of lives of the poor) and was regularly reviewed and revised. It was a commonly quoted and used document by donors for providing development assistance to Uganda. There was heavy dependence on donor funding for development management programmes and World Bank (WB) and International Monetary Fund (IMF) were key partners that partly dictated to government to develop guided poverty reduction strategies and had a great deal of say in management of financial resources, as the two largest development assistance contributors. A larger part of support was provided through basket funding and much less through project funding.

Every year, MFPED prepared a poverty reduction strategy paper (PRSP) as a basis for the budgeting process and thereby estimated how much resources would go into investing in the strategy plan as documented in the Public Investment Plan (PIP). In terms of interventions of development partners at central government level, donors fitted their development programmes as integrated in the PIP. Even though the overall reference document for planning was the PEAP, it would appear that interpretation of the five key pillars of the plan, a) Economic Management, b) Production, Competitiveness and Incomes, c) Security, Conflict Resolution and Disaster Management, d) Good Governance and e) Human Development, at national, district and lower planning or budgeting levels, could be difficult to visualise or might not exist in the perspectives of the bottom-up approach to planning.

The budgeting/planning process started in August/September to determine how much money would be available to finance the government programme, in the coming financial year, basing on economic and fiscal performances and donor resource envelops during previous years. A stakeholders' meeting was arranged/coordinated by MFPED, bringing together MPs, line Ministries, other government institutions, local governments, the private sector, civil society organizations (CSOs), the media and donors. The objective of the meeting was to discuss how the economy had performed over the previous years, how much financial resources would be available to government over the next three years, how much financial resources would be available to the sectors in the next three years, policies and activities to be undertaken in poverty reduction and how to overcome implementation shortcomings.

Each sector had a working group to discuss sector plans and priorities and monitored performance. It was at this meeting that budgeting ceilings were also determined for each sector, which was a basis for prioritisation. Following the main meeting, the sector working groups (SWGs) would start discussing sector priorities for the coming three years and how funds would be allocated according to the priorities. Each SWG prepared a Sector Budget Framework Paper (SBFP). All the SBFPs were then consolidated by MFPED into a Macro-economic Framework Paper (MFP) for submission to Cabinet for discussion and approval. Once approved by Cabinet, it was submitted to Parliament for final approval.

In specifically considering a development problem or need, the existing framework, in the first instance, did not offer any opportunity for important and emerging socio-economic issues, including newly realised concerns like disability that considerably impacted negatively on poverty eradication and currently not considered as priority, to be addressed. This was because the magnitude of the problem of disability could only be determined through needs assessment as a key pre-requisite for considering it as an important social development problem in the planning process. That was why the problem was not prioritised in the budgeting process as long as "the means determined the end". In the final analysis, whereas laws and policies were developed and made in order to give weight and emphasis for development process to address issues of rehabilitation of CWDs, the budgeting process did not allow these policies and laws to be effectively translated into development programmes.

Disability Considerations

According to the PEAP 2004/05 to 2007/08 under the Human Development Pillar, ***"The lack of participation and protection from abuse, violence, neglect, discrimination and exploitation results from and leads to poverty"***. This Pillar generically provided for a planning process that should incorporate requirements, aspirations and sustenance of P/CWDs under the Social Protection for Vulnerable Groups as OVC, the Elderly and PWDs. What seemed to be stressed more for PWDs was their representation in Parliament and in local councils, because such representation was assumed to give the PWDs, essentially adults, voice to lobby and access to services, and was stated without due consideration for CWDs who equally had needs, voices, aspirations and required provision of services.

Another example of actions to support PWDs was the recently passed Law on National Council for Disability to promote rights of PWDs as a watchdog arrangement. This had been interpreted and implemented at district and lower levels, by formation of District Disability Councils (DDCs) as well as lower down. However, on review of the prospective work plans or programmes of these Councils, nowhere was there indication that particular focus of attention on CWDs in programmes of work was discernible as discussed further in Chapter 7.

In the PEAP it was also mentioned that the Social Development Sector (SDS) was implementing community based rehabilitation (CBR) programme for the disabled in 13 districts (2003), including homecare visits, provision of assistive devices and vocational skills development centres. Therefore, the key policy framework to guide planning was the expansion of CBR services as priority requiring more public intervention, which might not be the situation on the ground. The examples of experiences of the districts covered under the baseline survey did reflect on and logically assessed this policy provision in the PEAP as discussed in the section below.

4.4 Local Governments Interpretation of Laws and Application of Planning Processes in Mainstreaming Disability Issues

4.4.1 Local Government Act 1997

At district and lower government levels, the Act mandated local governments to ensure protection of the rights of the child. The Act (simplified version 1997) Section 11 stated in part that ***all LCs had a duty to protect the well being of children in their areas.*** The Secretary for Children's Affairs, chosen from among members of the Council was responsible for all matters concerning children. The Secretary, assisted by other members of the Council, should ensure among others that children were taken to school, advised on the best ways to behave, children were given a balanced diet, clothed and taken to hospital or clinic when they were sick. Where there were CWDs, such as the deaf, dumb, lame or blind in their area, the LC should keep a register of such children and help them to grow up like other children without disabilities.

At district and lower local governance levels, the decentralization law devolved the mandate to the local governments to formulate, approve and implement respective development plans and budgets in the comprehensive District Development Plans (DDPs) that integrated plans of lower local governments. The MOLG provided the guidelines for the budgeting process. Even attempts by a few districts to come up with semblances of Five Year Development Plans were not based on socio-economic needs assessment, but emphasised the same budgeting structure. The guided attempt at district planning or budgeting was in the DDP as the authentic document that highlighted what was expected to be budgeted for and should attract and guide departments, sectors and the donors.

The technocrats were expected to interpret the PEAP, adapting it to the local situations and circumstances. Decentralization policy entailed bottom-up approach to planning where the grassroots determined their respective development needs. However, depending on the local development situations, as long as the budgeting process continued to be applied and enforced through guidelines issued by MOLG, the process could not be bottom-up or free.

When it came to focussing on and considering marginalized areas in development, which were indeed cross cutting in nature and not easily understood (also true at national planning level), in many respects such areas were neglected and left to development partners such as CSOs to handle. For example, none of the districts had articulated issues of the development of P/CWDs as deliberate policy to be translated into programmes in the development of plans and budgets and yet they formed a substantial percentage of the population.

This was attributed partly to a historical negative perception towards P/CWDs by the systems and structures that considered such persons as useless and attached no value to them. They considered disability to be planned for by communities, CSOs, etc and not government. As a consequence, CSOs that particularly targeted disability entered districts to implement their own programmes with no reference to the DDP. The districts, in effect, considered the CSO financial and other resources as extra and a relief on what they themselves received from central government in grants and those they locally generated.

4.4.2 Local Government Planning/Budgeting Process

According to the work plan strategy for each local government the planning and budgeting process started with preparation of the Annual Work Plan right from community level consultations involving key actors in the budgeting process in October each year. The communities, through their LC1 identified what they could do at their level, basing on what they considered for budgeting priorities and submitted to the Parish Development Committee, which in turn identified and sorted out what it could implement. These were submitted to the Sub-county Development Committee that were in turn consolidated and submitted to the District, basing on what could be implemented.

The proposals were then submitted to the District Planning Unit (DPU) and sorted out by sector. After deciding on what to incorporate, these were consolidated into sector plans. Ideally, this would have been the stage at which development partners, such as donors and CSOs and other stakeholders should have come in so as to avoid duplication in the planning and budgeting process in the wider context, presenting their respective programmes, to be incorporated in the respective sectors. Nevertheless, the Sectoral plans were submitted to and discussed by combined technical and political Sectoral Committees.

However, this stage-by-stage approach of bottom-up planning and budgeting process was fragmented and therefore a distortion as each tier of governance went through a guided and provided for process. The guided and subjective planning process did not originate from the people, instead they were directed, hence there was no ownership and key community areas needing necessary attention, such as disability, were not prioritised. In fact the respective Chief Administrative Officers (CAOs) and District Planners interviewed did confirm that disability was not one of the district and lower level local governance systems' priorities.

Whereas the Parish Development Plan should technically have been based on a more objective and encompassing needs assessments of the respective Villages within the Parish, these would reflect all development needs, regardless of resource requirements, that constituted the Parish needs assessment. The needs assessments of the Parishes would in turn form the Sub-county development needs assessment. The most important element in this argument was that the local people and respective structures were facilitated to reflect on their own situations and defined needs to be addressed and they would own such needs. Thus, disability, which was an issue of concern to many communities and societies, would have been addressed and included in the LC I–V levels of plans.

What should have been done and adopted should have been for the Villages, Parishes, Sub-counties and Districts to draw plans that were more objective and encompassing. It would then be at the stage of attaching budgets against the holistic plans that ceilings would be considered, yet the plans would remain relevant for future funding over time. This flexibility would have encouraged villages up to districts to look ahead and plan for longer-term development needs. In addition, development partners, such as CSOs would not prepare their own programmes for direct implementation but would use the district or lower administrative unit plan documents, and by collaboration, identify components that would interest them and utilise capacities in programming implementation within relevant sectors.

Some key reflections of budgeting for and integrating P/CWDs in Sub-county programmes (as Offaka in Arua, Parombo in Nebbi, Amacu in Lira) seemed to suggest that they uniquely met some specific (subjective) requirements in budgeting. They were obliged to remit resources for supporting CWDs in Special Units in Primary Schools, training of youth with disabilities at Vocational Training Centres (e.g Ocoko in Arua, Masaka, etc) and the resources were budgeted for in their plans. In general terms, Sub-counties recognised the importance of making budgetary provisions for taking care of P/CWDs. This was mainly a result of USDC's advocacy and lobbying in its programme districts.

4.4.3 Key Features of Planning/Budgeting Process

As a recent development, in districts where partners were substantial contributors to the district budget for particular sector activities and in order to avoid duplication in the planning and budgeting process in the wider context, such partners as CBOs, were invited to present their respective programmes at sectoral level, for them to be incorporated in those respective sectors. In some DDPs, the activities were identified but no resources attached to the budget lines. Another feature was that while budgeting was done fairly well for disability by government sectors, there were regular budget/funding cuts that often than not led to rolling over of planned activities or even phasing out altogether items considered of no immediate consequence. In terms of prioritisation, the merged political and technical (civil service) plans made it difficult to trace the defined budget lines as more of these went into administrative costs. Therefore, resources dedicated to P/CWDs activities, which commonly suffered budget cuts, were often rolled over to the next budgeting cycle.

From the district and lower level planning/budgeting experiences, resource allocation to the area of CWDs development did not feature directly, because it was considered with others (e.g Elderly and PWDs) and a non-priority area. Even so when resources from government and development partners were earmarked for PWDs, these tended to target adults and DPOs. Ordinarily these were included in the respective sector proposals and budgeted for according to particular activities in education, health and social services. In most cases earmarked resources were incessantly small.

Having extensively reviewed DDPs, the consultants concluded that the general trend was that the resources available to the respective districts tended to largely originate from Central Government Grants and donor contributions. Locally generated revenue resources were small in comparative terms. The overall amount of resources available to local governments annually were Conditional Grants, the utilization of which was predetermined at national level (MOLG) and Non-Conditional Grants both contributing 75% to 80%, Donors contributed 15% to 20% and Local Revenue made about 5% to 10%. A key feature of the devolved funds from central government was that they were provided under strict spending guidelines and therefore spelt no flexibility for reprioritization at district or lower level. The following areas commonly featured in the sector budgets for the District Annual Work Plans in both cases where USDC was active or not active:

a) Education sector – Refresher courses for SNE teachers under USDC and PAF funding; Sports for Disabled under schools funding;
b) Health sector – preventive, curative with no specific reference to CWDs (although there was a lot of funding in the GOU/UNICEF Country Programme to support vulnerable children which included CWDs);

c) Social Services sector – USDC and other NGOs and donors supported parents' mobilization and sensitization (e.g from PEARL (EU) funding).

4.4.4 Participation of CSOs in Programming/Planning

In the absence of a clearly articulated plan framework, spelling out areas of need in disability, relevant CSOs focussed on disability designed and implemented their own programmes/projects. They would come to a district, in most cases with a tailored and selected project areas and partners with whom to work and implemented such projects. They did not declare the amount of resources to the authorities or government partners put in such projects. In recent budgeting processes, however, a number of CSOs participated in preparation of and agreed their programmes to be incorporated in DDP. USDC took lead in this process and participated closely in planning its activities with district level government partners. In USDC programme districts therefore, USDC and other CSO plans were reflected in DDPs except that no resources were attached/reflected, such as for Adjumani, Masaka, Sembabule, Nakasongola, Arua, Hoima, etc.

Table 4.1: Local Government Budgets for Disability - some Non-USDC Districts for 2005/06

District LG	**Total Budget (Shs. Million)**	**Amount Disability (Shs. Million)**	**Items Covered**
Gulu	..	6.8	Disability & Elderly
Kabarole	..	5.3 3.4	Disability Council Elderly and PWDs
Kalangala	3,790.8	NIL	
Ntungamo	..	..	
Tororo	21,385.4	130.3	Disability & Elderly

Source: ***District Development Plans (DDPs)***
Note: ***The gaps (..) indicate figures not available***

Tables 4.1 above and 4.2 below give summaries of extracts from DDPs for Fiscal Years 2005/06 and 2004/05 respectively. Inspite of obvious data gaps, generally small budgetary provisions were made for disability. This was a clear elaboration of the minimal focus of resources on disability in the budgeting or planning process.

4.4.5 Reflections on Attitudes of Local Government Officials

Government policy was that rehabilitation should be part of a minimum package of medical services made available to all levels. The mandate of the district was to implement this minimum package by providing conducive environment and put rehabilitation on priority. The main issues in implementation were accessibility of services and follow-up to ensure effective rehabilitative support. It could be translated into an Ordinance as an affirmative action in form of an incentive to attract people to acknowledge it.

However, there was a general lack of knowledge of disability, commitment, devotion and how to articulate disability issues among the district leadership and civil servants or implementers, which led to non-provision of services and programmes for PWDs. One District Medical Officer told the LC5 ***'My office is budgeting for other things not for the disabled. Go to the DRO. The DRO is not effective. He was absent from the budget meeting.'*** The ACAO in Moroto said ***'If people with disability get money, the disability will disappear from the public'***. These examples were clear indications that government leaders and civil servants did not appreciate disability as crosscutting. The situation was made worse by the absence of demographic data, which would have informed them on the extent of different categories of disability.

4.4.6 Mainstreaming Needs and Concerns of CWDs in District Plans/Budgets

Budgeting figures as in Tables 4.1 and 4.2 suggested that very limited or no allocations were made in the DDPs for the disability area. In non-USDC programme districts, there were significant allocations in the DDPs/budgets of Tororo, Gulu and Kabarole. In USDC programme districts however, local governments made mostly token allocations in DDPs, although Masaka, Sembabule, Hoima and Adjumani made significant allocations covering SNE training, vocational training centres, etc. For example in the Sembabule district recurrent and development budgets for FY2002/2003 and 2004/2005 there were allocations of Shs.4.2m to cater for PWDs and Elderly and Remand Facilities, without specifying rehabilitation of CWDs. The parallel provisions for Youth and Child Affairs were Shs.9.7m, Shs.10.7m and Shs.1.8m for 2002/03, 2003/04 and 2004/05 FYs, respectively. These allocations again were not specific on the portions for rehabilitation of CWDs.

The negative attitudinal problem towards CWDs espoused by the implementers originated from the background where disability was considered as a curse by society. It led to rejection and sidelining of victims and related concerns. This was further complicated by the hindrances imposed by the current planning/budgeting structure. Therefore, budgetary provisions were made by the local governments under unclear headings in mainstreaming the needs and concerns of rehabilitation of CWDs. Disability should have been perceived as part and parcel of every activity planned for and adequate resources committed for its specific demands for special focus.

Table 4.2: Local Government and USDC Budgets for 2004/05 for Disability

District Local Govt.	Total Budget (Million)	Amount Disability (Million)	Items Covered	USDC Budget (Million)	Items Covered	Total Budget Disability (Million)
Adjumani	11,237.6	14.1 19.3 7.0 75.0 5.4	PWD Lead Advocacy Data PWDs R/Centre Appliances	68.85	Disability information and education Research lobbying and advocacy Capacity building Disability information and documentation Personnel and administration costs Capital costs	121.65
Apac	..	..	..	102.7	Disability information and education Research l, lobbying and advocacy Capacity building Disability information and documentation Personnel and administration costs	..
Arua/Yumbe	..	2.5 (Arua only)	Ocoko Vocational Rehabilitation Centre	410.5	Disability information and education Research, lobbying advocacy Capacity building Disability information and documentation Personnel and administration costs	413.0
Hoima	15,016.2	32.65	Special Education	100.3	Disability information and education Research, lobbying and advocacy Capacity building Disability information and documentation Personnel and administration	132.95
Lira	..	..	..	151.7	Disability information and education Research, lobbying and advocacy Capacity building Disability information and documentation Personnel and administration costs	..
Luwero	20,122.4	..	..	92.0	Disability information and education Research, lobbying and advocacy Capacity building	..

					Disability information and documentation Personnel and administration costs	
Masaka	28,983.7	18.0	Masaka Vocational Rehabilitation Centre	182.8	Disability information and education Research, lobbying and advocacy Capacity building Disability information and documentation Personnel and administration costs	200.8
Masindi	..	..	..	83.46	Disability information and education Research, lobbying and advocacy Capacity building Disability information and documentation Personnel and administration	..
Moyo	10,244.1	..	..	102.9	Disability information and education Research, lobbying and advocacy Capacity building Disability information and documentation Personnel and administration	..
Nakasongola	6,801.1	..	..	40.7	Disability information and education Research, lobbying and advocacy Capacity building Disability information and documentation Personnel and administration	..
Nebbi	13,156.6	..	..	88.3	Disability information and education Research, lobbying and advocacy Capacity building Disability information and documentation Personnel and administration	..
Sembabule	..	10.7 4.2	Youth/Child Affairs PWDs/Elderly	43.0	Disability information and education Research, lobbying and advocacy Capacity building Disability information and documentation Personnel and administration	..
Jinja	..	..	..	63.1	Disability information and education Research, lobbying and advocacy Capacity building	..

					Disability information and documentation Personnel and administration	
Soroti	13,307.0	0 0	SNE Disability & Elderly	63.1	Disability information and education Research, lobbying and advocacy Capacity building Disability information and documentation Personnel and administration	63.1

Source: **District Development Plans and USDC**
Note: **Gaps (..) indicate figures not available**

The local governments showed inadequate commitment, creating the impression that government did not appreciated disability as a major part of its social responsibility. The structures of government were still based on a traditional concept and system where disability was institutionalised, this time without adequate support. The CBSD that should be involved in sensitising communities had remained conservative in training and approach to management of issues of disability. The training of social workers on disability emphasised the concept of institutionalisation and was welfare oriented in provision of services. Hence, the effective involvement of local governments in mainstreaming disability depended very much on successively addressing the challenge of transforming this background.

To emphasise the observation above as example, the CAO in Hoima admitted that there was no specific plan on disability and CWDs although there was some assistance given to PWDs it was on ad hoc basis. The CAO emphasized that the Council was demand driven and responded to issues as they came. However, he agreed that it was the responsibility of Councillors and government officers to bring issues like that of CWDs to the Council. In most baseline survey districts, it was acknowledged that unless MGLSD headquarters went down to demonstrate teamwork, the role of CBSD in facilitation of communities and other departments was not recognised. The implementing departments, like DDHS, Public Health, Education, etc, operated in isolation, rendering CBSD without facilitation to perform its role in those departments. Hence, social healing/rehabilitation had never been emphasised.

4.5 Strategic Gaps

i) Policy

a) Policy formulation was a major domain of district political leadership. Although skills and knowledge were imparted by MOLG to LCs in interpreting the Decentralization Act and related Laws, the LCs had not come up with Ordinances and By-laws for interpreting the national disability related Laws and policies. The ideal was to bring the Laws closer and prompt local governments to interpret and translate local situations into development plans and implement them.

b) The budgeting/planning process seemed to raise very fundamental issues that had had impact on the development as well as governance processes at district and lower levels. There was lack of robust socio-economic planning focus at the moment, which stifled effectiveness of political leadership in policy formulation and implementation under the decentralized system of governance.

c) Interpretation of the PEAP at district and lower levels was difficult for holistic implementation where there was a gap of needs assessment and accurate and timely data and translation into district plans.

ii) Planning/Budgeting Process

d) Government at various levels did not see disability as life threatening as malaria, HIV/AIDS, tuberculosis, etc. While on the periphery disability did not appear as life threatening, it had psychological effect of social rejection that ate up and devastated the affected person. This meant that if current activities undertaken by USDC ceased, it would be difficult for government to take over such investments, as its priorities did not directly address P/CWDs.

e) The budgeting process was subjective and dependent on availability of resources from the central government and disability was not among priority areas of budgeting, hence the planning guidelines from the centre to the districts excluded disability.

f) CBOs/NGOs found minimal role for them in the local government budgeting processes, which provided no clear entry points for their programmes.

iii) Representation

g) The level of representation of PWDs in terms of numbers was inadequate for or conducive to supporting the disability cause. Such representation in District Councils and lower levels was weak as a result of low education and therefore articulation of disability issues. What seemed to be stressed more was representation, voice to lobby and access services without due consideration for CWDs who equally had needs, voices and required provision of services. That voice had not been effective

h) There was no mention of particular focus of attention on CWDs in programmes of work (work plans) anywhere District and lower Disability Councils were formed.

iv) Disability Information/Data

i) The magnitude of disability had not been adequately reflected or exposed due to lack of accurate and timely data. A framework for coordinated and sustainable data collection, analysis, storage and dissemination was still lacking at all levels. While Census 2002 data was expected to provide fairly comprehensive situation on disability, a lot more needed to be done to capture information in this area. A number of data collection exercises on disability had taken place in some districts by different agencies, mainly related to their work, there was so far no framework to enable all data users have access to such data or contribute to it.

CHAPTER 5: HEALTHCARE AND REHABILITATION FOR SOCIAL INTEGRATION OF CHILDREN WITH DISABILITIES

5.1 Introduction

In this Chapter the issues pertaining to the health care of CWDs are presented and discussed. The views gathered from the interviews are also presented as findings and later into the Chapter on recommendations.

Just like other children, CWDs required the whole spectrum of health care. In addition, because of their impairment, they required medical rehabilitation. In 1978, at Alma Ata[8], nations agreed that the strategy to improve people's health was through the Primary Health Care (PHC) strategy. Eight to eleven elements were identified as the main focus of PHC depending on the country priority. According to the 1978 Joint Report by WHO and UNICEF, PHC was to *'address the main health problems in the community, providing promotive, preventive, curative and* ***rehabilitative*** *health services.'* This Chapter examined factors that affected access to promotive, preventive and curative care on the one hand and rehabilitative care on the other. In terms of context, rehabilitation was not only limited to addressing the impairment but the environmental limitations that affected inclusion and participation. This was in accordance with the International Classification of Disability and Function (ICF)[9] that described disability as a consequence of environmental hindrances as well as difficulties arising from the impairment.

5.2 Profile of Common Childhood Disabilities

5.2.1 Prevalence and Profile of Disability

In all twenty-three districts visited by the consultants, childhood disability was a common occurrence with minor variation in disability profile from region to region. The political and technical officials; the parents and PWDs felt CWDs were many more than those enumerated in the 2002 Census. It was only in Kalangala where all categories of people interviewed reported low prevalence of childhood disabilities. This was attributed to the nomadic nature of life in Kalangala, where CWDs were unlikely to survive. ***'Perhaps these children are taken to the mainland to live with relatives because of the hard life here'***, explained the Chairperson of the DPO in Kalangala. Another district where most officials felt that the CWDs were few was Moroto. Just like Kalangala, the people of Moroto (Karamoja as a whole) lived a semi-nomadic life and in addition were in a precarious situation from seasonal cattle raiding battles.

The commonest disabilities reported in all the districts visited were epilepsy, mental retardation and cerebral palsy. These three conditions were consistently on top of the list throughout the country except in Karamoja where the CBR Coordinator at Matany Hospital and the Director of the only NGO for disabled reported hearing

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[8] Primary health Care, A Joint Report by the Director –General of the WHO & The executive Director of the United nations Childrens Fund, International Conference on Primary Health Care Alma-Ata, USSR, 6th –12th September 1978, Pg 2, Geneva

[9] International Classification of Functioning, Disability and Health short version; Pg 190; World Health Organisation Geneva; 2001; ISBN 9241545445

impairment as the commonest disability. They could, however, have also included pus in the ears as disability. The districts in conflict areas and their neighbours reported amputees as some of the common disabilities seen at service delivery points as in Moroto, Gulu, Kapchorwa and Soroti. An SNE teacher in Moroto said she had identified 3 child-amputees as a result of gunshot wounds. In Kapchorwa the amputees were as a result of Pokot cattle raids from Kenya, while Soroti received clients from Karamoja region and Katakwi to the regional hospital. All physiotherapists reported a growing concern from injection paralysis, which they suspected was caused by quack health workers. There were reports from some parents that the injection paralysis occurred from injections received from government health centres. Post-traumatic stress disorder (PTSD) was a common mental disorder in Gulu and was also reported by an SNE teacher in Moroto. A worker in Moyo for TPO an NGO that worked in Northwest for ten years did not recall PTSD in their work even among Sudanese refugees.

Panel II: List of Common Childhood Disabilities in the Districts by Diagnosis and Cause (reported by both Health Workers, District Leaders, Parents and PWDs)

Common Movement Disability (often referred to as physical disability by the informants)	**Mental Disability**	**Hearing Impairment**	**Visual Impairment**
Cerebral palsy, spina bifida, amputations, osteomeylitis, hydrocephalus, club feet, cleft lip and palate, foot drop, post - burn contractures, abnormal spine eg hunch back	Down's syndrome, hysteria, mental retardation, hyperactive children, epilepsy*	Otitis media (pus in the ear), damage to auditory nerve from drugs such as quinine and gentamyecin, congenital	Cataract, cancer(Moyo), trachoma (Karamoja), onchocerciasis (Hoima)

Note: **Although epilepsy is a chronic disease and not a disability, in Uganda it was considered a disability because of the high stigma associated with it. It was often incorrectly classified as a mental health illness because in Uganda the cadre spearheading service delivery was the mental health worker. Persons with epilepsy were identified late when mental limitation had set in so for the two reasons, epilepsy was referred to as a mental illness.*

The community, including health workers, was not able to differentiate completely between disabilities and their causes and the above Panel I was maintained to demonstrate this. The inability to separate the two affected data collection, especially for cross-sectional studies like this one. It should not, however, affect service delivery for both disability prevention and rehabilitation.

According to the 2002 Uganda Population and Housing Census[10] movement disabilities were the commonest (35.3%) followed by hearing disabilities (15.1%). In a community based sweep of the population, SCORE project found difficulty in

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[10] 2002 Uganda Population And Housing Census Main Report; Uganda Bureau of Statistics, P.O. Box 13 Entebbe, Uganda. website:www.ubos.org March 2005 Pg 17-19.

movement to be the commonest at 26.5% followed by seeing, hearing and epilepsy respectively at 23.5%, 18.5% and 10.1%.[11] In Jinja district, according to the 2003/04 report from the health sector[12], epilepsy was the 20th commonest disease burden in outpatients with a prevalence of 0.03% of the population of the district.

The census and related studies as well as the outpatient data supported the information from key informant interviews that movement difficulties were significant disabilities in Uganda. The successful immunization programme had virtually eliminated polio as a childhood disability so unlike in the 70s and early 80s polio was not an issue for children. Most children with polio though very few were above 14 years of age. It was only in Karamoja where the age limit for polio was put at above 10 years by the CBR Coordinator Matany Hospital. In support of this, data from USDC annual report 197/98[13] indicated polio was the third commonest disability at 13.8% and cerebral palsy fifth at 9.6%. By 2001/02[14] cerebral palsy, a multi-impairment disability was equal to polio. Epilepsy was the commonest disability[15] and this was also found to be so according to the interviews. Both epilepsy and cerebral palsy could be compounded by mental impairment including learning disabilities.

Bilateral blindness was found to be 1.6% in a study in Kamuli district. It was estimated that Uganda had over 8,000 blind children and 100,000 children between 11 and 18 years in need of spectacles.

Prevalence of disability was difficult to measure because of the different tools and methodologies employed. Table 5.1 below presents the prevalence from 3 different organisations. The estimated contribution of CWDs to the prevalence was estimated using the proportion of children below 18 years in the 2002 Census, which was 56.1%. This assumed disability was evenly distributed throughout the population, which was often not the case. The common presentation was a U-curve with higher prevalence in childhood and older people than in the youth and adults. However, for the purpose of estimating childhood prevalence the consultants chose to assume uniformity of disability rates in the different age groups.

Table 5.1: Prevalence of Disability from Different Sources

Source	**Prevalence %**	**Est. Prevalence of CWDs below 18 years (denominator is whole population, NOT children)%**
2002 UBOS National census[3]	4	2.244
2004 SCORE Northern Uganda[4]	5.1	2.7
2002/03 CBRMIS Tororo[6]	2	1.1
1998 OURS annual report[10]	4	2.244

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[11] Draft report Disability data collection Northern Uganda; April 2005; MoH, AVSI, CUAMM, CCM. P.O. Box 7272, Kampala.

[12] Annual report 2003/04 Jinja District Health Department.

[13] USDC Annual Report 1997/98. USDC P.O. Box 16346 Kampala usdc@ugasoc.org

[14] USDC Annual Report April 2001 to March 2002;

[15] USDC Annual Report 1997/98. USDC P.O. Box 16346 Kampala usdc@ugasoc.org; and USDC Annual Report April 2001 to March 2002;

From the above surveys (SCORE & National Census) and information systems (Tororo and OURS), it could be concluded that CWDs were approximately 2% of the population, 488,000 in total. This was probably an under estimation especially as some parents tended to hide or not to count CWDs among their children. For example OURS found the number increased after the initial registration because parents had evidence of benefit of bringing their children for services. In addition many more children had impairments that required medical services from time to time. However, because they did not experience any social restriction, the community did not consider them disabled.

5.3 Causes of Disability

The commonest cause of disability in children was reported to be childhood fevers. The parents as precedent to the child's disability commonly reported malaria with fits. Meningitis, congenital problems and difficult deliveries were additions by the teachers and health workers. The Director of District Health Services (DDHS) Kapchorwa District refuted malaria as a cause of cerebral palsy. He was of the opinion that malaria could cause epilepsy through repeated fits and behavioural disorders. Malaria was the most burdensome disease in Uganda and was endemic across the country except in highlands where it reached epidemic levels twice a year.

There was need for a study on the sequel of malaria and its relationship to disability in Uganda especially as health reports indicated on the burden of illness (morbidity) and death (mortality) without mentioning the burden arising from disability. The recognition of malaria as significant factor contributing to disability might increase resources to rehabilitation, which were currently skewed to malaria prevention and treatment.

Injection paralysis was caused mainly by quinine, which the physiotherapists suspected was given by untrained people. MOH was carrying out a study on injection paralysis, which should give insight into its prevention and management.

War affected the disability profile in two ways. The first was the direct one where amputees and other disabilities from gunshot wounds, bombs and landmine were reported more in the North than other parts of the country. FORDIPOM, an NGO for disabled had registered 3 children with amputation due to gunshot wounds from cattle raids. Post-traumatic stress disorder was prevalent in Gulu among children. Secondly, the indirect causes were as a result of breakdown of services and included cerebral palsy, epilepsy and especially in Moroto blindness from trachoma due to acute water shortage and deafness from chronic *otitis media.*

On a progressive note, no district reported having found CWDs from leprosy. Children who did get leprosy were identified early and treatment started before damage to the nerves sets in. In Moroto and Gulu districts, leprosy with impairments was found only among older persons. The successful immunization programme as already highlighted above had eliminated poliomyelitis as a cause of childhood disability. Childhood blindness was mainly from preventable causes and especially from vitamin A deficiency. The incidence of blindness secondary to vitamin A deficiency had probably been greatly reduced by the massive vitamin A supplementation programme and the extensive measles vaccination campaign. These programmes, however, would not affect the significant number of children who did not benefit from these campaigns (four years and above) and were irreversibly blind.

5.4 Significance for Service Delivery

The profile of childhood disabilities and their causes described in Sections 5.1 and 5.2 brought out the trend of disabilities and the direction services should be taking. First and foremost to confirm the obvious that CWDs were a significant fraction of the population. Secondly the disability profile had changed from polio to cerebral palsy, epilepsy and mental handicaps. The consultants suspected that the presence of these disabilities had always been high but due to lack of services, they remained hidden. These disabilities were now evident and could no longer be ignored as minor conditions on the edge of Bell's curve. Unlike polio, cerebral palsy and mental disorders in children required a multi-mix team of health workers as well as attention from the social workers. In addition these disabilities were difficult to comprehend and book in a category by the community unlike polio, which was a straightforward movement disorder. This increased the stigma and isolating what could not be explained. To add to the challenge was the international move from the medical rehabilitation model to the social/human rights model. This required that besides the impairment, the environment should be addressed.

There was therefore a need to change the health service paradigm from a vertical professional line orientation to one where the health worker's assessment covered the impairment, family and environment. For children it was imperative that service providers recognized that the primary care givers were an extension of the disabled child. Any health worker who interacted with a CWD should therefore be able to address within varying degrees, disease condition a child was presented with, the impairment, the concerns and ignorance of the parents and the physical environment the children was growing in. Professional referral should not be that of an assembly line but a whole person and their environment were referred.

5.5 Preventive, Promotive and Curative Healthcare for CWDs

All children required preventive, promotive and curative healthcare. The CWDs were more vulnerable than their non-disabled peers to the common infections and injuries that affected children. For example, a child who had to crawl to the latrine was more vulnerable to intestinal infections and infestations than one who walked to the same latrine. Children with cerebral palsy choked easily on food and saliva making them prone to pneumonia. The mentally handicapped might not have the mental capacity to tell safe from not safe food. Visual and moving difficulties increased susceptibility to injuries. CWDs should therefore be provided with every opportunity for prevention and promotive health services.

In the baseline study, most respondents said CWDs received immunization and treatment of an illness like any other children. Access to care however, seemed to be partly influenced by the attitude of the parent or caregiver. In Jinja, some parents said CWDs were not taken to hospital when sick until such parents were sensitised. In Karamoja it was reported that parents tended to ignore the CWDs and when the children fell sick they were not taken for treatment.

Health workers on the other hand treated the CWDs when they came across them in clinics. A nurse in the Young Child Clinic (immunization clinic) at Kasana, Luwero said she had identified many CWDs during the course of immunization both in static and outreach clinics. She saw mainly clubfeet, *spina bifida* and children who had brain damage from malaria and in most cases referred such children to USDC.

Health workers lacked knowledge on how to treat CWDs (Secretary for Finance Arua). In Kapchorwa district, the training of first line clinicians on disability under Disability Prevention and Rehabilitation (DPAR) Programme resulted in increased identification of CWDs. In some instances training health workers reduced the workload of the specialized health worker because cases that were previously referred to him/her were now managed at lower health units. The OCO of Kapchorwa was satisfied with the training of clinicians in management of common eye diseases because he now spent his time treating difficult eye problems since the minor eye problems were managed by Clinical Officers in general outpatient clinics. The training of Clinical Officers in prevention of deafness had increased the number of children who had had ear infection reduced and the hearing impaired assessed. USDC played a prominent role in training of the frontline health workers in prevention of deafness.

HIV was an important disease that CWDs must be protected from. The Secretary for Finance in Arua was concerned that the deaf children were not getting this information. This was especially serious when many parents especially from Jinja were concerned about the sexual abuse of CWDs. One child with epilepsy was taken to a witch doctor that sexually abused her and became pregnant. The child was back in school but was breast feeding a baby. The Ag DDHS of Arua was concerned about the sanitary arrangements for CWDs. Environmental sanitation was one of the elements of the MOH minimum healthcare package and should be available to CWDs.

In conclusion, CWDs did access preventive, promotive and curative health services although the level of attitude of carers influenced access. There was need for disabled children's advocates to include access of CWDs to preventive, promotive and curative services and not only for rehabilitative healthcare.

5.6 Prevention of Disability

Preventive, Promotive and Curative were primary and secondary disability prevention measures. The government laid emphasis on promotive and preventive arms of healthcare in a bid to reduce illness and death among its population. As an offshoot of this, disability too was being prevented. The HSSPs I (2000/01-2004/05) and II (2005/06-2009/2010) focused on service delivery as close to the community as possible and with maximum community participation. Several strategies were employed to reduce death and a few of the more prominent and successful ones are listed in Panel II below. It was beyond the scope of this study to discuss the strategies in detail. Some indication of their success was the reduction in childhood measles and no polio was reported below ten years of age.

Panel III: Preventive, Promotive Strategies

Preventive, Promotive strategies that prevent disability

- Expanded immunization programme
- National immunisation days and sub-days
- Child health days
- School health programmes
- Home based management of fevers
- Promotion of insecticide treated nets
- Wide spread and decentralized health education

Because disability was a marginalized area, some of the preventive programmes did not fully teach the client that one of the consequences of disease and poor nutrition was disability. For example, mothers in antenatal clinics in Kasana Luwero, Nebbi, Hoima and Apac hospitals could not relate their health education to disabilities. In addition the mothers were not at all prepared to handle the rare but possible incident of giving birth to CWDs. One doctor in Masaka Hospital said that when a mother delivered a child with some form of disability, they would detect it but not tell the mother, until discovered later. Common congenital conditions such as club foot, needed to be taught to mothers and they should be told where they could seek services as part of antenatal care. If this was not possible, Midwives needed to be trained to support parents who gave birth to disabled babies so that acceptance and seeking definitive care was done early.

5.7 Access by CWDs to HIV/AIDS Intervention and Preventive Services

HIV/AIDS epidemic affected CWDs in several ways. The already vulnerable situation of CWDs was worsened by orphanhood when parents died. Some CWDs were infected with the virus further increasing vulnerability and for some children the disability was sencondary to HIV/AIDS. A case control KAP study among deaf and non-disabled children in Ngora revealed that deaf children started having sex earlier than their non-disabled counterparts. In addition, their knowledge of transmission of the virus and protection was far less accurate than the control group. The teachers of the deaf did not know how to communicate issues of HIV and sex to the deaf children as some of the signs were not commonly used. This demonstrated part of the vulnerability to HIV of CWDs. Among the districts visited it was claimed there was no discrimination of CWDs from receiving ARVs. This needed to be verified in another study on access to HIV/AIDS services by CWDs. The teachers who were interviewed (including teachers for the blind in Morotro and Soroti) claimed that they did not discriminiate children when providing life skills education. The teachers had however, neither received any skills or advice on how to relay the messages on life skills to children with sensory impairments nor had they been informed on the special psychological issues of CWDs arising from low self esteem.

5.8 Traditional Birth Attendants (TBAs)

TBAs played a vital role assisting expectant mothers during nurturing of pregnancy and delivery. One TBA in Nebbi District said that she believed if mothers attended ante-natal clinics and followed what they were taught, the probability of delivering a CWD or severe attacks after delivery would reduce. She had been advising women to attend anti–natal clinics so that they would learn about how to protect themselves and their expected babies from diseases. TBAs were more accessible to expectant mothers than the health workers and if enlightened on causes of disabilities, they could be a good source of information and advice to mothers especially on prevention.

5.9 Rehabilitative Healthcare

5.9.1 Overview

Rehabilitative healthcare was one of the essential health services that should be available to all people although its target was mainly PWDs. The United Nations 48th Session, in Resolution 48/96, adopted 'The 22 Standard Rules on Equalization of Opportunities for Persons with Disabilities[16]. Rules 2, 3 and 4, medical care, rehabilitation and support services, respectively, addressed the impairment while the remaining Rules focused on the environment. With the guidance of the Standard Rules, MOH developed standards for guiding districts to develop and monitor the rehabilitative arm of PHC. The document entitled *'Essential Services for Rehabilitative Health Care for Persons with Disabilities in the District'* and often called the 'rehab package' described standards and their indicators for the following areas of service delivery:

- Staffing
- Services
- Equipment and supplies
- Management and support

The Standards were described for Community, Health Centres II, III, IV, District Hospital and District management/coordination levels. This report has presented the findings of rehabilitative healthcare along the 4 components in the 'rehab package'.

5.9.2 Human Resource for Rehabilitative Healthcare (Staffing)

Four thematic areas emerged from the qualitative analysis of the data from the interviews (FGDs). These were placement of staff or lack of it, staff training, attitude of health workers and their supervision to be discussed under the component of management and support.

a) Placement of Staff

According to the 'rehab package', the core rehabilitation staff required at district level were Physiotherapist, Occupational Therapist, Speech Therapist, Ophthalmic Clinical Officers, ENT Clinical Officers, Psychiatrist Clinical Officers, Orthopaedic Officers, Medical Social Workers, Orthopaedic Technological Officers and Medical Officers. No Speech Therapist was found in all the districts and referral hospitals visited. This cadre was only found at the National Teaching Hospital at Mulago. As a consequence, a specific curriculum at the Medical School was developed to meet this very wide gap in service delivery. Studies in Uganda and Nigeria[17] found that half of the CWDs had communication difficulty implying that half of them were not having their communication needs met. Another rare cadre was the Social Worker, found only in Gulu Orthopaedic Centre. Table 5.2 below presents the districts visited and

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[16] UN (1993). Standard Rules on Equalisation of Opportunities for Persons with Disabilities. New York: UN. http://www.un.org/esa/socdev/enable/dissre00.htm

[17] Sally Hartley and study on communication (details from Ddamulira)
CBRCBRCBR Joint Position Paper 2004 on CBR WHO, UNESCO, ILO

the rehabilitation staffing position. Only the commonly available staffs were presented. Specialist doctors were not included.

Table 5.2: Mapping of Selected Rehabilitation Staff

District	**Physio**	**O Th.**	**O O**	**OT/Tech**	**ENT CO**	**OCO**	**PCO**	**Psyc NO**	**Recom Norms**	**% Available**
Recommend LG Norm for General Hospital[20]	1	1	2	0	0	*1*	*1*	3	9	
Moyo	1	0	3	1	3 basic	2	2training	12	12	200
Luwero	1	1*	1	1	1	1	-	-	12	50
Nakasongola	0	0	0	0	0	0	1	1	12	16
Ntungamo	0	0	2	1	?	2	1	3	12	75
Kalangala	0	0	0	0	1	1	1	-	12	25
Moroto	0	0	?	0	1	1	-	-	12	25
Masindi	1	1 SNE		1	1					
Apac	1	1	1	1	1 Dip	2				
Kapchorwa	0	0	2	0	1 Dip, 1 basic	1	0	1	12	50
Adjumani	2	0	1	1	0	1	1	4	12	
Lira	1	1*		1	-					
Kasese	1	1	1	1	1	1	1	2		75
Sembabule	0	0	0	0	-	1	-	-		
Nebbi	1	1	1	1	1	1	1	4	12	90
Recommended Norm Referral Hospital	4	2	4	4	0 (2 ENT surgeons)	2 (+ 2 ophthalmologists)	2 (+ I psychiatrist)	8	24	
Masaka	1	1		1	-					
Arua	2	1	1	0	1 Dip	2	2	8	30	57
Gulu	2, 2*	1,1*	2	1, 1*	1	1	2	4	30	60
Kabarole	1	0	2	4	1	1	1	1	30	37
Jinja	3	1	3	0	1	4	3		30	
Hoima	1	1	2	2	1Dip,1 trainin	2	1	3	30	46.7
Soroti	1	0	3	1^	1 basic	2	3	2	30	43
TOTAL	21	10	25	16	19	26	20	45	288	
Total recommended (district + referral for the health facilites in this table)	42	21	56	28(all at regional referral level)	0	28	28	98	378	
Percentage in place	50%	50%	45%	57%	!	92%	71%	46%	76%	

Key:

* not on government payroll but are available in the district.

^ Orth Tech present and on payroll of government but there is no Orth. workshop.

! ENT CO are not yet recognised by public service

☐ Referral Hospital

Please note

- The analysis considered only the 'rehab staff' commonly found in the districts and referral hospitals. For example specialist doctors, social workers and artisans were not included in the analysis. This was to make any possible improvements as realistic as possible.
- Recommended norms were from hospital / district approved structures for Moyo (12) and Soroti hospital (30) for only the staff in the analysis.

None of the districts and referral hospitals had 100% of the required staff. Gulu was the best fulfilling 75% of the expected. Although Moyo scored 200%, this was deceptive because the majority of the staffs were Mental Health Nurses at the expense of other core rehabilitation staff, such as Occupational Therapists. The district, however, was the only one with all but one (Occupational Therapist) of the required cadre of 'rehab staff'. Although Gulu had scored highly, half of the staff were working within the hospital but supported by AVSI, an arrangement that was not sustainable. Arua, which had most of its staff on the payroll, but lacked an Orthopaedic Technologist, was in sustainable terms and better staffed than Gulu.

The worst performing districts were Nakasongola, Kalangala, Moroto and Sembabule. Moroto and Kalangala failed to attract and retain health workers. Those who did report after recruitment by either the local oovernments or NGOs left as soon as other opportunities presented themselves. Several reasons were given by the health workers interviewed and the district officials, including the fact that both districts were remote, had poor social services such as education, the urban centres were 'backward' and not conducive for vibrant social life and in addition, the districts were far from major towns and especially Moroto was insecure. Nakasongola and Sembabule, which were in a position to attract 'rehab cadres' had shown little interest in recruiting the staff, with the reason that they did not have District Hospitals. Nakasongola was particularly vulnerable because even with staff common to all districts such as the OCO and Psychiatric Nurses were absent and yet other districts without a district hospital such as Kalangala and Sembabule had succeeded recruiting these cadres.

The most available cadre in accordance to staffing norms was the OCO at 91% followed by the PCO. The core staff required for movemement and multi-impaired disabilities were the least available with only half of the expected staffing norms filled. These included the Physiotherapist (50%), the Occupational Therapist (50%) and the Orthopaedic Officer (45%). As noted earlier cerebral palsy was an increasing concern yet the core staffs to manage the condition was not available. Considerable review of the staffing norms needed to be made to match the new challenges. However, even before that were made, there was need to actively engage the various Service Commissions (PSC, HSC, etc) to ensure the core staff for the common disabilities were recruited. This was especially urgent for districts with no Physiotherapist or Occupational Therapist cadres. According to quantitative information, the order of the districts with most rehab workers is given in Table 5.3 below:

Table 5.3: Number of 'Rehab' Staff in the best staffed Districts (Extract: Table 5.2)

Position	**USDC supported districts**	**Non-USDC supported districts**
First	Luwero 29	Kasese 26
Second	Adjumani 28	Tororo 16
Third	Masaka 27, Moyo 27	Ntungamo 9

This was generally in agreement with the qualitative information. Gulu was absent from the best staffed in the table because data was collected from lower health centres and not from hospitals.

The key emerging factors for best performing districts in terms of staffing (taking quantitative and qualitative information) were:

- Presence of supportive CSO (USDC for Luwero, Adjumani, Masaka and Moyo; Church of Uganda for Kasese; Tororo Optic Centre for Tororo; AVSI for Gulu)
- Positive leadership especially DDHS/MS, eg Kabarole, Adjumani, Moyo, Masaka and Ntungamo
- Strong PWD leaders, eg Kasese, Tororo, Adjumani

Of the three factors the most decisive was the presence of a supportive CSO, which questioned the continuity and sustainability of the services once the CSO support was not available. Even in districts such as Moroto that had not emerged among the best in staffing, the 'rehab' service was dependent upon CSOs (Matany Hospital for CBR) and LAN for eye care services. It was only mental health which showed signs of sustainability because of the good availability of staff in all the districts visited and the growing contribution to purchase of mental health drugs. Mental health was followed by prevention of deafness services which was well staffed but lacked recognition of the staff on the formal government structures (see Section 5.13).

b) Misplaced Placement of Staff

An enigma existed in the rehabilitation service that was difficult to pin-point the cause. Arua Hospital, a Regional Referral Hospital, with a recently refurbished Orthopaedic workshop, had no Orthopaedic Technologist. An artisan based at Kuluva, a nearby NGO hospital, volunteered services from time to time at the workshop in the Referral Hospital. An Orthopaedic Technologist was in Soroti and on government payroll but was redundant because the hospital had no Orthopaedic Workshop. Ntungamo recruited an Orthopaedic Technologist but did not have an Orthopaedic workshop. The Technologist was recruited erroneously as the district sought for an Orthopaedic Officer. AVSI identified a disabled artisan, an expert in surgical boots 'on the street', to use the artisan's expression. He had worked in Mulago Hospital as a shoe-maker for over 15 years and was not retained after a retrenchment exercise.

Many of the Psychiatric Nursing Officers were in place but were not practicing their profession. Instead they worked as general nurses. Although they were the most numerous staff among the district 'rehab staff', they were not available to PWDs.

c) Staffing Norms

The district staffing norms met the needs of few PWDs. The norms had not changed despite the changing policy on disability, which resulted in great awareness among parents, the community and PWDs, about the need for rehabilitation services. The inclusion of PWDs in the political arena, the promotion of UPE and SNE, the spreading CBR programmes had far outgrown the staffing provision at district level. In addition, the population of Uganda had grown putting further demand on the rehabilitation service. Despite this demand for services, the districts Norms recommended one Physiotherapist, one Occupational Therapist and one OCO and PCO each. The hearing impaired people were not catered for yet hearing impairment was among the commonest disabilities in the country. Orthopaedic Technologist was not in the district staffing Norms yet more districts were advocating for or acquiring workshops in order to cater for their people with movement disabilities.

Demand for mental health services was growing and this required not only Psychiatric Nursing Officers but also Psychiatric Clinical Officers and Occupational Therapists. Although districts were provided with the option to recruit according to their needs, it was rare for a district to employ outside the Norms given by the central government. An example was Nakasongola where because there was no district hospital, the district had not recruited Physiotherapists or OCO but was dependant on neighbouring districts for services. Moyo, Kasese and Adjumani served as examples, which used the district staffing Norms as a tool and not a prison chain. Moyo recruited Orthopaedic Technologists and had adequate number and well distributed Mental Health Nurses well above the staffing Norms. Adjumani district had two Physiotherapists and Kasese recruited an Orthopaedic Technologist and a Physiotherapist who were deployed in the only district workshop, belonging to Church of Uganda hospital.

The hearing impaired was particularly disadvantaged because the cadre developed to provide services for prevention and rehabilitation was not recognized by Public Service. Their deployment and support depended on the individual favour of the health service manager. This led to frustration and redeployment of ENT COs to other general health care services, which were often well catered for and more lucrative.

d) Comparison in Staff Placement between USDC supported and non-USDC supported Districts

CSOs played a significant role in providing rehabilitation staff to district and regional hospitals. This was most prominent in physical rehabilitation where three scenarios existed. The first was where the CSOs played a significant role in lobbying the district to employ rehabilitation staff. The CSO might have started by supporting the rehab personnel (usually Physiotherapists and or Occupational Therapists) with monthly stipend while their formal employment was sorted out. This was the case with a number of USDC supported districts such as Luwero, Arua and Hoima. AVSI through the SCORE project used the same strategy in Gulu regional referral hospital where half of the staff was supported directly by AVSI and the other half supported by government for some after prolonged lobbying.

The second was when the CSO employed the rehabilitation personnel within the CSO run institution but the rehab worker extended his/her hours of work to include government institution. The Occupational Therapist and Physiotherapists in Tororo Optic Centre provided an example of this strategy. They spent one day a week in the government hospital running static services there.

The third was when the CSO employed the rehab worker and he/she worked in the CSO's hospital-catchments area or health sub-district. This was the case with the CBR worker in Matany hospital.

In blindness and deafness prevention, the staffs were often government employees although provision of services might have been supported by both Government and CSOs. This was the case in the eye care programmes supported by LAN and SSI.

CSOs, therefore, played and should continue to play a significant role not only in the staffing of rehab units but in their establishment as well. Their role as a catalyst for service development and for service provision needed to be recognised by government, not as an extension of charity to unfortunate disabled but as starting point to realising the rights of PWDs and bringing to the notice of government the need for rehabilitation services.

In the USDC Country Strategy 2000-2005, Output 3 states that:
Capacity within communities and government to provide care and protection for children with disabilities and to provide the necessary referral services increased.

Under this output, USDC planned to improve the capacity of Physiotherapy Units and Orthopaedic Workshops. Comparison between USDC supported districts and those without this support provided information on USDC's achievements as well as progress made in the districts of operation overtime as shown in Panel III below.

Panel IV: Staffing Comparison between USDC supported and Non-USDC Districts

Cadre and activity	USDC supported districts	Non-USDC supported districts	Conclusion
Presence of Physiotherapist	9 out of 11 districts 81%	6 in 8 districts 75%	Although Non-USDC supported districts had more Physiotherapists in total, they were concentrated in few centers. The 4 Physiotherapists in Gulu and 3 in Jinja make the difference. USDC supported districts have more Physiotherapy Units.
Presence of Occupational Therapist	7 out of 10 districts 70%	3 out of 8 districts 38%	USDC supported are twice as likely to have Occupational Therapists than non-USDC districts.
Presence of functional Orthopaedic Workshop	7out of 10 districts 70%	3 out of 8 districts 38%	USDC supported are twice as likely to have a functioning orthopaedic workshop than non-USDC districts.
Presence of ENT CO (basic and/or Diploma)	All USDC supported districts had ENT workers; Quantitative data indicated USDC supported districts had a total of 48 ENT workers.	All Non-USDC supported districts had ENT workers although the quantitative data indicated only 4 ENT workers.	This is a gross undercounting/ recording of ENT workers because USDC had a concerted effort to train basic ear care workers in the districts it supports. MOH has also carried out training across the country for basic ear care workers. What the figures do demonstrate despite the errors is there are more Ear care workers in USDC supported districtrs thatn in others.

Note that:

1. *Jinja and Soroti were considered as non-USDC only in this analysis since their programme in these two districts focuses on mental health and epilepsy.*

2 *In the case of Orthopaedic Technologist, presence staff was not used but instead the availability of the service was used in the analysis, to avoid a false impression in the case of Soroti and Ntungamo, where Orthopaedic Technologist were present and on payroll but with no Orthopaedic Workshops and therefore no service.*

3. *The analysis excludes Nebbi District.*

Information from the quantitative arm of the study seemed to support the qualitative information and revealed the decisive role played by USDC in staff placement and influencing the skill-mix in the districts. According to the quantitative data, (see Annex 2), mental health workers were the commonest cadres of health workers in all the districts followed by prevention of deafness workers who included basic ear care workers with two-week training and ENT diploma holders. The following had been extracted from Annex 2.

Commonest available rehab skill in all the districts visited, was the mental health worker at 29.2%, followed by hearing impairment (ear care) workers 17.7% and third commonest was eye care workers at 5.8%.

USDC supported districts had a total of 170 'rehab'/related workers compared to 107 in the non-USDC districts. (This information was only from 8 USDC supported districts and 8 non-USDC supported districts). On average the distrcts with USDC support had 21.3 rehab workers per district compared with 13.4 for the non-USDC supported districts.

When one considered the formal training of the rehab workers, the differece between the two sets of districts reduced (USDC supported distrcts had 125 certifcate and diploma holders and 100 for the non-USDC districts (Annex 2). The reduction was due to the higher numbers of semi-formal training conducted by USDC (especially in mental health and prevention of deafness), which increased the total of rehab workers per district but with lower diploma (formal) training in a rehab skill. This was further illustrated in Panel IV below.

Panel V: **Comparative Training Indicators (Averages and Ratios)**

	USDC supported districts	**Non-USDC supported districts**	**Ratio USDC :non-USDC**
Av number of 'rehab' workers per district	21.3	13.4	Almost 2:1
Diploma and certificate* holders	15.6	12.5	Almost 1:1

**certificate excludes short inservice courses of a week and less.*

USDC therefore, played a significant role in increasing the availability of 'rehab' workers in the districts through supporting mechanism for recruitment of formally trained rehab workers and through in-service training. The NGO had also output to show for its strategic objective.

5.9.4 Staff Training

a) In-service Training

> **We health workers must be oriented first.**
>
> *TB Leprosy Supervisor Gulu*

The TB and Leprosy Supervisor Gulu, the DDHS Apac, Secretary for Finance and Ag. DDHS Arua all expressed, in different interviews, the need for staff training or orientation to disability issues. The TB and Leprosy Supervisor advised that even those working with PWDs needed orientation and up-to-date information. Among the many challenges parents found in accessing services was the negative attitude of health workers. This attitude could be changed through in-service training.

Training of health workers was at two levels. The first was during basic training and the second, through in-service training. USDC, AVSI/CUAMM and the MOH had contributed substantially to in-service training of health workers. USDC had especially supported the training of front-line health workers in basic ear care, mental health and management of epilepsy. AVSI/CUAMM through the SCORE project had also trained front line workers in management of epilepsy. All three had also trained community volunteers in identification, assessment, referral and management of disabilities. In addition, AVSI had trained Physiotherapists and Occupational Therapists in common conditions such as cerebral palsy. MOH had trained health workers in Kapchorwa and Kasese on a cross-section of disability issues. All this training was appreciated and contributed to improved service delivery.

The training was appropriate since it addressed the most common disabilities of cerebral palsy, hearing impairment and epilepsy. The training that reached most districts, both USDC supported and non-USDC supported was the one for hearing impairment, though in the USDC supported districts more health workers were trained. The least accessed training was on cerebral palsy, which was limited to a few Occupational Therapists and Physiotherapists working in the SCORE project.

In Jinja, Gulu and Kasese there were Nursing Assistants (NAs) who had been trained over 5 years ago in cerebral palsy. The NA in Jinja Hospital had kept the department operational for 2 years when there was no Physiotherapist in the hospital. The District Health Visitor of Nakasongola (who was completely unaware that attempts had been made many years ago in selected districts to train NAs to provide rehabilitation to children with cerebral palsy), recommended that NAs be considered for rehabilitation work because they had a low turn over, were trainable and available in all HC III and HC IIs. She further reported that NAs were trained by Tutors from Mulago on epilepsy, organised by USDC and were providing a good service in the absence of Nurses. This was a good practice that USDC and similar organisations including the MOH could consider in order to establish sustainable rehabilitation services as close to the community as possible and provide a resource for advice to parents when outreach teams returned to the district Centre, an aspiration of USDC.[18]

The Acting DDHS Arua recommended the training of Environmental Health Officers to fill the gap between the family at community level and rehabilitations professionals at district level. According to him, these cadres of health workers linked the family to formal health services in many aspects of health care and could easily include disability in the schedule of duties. Environmental Health Workers could identify, make appropriate referral, advice and inform families, ensure adherence to therapies, address accessibility issues in the home in addition to extending all the services they currently offered to CWDs (home hygiene, sanitation, nutrition, etc). MGLSD was implementing a model CBR district programme in Tororo. In their structure at sub-

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[18] USDC Annual plan and budget 2004/05; Pg 1-2; March 2004; USDC P.O. Box 16346 Kampala usdc@ugasoc.org

county level, they included 3 supervisors of the community level CBR Volunteers. The three were the Community Development Officer (or Assistant), the SNECO and the Health Inspector or Assistant (Environmental Officer). An early and internal evaluation of the 'model CBR programme[11] revealed that using the trio was useful. The Health Assistant reduced the referrals that would have been made to health units, although in some cases, a Clinician would have been more useful.

Village health teams (VHTs) were a new structure that had been established by the health sector to improve access to services especially preventive and promotive. The VHT also provided a means of surveillance, which was important for planning of services. Although not fully established across the whole country, the VHT was an important organ that could be used to reach CWDs and their families with information, and very basic rehabilitation, identification and referral. The VHT if brought on board would help raise the profile of disability in health plans that were developed through the bottom-up approach. This would require the orientation of VHT to issues of CWDs and their families.

In–service training of government staff was another area where USDC made progress as laid out in its Country Strategy where one of the activities was to train government professional staff. The wide spread training in prevention of deafness and epilepsy was in the right direction and would address the two commonest disabilities in USDC data; Hearing Impairment and Epilepsy.[13]

b) Basic Training

The basic training of frontline Clinicians did not include disability except some aspects of its prevention. Even then, the approach was to prevent death not disability. The DDHS Jinja forwarded this as one of the reasons rehabilitation services remained behind other programmes in the district. He recommended that basic training of all Clinicians should include disability.

MOH had taken steps to address this through the review of basic training curricula of Clinical Officers, Nurses, Midwives and Health Assistants. It was planned that the improved curricula would mainstream disability in health services. Review and approval of curricula took unpredictable length of time and although CSOs could speed the process, this was an area that should be left to government unless government specifically requested for support in the area. The teaching of frontline health workers especially nurses, midwives, clinical officers and doctors needed not wait for the full process of curriculum review to be effected. Individual schools could be lobbied and slots identified for rehabilitation under current syllabuses. For example after teaching the management of common blinding diseases and their management, introduction to 'orientation and mobility' of the blind and their needs and potentials could be included as a one hour lecture and practicals in the nearest unit for the blind.

5.10 Rehabilitation Services

5.10.1 Service Standards in the 'Rehab Package'

The 'rehab package'[19] described standards for rehabilitation service provision at various levels of health care hierarchy. In the case of sensory impairments, this was not only limited to rehabilitation but to prevention of the impairment as well. Panel V summarizes the key features of the rehabilitation services to be provided and the findings from the interviews and FGDs were linked to many aspects of the 'rehab package'. It was against these factors that the findings of the study were discussed.

Panel VI: Summary of Standards from the Rehabilitation Package of *MOH*[9]

Community	**Health Centres II & III**	**Heath Centre IV/Health Sub-District (HSD)**	**District Hospital and office of DDHS**	**Regional Hospitals**
Identification, referral, follow up, counselling, production of simple assistive devices, simple repair of assistive devices	Identification, referral, follow-up, counselling, outreach activities, links with SNE, school screening, receive outreach teams	As for HC III. In addition, specialized clinics run by specialized health workers from district level. Ensure disability is in work plan of HSD.	Static services for physiotherapy, occupational therapy, mental health, eye unit, fabrication of assistive devices, regular outreach clinics to HC IV, inpatient services coordination with other sectors.	Static services with specialized doctors Outreach to district hospitals, other services as for district level.

5.10.2 Community Level Rehabilitation Services

The community level was the place CWDs should receive the bulk of rehabilitation services. They should be identified early, referred, provided with simple appliances, their environment modified to enhance their participation and the parents counselled and supported to provide love and care for their special child as they would for any other. From the discussions in the field very little of this occurred and CWDs grew in an environment of neglect and want. USDC laid strategies to identify CWDs through district leaders. As the services took root and there was evidence of improvement in a child's condition, the parents became the main advocates and mobilisers to other parents. The 'mature' service or well established service would have self referral of parents with their CWDs coming for services. All the parents from the USDC supported PSGs attested to the progress of having been identified by rehabilitation workers through community leaders and how they had identified and referred other parents for the services. In addition, PSGs served to provide counselling and encouragement to each other, as discussed in detail in Chapter 7 of this report.

In comparison, parents in districts that were not supported by USDC had difficulties in accessing services and receiving information about the services. For example the parents the team met in Kalangala and Moroto in Karamoja had not received any notice of a service but went out looking for a service for their children. The more

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[19] Essential Services for Rehabilitative Health Care for Persons with Disabilities in the District; Disability Prevention And Rehabilitation Section, Ministry Of Health, P.O. Box 7272, Kampala, Uganda. August 1999

enlightened and richer parents went beyond their districts to as far as Mulago hospital (mother of a child with learning disability in Kalangala) while the poorer parents did not even reach their district hospital (Moroto parents FGD). In general there was better identification in districts that had trained health and community workers (such as the USDC and SCORE supported districts) than in districts without such support.

The community was an amorphous entity that fortunately government had defined along administrative divisions of villages and wards. Several organizations, including USDC, attempted to bring services into the community through its own resource persons (volunteers) with great initial success, but the efforts had not been sustainable. The government officials especially in this case, Local Councillors representing PWDs, had not been very effective because of their low education and they too required allowances. The PSGs USDC was currently using were useful, however, they were not skilled enough to provide continuous care once the professionals had done their expert part of rehabilitation.

a) Soroti District Union

Soroti District Union participated in CBR programme by identifying CWDs at village level and referring them to rehabilitation centres like Madera hospital. Those with learning difficulties were referred to Nakatunya (hearing), Nyakayi P.S (hearing), Hilders Primary School (mental retardation), Madera School for the Blind (in collaboration with EARS) and also for treatment in individual health units as well as consulting with authorities and parents (parents at times came directly to the union).

5.11 General Outpatient Services

The rehabilitation service expected at this level in any health unit was identification, referral and health education. All the parents that the team met had been to an outpatient department for help for their CWDs. Many were not helped and they resorted to alternative traditional treatment. Those who were referred for a definitive service were discouraged because they were informed that the condition of the child was permanent and nothing more could be done. Many of the parents with children with epilepsy were given inadequate drugs and when fits continued they gave up until they heard of the epilepsy clinics. It was important to note that none of the parents interviewed, did not seek treatment for the child impairment. It was always the health system that let these parents down by having no service available or providing inappropriate advice such as ‘nothing can be done for your child’. Health workers were important opinion leaders within their communities and the message they imparted to parents would decide the fate of the child especially among less educated communities.

The young child clinics (YCCs) were important places for identification of CWDs or those with slow milestones (development). The nurse in the YCC in Kasana reported having identified clubfeet and *spina bifida* in immunisation clinic and she had referred these children to USDC. She however, did not refer those she had noted to have regressed in milestones after malaria. In order for the frontline health workers (Nurses and Medical Assistants) to be effective in supporting CWDs in their positions they needed to be trained in skills of identification of CWDs, how to refer and how to support the parents to overcome the negative attitude within the family and community.

5.11.1 Static Services

According to the MOH standards, static rehabilitation services were supposed to be available in district and regional referral hospitals. The availability of the static rehabilitation services was closely linked with staffing of hospitals, discussed in Section 5.2.1 of this report. In the Section below, issues for either emulation or improvement in the various static services were discussed.

a) Physiotherapy Services

Physiotherapy services were well established where they existed and the units adequately equipped with non-electrical equipment. The units that were visited were providing services as evidenced by record books, patients waiting to be served and the equipment in use. The unit in Kapchorwa was closed due to lack of a Physiotherapist and it was not yet equipped. The unit in Moyo hospital was open, equipped and staffed but patients were not treated in the unit. The unit which doubled as a plaster room seemed to be used more for the latter than its original purpose of physiotherapy. The unit in Adjumani hospital was closed because the 2 Physiotherapists were never available to offer services in the unit and in the wards among in-patients. The unit in Gulu was very well equipped and the staff worked with keenness and pride. The district or MOH headquarters in the previous 6 months had supervised none of the units. None of the Regional Physiotherapists had supervised their district counterparts, a role they did not seem to be aware of. CSOs (USDC, the Catholic Church and Protestant Church and AVSI) played an important role in improving and maintaining the quality of physiotherapy and other services. These CSOs could only work as a catalyst in situations of a committed Physiotherapist as observed in Kagando Hospital.

b) Occupational Therapy Services

Occupational therapy was a new and little understood service in Uganda. It was significantly more available in USDC supported districts. Where the service did exist, it was not adequately provided for except in Gulu, Nebbi, Hoima, Masindi and Arua. The occupational therapy units were more often than not within the physiotherapy unit and the Occupational Therapist would sometimes act for the Physiotherapist. This confusion of professionals hindered the development and evolution for both services and the confusion that surrounded them would continue. A health worker in Luwero thought one was an alternative to the other and therefore once one was available both services were in place. Sensitisation of health service managers about the different roles Physiotherapists and Occupational Therapists played in the rehabilitation process and separation of the services by having them in different locations in the hospital would enhance understanding of the staff so that they helped patients access and benefit from both services. Jinja and Soroti hospitals urgently required Occupational Therapists so that they could provide services to children who had been mobilized through the Mental Health Consortium (MHC). Many of these children had some form of learning disability or behavioural disorder and would benefit from occupational therapy. There was therefore need to advocate for the Occupational therapy services to be extended to Soroti and Jinja so that the consortium could provide holistic services for children with epilepsy and mental disabilities.

c) Fabrication of Orthopaedic Assistive Devices
USDC played a significant role in developing this service in Uganda by establishing an Orthopaedic Workshop in each of the districts it supportd. AVSI also established and supported a Regional Orthopaedic Workshop in Gulu. The SCORE project repaired Arua and Nebbi Orthopaedic Workshops. The government's contribution had been in employing the Orthopaedic Technologists, although this had not been universal. One Senior Orthopaedic Officer said that in Uganda there were only 12 Orthopaedic Surgeons confined to Mulago Hospital, 150 Orthopaedic Officers in Mulago, Mbarara, Masaka, Mbale, 4 Technologists and a number of Orthopaedic Technicians, (although there was a programme to train Orthopaedic Surgeons running for six years). The CSOs contributed to staffing of the workshops by providing Artisans and in some cases paying the salary of the Technologist while waiting for their recruitment.

The team got the impression that these services were the least appreciated and supported by Government. The central and local governments did not contribute to raw materials. The existence of the workshops even in government institutions was fully dependant and determined by CSOs. As a result in some districts the service was referred to as 'USDC workshop' of 'AVSI workshop'. To compound the dilemma of these workshops was lack of clear guidelines for their operations. The workshops depended on cost sharing of services to replenish raw materials. Since the ban in cost sharing, government provided funds for raw materials only once. Some hospitals had turned a blind eye and allowed the workshops to continue generating money in order to stay functional, for example Masindi, Luwero, Kabarole and Hoima, others such as the workshop in Adjumani deteriorated to a private workshop used to the advantage of the Technologist. In Masindi, although USDC handed over the Orthopaedic Workshop to the local government, in theory managed by a Committee, while in practice the Technologist was not supervised by the Committee and hence was running the workshop to his advantage.

During 2004, the Adjumani workshop distributed 2 wheelchairs, 27 crutches and 7 callipers. The wheelchairs were a donation from NUDIPU. In contrast, the Orthopaedic Technologist in Luwero had provided assistive devices to 30 patients during the half of 2005. One third (1/3) of the clients were children with cerebral palsy who required corner seats. Just like physiotherapy services, the more motivated the workshop manager (often the Technologist in charge), the better the support from the CSOs was utilized. None of the Orthopaedic Technologists recalled having received technical support supervision from a senior member of the profession. This could have been a demotivating factor.

The Karamoja region was in a more difficult situation since the nearest workshops were in Mbale and Gulu. The Mbale workshop was government supported and did not have the financial capacity to take services to Karamoja. The Karimajong were also reluctant to visit Mbale hospital for services due to poverty and tribal differences. The CBR service provider in Matany hospital had stated that he needed an Orthopaedic Workshop so that holistic services were provided.

A similar situation pertained with Kabarole Hospital workshop, which was the best equipped among those visited and was brought to that level by the International Committee of Red Cross. It served the area under Kabarole Regional Hospital composed of Kabarole, Bundibugyo, Kyenjojo, Kamwenge and Kasese Districts. The Government sent funds to provide services for the region, which to date remained unutilised by the districts except Bundibugyo. The districts did not see any sense in having to meet costs of outreach activities for the orthopaedic staff which they said ought to have been provided together with the service funds. The Bakonjo were reluctant to go to Kabarole hospital for orthopaedic services. They would rather do without if they could not afford the trip and upkeep for OURS. The funds sent to Kabarole Referral Hospital would have been meaningfully utilised to provide services in Kagando Hospital, which was already doing tremendous work in providing assistive devices. The focus and emphasis on regional hospital for provision of orthopaedic assistive devices overlooked the poverty situation of the potential beneficiaries that hindered them from meeting costs of travel and upkeep in the regional hospitals.

d) Mulago Hospital Support to the other Services both National and Private

The Orthopaedic Department in Mulago Hospital was reported by its staff to be doing quite well in providing services particularly to the ever-increasing urban population of Kampala City. The numbers were either constant or lower now as a result of work already done. From 1991 to 2001, MOH provided funds that enabled the Orthopaedic Department in Mulago Hospital to take services to the grassroots in Soroti, Kumi, Mbale, Tororo, Jinja, Masaka, Mbarara, Fort Portal, Hoima, Masindi, Kabale and Rukungiri to see both children and adults. The Senior Orthopaedic Officer in Mulago Hospital considered this a cost effective support. The North was cut off due to insurgency. However, this arrangement stopped and since then there was no specific arrangement to support the hospital. The strategy of supoorting regional and district units from Mulago was not sustainable. It was expensive and depleted the few staff for the large Kampala and surrounding district catchment areas. The strategy of developing the services at regional and district levels was more sustainable and provided accessible and more regular services.

A new project called Uganda Club Foot Project was launched to sensitise and train physiotherapy and orthopaedic staff in a new and more efficient method of correcting the condition. In addition people from within the local communities would be identified and trained, especially Traditional Midwives would be trained to recognise, refer and follow up persons with club foot whether babies with plaster of paris or older children and adults who had undergone corrective surgery. It was planned that information would filter through the trained people to parents/care-takers within their localities about deformity in children, causes, prevention and how parents must comply with treatment instructions.

There had never been special orthopaedic programme for children under Mulago Hospital arrangement. When Mbale CURE organised programme for children in Fort Portal as a pilot programme, 70% of the people who turned up were adults. The programme was stopped. The Senior Orthopaedic Officer viewed this as caused by the attitude of the people deep in the villages who saw disability as family problem that if exposed to medical treatment might bring curse upon them. Unfortunately this attitude was a severe hindrance to health seeking behaviour of parents for the success of rehabilitation service. The Senior Orthopaedic Officer argued that there was age limit for correcting deformity. For best results, identification must be done as early as day one of child delivery, consequently orthopaedic services engaged. If corrected early there would be no noticeable deformity on the child.

The Senior Orthopaedic Officer further lamented the negative attitude among planners that had hindered a national survey on CWDs. As a result the magnitude of disability among children and the types of disability were not known making planning of interventions and lobbying for resources difficult.

Mulago as a National teaching and referral facility ought to have provided specialised services not elsewhere in the country. This was so in many aspects of curative care but unfortunately in rehabilitation, better quality facilities existed in the regional hospitals with the exception of prevention of deafness. Ruharo Eye Centre in Mbarara had better and more specialised services for prevention of blindness and management of low vision. The exemplary collaboration among the eye care providers ensured the lack at the national referral level was not felt during training of specialists. Gulu regional referral hospital produced higher quality assistive devices than Mulago Orthopaedic Workshop.[20] With the challenges faced by Mulago, and the chronic low resources, the national facility had failed to play its role as a quality assurance body or to provide leadership and high quality staff for Uganda's Rehabilitation Services. Mulago needed to be supported to perform this role although this would require a new paradigm among the staff or a change of leadership. Without the drastic change in thinking, the resources could fall on unproductive ground.

A number of private workshops had emerged to fill the gap in orthopaedic assistive devices. Almost each major town in Uganda had private for profit facilities that provided orthopaedic assistive devices. One in particular stood out though private not for profit-Katalemwa Orthopaedic Workshop, a facility supported by Cheshire Home. The workshop was efficiently run and had higher productivity and better quality services than its counterpart in Mulago although the workshop was not yet able to produce artificial limbs. Other CSO workshops that were filling the gap were: Eastern region the Kumi Orthopaedic workshop in Kumi town and Buluba Orthopaedic workshop serving the Busoga axis; Western region Kagado hospital Orthopaedic workshop and Kuluva Hospital Orthopaedic workshop in Arua. The latter 4 CSO workshops were formerly specialised in leprosy but since 1999 had formerly opened their doors to other disabilities.

e) South Rwenzori Diocese - Kagando Hospital

South Rwenzori Diocese owns and manages Kagando Hospital. In this hospital, the backbone of rehabilitation activities consisted of 1 Physiotherapist; 1 Occupational Therapist; 1 Orthopaedic Officer; 1 Ophthalmic Officer; 1 Clinical Officer - mental illness; 1 Dental Surgeon was on study leave; 1 Clinical Officer – ENT; and 1 Resident Surgeon. Kagando Hospital had sufficient staff and basic but adequate facilities for rehabilitation with which it had so far performed well in rehabilitation of various types of disabilities. It was the most accessible and efficient for the people in Kasese District.

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[20] USDC Annual plan and budget 2004/05; Pg 1-2; March 2004; USDC P.O. Box 16346 Kampala usdc@ugasoc.org

'We are fidgeting but we offer a service. We consider it fidgeting because many times we think the cases are beyond our abilities. When we refer to Fort Portal or to Mbarara, the patients opt to die rather than go to these places. They say they do not have money for transport and upkeep in these distant places. However, the operations have always been successful. That is why I say that although we are fidgeting we do offer a service'. (The Physiotherapist)

5.12 Mental Health Services

Mental health services were available in all districts visited although in varying degrees. The commonest service offered was the treatment of epilepsy. The reasons for treating epilepsy under mental illnesses had already been explained in section 5.2 of this report. Moyo had the most comprehensive mental health service. This was due to the visionary leadership in the Health Department, the presence of USDC who supported health workers to reach the communities and work done by TPO, a CSO that continued the community level care of clients. The district leadership not only succeeded in coordinating both CSOs to the benefit of its people but also employed and deployed Mental Health Nurses across the district. Other districts following suite were Kapchorwa, which was planning to train health workers in lower health units to manage epilepsy. Kapchorwa had opted to use this strategy because of the lack of mental health workers in the district.

> Before USDC launched its programme in Masaka and Sembabule districts, mental illness drugs expired in stores because there were no people to use them. *(Focal Person for USDC work in DDHS office - Sembabule)*

Sembabule was another district that was very keen to see the growth of mental health services. The district had, with support from USDC, trained 15 health workers from HC II, III and IV in management of epilepsy. 94 community mobilisers had been trained and traditional healers trained in mental health and epilepsy. The response had been overwhelming with all health units providing epilepsy services and special epilepsy clinics recording as many as 70 patients (Mitete) per day. Just like elsewhere the satisfied clients became mobilisers. A child with epilepsy beat up a policeman and the child's father was surprised when police referred his son to hospital instead of court and prison. The child's fits were controlled and the father was mobilizing the community to bring out their relatives with epilepsy for treatment. The challenge was how to maintain drug supply after such massive response. So far the HSDs had been ordering and providing adequate supply of anti-epilepsy drugs.

Itojo hospital in Ntungamo district was another unit that had improved its mental health services. The decentralization of the services was a move made after Itojo was separated from Mbarara district and the regional hospital at Mbarara stopped outreach programmes to Itojo Hospital. Where the community had been mobilised, the response was good. Mental health was however; still low on the district's agenda and it was not catered for in the PHC outreach or in the drugs purchased by the HSDs. The hospital depended on quarterly supply of drugs from Butabika National Referral Hospital. Traditional healers were used often by the communities to manage mental illnesses and were in fact more popular than the hospital because they were easier to access. The hospital lacked space to admit violent mentally ill people.

The four districts described above, served to demonstrate the impact of the work of USDC. Moyo and Sembabule were providing vibrant mental heath services compared to Ntungamo and Kapchorwa. In Nakasongola, USDC supported the training of Nursing Aids to manage epilepsy. Where the Mental Health Consotium (MHC) existed, services for people with epilepsy had changed the lives of individuals with epilepsy and their families.

Maintaining drug supply at health units and most importantly with the client was a challenge to the programme. In Arua (Offaka Sub-county), where SCORE project was currently providing free epilepsy drugs, the community had wisely continued to collect money for the maintenance of the drug bank fund so that there was no interruption of supply of drugs once the project was over. A similar initiative might have to be started in Sembabule where the HSDs might not be able to cater continually for the growing demand. However, in an interview with the Principal Medical Officer coordinating Mental Health in MOH had directed each HC to spend 50% of its PHC funds on drugs. The Ministry created an additional Credit Line where each HC could order drugs from the NMS within limits and MOH paid directly.

The consultants learnt from the field that despite the above arrangements to avail drugs, there were complaints about unavailability of drugs in most HCs. For example, the consultants met clients in Lira who reported that epilepsy cases could not be treated because there were no drugs. The cry for drugs was seemingly the result of the HCs not purchasing adequate supplies of anti-epileptic drugs either because the burden of epilepsy was not reflected in the health facility's information system or the heads of the HSDs were under pressure to purchase drugs for priority programmes such as Malaria. The Principal Medical Officer coordinating Mental Health added that within the decentralised system, MOH headquarters did not force managers of HCs to do what they had been directed to do, when their priorities differed. It was observed that efforts to train health workers to support mental illness victims could be in vain when the attitude of HC Managers was negative towards supporting mental illness.

On average a child required US$5 a year of anti-epileptic drugs (calculated for phenobarbitone) and an adult US$10. Using the prevalence in Jinja for epilepsy[21] of 0.03%, Uganda had over 720,000 people with epilepsy who required US$7.2m worth of drugs annually; an increase of US$0.3 per capita. This would increase the expenditure on health from US$12.75[22] per capita to US$13.

Epilepsy was the most common or among the top disabilities reported in rehabilitation services across the country.[23] Large numbers of both young and old in every district visited suffered from epilepsy.. Epilepsy required a concerted effort

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[21] Annual report 2003/04 Jinja District Health Department

[22] Health Sector Strategic Plan II 2005/06-2009/01, Final draft; Pg 50, Pg 80 July 2005; Ministry of Health P.O. Box 7272, Kampala, Uganda

[23] Draft report Disability data collection Northern Uganda; April 2005; MoH, AVSI, CUAMM, CCM. P.O. Box 7272, Kampala.
USDC Annual Report 1997/98. USDC P.O. Box 16346 Kampala usdc@ugasoc.org
Assistance to Strengthening Essential Health Care for Persons with Disabilities, Project No: 2843, *Reducing Vulnerability By Increasing Access* Progress Report July 2003-June 2004, Pg 21-24. Disability Prevention and Rehabilitation Section, Ministry of Health, P.O. Box 7272, Kampala, Uganda.

similar to that of the National TB or Malaria programme with drugs available free of charge at all health units.

The Principle Medical Officer in charge of Mental Health gave some of the reasons mental health services had progressed faster than other rehabilitation services. There was a deliberate effort to provide mental health services in the PHC system and mainstream it in the general health services. This entailed equipping healthcare workers with necessary knowledge, skills, and attitudes so as to be able to identify and manage mental disorders at their respective levels and refer where necessary. It was hoped that this would be a more effective way of managing the increase in Mental Health disorders as a result of civil strife, due to political instability, the economic decline, increased unemployment coupled with poor job security, and HIV/AIDS scourge. These conditions exerted stress on individuals, with more chances of getting mental disorders.

Dr. Ndyanabangyi, the Principal Medical Officer in Charge of Mental Health described a draft mental health policy that would:

- Provide guidance for service development and provision at all HC levels and hospitals (2003 Clinical Management Guidelines (standard))
- Ensure mental health services reached vulnerable groups
- Develop an in-service training manual for PHC workers for refresher courses to equip them to marry Mental Health with general care. Reviewed curriculum for Principle Clinical Officers and Comprehensive Nurses to include mental health components. Reviewed essential drugs list to include mental health drugs to be managed right from HC II level, which originally were not included.
- Establish an inter-sectoral linkages such as through the VHT to take care of all health care issues
- Provide for periodic review of legislature
- Review distance learning courses with Manpower Development Centre in Mbale.

In terms of training, 300 health workers were trained by USDC and approximately 500 trained by Basic Needs Districts. With support from African Development Bank 12 Psychiatrists were trained, who provided training to 33 PCOs, 4 Psychiatric Social Workers, 4 Clinical Psychologists and 4 Tutors in Mental Health to contribute. Through this programme a framework for capacity building in schools and hospitals in provision of Mental Health had been established. A review of Mental Health recognised 6 conditions to be reported in the broad categories and these were schizophrenia, mania, depression, anxiety disorders, childhood mental disorders, alcohol and drug abuse, other mental conditions and epilepsy. It was hoped that this would motivate PHC workers to mobilise resources for mental health. It was planned to engage the public in education and raise awareness on mental health. Advocacy was included to engage various stakeholders of mental health to become more positive about contributing to its management.

Meanwhile, the review of staffing Norms put a Psychiatric Nurse at HC IV as the focal person to build capacity for implementation and monitoring of service provision for mental health. The policy recognised the role of traditional healers and the private health services sector. Children were addressed as special vulnerable groups and included CWDs and those with intellectual challenges.

The supervision of these services was in the Area teams; a strategy of MOH to supervise services in the districts. For example the member of the area team for Karamoja had played an important role in promoting the purchase of mental health drugs in the region. Another reason was the training of district and sub-district mental health cadres that was well established.

Uganda had capacity to train 3 cadres of mental health workers. These were Psychiatrists, Psychiatric Clinical Officers (PCOs) and Psychiatric Nursing Officers (PNOs). Recent loan from African Development Bank supported the training of 33 PCOs, Social Workers and Tutors. The loan was used to build new psychiatry units in regional referral hospitals.

The completion and implementation of the mental health policy would go a long way to addressing the patchy mental health services. Although more widely spread and deeper in terms of service levels reached than other rehabilitation services, mental health services were partly dependant on CSO support in the districts visited. One challenge of CSO 'directed' services was that it reached its target group without building adequate support mechanisms thus affecting sustainability. For example, Dr. Ndyanabagyi raised a challenge caused by training of mental health service providers without sensitising their immediate supervisors to appreciate mental disorders and on the required drugs and sundries that accompanied the new skills. This resulted in frustrated health workers and clients. The ultimate target of the training was not reached with the intended service. She emphasized the need for CSOs to work closely with government and at each level and phase of their programmes to plan and implement with relevant officials.

5.13 Rehabilitative Services for the Hearing Impaired

From the 1997/98 USDC report and the 2002 NPHC results, hearing Impairment was the second commonest disability. Services to increase participation (hearing aids for the impairment and sign language to reduce environmental barriers as well as interventions to reduce negative attitude) were largely not available. The low level of service development was not limited to Uganda but was world wide for several reasons including among others:

- Hearing impairment was a silent disability not noticeable to the public
- The deaf tended to live in their own communities due to communication problems
- The rehabilitation interventions were expensive and required specialists whether it was a hearing aid or sign language training.

In Uganda, the services for rehabilitation (tertiary prevention*), primary* and secondary** prevention were largely underdeveloped until 1998. Since then secondary prevention services developed rapidly across the country and USDC played a significant role in this endeavour. Middle ear infection, the commonest

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[*] Primary prevention refers to activities done to prevent a disease occurring for example immunisation is a common primary prevention strategy. Secondary prevention is carried out when the disease has occurred. It is usually medical or surgery treatment for example treatment of middle ear infection. Tertiary prevention is any measure to reduce the impact of the impairment. Rehabilitation is tertiary prevention.

cause of preventable deafness in Uganda was treated in all outpatient departments but was often missed or mismanaged. The chronic form was often neglected in the communities; in some communities it was surrounded by myths that the pus from the ears was breast milk. Community based studies[24] revealed that the prevalence of otitis media (middle ear infection) was not evenly distributed in Uganda but was more common in Masindi than in Kabale. The reasons for this were not clear.

MOH with support from development partners and the ENT Department of Mulago Hospital developed a diploma course in ENT for Clinical Officers and Nurses. A two-week course was designed to equip frontline health workers with skills in basic ear care. To date each district in Uganda had a health worker with skills in basic ear care. The aim was to have every HC III, IV and hospital with a Clinical Officer or Nurse with basic ear care skills.

All districts reported having a basic ear care worker. USDC supported districts had more than others for example in Apac, Sembabule, Nakasongola and Luwero had more than 10 persons trained each and these were reported to be still active. The team recorded outpatient treatment of approximately 5000 patients per annum. The training of ENT basic ear care workers had resulted in greater reporting of ear disease, which could be misinterpreted as an increase in ear disease. The reality was that formerly under-reported ear infection was being reported and the true burden was being revealed.

Only 3 of the 11 regional referral hospitals had an ENT Surgeon. Despite this gap, which MOH was filling slowly, the direction Uganda had taken to develop this service needed to be commended. Starting with basic ear care workers and specialised Clinical Officers was the foundation to developing the prevention of hearing impairment programme.

Tertiary prevention services for the hearing impaired were almost non-existent. Arua was expecting equipment for an ear mould laboratory and full audiometry equipment and this would make it the third *not-for-profit* centre next to Mulago and Ntinda School for the Deaf. Sign language was also underdeveloped in all the districts, though a course was conducted in Masindi for parents of deaf children from all the USDC supported districts during the course of this survey. Provision of sign language would help the deaf children but would be of no assistance to children with multiple disabilities such as those who also suffered from cerebral palsy. MOH, MOES and Mulago Hospital already developed a course in speech and language training.

5.14 Rehabilitative Services for the Blind/Visually Impaired

Many similarities existed between the services for prevention of deafness and those for blindness. Just like in the prevention of deafness, the tertiary level (rehabilitation) services were least developed. The primary and secondary services were highly evolved in terms of complexity of services for the different levels of health care. In addition, they were the most evenly spread of all the rehabilitation package services reaching the remote parts of the country. Every district visited had an Ophthalmic Clinical Officer (OCO), except Nakasongola and in all the districts Ophthalmic Assistants (OAs) were available. In non-USDC districts, the team found Kabarole

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[24] Turitwenka and Stewart Get from Stanly Bubikire MOH

Hospital active in providing ophthalmic services with a good team of 10 headed by a Principal Ophthalmic Officer working. The remarkable evolution and spread of the prevention of blindness programme could be attributed to:

- The global interest, which had resulted into national focus on prevention of blindness. In prevention of blindness large numbers of people could be effectively reached with lower resources than deafness. Global mobilisation of resources through Rotary Club International and its partners as well as through organisations like SSI provided adequate resources to prevent blindness worldwide. In Uganda, this translated into organised funding of the programme through SSI, LAN and *Christofel Blinden* Mission (CBM). SSI supported the eradication of river blindness through building community initiatives for prevention through long-term administration of drugs.
- Prevention of blindness had had focused leadership in Uganda with two National five-year Strategic Plans for Prevention of Blindness implemented and a third was in preparation. A National Coordination Committee that did not have the cumbersome issues related to inter-sectoral coordination was in place. (The Coordination Committee for Prevention of Deafness was composed of MOH, MOES and CSOs unlike the National Prevention of Blindness Committee (NPBC), which was composed of the health sector and CSOs within the health sector only).
- The staff providing services in the prevention of blindness programme was the OCOs who were recognized by Public Service and according to the staffing Norms of the district should be available at the HSD.
- A referral system existed from the community where science teachers were trained to identify children and community members who required eye care services in the district where the OCOs and OAs carried out static and outreach services. Seven of the eleven regional hospitals had an Ophthalmologist who was supported to carry out static (including surgery) services and outreach to districts for surgery. Three tertiary centres supported the whole system with training, expert supervision and highly specialised services. These were Ruharo Eye Centre in Mbarara, Mengo and Mulago Hospitals in Kampala. In addition, Jinja Hospital trained OCOs through a well-established course and low vision workers in a course that was two years old.
- Data on disease burden was regularly analysed and steps taken to meet new challenges. For example when cataract operations were far below the WHO targets, Tororo Eye Centre instituted a community programme that greatly increased the up-take of the service. The OCO Kapchorwa observed he was not being utilised effectively because he was burdened with minor eye problems so he trained Clinical Officers running outpatient clinics in health units. This increased the number of appropriate referrals and proper utilisation of his skills. It also saved patients' resources and increased confidence of the lower level health workers.

USDC had correctly not put many resources in this well developed aspect of the 'rehab package'. The minimal resources it provided were when the OCO joined the rest of the rehabilitation team for outreach.

Tertiary prevention of blindness on the other hand was extremely underdeveloped. Blind children did not receive training in orientation and mobility at home and at school. The Blind Annexes in schools for the blind were ill-equipped to meet the needs of the blind pupils. Details of this challenge were described in Chapter 6. Kyambogo University trained workers to carry out orientation and mobility but their presence and impact had not been felt because they lacked support to carry out these services. Their training did not include training of very young children under the age of 3 years. This challenge was largely left to the parents and the blind child. Within the health sector, the Occupational Therapist ideally should be providing this service. However, the curriculum did not address the blind in terms of orientation and mobility but only in production (for example hand craft). SSI was involved in supporting training of persons whose role it was to support the blind in re-orientation activities. Physiotherapists also required these skills because of the multiplicity of impairments that children had and also currently there was no other cadre to provide the service at community level.

5.15 Major NGOs Supporting Eye Care Services

There were four NGOs that significantly contributed to eye care services in Uganda. These were LAN, SSI, Tororo Optic Centre and CBM. They used a similar strategy with modifications to reflect individual missions. LAN and SSI worked through government structures and supported them to deliver services. This support often started with the establishment of an eye unit in a district hospital or an eye department in a regional referral hospital. CBM established its structures in a faith-based organisations and its support, however in peripheral units was through both government and CSO facilities. SSI provided CBR for the blind targeting older children and adults. Below, activities and strategies of SSI were presented as an example of a comprehensive approach to eye care.

5.15.1 SSI, an Example of Eye Care Supporting CSO

SSI dealt with sight problems. The programme office in Hoima co-ordinated Hoima, Masindi and Kibale districts through the Comprehensive Eye Care Services (CECS) programme. SSI estimated the population coverage of the region to be 1,232,422 out of which blindness prevalence was estimated to be 0.9% (11,091 people). The major types of visual impairment in this region were cataracts 50% (5,546), reflective error 10% of the total population (369727), irreversibly visually impaired 25% (2773), glaucoma 7% of the blindness prevalence (776), diabetic retinopathy 3% (333). The major causes of visual impairment were cataracts, trachoma, *onchocerciasis* (endemic in Hoima). It was estimated that 8000 were blind and needed particular services, 10,000 aged between 11 years to 18 years needed glasses.

CECS was part of the implementing arm of SSI programme with special intensive focus on *onchocerciasis* with a view to eradicate it in the long run. SSI approach involved facilitating the community in taking up responsibility for decisions on how to implement the programme for their own benefit. CECS availed drugs, sensitised the community on the importance of using the drugs continuously and of the importance of it being managed by them. CECS allowed the community to select persons they trusted could handle distribution of drugs to their benefit. CECS trained the selected persons to distribute the drugs according to prescriptions of standard measure of height. CECS avoided payment of incentives to the trained persons who carried out the distribution either when the community gathered in one place or when they made home-to-home visits. It also trained the distributors in record keeping and supervised the implementation.

CECS had three major components of its programme in this region, namely a) provision of eye care services (construction of the Eye Unit in Hoima Hospital where eye operations were undertaken); b) educational provisions to promote education of the blind; and c) rehabilitation of the blind.

In rehabilitation of the blind, it organised outreach programmes to health centres and to schools to screen eye problems and make referrals or recommendations. CECS provided orientation and training for the people working in this section. CECS further helped the blind on how to earn daily living. The teaching was based on their own initiative on what they wanted help in learning to do.

The SSI programme approached eye problems in this region from holistic point. The all encompassing approach and the involvement of the people themselves to take initiative and responsibility to understand *onchocerciasis* built capacity that tackled eye problems in a more effective way, and showed a commitment to eradicate the disease and leave the people with visual impairments socially adjusted with skills and social understanding of the disease. The involvement of local actors is an effective way of linking services to the people. The Coordinator of CECS stated that the work of CECS improved the life of people who now had confidence and energy to undertake various activities for their living. The visually impaired could go to school. The community was sensitised to understand that some causes of visual impairment could be dealt with, and those already totally blind could be assisted to study. These were due to the availability of services. Construction and equipment of resource rooms for reference was an acknowledgement of the rights of CWDs.

5.16 Outreach Services

5.16.1 Overview

All districts visited had outreach services within the rehabilitation services. The purpose of outreach was to take services as close to the community as possible. Four main services were reported from all FGDs with health workers except in Kabarole, Ntungamo and Kasese. The four services were assessment, provision of treatment, referral and health education. The team was able to join the outreach in Nebbi and Apac. The outreaches were of three types based on the composition of the team. In non-USDC supported districts, they were part of the health unit's responsibility and were coordinated by the Public Health Department (using PHC funds). In this type of outreach, a team composed of workers from different health programmes; reproductive health, immunisation, prevention of blindness, prevention of deafness (where an ear care health worker exists), Physiotherapists, Mental Health Worker and others depending on availability of cadres, went out as a team often to a Health Centre III. This type of outreach was limited to the catchments area of the hospital so that cadres with a district responsibility such as Physiotherapists were not able to reach all parts of the district. Kapchorwa, Kasese and Soroti rehabilitation workers faced this problem.

The second type of outreach, which was present in all USDC-supported districts and in other districts such as Gulu where NGOs supported the rehabilitation service, the rehabilitation team went out alone; usually composed of Physiotherapist, Mental Health Worker, ear care, or eye care worker and Community Development Assistants. The funding agent; USDC, CUAMM or AVSI coordinated this type of outreach. In some districts the MOH provided funds for outreach and arranged for the districts to coordinate the outreach.

The third type of outreach was when a single programme went out alone. This was very common in eye care programmes and occasionally in movement disabilities especially when the Physiotherapists went out to follow up post surgical cases (Arua). This was the type supported by SSI in Hoima, Masindi and Kibale for visual impairment.

Many challenges faced the outreach services in terms of the uncoordinated support from various CSOs; and their usefulness in terms of coverage, population covered, its interference with normal hospital service delivery was questioned. The programme manager of AVSI SCORE project, in Gulu, warned that outreaches might be a disservice if they continued to be run the way they were currently.

5.16.2 Quality of Rehabilitation Services

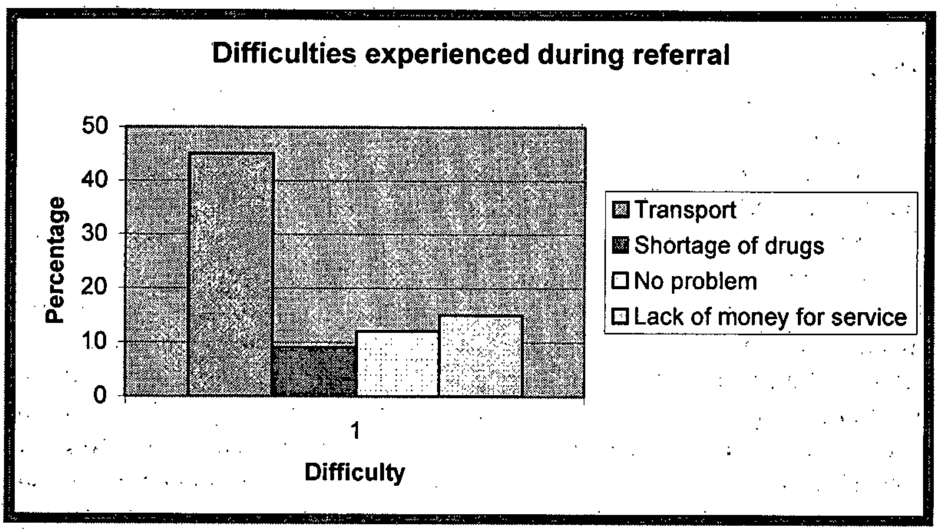
Rehabilitation and especially that for mental and movement disabilities required long interaction between the professional and client/patient. One Physiotherapist informed the team that the minimum time for each patient should be 20 minutes if meaningful rehabilitation was to take place. Disability unlike uncomplicated malaria required regular follow up for effective fulfilment of the rehabilitation plan. During outreach, this was not possible because of the large numbers of those who turned up, late arrival of the team, the need for the team to leave early for various reasons, for example distance from the district headquarters. Except in epilepsy where maintenance drugs were given, no effective service was offered to the disabled. Workers who joined an integrated PHC team especially volunteered this information. In Gulu, the AVSI Programme Manager also questioned the adequacy of outreach to provide rehabilitation services. The best that outreach could offer is identification, referral and advice. However, it has done overwhelming sensitisation to change attitude of parents to acknowledge that services for rehabilitation can change lives of CWDs. Where drug treatment was required such as in epilepsy and secondary prevention of deafness and blindness, this was possible.

Outreach was used in PHC to support community-based workers. The community worker should bring the clients he/she had found difficult so that advice on management could be given. In the current setting, outreach provided both the community level and expert cared, which was impossible to do leading to frustrated clients. The SCORE programme upon realising the coordination problems and possible overlap of services, had withdrawn outreach support in districts where USDC was offering this and was working with USDC to ensure clients reached Gulu Orthopaedic Workshop for assistive devices.

5.16.3 Incomplete Referral Cycle and Inadequate Follow-up

The ideal referral system should run vertical from less to more complex services. It should be bi-directional so that a person was referred from the complex, specialist level to the less complex and generalised levels and finally back to community. In addition, referral should have a horizontal direction where the health sector receives and sends clients to other sectors such as education and social services. Clients identified through outreach were referred to either the district level or regional level depending on the service required. Unfortunately very few of those referred reached the next level, mainly due to poverty. This led to frustration of both the client and rehabilitation worker. For example in Kapchorwa, using MOH funding, outreaches were conducted by the orthopaedic team, including an Orthopaedic Technologist and patients measured for assistive devices. The team gave dates for the clients to come to Kapchorwa for their appliances. Using the same funds, appliances (mainly crutches were made). To date only two out of twenty clients reached the hospital for their crutches. The remaining crutches over time had been given to fracture patients. Similar incidents were reported from Hoima, Masindi, Gulu and Arua where referral to higher level failed for various reasons. In an evaluation of Tororo CBR, 45% of respondents (PWDs or their family) said transport was the main limiting factor for referral[25] followed by maintenance costs.

Panel VII: Difficulties Experienced During Referral



USDC realising the problems families faced in reaching services after referral, had always provided for the very poor even when it (USDC) changed strategy from relief to development. Without this support the services that USDC had helped to develop at district and other levels would have been futile. Tororo district[11] where the district provided transport (from locally generated funds at sub-counties) for very poor families to reach Mbale hospital for surgery and paid for assistive devices (grant from NAD), was an example of a local Government playing its role.

Follow-up, which was an immensely important aspect of rehabilitation, was weak throughout all districts. In the focus group discussions with 'rehab' staff from Arua Hospital, disappointment was expressed over poor follow up, especially the post-operative, resulting in reoccurrence of the disability. This was most common after clubfoot surgery resulting in wastage of resources. Sometimes the client would suffer through a secondary operation. Common examples given elsewhere were when a child through regular home visits started walking but not yet fully independent. For one reason or another, follow up stopped and the child outgrews his/her appliance, was not exercised and reverted to crawling. This occurred in all districts due to lack

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[25] Nganwa AB, Mwesigye J, Ddamulira M; Is It Ours? An internal evaluation fo the Tororo Community based rehabilitation Programme, July 2004 Pg 9; Pg 22 Ministry of Gender, Labour and Social Development, P.O. Box 7136, Kampala, Uganda.(unpublished).

of community level skilled personnel to follow up therapies. In Itojo Hospital in Ntungamo District, the absence of outreach activities and the lack of follow up had increased rate of relapse in mental health.

It was only in Tororo where the district CBR programme had community volunteers to follow up the clients. PSGs/PAs might be able to follow up their peers on utilisation of drugs for example in epilepsy, but they would not be able to follow up other long term therapies such as exercises, mobility and activities of daily living. This gap at community level needed to be addressed at national level and strategy devised which all CSO and Government support programmes could utilize. There was need to explore using health workers such as Nursing Aid to fill this gap. If resources and political will permit, a cadre to provide comprehensive medical rehabilitation could be created and was given three to five villages to cover. Zimbabwe scored successes using such a health worker established after independence. Uganda needed to learn from the experience of Zimbabwe and Tororo model District.

5.16.4 District Plan for Outreach

Within the health sector plans were implemented at the health sub-district level. This was the level where funds were turned into services. Unfortunately, not all cadres of health care provision were available at this level. Hence, as mentioned earlier, rehabilitation workers who depended entirely on PHC funds, for example, the Physiotherapist in Kasese, could only provide outreach within their HSD. District officials reported (DDHS Jinja, Ag DDHS Luwero) that it was up to the Health Sub-district to identify their needs and plan for rehabilitation services by budgeting for the outreach of 'rehab' personnel to their respective HSDs. This had rarely happened because heads of HSD were not sensitised on rehabilitation and the needs of PWDs. It was only two HSD in Luwero where the health sub-district provided funding for outreach by the rehab team from Luwero to the HSD. During the last financial year (2004/05) only one HSD had budgeted for disability services.

5.16.5 Surgical Outreach

Surgical outreach programmes had been used by orthopaedic and ophthalmology services to provide surgical referral to regional referral hospitals and in some cases, district hospitals far from the capital. Outreach by Ophthalmologists and Cataract Surgeons were supported by the three main funders to the prevention of blindness programme. These were SSI in Hoima, Masindi, Kibale, and Apac; LAN in Arua, Lira and Apac. Orthopaedic surgery outreach had been supported by CBM in Matany and Kumi; by USDC in Arua, Hoima and Lira Hospitals; supported by both Red Cross and MOH in Kabarole Hospital; and by the Church of Uganda under Rwenzori Diocese in Kagando Hospital.

Outreach surgery had helped to change the quality of many lives but needed improvement in coordination and post surgical care. From the focus group discussion in Arua, rehabilitation workers expressed concern over recurrence of disability due to poor follow-up, an issue already discussed. Another concern expressed was the inadequate preparation of the hospital for the large numbers of admissions. The inadequacy made patients spill over into the physiotherapy department. The department did not have nursing staff so the Physiotherapists had to take on the day and night nursing duties of patients staying in their ward. CUAMM planned to support the construction of an orthopaedic ward and this should ease the problem of space and poor nursing care.

The nursing staff were also not sensitised about the surgical outreaches service. They believe the team from Kampala and the local theatre workers got very good allowances, the team that identified the clients received allowances and then their nursing efforts were not appreciated in a similar way. This had resulted in neglect of patients, which had sometimes led to sepsis. The health workers also pointed out that the team did not leave behind skills. For example the orthopaedic officers in Arua were not involved in theatre because the team brought its own orthopaedic officer a non-essential member of the team. There was need to sort out this administrative issue before more clients suffered and the negative attitude to the surgical out reach spread to the other disciplines.

5.17 Management and Support

The backbone of any service is its management and support mechanism. Skilled personnel, adequate equipment and supplies would not automatically translate into quality services. According to the rehabilitation package, each level of health care should have a disabled person on the health unit management committee, supervision provided through integrated supervision already in existence in the districts, continuing medical education should include topics on disability and each DHMT should have a focal person for medical rehabilitation. All the USDC and MOH/DPAR supported districts had focal persons for medical rehabilitation if not by designation, by duties performed. The focal persons positively supported the development of rehabilitation services by providing a link between NGOs and other sectors that addressed PWDs and the health sector (Tororo) and ensuring rehabilitation was addressed in district planning process (Kapchorwa). The focal persons faced a number of challenges:

- They worked far from the district headquarters and often were not supported to participate in district health sector meetings.
- They did not have an opportunity to interact and learn the needs of other disabilities other than the one they were professionally involved in.
- Disability was a low priority and they lacked lobbying skills.
- They were not well recognised due to little financial support to their programmes and few or no guidelines from the National level.

Many health programmes had a focal person who might or might not be on the approved public health structure. For example every district should have a TB/Leprosy supervisor, Information systems supervisor, Environmental health officer and others. There was needed to evaluate the focal persons for disability programmes and develop a guideline about their roles and responsibilities. The focal persons needed greater support from MOH headquarters to raise their profile.

Supervision of medical rehabilitation services was weak across the country. This was especially so for physiotherapy, orthopaedic services (both officers and technologists) and prevention of deafness. In these three areas, supervision from the National level was extremely weak or non-existing. For example the orthopaedic officer in Adjumani hospital did not recall any technical visit by a member of his profession. Local supervision within the hospital was weak because the rehab services were not perceived as mainstream hospital services. Because the 'rehab' services were little understood by hospital administration, there was a tendency to visit these units. The Medical Superintendents who should provide supervision and support were not clear on the outputs from these departments (MS Adjumani). In addition, these departments did not submit quarterly or monthly reports to their immediate supervisor but had their allegiance with the external organisation supporting their outreach work. The physiotherapy department in Moyo hospital doubled as a plaster room and had not been visited the hospital's top management since they were allocated the room. The exception to this was Kagando Hospital in Kasese district where the medical superintendent was fully supportive of the rehab units and planned for expansion of the service.

DDHSs were often de-linked from rehabilitation services, some because they had never been sensitised (Kabarole) and others because they were negative to the service, considering it to be an appendage to service delivery when curative care failed (Kasese, Moroto and Tororo). The DDHS of Kapchorwa was very knowledgeable about the rehabilitation programme. The district had even developed a sensitisation poster urging parents to take their children for rehabilitation.

Other aspects of management and support were discussed in chapter 3 of this report; however it was an important area that both USDC and the MOH needed to strengthen especially the technical supervision aspects of the programme. This was an area where the MOH should provide a leadership role if quality of services was to improve. Supervisors who did not have technical skills in therapies and fabrication needed tools to help them in quality assurance of the service under their jurisdiction.

5.18 Challenges

The general health framework for supporting disability existed in all health units, including ordinary facilities, workers and in some cases budgetary resources. However, there were those inherent attitudes and perceptions explained in Chapter 3 that disability was regarded by health planners, workers and administrators as a problem that was out of reach and could only be managed in a special manner, using special facilities, personnel, equipment and programmes such that existing framework was not designed to address rehabilitation of disability and specifically CWDs. Some of the challenges were as follows:

a) The directive that provided for 50% of the PHC funds to be spent on drugs; and additionally Credit Line where each HC could order from the NMS within limits for MOH to pay directly was not observed. There were several reports from the field about shortage of drugs in the face of growing needs,

b) Training of mental health service providers without sensitising their immediate supervisors to appreciate mental disorders and on the required drugs and sundries that accompanied the new skills resulted in the ultimate target of the training not being matched with the intended service.

c) Health workers and clients remained frustrated and hence, rehabilitation services were not easily available and when they were, they were not accessed on a regular basis for complete child development.

d) When offered, the services were impairment oriented and did not take into consideration the whole spectrum of disability (impairment, difficulty in performing activity, limitations in participation).

e) There were indications that parents did seek for services but were limited by the lack of services, attitude of health workers and costs of transport. Transport providers were often reluctant to carry mothers with CWDs.

f) There was poor staffing at Health Units. Very few health workers received training to re-orient them to work with rehabilitation. Hence most of the not oriented health workers were not in position to provide rehabilitative services and display the kind of attitude conducive to draw parents and CWDs away from seeking for health services. They were unmotivated and unsupervised.

g) Lack of knowledge by frontline workers: None of the structures that related more regularly with the community (Nurses, Clinical Officers, Nursing Aids, etc) had been trained, leading to their non-involvement in sensitisation activities and attending to the needs of CWDs

h) Health services, especially outreach were poorly coordinated and allowance oriented, hence 'killing' static services where no allowances were paid.

i) Although MOH was in the processes of developing various specific disability policies to address each disability type, the practical implementation of these policies remained a challenge for the Health Facilities within the autonomy of decentralisation system.

j) In districts where USDC and other CSOs had CWD programmes, disability was regarded as a CSO focus area for them to accommodate. Arrangements such as outreach, provision of epilepsy drugs, and orientation of medical professionals to handling disability, were left to CSOs.

CHAPTER 6: INTERVENTIONS IN EDUCATION SECTOR FOR REHABILITATION OF CHILDREN WITH DISABILITIES

Introduction

All children have a right to education which is one of the most important factors that can make a meaningful change in their lives.

Kofi Annan, Secretary General of the United Nations, was quoted by 'Enabling Education Network (EENET)' issue of June 2004, as having acknowledged that education is a human right with immense power to reform. On its foundation rests the cornerstones of freedom, democracy and sustainable development…there is no higher priority, no mission more important, than that of Education for ALL.[26]

Thus, education is one of the best investments a country can make for its citizens as it positively affects the socio-economic behaviour such as productivity, living standards and health behaviour.[27] However, for this to be attained, the education provided should be of high quality in terms of content, methodology, infrastructure, learning materials, equipment, trained teachers and a positive learning environment that promotes learning. Although all children have a right to education, access, retention and participation of CWDs in school has not been an easy and smooth process, due to different factors.

The survey examined the provision of rehabilitative services in the Education Sector first at the national levels in terms of policy. At implementation level, the survey examined the provision of education to CWDs at national, district, school and community/home levels with a focus on planning and budgeting, training of teachers and the curriculum, provision of educational materials and equipment; standards for SNE; mobility aids, environment and structures and assessment of learning outcomes. The study also looked at gaps/challenges in provision of education services to CWDs.

6.1 Educational Limitations for Children with Impairment

When the body organ of a child was damaged moderately or severely, the child experienced limitations in learning, particularly in the case of severe impairment. Such a child required special teaching and learning skills, as well as equipment and facilities to facilitate effective learning. In education, rehabilitation should address both the special learning needs for the specific impairment and the environment in which the child lived and learning occured. Within the environment the child lived or studied, he/she needed recognition of his/her potentials, rights to respect, access, participation in learning, as well as social acceptance. This extended to provision of equal opportunity in education in terms of the extra requirements. This would also liberate the child with impairment to learn effectively.

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[26] EENET. .Produced in cooperation with UNESCO, Issue 8 Special Edition: Salamanca –Ten years On, June 2004

[27] Uganda Society for Disabled Children: Accessibility and Relevance of Education for Children with Disabilities in Uganda, October 2003

In Chapter 3, the survey findings indicated that the negative social beliefs denied CWDs opportunities to engage in meaningful learning. Hence, in education, disability in children was the failure to recognise and provide for the special requirements of such children that limited their ability to participate effectively in the learning process, in a manner or to the extent expected of children without impairment. The failure to recognise the special learning needs of CWDs was tantamount to lack of social recognition for their rights as children. The lack of social recognition undermined a child's self esteem and confidence that were important in the development of her/his potential.

The common types of disabilities in the schools visited by the team of consultants were mainly visual impairment/blindness; hearing impairment/deafness; physical impairment; epilepsy and mental retardation (who were slow learners). However, in some schools there were few cases of cerebral palsy, hydrocephalus; speech impairment, and autism. Although the number of CWDs varied from school to school (special schools, integrated and inclusive schools) they all had special learning needs.

6.2 National Level Provisions for Education of CWDs

6.2.1 Policy, Planning and Budgeting

Before 1980, Uganda did not have a policy on education for people with disabilities. However, education of CWDs had started with the aim of providing basic education and training in vocational skills for self-sustenance by NGOs that were involved in work with P/CWDs. Changes later took place following the Kajubi Report (Kajubi Commission of 1987) of 1989 that emphasized the need for support of Special Needs Education (SNE) activities in the country. This started the trend in thinking about education for CWDs, which eventually changed to academic excellence with limited focus on vocational training.

In Chapter 4, a number of international Conventions, Standards, Frameworks, and National Constitution, legislations and policies were in place to address education of disadvantaged children, including CWDs. The Universal Declaration of Human Rights and the Convention of the Rights of the Child, talked about education for all children without specific mention of the special needs of CWDs. The absence of specific mention of provision for the special needs of CWDs did not oblige countries to focus on the CWDs. However, **The World Declaration on Education for All and Framework for Action to meet basic learning needs** (Jomtein1990) and **The Salamanca Statement and Framework for Action on Special Needs Education** (Salamanca, 1994) recognised and emphasized among others the right of all children including those with temporary and permanent needs for educational adjustment to attend school and therefore provided for CWDs. Being a signatory to the World Declaration on Education for All enabled Uganda to sign an agreement with the government of Denmark (in 1992) to provide for technical and financial support to education. This was specifically in the field of Special Education.

As a result, at the national level, **Article 30 of the Constitution of Uganda** provided for the rights to education by all; backed up by Article 35 of the same Constitution, which stated that Persons with Disabilities (PWDs) had a right to respect and human dignity and held the State and society responsible to ensure full realisation of their mental and physical potential.

Subsequent developments within the context of education for all children, translated the above international frameworks/agreements and the national constitution into policies to guide implementation. **The 1992 White Paper on Education** spelt out government's commitment to provide primary education to all children irrespective of origin, social groups or gender and emphasized among other things, integration of P/CWDs into ordinary schools. The Government White Paper on Education Policy Review Commission Report entitled **"Education for National Integration and Development"** in relation to SNE stated that PWDs and other children at risk should have the right to join a school and level commensurate with their qualification, interests and abilities; choose any subject he/she was able to do including sciences and be availed equal opportunities for training and employment. Hence, the MOES, as the main provider of educational services, recognized that the special needs of CWDs for learning must be met to enable them to participate equally in attaining full education.

The Universal Primary Education (UPE) of 1997 provided for improvement of the education of children with special needs for learning, including those with disabilities. This accorded free education to four children per family with disabled having a priority over normal children. Furthermore, the **Education Strategic Investment Plans** (ESIP 1997, 2003) and the strategic programme framework (ESIP Framework) spelt out strategies for ensuring equity of access to all levels of education as one of the major focus of basic education particularly on primary education under UPE.

The Kajubi Report of 1989 and the international frameworks/agreements and national policies resulted in MOES pronouncement in 2003 on SNE. According to MOES in 2003, SNE referred '**to all the barriers to a child's learning and development. These may be physical, mental, psychological, and environmental. Special needs therefore, includes children with disabilities (those who do not see, hear well, limited with movement possibility and developmental impairment, epilepsy, hydrocephalus), street children, child soldiers and those formerly abducted, children who have never been enrolled in school and those who dropped out, orphans, children who are culturally and geographically isolated, traumatized children (those living in a war situation, children suffering from HIV/AIDS and other illnesses), children from poor families, gifted and talented children, child heading families, child mothers, sexually abused children, neglected and abused children, children with epilepsy, children living in difficult circumstances such as pastoralists, and children with autism. SNE aims at providing adjusted quality education to all children who may, for any reason, have temporary or permanent needs for adjusted education to enable them learn**'.

The consultants learnt from the Principal Education Officer SNE/Guidance and Counselling in MOES that **Inclusive Education** was a follow up of the above education policy framework. It was education for all children just as UPE. All children including CWDs should go to the nearest school to his/her home so that his/her access into school was not hampered by distance. He/she should also learn with non-disabled children.

Although SNE started specifically with the learning needs of CWDs, the Ministry recognised other areas (18 areas) included in the above definition. Hence the policy covered all the educationally disadvantaged children, among which were CWDs. SNE was embedded in the National Orphans and Other Vulnerable Children's (OVC) Policy (2004). The policy recognized disability as one of the barriers to access and full participation of children in education. It emphasized among its educational interventions the promotion of access and retention of OVC in school. However, the policy was too generalized. Hopefully, CWDs would be focused on at implementation level.

Planning and Budgetary Provisions

At national level, planning and budgeting for SNE was done by MOES through the Department of SNE/Guidance and Counselling. The plans then became part and parcel of the Ministry plan and budget. However, the fact that SNE/guidance and counselling cut across all levels of education, it was budgeted for under primary, secondary and tertiary education. This meant that for any budgetary allocation, the department had to request for these levels. The department only had a direct recurrent budget to cover such items as salaries.

In 2001/02, a budget line was created under Medium Term Budget Framework (MTBF) to fund some activities in the department of SNE/Guidance and Counselling. A subvention grant was also created to support SNE. Eighty seven (87) Special Schools and Units catering for CWDs were receiving subvention grants to support items like specialised scholastic materials, simple equipment and feeding. However, the amount of money was not adequate at all to support these children in the schools. Parents were requested by the schools to contribute to maintenance of the children.

6.2.2 Establishment of Structures to manage SNE

a) The establishment of SNE/EARS Programme in the MOES

The programme of SNE/EARS was aimed at providing a comprehensive programme of assistance characterised by equal educational opportunities to learners between the ages of 0 to 18 years with special educational needs. It further aimed at providing the needed support to the learners, parents, teachers and other service providers. In 1997, the programme funded by DANIDA built and equipped centres in 45 districts with district support. These centres included resource rooms, staff houses and office blocks. The structures provided the foundation for SNE in those districts.

b) Establishment of a Department of SNE/Guidance and Counselling

A fully-fledged Department of SNE/Guidance and Counselling was established in MOES with the main aim of translating the international and national policies and provisions related to education of children with special needs, including CWDs, into practical reality. As one of its activities, a manual for guidance and counselling to help teachers, parents and school management committees in providing guidance and counselling to all children was developed with special components on SNE.

The Department was concerned with ensuring that facilities for SNE were available for the CWD. It has a procurement unit that provided necessary teaching and learning equipment and materials for SNE to schools through districts. It was linking with districts in training of teachers in SNE.

6.2.3 Provision of Learning Centres for CWDs

Special Schools

Traditionally, the CWDs remained unattended to in the homes. It was often at mature age that some were exposed to vocational skills training. Gradually the government catered for the special learning needs of CWDs through establishment of Special Schools either for specific types of impairment or mixed, like in Masindi Centre for the Physically Handicapped. These schools were few and scattered in different parts of the country. Both the Anglican and Catholic Churches and other NGOs were instrumental in their collaboration with the government in establishing and supporting these schools, to compliment the efforts of Government. For example, *Christophel Blinden* Mission (CBM) supported Ngora and Ntinda schools with limited contribution from government. Plan International was operating in Masaka and had built a school for the deaf in Degeya in Masaka.

Among CSOs, Rotary Club in Masindi gave different services by providing supplies in liaison with other institutions to fill gaps and address resource difficulties to Masindi Centre for Physical Handicapped. It was also involved in indirect lobbying in identifying partners that could help to meet certain needs such as supply of water. USDC had supported construction of buildings in Masindi Centre. The table below shows the existing special schools in the country.

Chart 6.1: Special Schools in Different Districts in Uganda

District	School	Number of CWDs	Number of teachers	Comments
Schools for the Deaf				
Lira	Nancy School for the Deaf	370	12	Started in 2001. Well equipped with materials for learning. Enrolment is increasing
Kumi	Ngora School for the Deaf			
Soroti	Madera P.S for the Deaf			
Masaka	Kitengeza Good Samaritan P. S	74 (40 boys and 34 girls)	9	Private school for hearing impaired children
Kampala	Uganda School for Deaf, Ntinda	197 (8 are deaf-blind)	28	The school mainly has sign language manuals although they are not enough. Need more visual aids and pray materials. The school is national and has a few students from neighbouring countries. Founded by Church of Uganda.
	Kampala School for Physically Handicapped	90	14	The school has CWDs with mental and physical disabilities. Teachers include grade 3, grade 5 and vocational training instructors
	Kireka Home for Children with Special Needs	78 (11 deaf, 67 mental and multiple impaired)	18	The mentally impaired learn in groups A to E according to individual capacity. Only deaf in normal classes. School offers vocational skills. There is a shortage of classroom space and sanitation facilities.
Masindi	Masindi Centre for the Physically Handicapped	117	20	Supported my MES and donors. Well equipped. Enrolment only limited by availability of facilities. Provides nursery, primary and vocational training (tailoring, leather, carpentry and agriculture).

This trend had continued. Building of more special schools had been influenced by Disability Peoples' Organisations (DPOs), which lobbied the President of Uganda in 2001 for establishment of additional special schools and four such schools were pledged. The Principal Education Officer, MOES confirmed that consequent to the discussions with the DPOs, two 2 primary and one secondary schools were being established in Gulu, Mukono and Wakiso, respectively. Two more primary and one secondary school were to be established in Arua, Fort Portal and Mbale,. respectively

Mainstream and Integrated Schools/ Inclusive set-up

MOES encouraged mainstreaming of CWDs in ordinary primary schools. Mainstreaming of children with special learning needs meant that all children including those with special needs such as CWDs have access to education in an ordinary school and learn with other children. CWDs were brought into mainstream inclusive schools with the implication that the individual schools would adjust to ensure that the children fitted in available improved environment and for teachers to have the responsibility of supporting the learners including those with special needs. The Ministry emphasised change of attitudes, behaviour, appropriate teaching methods, curriculum, environment and allocation of human and financial resources to meet the needs of all learners including children with special needs. Furthermore, it was expected that efforts should be made to ensure that learners with special needs had equal opportunities to participate in all school activities, including extra curricular activities.

Recognising that there were CWDs with severe learning difficulties, the government supported building of special units/annexes/resource rooms in a number of schools where extra lessons and special learning and teaching materials or equipment were provided to CWDs. During such remedial lessons, children with special learning needs, such as CWDs, got more opportunities to learn skills in sign language or Braille. This enabled the children to receive individual attention and encouragement from teachers during the learning process. However, the majority of schools in this category did not have any resource rooms or materials and equipment to support learning needs of the CWDs.

Another category of schools where CWDs were mainstreamed in ordinary primary schools was referred to as **integrated.** This was where CWDs were taught separately from other children within the same environment of ordinary schools. The CWDs only came together with the other children in some activities such as games. For example, the consultants observed in St Bernadette Primary School in Hoima District, and Rwera Primary School in Ntungamo District, that the children with hearing impairment were being taught separately from other pupils. Some respondents expressed the view that the separation of the children from their peers in class socially isolated them, denying them opportunity to interact and learn from able children. Yet, the teachers that were teaching in separate classes could be used to teach classes with all children mixed together. This would promote closer communication, sharing among the children and more social acceptance where the CWDs and the normal children would interact together.

Vocational Schools for Youth and Adults

USDC entered into arrangements with the local governments to build and renovate buildings of the regional Vocational Training Centres in Masaka and Arua in order to reactivate the training of youth with disabilities in various marketable skills to enable them live self-reliant life. The local government of each district where the centre was situated had been brought in to avail land (Centre), provide funds for some activities, such as pay for tutors, and cover some utility bills. Sub-counties also made contributions for training of youth from their respective areas. Additionally each region served by the training centre was expected to contribute for the youth they sent to the centre for training. Other organisations had been supporting the youth training in the centres. For example, UPACLED had sponsored 20 youth with learning disabilities for one and half years training in Masaka, while the rest of the expenses were met by USDC.

According to Asamo...[28], the DPOs were running rehabilitation centres that offered vocational skills to PWDs. For example Uganda National Association of the Blind (UNAB) was offering knitting, baking, FAL and agricultural skills to the blind together with Blind But Able (BBA) organisation. Uganda National Association of the Deaf (UNAD) was offering carpentry, tailoring, sign language and agricultural skills to deaf people. Unfortunately, the male PWDs got more opportunities in these initiatives than the female ones.

With increased need for teachers in special needs, the Uganda National Institute of Special Education (UNISE) was established by an act of Parliament in 1998 specifically for training teachers in special needs education at diploma level.

6.2.4 Establishment of Institutions and Training of Teachers in SNE

The need to teach and manage children with special learning needs, such as the children with impairment and disability (CWDs), with special skills to ensure effective learning that offers them opportunities to develop their potentials, was realised by the government and the world over. Government through MOES was the major actor in training teachers of all categories except for universities where the private sector had come in. However, the traditional training for teachers all over the country did not provide teachers that qualified with special skills to handle children with special learning needs. Hence, most teachers did not have knowledge and skills to teach CWDs. Few teachers trained in special needs skills had received the training from abroad. These were specialized in a particular disabilities such as mental retardation, visual or hearing impaired hence a teacher would be limited to handle one type of disability. From 1988, the MOES embraced the need to provide special requirements and skills to meet the learning needs of CWDs and came up with a programme for training teachers, with support from DANIDA.

a) Establishment of UNISE & Training of Teachers

The Uganda National Institute of Special Education (UNISE) at Kyambogo, was established and became the only institute of higher learning conducting courses for special education as early as 1988. This enabled a number of already trained teachers with interest in managing the learning process of CWDs to be trained in special needs education at UNISE through government sponsorship. They acquire knowledge and skills so that they could teach children with special learning needs. UNISE conducted the following courses:

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[28] Ms Asamo Grace Helen: Education for Women and Girls with Disabilities in Uganda.

- One-year postgraduate diploma in Community Based Rehabilitation (PGD/CBR).
- Two Years Bachelors Degree in Special Needs Education (BED/SNE).
- Two Years Diploma in Special Needs Education (Dip SNE).
- Two Years Diploma in Community Based Rehabilitation (Dip CBR)
- Two Years Diploma in Mobility Rehabilitation (Dip MBR).
- Proficiency Courses in SNE Management and Supervision, remedial work, peripatetic delivery, Braille, Sign Language, Speech and Language difficulties.
- Certificate in SNE (Cert. SNE).

b) University Level Training of Teachers in SNE

UNISE was transformed into the Faculty of Special Needs and Rehabilitation Studies at Kyambogo University, training teachers in SNE, consisting of three departments namely: i) Special Needs and Rehabilitation Studies; ii) Adult Community Education and iii) Community Disability Studies. Under the Department of SNE and Rehabilitation Studies there were a number of sections namely; Visual Impairment, Hearing Impairment and Learning Difficulties Studies. The education abstract in Table 6.1 shows that 50 males and 32 fwemales received a bachelor of Education courses from 2000 to 2003, while the baseline surey shows that 26 teachers received at bachelors' degrees nd 1 in Masters degree. The training of teachers in SNE at the University levels provided opportunities to train secondary school teachers in managing CWDs at that level. However, that level of training was at the moment individual choice to take up.

c) Training in SNE in PTCs

Another effort at training teachers in SNE was the incorporation of SNE in all the 45 Primary Teacher's Colleges (PTCs) training curriculum from 1998. This was confirmed by tutors in PTCs in Ntungamo and Arua districts and by MOES. All PTCs established posts of Tutors for SNE to provide for the training of teachers in SNE. It was hoped that students who graduated from the Colleges would have skills to teach CWDs in any school including mainstream schools. However, it would be appreciated that most PTC's neither had the tutors, nor did the curriculum provide adequate skills to enable the qualified students teach effectively in SNE.

d) Other Training by MOES

Training for teachers was conducted countrywide by MOES in different districts and in different areas of SNE funded by DANIDA. USDC was a major partner in building the capacity of SNE teachers in USDC supported districts. The training was for 5 days in different areas of disability. The aim was to help teachers to handle CWDs within a school environment. The training basically covered identification, assessment, referral and placement of children with impairment in appropriate schools or for medical advice and care. It further included guidance and counselling to handle CWDs reaching adolescent stage. USDC further trained teachers and health workers in sign language in order that they could adequately help the children. This opportunity had not been extended to parents. However, a few schools with teachers with skills in sign language arranged programmes to train parents and other teachers. For example this was the case in Kitengeza, Kamurasi and St Peter and Paul Primary Schools.

SSI through CECS also supported two weeks training of teachers (referred to as Itinerary Teachers) to identify children with eye problems, assist them and refer them for medical care. These teachers had extra work in addition to normal teaching in terms of the geographical areas to cover. They were supported with a bicycle each and lunch allowance. The same Itinerary Teachers together with Assistant Community Development Officers (referred to as mobility orientation rehabilitation assistants (MORAs)), received one-week refresher course annually. All the trainings were provided by qualified facilitators from Kyambogo University (UNISE) who also developed a training guide. CECS also identified and trained one teacher in every school that had blind pupils to support their learning.

It was important to note that these trainings were short term (about 1 week) and only enabled the teachers to be oriented in SNE. However; they were useful in ensuring that children with special needs were attended to.

6.2.5 Teacher Training Curriculum

The curriculum for training of teachers was first in special education. As stated before, it was aimed at producing teachers who were specialised in particular disabilities such as hearing impairment, vision impairment or mental retardation to teach CWDs in exclusive schools. The training was offered by a few institutions/centres in Uganda, Kenya and others trained from abroad. The curriculum later changed to SNE that was aimed at producing teachers with general knowledge about a wide range of special learning difficulties as well as teaching children in an inclusive setting. This change was also in response to the UPE and inclusive education policies that had contributed to increase in enrolment of children with special learning needs. The Dean, Faculty of SNE and Rehabilitation in Kyambogo University testified that the SNE curriculum enabled teachers to get exposure to SNE so that they were able to handle the growing numbers of children with special learning needs. While it was appreciated that the SNE curriculum catered for the various needs of different categories of children with special learning needs, it was found that it did not equip learners with skills to handle severe cases of disabilities. This was a disadvantage to these children, through denying them rights to attain quality education.

In the PTC curriculum, it was found that aspects of SNE were available, but skills training non-existent. The time given for SNE in the curriculum was only 72 hours in the 2 years course as seen in the Gulu SNE guideline (Chart 6.3). This was inadequate if skills training were included in the content. The consultants were told that many SNE teachers, particularly those trained in the PTCs, were not able to teach special skills (teach sign language or use Braille) to CWDs because of the way they were prepared. This inadequate planning for skills in the curriculum for training teachers had both wasted resources and undermined the education of the CWDs as teachers had to go for further training in order to be competent. Yet, teachers in most cases catered for the training from their own resources, which discouraged them.

Chart. 6. 2: Special Needs Education Guide, Gulu Core PTC

YEAR ONE
Term 1 (12 hours) - Basic Concepts in Special Needs Education: Attitude concerning Persons with Disabilities
Term 2 (12 hours)- Provision of Special needs Education in Uganda
Term 3 (12 hours) – Types and Causes of Impairment
Prevention of Impairment
YEAR TWO
Term 1 (12 hours) – Meaning and Classification of Different Impairments
Term 2 (12 hours)
Specific Learning Difficulties (meaning, types, differences and similarities, responsible factors, interventions, school practice)
Secondary and Additional Impairments
SNE and the Community
Term 3 (12 hours) – Social, Pre-vocational and Vocational training
Final school Practice and examinations

One SNE teacher in Masaka district who had just graduated from Kyambogo University with a Diploma confessed, **"I have just left College but I cannot sign nor teach Braille because the curriculum was very shallow. There were 5 of us from Masaka and we were eager to learn sign language and Braille but we were disappointed as none of us picked these skills".** This statement even challenged the Diploma curriculum. This meant that some children with severe disabilities would not get appropriate educational services.

Fortunately, MOES and Kyambogo University were aware that the Primary Teachers' Curriculum does not provide special skills in SNE for areas like sign language and Brailles with general information about disability that had little SNE content and inadequate time for specialization.

> **"Kyambogo University responds and reviews the curriculum and modifies it whenever the MOES raises concerns. Because of issues raised earlier by the Ministry, the curriculum is currently under review with the intention of giving students skills in both Braille and sign language. The revised curriculum is likely to be in use next academic year (August 2006)".**
> ***The Dean Faculty of Special Needs Education and Rehabilitation Kyambogo University said***

Moreover, Kyambogo University reiterated that the PTCs had no SNE tutors with skills to adequately teach in SNE. This statement was partially confirmed when the consultants learnt that the teacher in charge of SNE in Arua Demonstration P.S, was also the Tutor for SNE in Arua PTC. Lack of tutors also undermined the education of children with special needs. Hence, it was not only an appropriate curriculum that was required to promote education of CWDs but also tutors to train the teachers at different levels.

6.2.6 Adequacy of teachers trained in special skills to teach and manage CWDs

It was important to note that despite the effort made by the MOES to provide training in SNE, the teachers trained were not enough to provide SNE in all schools. There was no continued and adequate budgetary provision for retraining of teachers already in the field to meet even half of the needs of CWDs. Yet with the growing numbers of CWDs, there was increasing need for well-trained teachers in SNE.

The Tables 6.1 below obtained from education abstract from UNISE records show that UNISE trained a total of 900 teachers in the conventional programmes with various qualifications (certificates) and 2180 teachers in Diploma in SNE External (Dip. SNE(E)). This is confirmed by the tables derived from the baseline survey (Annex 2) which indicate that 668 teachers from districts of survey received certificate courses ranging from less than one week to three years. This could probably include those who had special needs education component in their normal teachers training courses. Annex 2 also shows that 363 teachers received training at Diploma level. This number is comparable to the nationa wide education abstract in Table 6.1 a) and b) below, understanding that some of the survey districts did not provide adequate information due to inavailability of records.

Table 6.1: Students who completed Programmes in SNE and Rehabilitation

a) Conventional Programmes

	B.Education		**PGD.CBR**		**DIP.SNE**		**DIP.CBR**		**DIP.MBR**		**CERT.SNE**	**Total**
	M	F	M	F	M	F	M	F	M	F		
2003	13	5	9	4	39	25	9	9	10	5		
2002	7	7	2	3	46	27	9	1				
2001	11	10	9	2	49	35	12	3	6	7		
2000	19	10	7	4	29	39						
1999			13	1	37	31						
1998			13	1	24	20						
1997			10	3	26	29						
1996					39	41						
1994					39	41						
1992					16	9						
1991					17	8						
Total	50	32	63	18	361	305	30	13	16	12		
G/T	**82**		**81**		**666**		**43**		**28**			**900**

Note: From 1990 to 1996 admission was done bi-annually. At that time there was only one programme – Diploma in SNE.

b) Summary of Diploma in Special Needs Education External (DSNEE)

YEAR	MALE	FEMALE	TOTAL
2001	264	172	**436**
2002	401	296	**697**
2003	571	476	**1,047**
Grand Total			**2180**

Source: Kyambogo University

The tables above show increasing trend in numbers of teachers trained for both male and female students, and in the variety of types of training from the year 2000 to 2003. This is affirmed by the information on annex 2. Overall, the numbers of male students were larger than the females. There was also a large number trained at Diploma level in SNE External (DSNEE). The centres where the DSNEE were done such as Kamurasi Demonstration School, visited by the consultants, became good examples of inclusive education.

Whereas the UNISE trained teachers were probably the best trained for primary education and could be relied on, these numbers were too inadequate compared to the demands for teachers in SNE. The situation was made worse by the fact that there were now more than 56 districts in Uganda. The above figures would mean that there were less than 5 teachers with SNE skills available to each district to handle all the CWDs in all schools including schools with special units. A good number of the trained teachers were promoted to SNE/EARS Inspectors or head teachers, and a number were managing the special units or resource units.

Special needs education takes the lead in the short courses. Annex 2 shows a growing increase in interest in teachers to take long term courses of 1 to 2 to 3 years in special skills to teach and manage CWDs.

The Table below shows a summary of the trainings carried out and the number of teachers that were trained under DANIDA programme by 2001.

Table 6.2: Teachers trained under DANIDA Programme of SNE by 2001

Type of workshop/seminar	Number of participants		
	Males	**Females**	**Total**
Sign language	568	524	1092
Braille	335	346	681
SNE for nursery teachers	56	70	126
Making and use of assessment Tools	83	55	138
SNECOs	624	408	1032
Production and use of educational materials	142	111	253
Integration of children with SNE	14	11	25
Use of Audiometer	54	57	111
Annual meeting of DEOs, DIS, MIS and in charge SNE/EARS in districts			This is an annual invent attended by all listed participants
A study tour to Kenya conducted	04	01	05

Source: USDC Annual Report 2001

According to information on Annex 2, the number of teachers trained in special skills to manage CWDs in different districts varied. There were more trained teachers in USDC districts than in non-USDC districts even though only 9 out of 15 USDC districts submitted data. This probably implied that better quality education for CWDs was provided in USDC districts. It was also important to appreciate that aamong the teacher that underwent long courses, quite a number came from non-USDC districts. It should be noted however, that the nature of the baseline survey did not establish the overall need for SNE teachers in different districts. The gap was therefore not known.

More analysis of the training of SNE teachers indicated that the length of training varied, ranging from less than one week to 1 week to 2 months, to 6 months, to 1 year, to 2 years and to 3 years. Table 6.4 below shows that for both USDC and non-USDC districts, most of the teachers were trained for shorter periods of less than 6 months, although more trained teachers were in USDC districts. This type of training only provided general information about disabilities that enabled identification, assessment and referral of CWDs. This supported information from PTCs and Kyambogo University that the teachers graduating did not have adequate skills in sign language and Braille. This implied that these teachers were not able to teach skills to CWDs such as Braille and sign language. Hence, the education for CWDs who needed such skills was denied quality education. Few teachers received training in special skills such as Braille or sign language, which involved longer periods of training. This varied from district to district. For some districts like Masindi, Lira and Apac, there were more teachers who received training for 2 to 3 years who had diplomas and degrees, than others. These improved the quality of teaching CWDs although it also depended on the skills they acquired.

The Quantitative Data Annex 2 on Type of Training and Length of Training by District and Table 6.3 below showed that teachers were trained in different aspects of disability ranging from SNE, hearing, mental and vision impairment management, Braille, sign language, cerebral palsy, mobility and rehabilitation, SNECO workshops, awareness and identification of CWDs and classroom management. This information agreed with the qualitative information elsewhere in the report.

Table 6.3: SUMMARY OF SPECIAL NEEDS TRAINING BY TYPE AND LENGTH OF TRAINING – BASELINE DISTRICTS

	Length of Training								
Type of Training	**< 1 week**	**1 week - 1 month**	**2 to 5 months**	**6 - 11 months**	**1 yr**	**2 yrs**	**3 yrs**	**On Job**	**Total**
Special Needs Education (SNE)	22	148	8	3	14	189	135		**519**
Mental Retardation		5	1			2	1		**9**
Hearing Impairment Management		10				3			**13**
Sign Language	4	42	1	1		5	1	1	**55**
Brakey		2							**2**
Autism		6							**6**
Epilepsy		2							**2**
Contin. Professional Development (CPD)		2	2						**4**
Education						1			**1**
Capacity Building/Workshop(SNE)	24	89				2			**115**
Visual Impairment management	2	39	1			5		2	**49**
Cerebral Palsy		6	1						**7**
Braille		46	2		1	2			**51**
Awareness(SNE)		30							**30**
Identification of CWDs	4	25				1			**30**
Ears Centre Management			2						**2**
Orientation Course(Special Needs)		10				3			**13**
SNESCO(Workshop)	4	78			8				**90**
Mobility and Rehabilitation		1		1	1	3	1		**7**
Refresher Course		2			1				**3**
Advocacy for pupils with Special Needs		1							**1**
Classroom Management		2							**2**
Psychosocial		12							**12**
Visual and Hearing Impairment		2							**2**
Speech Impairment		1							**1**
Inclusive Education		22							**22**
Educational Material		2							**2**
Guidance and Counseling		1							**1**

It should be noted however, that the quantitative data on training of SNE teachers and the data collected through interviews in some districts did not tally as could be seen from the Annex 2 and Table 6.4 below respectively. This discrepancy could be partly explained by the inability/lack of interest of district education offices to collect and document correct information about teachers trained in SNE in their respective districts. Hoima district had only 30 SNE teachers according to Table 6.4, yet a special school like Uganda School for the Deaf had 28 trained SNE teachers. It made it difficult to determine the gaps in requirements for teachers with special skills in order to make concrete recommendations. This further compromised the quality of education of CWDs.

Table 6.4: Number of Teachers trained in SNE in different Districts

District	Number of schools	Number of SNE teachers
Hoima	197	30
Lira	300	35
Kasese	258	22
Khabarole	109	8
Adjumani		4
Gulu		6
Nebbi	220	105
Arua		(2 for sign language)
Moyo	78	160 (2 for teaching Braille)

Note: this data was collected as part of the qualitative information gathering. It affirms discrepancies in data collections.

Despite the glaring limitations in numbers of teachers with knowledge and skills to manage special learning needs, the consultants learnt that there had not been much initiative in the districts to use available trained SNE teachers as resource people to build teams with knowledge about SNE. This would have made it possible to have many more teachers subsequently equipped with SNE skills, hence, build capacity of the districts.

6.2.7 Education Standards for Children with Learning Needs

The 1997 Local Government Act, Article 8 provided for central and district inspection of schools on issues of quality. In order to ensure that providers of education services availed the necessary facilities and environment for the education of all children, Education Standards Agency (ESA), formerly a department of Inspectorate under MOES was established in 2000. It developed the Basic Requirements and Minimum Standards Indicators for Education Institutions (Standards) currently in use. In order to support inspection of schools in the country, ESA worked with Centre Coordinating Tutors (CCTs) and District Inspectors of Schools.

When the consultants read through the 'Standards' and discussed with the Deputy Director ESA about different aspects in the basic requirements for ensuring effective learning and teaching of SNE, the guideline was found inadequate on SNE. For instance, on standards for health and sanitation, there was no mention of special latrines for girls and boys with impairment, on effective learning, there was no mention of remedial teaching for CWDs and for co-curricular activities like child rights clubs (CRCs) from which SNE children benefit was not included. This implied that SNE was not effectively monitored hence weaknesses were not likely to be detected. This was unfortunate as CWDs were still being pushed to go to school.

ESA had developed a Quality Indicators Handbook/Monitoring Instruments for learning and teaching. However, this was still in the process of being printed. The Quality Indicators Handbook mainly focused on primary school and had a component on SNE. ESA respondents indicated that there was need to focus more on developing indicators for secondary schools. ESA carried out national inspection once every 2 to 3 years using a team of diverse levels and people involved in education services. Information obtained from inspections enabled District Inspectors and the Guidance and Counselling Department on how to improve learning and teaching. However, the inadequacies in the standards regarding SNE would lend the teaching and learning of CWDs to be inadequately monitored. The department had also developed a manual for guidance and counselling to help teachers, parents and school management committees. The consultants were informed that the manual had special components on SNE.

6.2.8 Assessment of Learning Outcomes of SNE.

The assessment for all children at a particular level of education was the same without any differentiation whether one had severe disabilities or not. Only children with hearing impairment had considerations of an extra 30 minutes during examinations. Yet CWDs had many constraints that needed special attention if the assessment of their learning was to be fair. The situation was found to be worse for children with hearing impairment.

The consultants were told that physically impaired children especially those who crawled had problems of keeping their work clean. The consultants saw children who were writing with their toes because they did not have complete arms with hands and fingers. Hence, marking the work of such students would require appreciation of these experiences. It was established that blind children who did not have access to Braille used typewriters and experienced difficulties in adjusting ribbons on typewriters during examinations. This puts them at a disadvantage because invigilators did not assist them. Furthermore, teachers said that marking blind children in Braille was difficult if the marking was done by one person. This was because one person was required to interpret the work while a second one marked the work. One SNE teacher in Masaka explained it as follows

> ***"One teacher cannot examine a vision impaired child's paper alone but needs two SNE teachers, one interpreting the child's answer in Braille while another teacher, who knows whether it is right or wrong, marks".***

Yet there were few teachers who were knowledgeable in Braille. Teaching structured subjects such as Mathematics and Science to blind children was also difficult. Textbooks in Braille were rare in schools and only available for English and SST. This implied that assessment of such children might not be fairly done and could affect their achievement.

Deaf children have many concerns that needed serious consideration. One was that teaching sign language was difficult for teachers, particularly in subjects like science and SST. This meant that what teachers passed on to the children was also inadequate. This affected their learning, performance and achievement. Some deaf children had other disabilities, which might not be very obvious and which UNEB might not take into consideration. For example many deaf children had mild mental retardation. The head teacher, Kireka Home for Children with Special Needs commented as follows:

"UNEB does not understand that deaf children have difficulties in reasoning and interpreting things. In examinations, they mainly depend on pictorial questions. From our experience in assessment of many of the deaf children, teachers have found that they also have multiple handicaps such as mild mental retardation and hearing impairment. This makes their reasoning capacity to be low".

Thus, such children tended to repeat the same class until they were able to understand and demonstrate ability to go to the next class. Children with hearing impairment also would write slowly, which made it difficult to complete examinations in time. The 30 extra minutes were therefore inadequate. The head teacher of Masindi Centre for Physically Handicapped supported this as follows:

"Deaf children can never write like other children. They have problems of speed and write slowly. It therefore takes longer to complete a paper. Yet, this is not taken into consideration in examinations and in marking their papers".

Because sign language teachers were few, invigilators often did not know sign language hence they could not help deaf children who needed help. This put them at a disadvantage. The level of examinations set by UNEB was also said to be too high for deaf children yet there were no interpreters. Other problems included the fact that the deaf also interpreted words differently, wrote sentences the other way-round and their language was shortened. The head teacher, Uganda School for the Deaf explained it as follows:

"The language for the deaf is different in that it is shortened. They also have difficulties in relating some words to their language. Yet the system does not provide interpreters during examinations. The deaf interpret some words differently for example a sentence –'I will go to Kampala tomorrow' will be written as 'Me Kampala tomorrow'".

This was a beautifully shortened sentence in sign language, but incomplete in English grammar therefore in marking, this sentence would be marked wrong yet it was a complete sentence in sign language.

All the above indicated that the assessment system of education was unfavourable to CWDs. This was bound to affect their performance and achievement. It was necessary that the concerns of the different disabilities be critically examined and addressed. The Director of Kampala School for Physically Handicapped narrated her experiences in handling problems related to examinations. She told the consultants that she had been fighting to keep her children for a longer time in examinations than prescribed for ordinary children to enable them complete papers. According to her, different problems of the different disabilities needed to be handled differently. For example, those who used feet to write must be treated differently within different timings. Those whose heads could not give instructions to the hand to write needed oral examination to bring out the intelligence in them. From the stories of this school, it could be considered for 'best practices' in teaching and training children with severe impairments. This clearly showed that CWDs deserved a special examination system to meet the different needs and to make the system fair to all children.

It was gratifying to learn from the DPOs and the Principal Education Officer SNE in MOES that the above problems had been discussed with UNEB. Subsequently, a desk officer to handle issues of disability had already been recruited. However, it was hoped that most of the above mentioned concerns would be addressed for all CWDs with different disabilities to make assessment favourable for all children.

6.2.9 Establishment of Structures to manage SNE

Establishment of Resource Centres

DANIDA initiated the EARS/SNE programme in 46 districts. This was implemented from 1997 to 2003. DANIDA supported establishment of EARS/SNE resource centres in each district of Uganda. These were classrooms with specialised equipment and educational materials where children with special learning needs could be withdrawn for extra specialised teaching based on their needs. It also provided teachers' houses as well as educational materials and equipment that were distributed to schools with annexes/resource rooms. Double cabin pick-ups were procured for the districts to facilitate the movement of staff. Two motor cycles were procured for Kalangala District, and 1053 bicycles distributed to teachers referred to as Special Needs Education Coordinators (SNECOs). Eight (8) show-down tables and bells were procured and distributed to schools/units for children with visual impairment. Six hundred (600) volumes of Braille books for P5-7 and over 600 Braille kits were procured and distributed to schools/units for children with visual impairment.

When the DANIDA programme was phased out in 2003, the centres were left to each district local government education office to manage. The districts managed the centres in different ways, in some cases converting them into departmental offices. Support facilities like vehicles were put to departmental usage and actually run down. Some of the staff quarters built for special needs at resource centres were now occupied by other district officials. There was minimal input from the district budgets to maintain and sustain what had been established by the DANIDA programme.

Chart 6.3: Schools with Units for CWDs in USDC and non-USDC Districts

District and founding body	Name of School	Disabilities addressed by unit
Arua	Arua Demonstration School	Visual impairment
	Ediofe Girls School	Visual Impairment
	Mvara Secondary School	Visual Impairment
	Eruba Primary School	Hearing Impairment
Hoima	St. Bernadette P.S	Vision & hearing impairment
	Bujuni Boys P.S.	Visual impairment
	Kitana P. S	Hearing impairment
Gulu	Gulu P.S	Vision impaired
	Laroo P.S	Hearing impairment
	Gulu High Sec. School	Visual impairment
	Gulu Prisons P.S	Mental retarded
Lira	Ngetta Girls P.S	Visual and other disabilities.
	Ojwina P.S	Mental and multiple
	Agidak P.S	Visual impairment
Moroto	Kangole Girls P.S	Visual impairment 9 children
	Kangole Girls Sec. School	Different impairments
Tororo	Agururu P.S	Hearing, visual, mental
	Agola P.S	Deaf and Blind
	Kainja P.S	Different disabilities
	Butaleja Integrated P.S	Different disabilities
	Merikiti P.S	Mentally impaired
Ntungamo	Rwera P. S	Hearing and mental
Nebbi	Angal P.S	Vision impaired
	Paidha Demon. P.S	Hearing impaired
	Pajobi P.S	Vision impaired
Masaka	Misamvu Demonstration P.S	Different disabilities (45 CWDs with 18

		mentally impaired)
	Bugabira P.S Kitengesa P.S Bwanda P.S	Hearing impaired Hearing impaired Hearing impaired
Iganga	Iganga Secondary School Buckley High School (P.S) Bishop Willis Demon. P.S	Different disabilities 21 children Deaf and Blind (68 deaf and 10 deaf/blind children) Different disabilities (total 26 children)
Kapchorwa	Kapchorwa Demon. P.S	Vision, hearing and mentally impaired children

Most of these schools were for the visual and hearing impaired. This could be an indication that there were more children/people with visual and hearing impairmemt in number or being provided for. This is a challenge balance support to the different types of impairment.

Chart 6.4: Quality of Resource Rooms/Annexes in some Schools visited

Districts	**No. Resource Centres**	**Supported by**	**Nature of support**
Hoima	3 (St. Bernadette and Kitana PS)	USDC 2 Sight Savers 1	Resource materials like Braillers, books, etc Construction of building -Resource materials
Moyo	1 (Moyo Girls PS for blind)	USDC An individual from Germany	Construction of the building Scholastic materials like books, Braillers, etc
Apac	-	-	-
Luwero	1 Luwero Boys P.S-	-	-
Masaka	2 (Misanvu Unit and Budenga Unit)	USDC 2	-Constructed the two units Refurbished Kimanya PS Gave scholastic materials
Masindi	2 Masindi Centre for Physically. Kamurasi Demonstration School.-multiple	USDC 1 Sight Savers	Constructed a building, and provided few scholastic materials
Nebbi	3 (two for blind and one for deaf)	USDC 2 Dept. DEO 2	Braille machines, Braille papers, play cards, Ludo etc Gave them some little money
Arua	5 (Ediofe, Eruba PS and Arua Demon. School)	USDC 2 DANIDA Lions Club	Renovated the two schools, 9 Braille machines, 3 type writers, Braille machines Food, blankets
Iganga	2 Iganga Dem., Burkley High		
Kasese	Mpondwe		

In the districts visited, some Local Governments, USDC and SSI through CECS supported building and equipment of resource rooms in schools. This was in recognition of the extra time and attention required by CWDs in order to access equitable education. However, the number of schools with resource rooms was very small compared to the number of schools in each district that had enrolled CWDs. This meant the CWDs were denied opportunities to access equitable and quality education in the schools they joined. In order to support the many CWDs who joined primary schools within their localities, in fulfilment of the inclusive education, there was need for more effort to establish resource rooms in as many schools as possible.

Both the Church of Uganda and the Catholic Church had been involved in founding special units for CWDs in primary schools. USDC came in to support some of the units.

6.2.10 Instructional Materials and Equipment

Children with severe learning difficulties required special learning aids, materials, equipment and other resources to help them learn. For instance, children with visual impairment required Braille machines and paper, slates, counters, and white cane. Children with hearing impairment required hearing aids, visual aids (toys, charts. play materials), and photocopiers for schools to produce more visual materials, video/films and teachers with skills in sign language. DANIDA provided materials and equipment (Braille machines, Braille paper, manuals and others).The consultants observed that special schools were better equipped with the required materials and equipment than mainstream schools. Among the mainstream schools, those with resource rooms were fairly well equipped with Perkins Braille machines, Braille paper, sign language manuals while others simply did not have anything. Chart 6.5 below gives examples of special schools and those with units that had materials and equipments at the time of the survey.

Chart 6.5: Equipment and Materials Position in Special Units

School	Equipment/Materials	Comments
Agururu PS, Tororo	6 Braille machines, white canes	These are inadequate
Spire Road PS, Jinja	10 Braille machines, 30 slates, Braille kits, Braille paper	Fairly well equipped
Misanvu PS, Masaka	2 Braille machines	Lack Braille books and machines are inadequate
Moyo Girls PS,	6 Braille machines	No text books in Braille (including Mathematics)
Rwera PS, Ntungamo	Sign language manuals	Lack hearing aids. No Braille machines and books although no blind children yet.
Ngetta Girls PS, Lira	20 Perkins Braille, hand frames, Braille paper, Braille text books	Fairly well equipped although frequent breakdowns of Braille machines
Rukoki PS in Kasese	Braille machine, Braille paper, Braille text books	These are inadequate. Lack sign language manuals and hearing devices
Kamurasi Demonstration School	20 Braille kits and Braille books, Sign language manuals, reading cards	There are no Braille machines.
Arua Demonstration PS	Few Braille machines	Only used during examinations
Mvara Secondary School	4 Braille machines	Only used during examinations.
Ediofe Girls PS	5 Braille machines	These are inadequate
Kangole Girls PS	7 Braille machines (only 2 working, rest beyond repair)	1 of the 2 working Braille machines belongs to a teacher, hence the need for new machines
Uganda School for the Deaf	Sign language manuals	Lack play materials, toys, charts, other visual aids and equipment
Masindi Centre for the Physically Handicapped	Have sewing machines, leather and carpentry equipment, agricultural tools, sign language books and computers	No hearing devices

According to information provided by the schools visited, the few Braille machines available were kept mainly for examinations only for fear of constant breakdowns. The

District Inspector of Schools/EARS in Arua said she was keeping 30 Perkins Braille machines in the store, ever since they were given by DANIDA, while the students and pupils in Mvara Secondary School, Arua Demonstration School and Ediofe Girls Primary School did not have machines for daily use and probably adequate numbers for examinations as well. Moyo district has had to send one boy to Mvara Secondary School with own Braille machine because of this apparent shortage. The hording of the Braille machines was therefore seen as counter productive at a time when efforts were being made to advance education of CWDs.

USDC equipped a number of resource rooms for SNE, both those it rehabilitated and those built by others. The main material and equipment provided include Braille kits, materials and Perkins Braille equipment, sport balls, game kits, and child focused story books that enhanced learning of CWDs. SSI was in the process of furnishing the resource centres they constructed in Masindi and Hoima Districts with equipment and materials (such as Braille machines, paper, tactiles, etc) required for effective management of the centres.

It was evident that most mainstream schools did not have the required materials and equipment. These gaps made it difficult for teachers to teach and for CWDs to learn effectively. For example in Aber Primary School in Apac district, a non-disabled child lamented: **"We do not have machines for blind children."** With apparent increasing consciousness about education of CWDs, and the subsequent increased enrolment, there was need for more efforts to support the schools with provision of educational materials and equipment for the learning of CWDs. It was reported that there was a shortage of Braille paper countrywide hence schools were using Manila paper, which was destructive to the Braille machines. Many schools also raised issues about breakdown of Braille machines, which they found expensive to repair, particularly as there were no technicians within easy reach to maintain the machines.

Despite the above problems, MOES was trying to provide educational materials particularly textbooks for CWDs. For the financial year 2003/04, the Ministry provided Braille textbooks for P3-4 while for the financial year 2004/05, it provided Braille textbooks for P5-7. It was in process of procuring other materials to cover other disability areas which included wheel chairs, crutches, assessment tools, hearing aids and sign language dictionaries for distribution in schools for the period 2005/06 financial year. This would contribute to improving quality of education for CWDs. The major challenge with the procurement of materials and equipments was the limited numbers vis-à-vis the large number of CWDs. More materials were required for impact to be realised.

6.3 District Levels of Provision for Education of CWDs

6.3.1 Planning and Budgeting at District Level

When DANIDA wound up in 2003, districts were expected to take up and support the SNE programme. However, this did not happen as expected and different districts did it differently. The consultants found that although all districts planned and budgeted for SNE, how they made budgetary allocations varied. While some districts made small budgetary allocations to SNE, others were supportive. For example, in Sembabule district, no funding was released for SNE for the year 2004/2005. The same situation was found in Tororo and Adjumani districts where no funds had been released for SNE for the last four years. It was found that even the whole education sector was under funded. For example in Apac, only 25% of the budget was allocated to education yet planning took 49%. This was clearly an imbalance considering that education was one of the top priority objectives of the PEAP.

Some districts were trying to cater for SNE in their plans and budgets. This was observed in both USDC and non-USDC programme districts. One such district was Ntungamo where the local government had built 2 classroom blocks under LGDF and contributed funds (Shs.34 million) towards building a big dormitory for CWDs at Rwera Primary School being developed as a centre for CWDs. It also allocated Shs.5m towards assistive devises for the financial year 2005/2006. Other examples were Masaka where the local government was behind the rehabilitation of Masaka Vocational Institute and used to contribute financially for its management although this contribution had not been paid for the past few years. In Jinja, the Local Government was remitting a monthly contribution to cater for feeding of CWDs in Spire Road Primary School Blind Annex while in Gulu district, the DEO indicated that the district had budgeted for wheelchairs, appliances, Braille equipment, books and paper and there were provisions for assessment and supervision. Arua District Local government had made budgetary provisions for supporting management of Ocoko Vocational Training Centre, although it failed to remit Shs.3m per month. These efforts were commendable although more support could be provided since it was their responsibility.

The survey found out that according to the decentralization policy, districts were supposed to identify and determine their priorities and needs. Thus, those districts that were not catering for SNE were running away from their responsibilities. This could be a result of negative attitude. Districts might be expecting central government to send them funds to cater for CWDs instead of perceiving themselves as the ones responsible for CWDs. The challenge was for districts to build a more clear understanding and perception about their responsibilities as far as SNE was concerned.

Government provided a subvention/conditional grant to districts to cater for CWDs. This helped to support schools with many CWDs particularly the special schools and those with units/annexes to cover accommodation and feeding of the special needs children. However, the remittances were irregular and the amounts too small (Shs. 10,000 per child per term) to effectively support the CWDs. According to head teachers and SNE inspectors interviewed, this was making the running of schools with special units difficult especially where the CWDs were in boarding facilities. Some parents, whether because of negative attitude or poverty, were not able to supplement what government provided. Yet for CWDs to learn they needed a conducive environment. Government and parents whose responsibility it was to provide education to the children were not meeting their obligations fully.

All districts got the UPE Capitation Grant of which 35% was for scholastic materials, 20% for co-curricular activities, 15% for management of the school, 10% for administration and 20% for other items. It was sad to note that CWDs were not benefiting from these funds for example for educational materials. The excuse was that the UPE Capitation Grant reached districts already with guidelines on expenditure and SNE was not mentioned. Again, this could be an issue of negative perceptions and attitude among the personnel in charge of implementation of UPE Capitation Grant and other programmes. They might not have perceived CWDs and SNE as of importance, hence funding of SNE in districts was not adequately promoting education of CWDs. This unclear situation could mean that both district local governments and the central government attached little importance to the learning needs of CWDs. If there was more commitment, then more funding would be made available. This would make it possible to train more SNE teachers, provide more equipment and materials as well as CWD-friendly infrastructure.

6.3.2 Disability-friendly Structures

All children including those with disability needed to learn in an environment that was friendly and conducive. A friendly and conducive environment enabling easy mobility of CWDs would include disability-friendly structures such as ramps, walkways and furniture so that they sat and moved comfortably. It would also need special latrines, which were tidy. According to the Principal Education Officer SNE in MOES, the Ministry guidelines provided for construction of accessible classrooms and toilet facilities in all schools where UPE funds were channelled for construction purposes. It was therefore a requirement that schools had ramps on all new classroom buildings to aid mobility of CWDs, especially those with wheelchairs and special latrines.

The survey established that schools had been constructed by the central government through various facilities, such as school facilities grant (SFG), classrooms completion grant (CCG) and through arrangement with donors. According to the survey, few schools with CWDs in both USDC and non-USDC districts had ramps and latrines that were appropriate and built according to specifications. The DEO in Nebbi said that his department had made efforts to impress the need for disability-friendly environment upon the Local Government. Although the deputy DEO in Yumbe District said that as the desk officer in charge of signing works approval forms, he followed up the construction of ramps to ensure they were according to specifications although the consultants did not have any opportunity to see ramps in any of the schools visited. However, one would wonder why other deputy DEOs did not follow up construction of ramps in schools. Nancy School for the Deaf in Lira District and Masindi Centre for Physically Handicapped had attempted to provide ramps that were wide and accessible by children with wheel chairs. They also had latrines with rails/handles to aid such children with mobility problems including those crawling. These were good examples of schools with CWD-friendly structures.

However, it was observed that very few schools had disability-friendly structures. This was confirmed by the SNE Inspector Kasese district who said ***"We have 258 government aided schools in Kasese district but only 4 schools have ramps. Even those with many CWDs including Rukoki Demonstration School which has a special unit for CWDs do not have ramps".*** In other districts such as Hoima and Masindi, the ramps in schools were often too steep to be used by children in wheelchairs and in a few cases where special latrines had been constructed, rails/handles were too high while latrine doors were too narrow for wheelchairs to pass. This was an indication that supervision of construction of these structures was inadequate.

The Districts Engineers responsible for monitoring construction work and to ensure that the facilities were properly constructed according to specifications, did not do their work. DEOs and Inspectors of Schools in charge of SNE could have also given support. It was difficult to say whether supervision and monitoring of these facilities were just inadequate, or there was simply no commitment and consciousness about the need to ensure the structures were provided. Often the blame was put on contractors who claimed the ramps and special latrines were not in the architectural designs. There was no indication that committed district authorities and MOES representatives took up this issue with the technical offices. The negligence or negative attitude or disregard for the needs of CWDs among technocrats and contractors contravened the guidelines in the 'inclusive education' policy.

The general physical environment in special schools was of concern, except when limited by resources. The 'talking compounds' in some of the schools showed that they cared for their disabled pupils. However the environment particularly the compounds of most mainstream inclusive schools showed that they simply did not mind about the presence of the blind or those on wheel chairs.

6.3.3 Advocacy through Outreach Programmes

The USDC disability information and education strategy was among the best practices in addressing issues of rehabilitation of CWDs. SNE/EARS inspectors in USDC programme districts were among the outreach programme team members that mobilised and sensitised parents to send CWDs to school and take them for medical treatment. USDC facilitated capacity building of different people including teachers to play a more active role in sensitising the community about disability and CWDs in particular. It worked with other CSOs in different districts to support the commemoration of special occasions such as the International Disability Day to reach the top leadership and have CWDs participate. This helped to show the potentials of CWDs and hence advocated for them. In Apac district, USDC worked with Action Aid International to lobby local government to improve education of the girl-child including those with disabilities.

USDC provided support to supervision of EARS, trained teachers in identifying and assessing special educational needs of CWDs and medical referral or social placement (psycho-social counselling and relocating), training in management of epileptic fits at school and reminding the child to take drugs.

6.3.4 Provision of Monitoring/Supervision Services for SNE and Management

Structures Responsible

MOES provided for SNE through the Departments of SNE, Career Guidance and Counselling headed by a Commissioner. District Education offices coordinated SNE activities at district level through District Education Inspectors specifically through the SNE/EARS Coordinators. Each District Education office was allocated specific Inspector(s) of Schools to be in charge of the EARS/SNE. Most SNE/EARS Inspectors were trained in special needs and were therefore teachers with skills, able to provide the necessary support to schools, coordinating with other service providers, while guiding and counselling parents. They were also able to pass on special skills such as sign language and Braille.

The survey found that in both USDC and non-USDC programme districts, the SNE Inspectors were not adequately facilitated to do their work. For example, they did not have transport to carry out supervision of the effectiveness of teaching and learning in special learning needs children. The reason given for this situation was lack of funds. It should be noted however, that USDC programme districts were better off because the SNE/EARS Inspectors of Schools would do some inspection and monitoring of SNE whenever they got some support from USDC. It was learnt that with restructuring of local government, the position of SNE/EARS Inspector was abolished and instead all Assistant Education Officers would be charged with all education programmes including special needs. The new officers would however require training as many of them were not knowledgeable about SNE.

More support to supervision and monitoring of special needs supervision was at sub-county level provided by SNECOs. The position of SNECOS was not official but an arrangement between MOES and districts to have teachers with knowledge about SNE to provide support to schools. It was found that one SNECO was responsible for a number of schools in some cases 18. A SNECO had 2 days a week to reach out to the schools under his/her jurisdiction where support would include identifying, assessing CWDs; placement in school or medical rehabilitation; advising teachers on how to handle CWDs and in making learning and teaching materials as well as helping parents in how to handle CWDs in their homes. The challenge on ground was that the SNECOs did not have adequate time to supervise the schools allocated to them, neither did they have time to carry out home based training of parents or CWDs. The work was however appreciated by the Inspectors, DEOs and parents as they worked voluntarily yet they also had to teach.

While the SNECOs would be willing to take on the extra responsibility of coordinating and helping children with special needs, many said their work did not receive sufficient recognition because they did not receive support from the districts. While some facilitation was provided to some, they said it was inadequate and irregular. The bicycles they had received from DANIDA were old and not maintained by the Education Department. This voluntary work was supplementing government efforts in supporting SNE which did not have enough qualified teachers. MOES and local governments needed to review the role of the SNECOs and decide the best way forward. Some of them were very demoralised and no longer reported to SNE/EARS office nor did they support children outside their schools. In the absence of enough qualified teachers, use of volunteers in advancing special needs education should be appreciated.

Districts also had supervisors known as Centre Coordinating Tutors (CCTs) whose role was to provide technical support to head teachers and school management committees so that schools were managed professionally. They organised seminars and workshops for head teachers in schools, school management committees and PTAs. The survey found out however, that CCTs were not working closely with SNECOs and SNE teachers in provision of SNE in schools. However, this linkage would have been possible if there was more understanding of how they could work together to ensure that school managers fully appreciated the needs of CWD and the role they could play to improve their education.

Standards for Supervision in Districts

Supervision of SNE at district level was done by Inspectors SNE/EARS using a standards guideline. The baseline survey found that the standards guideline used by District Inspectors was inadequate in SNE as it did not cover SNE. For example the guidelines used in Kasese district had no mention of SNE in all the areas for supervision; hence the needs and weaknesses identified during inspection were not documented since they were not in the guidelines. This gap was unfortunate as this meant that SNE was not effectively supervised or monitored or if at all, it was probably a by-the-way. This could have been an indicator that the Inspectors who were specialists in SNE also needed more sensitisation about disability and the importance of having SNE incorporated in the supervision tools.

SNECOs were using a different tool in supervising teachers in SNE although the consultants did not have a chance to see a copy. The main purpose of the tool was to collect information about the learning and teaching processes in SNE including the constraints and strengths in addressing the different needs of children with special learning needs. While this tool was not official, it enabled DEOs and districts to be aware of the weaknesses and needs of CWDs and teachers in schools, which was important if the quality of SNE was to improve. This guideline could be adopted to strengthen the one being used by SNE/EARS Inspectors so that more data could be collected about CWDs and the SNE teachers. This also would call for a revisiting of the role of SNECOs in districts as they were making an important contribution to education of CWDs particularly in absence of enough qualified teachers in SNE.

6.4 Implementation at School, Community and Family levels

6.4.1 Enrolment of Children with Disabilities in Schools and Institutions

Despite the fact that there were few teachers who understood and could provide for the learning needs of CWDs, other important factors attracted parents to send their CWDs to school. This included outreach sensitisation programmes, school sensitisation and consciousness of parents about the importance of developing potentials of children, the medical rehabilitation that improved physical health of the children and the positive policies. All these combined to draw many CWDs to school. This led to a general increase in enrolment of children with disabilities in different categories of schools. The findings of the survey in both USDC and non-USDC districts testified that a good number of children with different types of disabilities were enrolled in schools.

A number of districts under the survey had documented CWDs. Tables 6.6 and 6.7 below give examples of enrolment of CWDs in schools in Nebbi and Kasese districts, respectively. The two Tables give a good comparison in the nature of data collection between USDC districts that had been sensitised on disability types, therefore could separate data by types, and non-USDC districts that were not adequately informed about disability types. The number of the disability categories in each district varied. For example, Kasese district did not indicate the types of disabilities in schools in Table 6.7 below.

Table 6.6 Enrolment of CWDs in Nebbi District (USDC District)

Disability Type	**P1**		**P2**		**P3**		**P4**		**P5**		**P6**		**P7**		**Total**	
	M	**F**	**M**	**F**	**M**	**F**	**M**	**F**	**M**	**F**	**M**	**F**	**M**	**F**	**M**	**F**
Visual	179	134	130	112	149	147	130	122	122	100	72	64	77	40	**859**	**719**
Hearing	225	216	183	152	229	136	116	99	60	55	40	29	44	20	**897**	**707**
Mental Retardation	104	147	94	86	93	82	66	51	62	36	35	25	30	7	**484**	**434**
Physical Handicap	104	96	87	82	163	108	82	62	69	51	41	28	41	18	**587**	**445**
Autism	19	20	28	11	14	15	13	10	6	1	4	4	4	0	**88**	**61**
Others	31	29	49	18	26	39	21	31	17	17	12	16	13	6	**169**	**156**
Total	**662**	**642**	**571**	**461**	**674**	**527**	**428**	**375**	**336**	**260**	**204**	**166**	**209**	**91**	**3084**	**2522**

Source: SNE/EARS Project Proposal titled ***Improving the Quality of Life of PWDs*** (based on EMIS FORMS – 2004)

Table 6.6: Enrolment of CWDS in Kasese District (Non-USDC)

Class	Male	Female	Total
Primary 1	426	370	796
Primary 2	277	233	510
Primary 3	390	323	713
Primary 4	296	277	573
Primary 5	279	236	515
Primary 6	248	199	417
P7	141	162	303
Total	2,027	1,800	**3,827**

Suffice to say that the above Tables presented hope in documenting disability in school. Most districts however did not have sufficient data on enrolment of CWDs in school. One reason for this was insurgency in districts like Lira and Gulu. Lack of funds to collect data also seemed to have held precedence over other reasons. However, lack of interest and knowledge about relevance of such information might have contributed substantially. The data collection process for school enrolment was not entirely accurate. For example, the DEO of Nebbi said that whenever head teachers were asked to provide data on enrolment of CWDs, they tended to exaggerate figures in the hope that they would receive more financial resources under the special grant for disability. Similar comments were made elsewhere when the consultants asked for data. In actual fact, most districts did not present clear and justifiable data on enrolment of CWDs in schools to enable appropriate representation of their educational needs except Nebbi District. This challenged the authenticity of the data and made it more difficult to determine the percentage of CWDs in school against the total number of CWDs.

Presented in Table 6.8 is data from MOES (2003), which showed that the number of special needs children in institutions of learning was small compared to 'able' children.

Table 6.7: Total and Special Needs Enrolments in Primary Schools in Uganda 2003

Institution Enrolment	**Male**	**Female**	**Total**
All Primary school enrolment	3,872,589	3,760,725	7,633,314
Government Primary schools	3,472,493	3,363,032	6,835,525
All secondary schools	374,659	308,950	683,609
Government secondary schools	191,718	144,644	336,362
All post Primary Enrollment	18,271	8,042	26,313
Pupils/Students with Special Needs			
Primary (all schools)	133,487	114,466	247,953
Government Primary	77,983	43,771	121,754
Secondary	30,107	8,442	38,549

Source: Summary Education Management Information System (EMIS) Statistics

Besides lack of data in some districts, it was learnt that there were still many CWDs out of school who had no access to education or rehabilitative services. Hence, despite the fact that national policies accorded them this right, education was not yet a reality to some CWDs. More specific focus on schools by type helped in understanding where opportunities existed for more enrolment. The consultants compared enrolment by the different settings of schools that provided learning opportunities for CWDs.

Special Schools

Special Schools in a number of districts showed that enrolment of CWDs was small. Reasons for this were many. However schools visited and some parents attributed this to high costs charged by these schools, many of which were boarding. Yet many parents were poor. Transport costs and the long distances the children have to travel also put off parents particularly those living in rural areas. Another factor was the negative attitude of parents as some parents thought it was a waste of resources to invest in CWDs. The SNE teacher in charge of the SNE unit at Ediofe Girls Primary School said that many times the parents did not pick their children for holidays or did not return them for the following term. However, because of the teacher's commitment and interest in the children, he would personally go to pick them from their homes on bicycle. The isolation of the children from their families and the lack of interaction with 'normal children' outside the school could be another factor why parents were not enrolling their CWDs in special schools. Lack of interaction was identified in a number of special schools such as Kireka Home for Children with Special Needs and Uganda School for the Deaf at Ntinda where the schools were separated from each other by just a fence and the children never get a chance to interact. Yet interaction was important as it enhanced socialisation, learning skills and sharing among the children.

Integrated Schools and Inclusive Mainstream Schools

Many CWDs were enrolled in schools with units/annexes or integrated schools. However, the numbers enrolled per school were limited due to the small provisions made for them in the school. Not only were the materials, equipment and teachers limited but the furniture and some cases accommodation facilities limited the numbers that could be admitted in school.

In mainstream schools, the numbers of CWDs enrolled were large despite the fact that some schools did not have any trained SNE teacher. One example was Kikonge PS in Masaka which had 25 CWDs at the time of the survey yet there was no SNE teacher. The reason for this was because the inclusive policy of education acted as a catalyst to interest both parents and the CWDs to go to school; and for administrators and school management committees to accept them and cater for their needs. Hence many CWDs were enrolled in school.

For some schools with large enrolment, they received some educational materials and teachers to ensure that the children got equal opportunities to learn. Such schools included Mpondwe Primary School in Kasese that had 27 CWDs and Mvara SS with 12 students with vision impairment (from S1-S6). These had SNE teachers, materials and equipment though few. Where the school environment was as ideal as elaborated by the Director of Kampala School for the Physically Handicapped, it would follow that many more CWDs would continue to enrol in such a school. The opportunity to mix and interact in mainstream schools broke the cultural barriers and was a great opportunity to transform societal attitude. Hence, many non-disabled children were positive and supportive of CWDs. Despite increased enrolment of CWDs in different schools, the quality of education provided for these children, particularly in integrated and inclusive settings still posed a number of challenges.

Post Primary Education

The 1991 National Population and Housing Census Report indicated that the enrolment of CWDs formed only 2% of females and 6.6% of males of the total enrolment in secondary and higher levels of education. This showed that access to education by CWDs and more so by girls with disabilities was grossly inadequate. Concerted effort was needed to redress this. Although this statement needed to be supported by concrete data, which was not available, the magnitude of disability in children was truly big.

The survey found that a small number of CWDs were enrolled in the existing post primary institutions both secondary and vocational which were too few to cater for the needs of CWDs completing their primary school cycle. Only 6 secondary and 3 vocational institutions were seen from the different districts visited. These were catering for post-primary educational learning needs of different types of disabilities mainly visual, hearing and physically impaired. The Chart below shows some of the post primary institutions catering for education of CWDs.

Chart 6.6: Post-Primary Education Institutions in selected Districts

District	Institution	Type of Institution	Category of Disability in institution
Hoima	St Andreas Bukumi	Secondary Secondary	Blind Blind
Lira	Community Polytechnic (an extension of Nancy school for the Deaf)	Vocational	Deaf
Masaka	Masaka Vocational Institute	Vocational	Physical, mentally retarded
Arua	Ocoko Mvara SS	Vocational Secondary	Youth of different disabilities Blind
Iganga	Iganga SS	Secondary (mixed)	Different disabilities (21 CWDs mainly boys from S1-S6)
Nakasongola	*St Joseph SS	Secondary	Positive to CWDs and has 1 physically impaired pupil)
Luwero	-	-	-
Moroto	Kangole SS	Secondary	Blind
Nebbi	-	-	-
Kasese	*No Institution but Bwera SS is positive and has I physically impaired pupil		
Kabarole	-	-	-
Adjumani	-	-	-
Masindi			
Kumi	Ngora SS	Secondary	Deaf
Moyo			

The inadequacy and difficulty to access post primary institutions was one of the factors discouraging parents from taking their CWDs to school, as they did not see any future for them. The Director of Kampala School for Physically Handicapped shared experiences of the school's struggle with placing those capable of continuing to secondary education in acceptable environments which he said was very hard. The few schools with CWDs had very few children, for example Bwera Secondary School had one severe case of physical impairment and St Joseph S.S also one physically impaired student. This was an indication that those institutions were friendly to CWDs and could accept more. The new secondary schools being built in the country (in Wakiso and Mbale) would go a long way in increasing enrolment of CWDs in post primary institutions.

6.4.2 Gender Focus on Enrolment

Analysis of the data on total school enrolment (Table 6.8) showed that females formed only 2 percent as compared to 6.6 percent of the male counterparts of total secondary schools enrolment. According to the 2001 enrolment of CWDs in all the districts of Uganda, compiled by MOES (SNE), more boys (55.2%) were enrolled in schools than girls (44.8%). The CWD enrolment data for Kasese, Arua and national 2003, equally showed low enrolment for girls with disabilities. Asamo[29] picked on specific data from a few schools on specific disabilities to portray the gender imbalance in enrolment as shown in Table 6.8.

Table 6.8: Gender Difference in Enrolment of Girls and Boys in Schools

Name of School	Number of girls	Number of boys	Total
1. Kampala School for Physically Handicapped	26	36	62
2. Ntinda School for the Deaf	82	94	176
3. Gulu Primary School (Blind Annex)	5	24	29

The reasons for the above imbalance were many, some of which were school based such as unfriendly school environment, negative attitude of teachers, lack of educational materials and equipment. However, others could be related to distance from school, negative attitude towards girl's education and failure of parents to provide school requirements. In Nebbi district, it was learnt from the District Education Officer that because of the different constraining factors, such as communication gaps, the completion rate of the primary school cycle of CWDs was estimated at 20%, which means that 80% did not complete P7. Of the 20% that completed, 20% were girls and 80% boys. This meant that the girls with disabilities were marginalized more than the boys.

When girls had severe disabilities they experience discomfort from inability to take care of selves. The natural process of their development and changes they experienced paused many demands for support, which resulted in psychological torture if not humanely managed. This acted as a major hindrance to their education. For instance, many dropped out of school because of the discomfort they experienced during their menstrual period.

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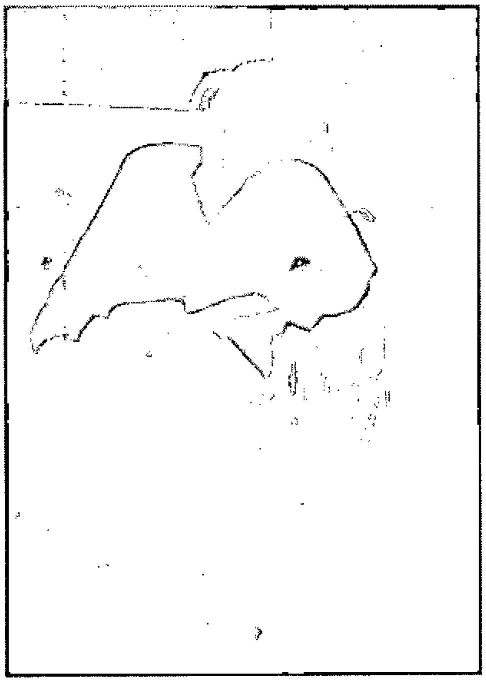
[29] Ms Asamo Hellen Grace: Education for Women and Girls with Disabilities in Uganda.



Biryeri Harriet in Bwera Secondary School had very severe physical disability to the extent that she could not move out of her wheelchair to go toileting. Talking to her, the consultants learnt that she experienced and lived with many discomforts due to her inability to support herself on her own. She was very appreciative to the warden of her hostel and her sister who were both of great help in caring for her. The girls in the hostel were equally very helpful to her. Biryeri Harriet said she was forced to miss classes during her menstrual period. The path from the hostel to the school and the coumpound was not friendly to her movement on the wheel chair. For such a girl to fully appreciate access to education she they needed substantial understanding and commitment to support them.

6.4.4 Provision of Mobility Devices

It was parents' responsibility to provide assistive devices (wheelchairs and white canes) to their CWDs to enhance their mobility. The survey found that this was affected by two main factors. One was that mobility devises were expensive and not affordable by the majority of parents. Secondly, some parents simply failed to own this responsibility. The MOES had been supportive and provided some appliances to some CWDs. Local governments in some districts visited such as Kasese, Hoima, Masindi, Apac had also been supportive in providing white canes, wheel chairs and tri-cycles through District Education offices. Other CWDs obtained them from CSOs such as USDC, the Rotary Club, NUDIPU, and the Toro Kingdom that provided wheelchairs. However, in proportion to possible estimates of the total population of CWDs, few had benefited from these provisions.

In Kabarole district, Sharon Atuhaire (girl aged 13 years) from St. Peter and Paul Primary School was withdrawn from school in 2003 due to difficulties of transport. In Masindi, parents and teachers said that hearing and visually impaired children found it difficult to go to school for fear that they would meet accidents. Parents could however make more effort to provide these appliances or to ensure that CWDs who were not able to take themselves to school were accompanied.

6.5 Interventions towards Social Recognition and Acceptance of CWDs

In Chapter 3, impairment was looked at as something far-fetched and detached from human responsibility. This type of attitude prevented societies in Uganda from recognising the potentials in CWDs and assuming responsibility to provide for them. Sally Hartley (International Journal of Disability, 2002) estimated that only 1% to 2% of children with disabilities in developing countries were in school (Ainscow, Jangira & Ahuja, 1995; Baine, 1993; Kisanji, 1998; Mittler, 1993). The reasons for this among others included a general lack of awareness about disability and the low priority given to educating CWDs.

In order to meaningfully provide adequately and appropriately for learning needs of CWDs, the deep-rooted negative social perceptions about these children needed to be addressed and transformed. This would ensure that all CWDs developed their potentials and lived independent and self-reliant lives with dignity, participating and contributing to social processes. Education personnel needed to view CWDs with positive attitude so that the education they got leads to transformation. This would require concerted effort by all stakeholders including parents, schools, the community, government, CSOs and children themselves.

It was shown that when CWDs lacked emotional support from caregivers and parents, there was likelihood they would be attracted to stay in a school environment that provided social acceptance outside the family, even if they did not receive adequate attention in learning. Hence, once in school where they found acceptance, they were attracted to enrol and remain in school.

6.5.1 Schools as Agents of Advocacy to Parents and Other Children

The government, DANIDA and USDC expectations of the SNE teachers was first of all to teach the CWDs, but also to talk to other teachers and parents about disability and the roles they could play in the rehabilitation and learning of CWDs. The tendency was that only parents whose children were in schools benefited from that opportunity but later parents, teachers and pupils were targeted. Hence, a good number of SNE teachers in both USDC and non-USDC districts were playing an important role in advocacy and sensitisation about disability to ensure that CWDs were accepted by fellow pupils, teachers and parents. SNE teachers, especially in USDC districts, participated in outreach programmes to the community to provide support to parents and severe cases of CWDs especially in training about daily living skills. This contributed to changing attitudes towards CWDs and in sending them to school.

In Kitengesa Primary School in Masaka, SNE teachers trained parents in how to manage their deaf children and communicate with them. In many schools visited such as St Bernadetta PS in Hoima, Kamurasi PS in Masindi, Ngetta PS in Apac and Ekwela PS in Lira, school management committee members and teachers confirmed that their schools were carrying out sensitisation about disability regularly. In Misanvu PS in Masaka, sensitisation of teachers was held 5 times a term. PTA meetings and other parents' meetings were also used to sensitise parents about SNE and services available for rehabilitation of CWDs. Head teachers gave testimonies of positive changes they had observed among parents some of who were not providing for their children before. Teachers were changing attitude as a result of sensitisation and were showing love and assisting the CWDs whereas before they would call SNECOs and SNE teachers to "help their children". This positive attitude was making schools more CWD-friendly thus more acceptable by both teachers and pupils.

A few schools visited by the consultants among the mainstream schools with inclusive settings showed positive examples of socially acceptable environments for CWDs. These included St Peter and Paul Primary School in Kabarole District and Kamurasi Primary School in Masindi. The head teachers of these schools were very keen and committed supporters of the education of CWDs and were emotionally attached to the care of pupils with disabilities. In St. Peter and Paul Primary School, the head teacher had a key message displayed in her office for the school (teachers, children and others in her office), which read: "***Disability can happen to anybody. Never tease a child with***

disability. Make friends with a disabled classmate. Help children with disabilities. Find games to play that can include children with disabilities". The head teacher ensured that CWDs were recognized and accepted in the school and followed up on those who missed coming to school. She said it was difficult to deal with children at the beginning but they learnt sign language to enable them communicate.

One of the SNE teachers, a specialist in sign language had picked keen interest in teaching sign language to the whole school starting with teachers. As a result, teachers had also picked interest in the CWDS and this stimulated interest in the non-disabled children as well. Two teachers were undergoing holiday training in SNE at UNISE to ensure that they fit within the environment. The interest in CWDs was the driving force in the school and was quite captivating. They all expressed concern, love and care for each other and said that they share and cooperate. Although the other children were not specifically taught sign language, they were learning and using it. Teachers were partly using total communication using sign language in class and at school assemblies. Teachers said that the CWDs were enjoying freedom equally as other children in the school and were using the library without fear. This attitude greatly contributed to social acceptance of the CWDs in the school.

In Kamurasi PS, the Head teacher had ensured that the whole school had learnt to sing the national anthem in sign language and all children and teachers enjoyed singing signing. This strategy of total communication needed to be copied by other schools as it encouraged learning of sign language and social integration of deaf children. It promoted a friendly environment where deaf children felt they were also loved and accepted by the rest of their schools.

A number of schools visited showed that they had accepted CWDs to the extent of involving them in school leadership such as prefects. These were respected by both the CWDs and the able children. This showed that CWDs also had the ability if given opportunities. It boosted the morale of fellow CWDs and parents who saw that their CWDs had potential and also helped to build the self esteem and confidence of the leaders with disabilities. One prefect at the time of the visit of the consultants was a blind child. Kamurasi Demonstration School in Masindi had 4 disabled children as prefects out of 25 prefects in the school and Mitete PS in Sembabule district had 4 prefects out of 21. Other schools were involving the CWDs in clubs such as drama, music, and dance. Some were teaching the CWDs handcrafts. All these gave the CWDs opportunities to show their skills. While parents were encouraged to see the potential of their children in learning skills, the perceptions and attitudes of other children and teachers also changed for the better as they came to appreciate that CWDs had talents and potential. This was contributing to social recognition.

USDC started **child rights clubs** (CRCs) in a few schools as a pilot. The aim was to enable pupils in school both the CWDs and the able children to know their rights. This was because most times, the rights of children particularly the CWDs were abused, discriminated, or services for them were missing. Hence they should be aware of these rights so that they could demand for them in schools, in homes where they live and in the community. For instance, they should demand for textbooks, sporting activities, accessibility on the compound. When the children were empowered, they were expected to demand for their rights themselves as this carried more weight when educating the public and policy makers on their rights. Teachers were trained in child rights as patrons in the hope that they would train pupils both disabled and able in their schools. The clubs took off attracting a number of children the majority of who were CWDs. Kikonge PS in Masaka was one of the schools visited that had an active CRC.

The CWDs told the consultants that they had learnt to speak out, ask questions, and demand for their rights which was not the case before. The children in the club both CWDs and the able children showed respect and love for each other without discrimination and interacted happily. This was an indication that CRCs had potential in changing negative attitudes, building confidence among CWDs and promoting respect of CWDs among fellow pupils. It was learnt that public events such as the international Disability Day gave opportunities to CSOs such as USDC and the MOES to talk about rights of CWDs and services lacking.

The above examples showed that it was possible for a school to contribute effectively to changing negative attitudes and perceptions about CWDs and in the process, promote social acceptance. When the school leadership was at the forefront in stimulating the effort, then the process was faster. The consultants observed a high level of confidence with which these socially accepted children behaved in a free manner. This was both in the schools with units and inclusive schools in which the MOES had the challenge of ensuring that such an environment existed in all schools.

6.5.2 Parents as Agents of Advocacy in Schools and Among other Parents

USDC initiated the strategy of Parent Support Groups (PSGs) in an effort to make parents participate more in the rehabilitation of their children as already explained in Chapter 7. Through outreach sensitisation programmes by USDC and after seeing success stories from some of the rehabilitated cases, parents became more supportive of their children's education. Parents were in a better position to influence other parents to change attitudes and perceptions about disability and education of their children. In districts where parents had mobilised themselves into PSGs, such as in Lira, Apac, Masindi and Hoima, they were taking the initiative to sensitize fellow parents with CWDs in their communities, encouraging them to take them for medical rehabilitation and to school. In Apac district, a PSG called Chegere Parish CWD Association, had sensitized teachers in four schools after observing negative attitudes of teachers in those schools. In Masindi district, a PSG based in Kamurasi Primary school was helping CWDs in the school to learn vocational skills such as making mats and baskets as well as bringing food to support feeding them. They were also helping other parents with identification and assessment of their children and encouraging them to bring CWDs to school.

What was interesting was that parents who did not have CWDs in the school were also bringing food. The CWDs told the consultants they liked being helped by their parents in learning vocational skills. These efforts were helping to change negative attitudes about CWDs both in school and in the community. One parent told the consultants that before, he thought taking his CWD to school was waste of time but through assistance of other parents, he now liked his child. All this showed that parents had a big potential in changing negative attitudes among fellow parents, teachers and CWDs themselves. In the absence of enough trained teachers in SNE, parents with more awareness about disability and the importance of education rehabilitation of their CWDs had the potential and ability to change negative community perceptions about disability.

6.6 Challenges/Gaps in Education of CWDs

While the baseline survey established that many efforts and opportunities were being made by different actors in providing SNE to CWDs, many challenges/gaps also existed both at national, district and community/home levels.

a) Planning and Budgeting for SNE

The funding for special needs education both at national and districts levels is low and does not match the number of CWDs in school and the facilities, trained teachers and other requirements that are needed to provide quality education to the children.

Districts were supposed to take over the SNE programme in terms of funding and support when DANIDA wound up in 2003 but they did not take total ownership hence planning and funding of SNE were inadequate.

Lack of data on the number of CWDs in and out of school in all districts made the situation worse because the districts did not know for how many CWDs they were planning and budgeting.

Some SNE Inspectors of Schools took the efforts made by other organisations to support CWDs as a source of income because they would continue to budget for some items even when they were in store. This would mean that they received funds whose expenditure was only known to them and claimed that they had bought new materials/equipment. One example given in confidence was in Arua Local Council that approved purchase of tactiles when in fact these were in store.

b) Inadequate numbers of teachers trained in special needs education

The number of trained teachers in SNE was too small to cater for the large numbers of children with different types of disabilities enrolled in school. The majority of the teachers trained in SNE had inadequate skills which did not prepare them enough to properly teach the children, particularly those with severe disabilities such as the hearing impaired, the vision impaired and those with mental impairment. This problem was accentuated by the following factors:

i) Because of high enrolment, classes were too big for one teacher to be effective and give attention to CWDs. Hence, the ratio of pupils to teachers was too high. For example in Nebbi district, SNECOs indicated that the teacher/pupil ratio was about 1:100, but went up to 1:150 in some schools. However, the ratios recommended by the MOES were 1:55 for ordinary classes, 1:10 for some children with special learning needs and 1:3 for more severe ones. However, these ratios were not possible. Table 6.10 below presents some of the examples of high ratio in different schools.

Table 6.9: Teacher/Pupil Ratios in Respective Schools

School	Number of SNE Teachers	Children with Special Needs	Teacher/Pupil Ratio
Kamurasi Dem. S. Masindi	3	60	1:20
Agururu PS, Tororo	6	103	1:17
Misanvu PS, Masaka	5	57	1:11
Rwera PS, Ntungamo	3	47	1:15
Rukoki PS, Kasese	3	83	1:28
Kikonge PS, Masaka	1	40	1:40
Uganda School for the Deaf, Kampala	28	197	1:07
Kireka Home for Children with SN, Kampala	8	78	1:13

The big numbers of children were found in the mainstream schools with inclusive settings where SNE teachers were also very few or non existent. The absence of SNE teachers with appropriate skills and the necessary facilities to facilitate their learning therefore left the CWDs together with their parents in bewilderment with the children being redundant in some cases. This negatively undermined the education of CWDs. However, it was important to learn from the Officer in charge SNE in MOES that there were chances to change the teacher/pupil ratio when classes exceed 10 CWDs per class if only District Education Officers could report the matter to MOES which would also advise Teaching Service Commission to lift the staff ceiling.

iii) There was random transfers of SNE teachers without due consideration whether there were many CWDs in the school or not. This concern was expressed by most SNE teachers and head teachers interviewed. For whatever reasons, random transfers discouraged teachers, including those who had not yet gone for SNE training.

iv) The qualifications in SNE were not recognized or rewarded by Public Service Commission hence teachers with these qualifications were not promoted through a salary increment. This was therefore demoralising both to the SNE teachers and those who had interest and would have gone for training. The Principal Education Officer SNE in MOES agreed that there was urgency for this to be positively handled as these teachers were making an important contribution to education of CWDs.

Coupled with inadequacy of trained teachers in SNE, inadequacy of educational materials and equipment and negative attitudes of teachers, education of children with severe disabilities was inadequately addressed in school. SNE teachers who were supposed to do this were overstretched and not facilitated to reach CWDs in homes who were not able to go to school. Hence lack/inadequate numbers of teachers trained in SNE was a big hindrance to the education of CWDs.

c) Negative Attitude of Teachers, Parents, Leaders

The negative social attitude towards CWDs was manifested in teachers who had not had any training or sensitisation in issues of disabilities. These did not acknowledge the potentials in the children with impairment and their right to learn thus deserving special skills. Since they were the majority in mainstream schools, they had no regard for CWDs. SNE respondents in Arua District estimated about 70% of the teachers in the District to have taken backseat in discouraging others from helping CWDs. Pupils with special learning needs in Kamurasi Primary School in Masindi District said that some teachers abused them, used rough language saying things like; ***'You pretend not to see when it is not true'.*** This set a bad example for peers and made CWDs grow wild. It did not augur well for relationship building between teachers and pupils. One pupil in Ediofe Girls School was reported to have said about a bad teacher, ***'I hear some of you are pregnant, I wish you could produce children with impairment'.*** This would discourage CWDs to remain in school. Yet teachers who did not have exposure to SNE were the majority particularly in mainstream schools with inclusive settings. These would continue to undermine education of CWDs unless they were sensitised and trained about disability and how best they could support education of CWDs.

While negative attitudes were generally changing in schools and community/home levels, negative attitude was still rife particularly among leaders and parents. For example in Aber PS in Lira district, some CWDs told the consultants that they preferred staying at school because teachers and other pupils showed them love and shared things with them more than their parents. One community leader thought that by giving a few wheelchairs to CWDs, a district had fulfilled its responsibility to CWDs. Hence, making sure that there was social acceptance of CWDs in schools, homes and communities, still posed challenges.

d) Inadequate Educational Materials

There were inadequate teaching and learning materials in all schools visited both at primary and secondary schools (in both USDC and non-USDC schools). This gap was mainly found in mainstream schools with inclusive settings some of which had no materials at all. There were shortages of Braille machines, sign language manuals, hearing kits and there was a shortage of Braille paper countrywide. This was a challenge in the presence of the inclusive policy and UPE which encouraged all children including CWDs to go to school. It would be a pity if CWDs went to school and did not learn because of shortages of educational materials. Furthermore it would discourage parents to keep their CWDs in school if they knew that they were redundant because of scarcities in educational materials.

e) Tools for Standards for SNE inadequate

Both the national education standards tool by ESA and the district monitoring tools used by SNE Inspectors were inadequate as far as SNE was concerned. They completely lacked the basic requirements that SNE should have.

The standards should include benchmarks in SNE in relation to classroom teaching and learning processes, provision of facilities to ensure a conducive environment for learning of CWDs such as materials, equipment, CWD-friendly environment such as ramps, appropriate latrines, etc. The question was – How could schools, teachers and districts ensure that these requirements were available when the national standards did not mention them? These gaps meant that SNE was not adequately monitored and hence weaknesses and needs were not brought out and addressed by those responsible. The issue of SNE standards in schools would remain a challenge unless SNE was included in the inspection tools.

f) Unfriendly Examination System for CWDs

All children in school both CWDs and the able at the same level of education did similar examinations. Yet, CWDs, particularly those with very severe disabilities such as the hearing, vision and mental disabilities, had very many concerns and problems that had not been adequately taken into consideration by the education assessment system. For example, it was not fair to assess deaf children who used shortened sentences and interpreted some words differently as normal children. In the same way, CWDs writing with their feet could not be on the same level ground with able children.

g) Inadequate Post-primary Institutions Catering for CWDs

Post-primary schools/institutions (particularly secondary schools) that catered for education of CWDs were too few to absorb the growing number of CWDs completing the primary school cycle. Although more post-primary institutions were being constructed by MOES, they were still too few. Without adequate post-primary institutions such as secondary schools, colleges and vocational institutions that offered education to CWDs, wastage would continue to result. Such wastage discouraged parents to take their CWDs to school.

CHAPTER 7: SOCIAL REHABILITATION OF CHILDREN WITH DISABILITIES

In this Chapter, a review of the social policy environment and related rehabilitation services provided was made. The key policy and service providers included the central and local governments, CSOs, parents/guardians, siblings, neighbours, the local community or society, etc. Services provided for medical and educational rehabilitation had already been respectively discussed in Chapters 5 & 6.

7.1 Evolution of Rehabilitation of Persons/Children with Disabilities

In Uganda, people traditionally lived with the disabled persons in their families and communities as a matter of responsibility, irrespective of severity of conditions. Such responsibility was mainly geared towards social protection and support for the disabled persons and their parents. With the coming of western culture, Government, the public and communities recognised and considered disability as an area where social, medical and educational services could only be provided in a separate and institutionalised setting. This was manifested in separate schools, homes (asylums) and centres built to specifically admit disabled persons/children. Rehabilitative services were subsequently provided at or through such institutions. In addition, disabled persons were taught specific life skills only identified for them, including making crafts, tailoring, cobbling, carpentry, etc, in order to equip them to live independent life after leaving the vocational institutions or homes. Such programmes also helped to stop P/CWDs from begging on the streets in towns and their localities.

This approach had evolved over the years and government and its partners (civil society organizations (CSOs)) in the area of disability emphasised integration than separation in the rehabilitation process of P/CWDs. In particular, CWDs were targeted for integration in the rehabilitation process, for them to be provided early medical rehabilitation services in order to medically recover. This prepared them for rehabilitation through education and learning and then social rehabilitation for independent socio-economic living environment, including reduced burden of support on family, community, etc.

Perhaps the fundamental question of **'What is Social Rehabilitation?'** needed clear definition and answer. A great deal had been said about procedural matters of sensitization, mobilization, protection, etc which did not adequately define social rehabilitation. Therefore, social rehabilitation transcended both sensitization and mobilization and required an integrated mode of social acceptance, support and facilitation of P/CWDs to live fairly independent life within that conducive and socially facilitated environment. Such environment was created by positive participation of parents, siblings, family, society, government, CSOs and P/CWDs themselves. Since social rehabilitation was an accepted norm in terms of disability, it would be important for government to take leadership role and come up with a strategic programme that defined social rehabilitation and clarified responsibilities for the identified actors in meeting the goals of service provision or delivery.

7.2 Social Rehabilitation Policy - Implementation and Practice

As discussed earlier in Chapter 4, SDIP and social policy framework for disability was provided by/under the leadership of MGLSD and the subsequent actions were guided by the SDIP 2003-2008 (December 2003). In order to interpret the Plan for implementation, specific policies were put in place including Social Sector Policy, Disability Policy, Orphans and Other Vulnerable Children (OVC) Policy (November 2003) and National CBR Programme, etc. These policy frameworks were reviewed by the consultants and evaluated against whether and how they supported the provision of social rehabilitation services to P/CWDs.

7.2.1 Social Sector Policy

MGLSD was lead agency for implementation of the policy in collaboration with partners and stakeholders, including other government sectors, local governments, CSOs and CBOs. There were difficulties encountered in implementation of this policy in relation to disability. First, the system of prioritisation in budgeting left out disability. Secondly, the institutional framework in MGLSD was weak to provide leadership, creating a vacuum that other government sectors and CSOs tried to fill to provide social rehabilitation services to P/CWDs. Lastly there was the problem of interpreting the policy at lower levels, leaving it to any form of interpretation.

7.2.2 Disability Policy

Implementation of this policy was largely undertaken by legislation to create institutional frameworks for support to disability such as for political representation. DPOs were formed as well as umbrella associations or unions to take care of general and particular disability interests. However, the stress on representation did not give adequate social protection for PWDs as this was not financially facilitated well enough. Umbrella organizations did not equally provide for their members because they depended almost exclusively on donor support. Therefore, these organizations were based on narrow programme focus with virtually no impact on social rehabilitation of ordinary P/CWDs. There was a lot to learn from experiences of NAD and USDC in terms of institutional framework used to form them and evolvement into benefactors of the current magnitude. The available option was to mobilize the entire civil society to support disability and formation of PSGs/PAs could be the bedrock for social management of disability in society.

7.2.3 National Orphans and Other Vulnerable Children (OVC) Policy

Under OVC policy, children suffering under difficult circumstances alluded to disability in terms of categorization as a target group, thus it did not clearly target CWDs. In the PEAP, budgeting for PWDs were separated and listed under Support to PWDs. In both cases, however, the focus on P/CWDs was limited. The implementation framework included roles for MGLSD, other central government ministries, NCC, local governments, development partners, CBOs and CSOs. For example, NCC was mandated to implement provisions of the OVC policy on behalf of government. It dealt generally with children without distinction made of CWDs and therefore, there was no direct focus on CWDs. In its annual report there was reference to CWDs, but based on information from CSOs. In terms of spread, NCC had no district or regional contact offices. It mainly dealt with relevant district government sector departments and grass-root CSOs basing on information provided by them.

7.2.4 National Community Based Rehabilitation (CBR) Programme

Having learnt from the experience of the NAD funded CBR programme in ten districts and USDC programme in 13 districts, government decided to focus CBR in Tororo district as a model. All the implementation indications seemed to suggest that it was on course. The programme implementation was through the combined efforts of disabled persons themselves, their families, communities and appropriate sectors of health, education and social services, focussing on improving the quality of life of PWDs as a marginalized, isolated and vulnerable group.

However, for CBR to be the alternative to traditional rehabilitation process discussed earlier, it needed to be extended to all districts of Uganda in order to realise tangible and integrated social rehabilitation of P/CWDs. Current dependence on donor funding limited such expansion of CBR to all districts and where CBR was implemented in the ten districts, the consultants found no or minimal trace of government ownership for continuity (e.g Ntungamo experience). Government could have learnt from and used the CBR programme model implemented by USDC with telling impact on social rehabilitation of P/CWDs.

7.3 Social Rehabilitation Services for P/CWDs

7.3.1 Awareness, Mobilization, Sensitization and Consciousness Building

Social rehabilitation through awareness raising, mobilisation, sensitization and consciousness building was manifested in provision of information and education especially on the causes of impairment by type, their management and prevention, availability of rehabilitation services and urging parents and communities to bring forward CWDs for medical treatment and operation so as to be able to demonstrate transformation in the health of CWDs. In Chapter 3 it was indicated that there was a general negative attitude towards P/CWDs, which had not only persisted, but had been brought to light through efforts to address it.

The chances for survival for children born with disabilities were at severe risk and not many people wanted to hear about it because it was a curse. It was therefore, important that information and education on disability was a prerequisite to understand and appreciate it in order to change perceptions, attitudes and provide social rehabilitation and healing to P/CWDs. It was hoped that the parents could develop attitudes that enabled them perceive their children with a positive consciousness and passion to appreciate the fact that disabilities in their children could be rehabilitated and their potential developed to enable them live independent lives.

Key among social rehabilitation service providers in this area included USDC. In its programme implemented in 13 districts it embarked on activities to promote better understanding of impairment, through the strategy of Disability Information and Education using a multi-sectoral approach. Using this strategy, USDC supported organisations and partners to carry out sensitisation at different levels, through one-to-one interaction, seminars, community gatherings, radio programmes, and International Disability Day celebrations. USDC facilitated such actors by availing information and providing logistics to play roles in sensitising CWDs, their parents and the community at large on causes of disability, types, prevention, management and availability of rehabilitation services. Parents were called for meetings to hear their views and in turn explain to them how to handle the CWDs. It provided guidelines for medical reference, treatment and operation so as to demonstrate transformation in these children, while at the same time influencing a turn-around in the negative attitude towards disability.

USDC played a key role in attempting to demystify disability through providing relevant information and education. It realised that change of attitude would require long term assistance through multi-sectoral approach to sensitise the public, authorities, parents, structures and processes to come to consciousness that persons, specifically CWDs, had equal human rights. The capacities of P/CWDs must be built to avail them equitable opportunities for rehabilitation; growth and development in order to enable them achieve full potential.

Government departments/staff also provided services and during outreach programmes the ACDOs, EARS, DROs and medical professionals mobilised and sensitised parents to take CWDs for medical treatment and send them to school. With support from NAD, government implemented CBR in 10 pilot districts of Bushenyi, Mbarara, Kabale, Iganga, Tororo, Mbale, Ntungamo, Mukono, Kamuli and Rukungiri. However, according to the programme evaluation in 2000, the local governments did not own the process and the bottom-up approach originally envisaged, as implementation framework did not work. Tororo district was therefore selected as a model district to implement the bottom-up approach for the current CBR programme this time funded by NAD and the local government.

In the Tororo experience, the local government was directly involved in implementation of the CBR programme under CBSD, with the DRO as Programme Manager. At the central government level MOGLSD was the executing agency. The programme was supported through funding and technical assistance from NAD. The donor covered about 75% of total resources while GOU contributed the balance as counterpart funding. The consultants found that the programme had similarities that were easily related to the CBR programme implemented by USDC.

The CBR programme in Tororo started in 1994, with a pilot phase in 16 Sub-counties. At the end of the pilot phase for 10 districts in 2002, Tororo was then selected as a model and all Sub-counties were covered. The overall strategy of the programme within community development was the rehabilitation of all PWDs. This was implemented through collaborative efforts of PWDs themselves, their families, communities and government sectors of health, education and other social services using multi-disciplinary criteria in implementation. It focussed on improving the quality of life of P/CWDs as a marginalized, isolated and vulnerable group.

The main objectives of the programme were to a) achieve full integration of PWDs into the mainstream of society while empowering them to take part in development process by increasing their job opportunities and other productive measures, b) create and build capacity of PWDs, their families and the community to identify and manage disabilities, c) promote participation of PWDs in planning, implementation, monitoring and evaluation processes, d) promote social, economic and political integration of PWDs within their communities by enabling them to access all district programmes. As a result, the implementation made marked progress in addressing issues of P/CWDs, according to the draft Programme Review Report 2004.

The Ntungamo experience was that the CBSD implemented CBR programme from 1997 to 2000, with funding from NAD. All staff of the department were trained in CBR, including the Acting Director. However, since the programme ended, there was no other programme in the area of disability even at the initiative of the local government (a typical example of project funding and implementation by a donor without ensuring takeover and/or ownership by a competent government agency). To date, the staff continued to use their experiences and training to perform responsibilities of identification and referral of disability cases to service providers in process of their routine work.

They also continued to sensitise parents on appropriate behaviour of living with CWDs like cleaning, home based therapy and advising them to take such children for medical rehabilitation and to school. They were referring them to Organized and Useful Rehabilitation Services (OURS) based in Mbarara. The extension workers (CDAs) were knowledgeable on disability types, assistance by type and many times helped parents to make simple assistive devices. OURS was implementing medical rehabilitation in outreach in three Sub-counties of Ntungamo, Ruhama and Rukoni in Ntungamo district. However, this programme was also phased out.

According to the Acting Director, other programmes undertaken by the CBSD included mobilization and sensitization in agriculture, early childhood development, water and sanitation, OVC, girl child education and functional adult literacy (FAL). So in the process of implementation of these programmes, the same funds facilitated implementation of the CBR programme in the field. In the course of training caregivers for OVC, issues of CWDs were included. At the time of the baseline field survey, 84 caregivers at family level had so far been trained. As a consequence, parents were beginning to take responsibility and were forming CBOs. For example, CBOs already formed included Family Therapy, Rukoni Association of Parents of CWDs, Ntungamo District Parents Association of CWDs, etc. The result was a realization by parents to consider CWDs like any of their able children and were caring and providing for their education.

Through PSGs/Parents' Associations (PAs), fellow parents were sensitised to ensure that facilities constructed in schools, health centres/units, homes and all public places were disability-friendly. The PSGs/PAs provided counselling and guidance to the CWDs and fellow parents and ensured that CWDs within their communities were taken for medical attention and to school. They were effective in informing communities about outreach programmes through radio announcements and talk shows.

Membership of the PSGs, particularly in USDC programme districts grew both in numbers per district and in sub-groups (Table 7.1). They followed up, supported each other and shared experiences on how to manage disabilities of their children especially homecare. The consultants learnt during focus group discussions (FGDs) that parents understood that impairment in their children could be treated and managed. The children needed to be given opportunities for rehabilitation, learning and be supported to function like normal people.

Table 7.1: Formation of PSGs supported by USDC

District	Number of PSGs	Linkages + Comments
Apac	5	
Arua	9	Eruba PSG for deaf children prepared a project proposal for NUSAF income generation support and contributed to building of a classroom block for the deaf. Dadamu PSG for Epilepsy prepared a income generating project proposal for NUSAF support.
Hoima	12	2 PSGs linked to World Vision for income generating activities support in improved cattle breed

Lira	5	
Luwero	5	
Masaka	10	
Masindi	5	Kamurasi PSG – income-generating activities (brick making, goats rearing, poultry keeping and vegetable growing).
Moyo		PSG linked to NUSAF. Received training, eventually leading to income generation activities at family levels.
Nakasongola	4	
Nebbi	6	
Sembabule	4	
Yumbe	7	

7.3.2 Care and Support

CWDs needed very close provision of care and support services wherever they were. They needed to be fed, clothed, provided shelter, loved and provided stimulation to acknowledge they were part of the family, society or community. Parents were the primary caregivers to their CWDs. They were the closest and most logical persons who understood the way a child experienced impairment and the social attitudes unleashed on such a child. They experienced life with CWDs and attempted to manage them with or without support. In social and medical rehabilitation of CWDs they were strengthened to manage their CWDs, organised resources like for treatment of epilepsy, identified other CWDs and managed their rehabilitation individually or collectively or referred to where they could be managed.

Parents were an important medium to sensitise fellow parents in taking care of their CWDs. Their experiences were important in bringing to the fore attitudes unleashed on the CWDs, effects of their positive or negative attitudes on the care they gave to the children and efforts by different organisations to make positive use of the knowledge and experiences of the parents to invest into effective medical and social rehabilitation of CWDs. USDC adopted the approach of facilitating the formation of PSGs in USDC programme districts to enable the parents support each other and eventually collectively own processes of rehabilitation of their children.

This was considered one of the best practices of USDC in supporting medical and social rehabilitation of CWDs. The efforts to make positive use of the knowledge and experiences of the parents to invest into effective medical and social rehabilitation of CWDs were further enhanced through the PSGs. Some of the direct support services provided by members of PSGs included management of their individual CWDs, organisation of resources through IGAs, identification of CWDs and management of their treatment collectively or reference to where they could be better managed.

Generally members of PSGs in USDC programme districts and PAs in other districts acted as referral points where other parents went for advice before going to hospital and they mobilised others for outreach and surgical camps. They observed family and community relationships to determine elements of discrimination or otherwise, initiatives of parents to follow up CWDs in school and regulations for administration of drugs. They further helped the rehabilitation workers learn from experiences of their daily living, as well as parents to learn from each other's experiences.

7.3.3 Capacity Building

Capacity building was considered in a number of dimensions. It partly involved building capacity of caregivers, including parents (family) to take physical and moral care of

CWDs, PSGs in group based management of disability (e.g access to IGA resources, assistive devices and appliances), P/CWDs in acquiring knowledge and skills training to self-manage and procure life skills for fairly independent living.

USDC, as part of its strategy of capacity building, undertook activities that strengthened capacities of parents to access rehabilitative services, ensuring that such services were within reach, outreach programmes, facilities within close-by hospitals and other health units and training of personnel to provide rehabilitative services. USDC met costs of referral services in the regional referral (Arua, Lira, Hoima, Masaka) and Mulago national hospitals, for surgical operations to rectify or improve on the disability, Mbale Cure hospital for hydrocephalous and after operation care either in the convalescence hostels (Hoima, Masaka and Arua or Cheshire Home in Katalemwa) or at home.

USDC supported training of parents through medical professionals to learn skills of home-based management of different disabilities and post-operative care and guidance, so that they continued with rehabilitation and management at home. To ensure continuity in teaching parents skills for home management and mentoring each other during home management, USDC supported training of PSGs in skills of managing CWDs.

Both USDC and government through Community Development Offices facilitated capacity building of PSGs in group-development (organisational self-assessment (OSA), vision, mission, goals and objectives, constitution making and activity/work plans development, registration at sub-counties with offices of Community Development Assistants (CDAs) and group dynamics) for better care and support.

UPACLED was another NGO focused on formation of district branches, conducting training workshops for members and creating awareness. The organization also held capacity building workshops to enhance the capacity of its members and create awareness about the needs of children with learning disabilities. It trained parents in counselling and supervision at individual and family levels so that they could reach out to other parents in their communities as well as how to stimulate and care for their children. A few members had been trained as trainers in each of the 18 districts to train other parents in organic farming, intensive farming and gardening. From evaluation of the programme, the NGO found out that training of parents had helped to increase awareness and experience sharing among them on proper nutrition for CWDs and how to care and cater for their other needs. UPACLED further reached out to parents through radio programmes, newsletters, seminars and brochures. These actions further enhanced social rehabilitation of CWDs through participation and empowerment of parents or their groups.

SSI approach in Hoima and Masindi districts involved facilitating the community in taking up responsibility for decisions on how to implement the *onchocerciasis* programme for their own benefit. As part of the insurance of drugs availability, CESC emphasised sensitisation of the community on the importance of using the drugs continuously and of the importance of the programme being managed by them. CECS allowed the community to select persons they trusted could diligently handle distribution of drugs to their benefit. CECS trained the selected persons to distribute the drugs according to prescriptions of standard measure of height. CECS avoided payment of incentives to the trained persons. Their commitment and initiative to plan the distribution either when the community gathered in one place or when they made home-to-home visits was important. CESC trained the distributors in record keeping and supervised the implementation.

Child Care International (CCI) in Kalangala district provided a home and support to street children (children left without any care), the needy, orphans and among them some CWDs. Besides being enrolled in nearby primary schools and provided basic needs such as clothing and other necessities, the children were trained in basic skills in agriculture, animal husbandry, and poultry so that in future they could be on their own. Among them there were three CWDs at the home with two staying with their parents (2 deaf, 1 lame), 1 girl with disability on one arm, while two other CWDs (a girl and a boy) were studying in Ntinda. The home-like living environment (including capacity building) gave hope to such CWDs. Some of them passed PLE and were admitted to secondary schools and came back to stay at the Home for holidays.

7.3.4 Child-to-Child Activities

Child-to-child activities provided social acceptance, relief and support to CWDs. There was a feeling of sympathy and empathy for the CWDs among able children, which actually drew the latter to help and care for them. Siblings of CWDs supported them by washing their clothes, giving them food, going to school together, playing with them and helping with the impairment. For example, one boy with an epileptic brother helped him manage the attacks when he got a seizure. He felt touched that his brother had to go through painful experiences of the attack. This was quite a humane feeling of social care, acceptance and support at family level by a sibling.

Classmates/Pupils shared a number of experiences of interacting and playing with CWDs. Able colleagues shared desks in class with CWDs. Some CWDs were elected to responsible class positions, they were involved in extra-curricular activities like sports, debate and drama clubs and CWDs felt included in the school/social set up.

7.3.5 Conscientization

The appreciation of disability was a much deeper understanding, with diligent and painstaking response through positive change in attitude. This was the guiding essence of acceptance of disability and P/CWDs as a manifestation in society in terms of passion, equity and equality. Parents and PSGs were key service providers in support of CWDs. For example, Chegere Sub-county PSG in Apac, Offaka Sub-county PSG in Arua and Bulalo PSG in Hoima shared similar experiences, which presented models of what PSGs should be. They appeared to have developed collective efforts to manage issues of CWDs effectively from home to home. As a result, through the PSGs, parents were no longer ashamed of their CWDs. This was a landmark in achievement in change of attitudes.

7.3.6 Counselling and Protection

Disability presented a state of trauma to the sufferer, especially in terms of participatory limitations and access to services, and to the family in perception and attitude. Indeed in Chapter 3 it was mentioned that P/CWDs felt rejected by family, peers and society. Families of CWDs found themselves isolated and looked down upon. These kinds of situations of despair needed counselling and protection services to reverse the negative effects and trauma in order to develop positive participation and living. In the baseline districts, a few CSOs provided such services and among them were the following:

TPO as an international NGO operating in Moyo/Adjumani, Gulu, Soroti, etc, was mainly concerned with issues related to depression as a result of people having been traumatised by conflict, war and disasters that affected the mental health of victims. TPO undertook awareness creation, individual counselling of identified people, families and groups with similar problems and taking counselling programmes to communities and the general public. It conducted community psycho-social workshops, made referrals to other service providers such as NGOs, Government Departments like Probation and Welfare, medical care, education, Police, religious organizations (all community support structures), etc.

FORDIPOM a CBO in Moroto was started in 2004 by one of the SNE teachers (also a parent of a CWD). It carried out identification of CWDs who were hidden and denied access to education. It was, at the same time, carrying out mobilisation of parents to take CWDs to school and giving guidance and counselling to PWDs.

UHRC was established by Article 51 of the 1995 Constitution, with clearly set powers and responsibilities to ensure protection of the human rights of all persons. The Commission handled assortment of human rights violations, complaints and related issues. However, it received no human rights violations of or complaints lodged by CWDs. This did not mean the rights of CWDs were not violated. It had to do with the Commission's methods of work and showed how distant it was from monitoring protection or human rights violations of CWDs as well as their parents and in seeking redress.

7.3.7 Lobbying and Advocacy

At national, district and lower governance levels, social development, health and education personnel needed to view CWDs with positive attitude towards transformation and utilisation of their full potential. The multi-sectoral approach involved the relevant sectors - health, education, community services, disabled persons organisations, and grew to include parents in PSGs and CWDs themselves who made presentations on their experiences.

USDC was a major participant in the area of lobbying and advocacy for CWDs. It used its own lobbying and advocacy strategy in its programme implementation. National level lobbying and advocacy were targeted at the mainstreaming of disability issues in all national programmes, especially through legislation, policy formulation, the budgeting process and service delivery frameworks. At sectoral level, USDC worked with the relevant ministries in programming rehabilitative services (health, education, social services) based on its own CBR experience. USDC would have wished that sector ministries took full responsibilities for delivery of medical, educational and social rehabilitation services to CWDs.

Lobbying and advocacy at local government level were similar in nature as at the central level. USDC through implementation of its own programme in 13 districts utilised services of implementing agents/partners (government, CSO, CBO officials and representatives of DPOs) to dialogue with them, lobby and advocate for CWDs. It used sensitisation meetings that targeted key local government officials, opinion leaders, etc to discuss the need to integrate and budget for CWDs. The commemoration of special occasions, e.g International Child Related Day, was used to reach and lobby the top leadership and to show potentials of CWDs. During the USDC quarterly review and planning meetings with implementing departments, representatives of PSGs and CWDs were invited so that they aired out benefits, changes and challenges they received and experienced. This was also an advocacy strategy to engage the local government join in rehabilitation actions.

UPACLED shared the same desires to alleviate the two major problems, which children with learning disabilities experienced, namely a) lack of awareness about their abilities, potentials and value to their families and community and b) the attitudes of parents and families towards children with learning disabilities. Advocacy was therefore its main activity. The organization trained parents and its staff about rights of children with learning disabilities and how the political and administrative structures of government worked. Save the Children Denmark and NUDIPU assisted the organization in training.

NUDIPU already formed branches and had membership in all districts. Using these structures it carried out advocacy and lobbying for the welfare of its members in service delivery. However, not all the union branches were directly targeting CWDs, although a number, like in Soroti, Masindi, Ntungamo, Kabarole and Nebbi, were advocating for disability-friendly infrastructure (environment) in public areas (schools, public buildings, etc) and these attracted CWDs to physically move around with minimal impediment.

Child Rights Clubs (CRC) in schools provided opportunities for able children and CWDs to participate, learn, know and lobby for their rights, in their families and the society in which they lived. Such school activities resulted in total inclusion of CWDs and built confidence in them as well. A great deal of the attributes manifested themselves in total communication as equals in terms of opportunities that positively contributed to the social healing process of CWDs.

UHRC provided advocacy services to PWDs, but did not specifically target CWDs. Nonetheless where the Commission conducted or held public hearings it involved organizations supporting CWDs like USDC. As a recent development, UNAIDS suggested to the Commission a specific area of vulnerable persons for special attention. Subsequently, the scope of vulnerability was broadened to include refugees, internally displaced persons (IDPs), minorities, people living with HIV/AIDS, P/CWDs, etc. Originally a special desk for vulnerable groups was set up at the Commission. The desk was upgraded to a full Unit. The Unit developed a framework and principles to guide its work in the area of vulnerability. After the design stage, the Commission would soon call together vulnerable group stakeholders and organizations to discuss an implementation strategy to be based on sensitivities of the affected vulnerability areas.

7.3.8 Representation of P/CWDs

The Local Government Act provided for political representation of PWDs at district and lower levels. All levels of councils had both male and female political representation of PWDs Councillors to contribute to decisions in the Local Councils. The consultants were informed that the level of representation was not adequate for or conducive to supporting the disability cause. Such observations were reflected in the views expressed by district leaders/administrators, CSOs, DPOs as well as PWDs themselves.

However, the baseline survey showed evidence of the contributions of PWDs Councillors being sidelined by other members, or when the ideas were accepted and included in the plans, funds were not released. This could be an issue of negative attitude among other

Council members. It was learnt that even at Sub-county and lower levels, the representation of PWDs was not effective because those elected were lowly educated and not sensitised to articulate disability issues in the Councils and secondly, there was generally negative attitude among leaders and communities towards PWDs.

Union members in both USDC and non-USDC programme districts argued that the PWDs Councillors who were members of the District Unions had not brought up issues of disability in the Councils. This was due to lack of knowledge and confidence to articulate disability issues and fight for their rights. The LC V Vice-Chairperson Apac district commented: ***"PWD Representatives are not very effective especially at lower levels. The reason for this is that the perception of PWDs themselves is negative because they think that as disabled people, others should talk for them and do things for them. Many have low level of education and therefore are not able to articulate issues of disability effectively and advocate for them. Even at LC 5 level, representatives are not articulating issues of concern. Because of lack of capacity, PWD Representatives at lower levels leave decisions to the Chairperson".***

As observed above, the Unions were making a contribution to P/CWDs in the area of representation, but more could be done. Their work was constrained by lack of funds. Members of the different Unions indicated that there was little impact of their work on disability. However, there was some change for example in Soroti, where parents of CWDs were encouraged to join the Union and PSGs in order to access services. So far 15 groups (both able and disabled) had accessed NUSAF support in project funding. PWDs were becoming self-reliant, cared for their families, and created awareness through existing leadership down to the grassroots.

As a result of the advocacy work of the Unions, PWDs were participating in small projects such as piggery under government programmes including NAADS although initial funding was from members. PWDs benefited from other programmes such as those under poverty alleviation as seeds distribution and restocking. The Unions were also encouraging vocational skills training for P/CWDs.

7.4 Strategic Gaps and Challenges

Parents and PSGs/PAs

a) Parents and PSGs/PAs relied heavily on USDC and other CSO support, as they were currently not linked to any government structures. Inadequate provisions other than those by USDC/CSOs and CBR in Tororo had been invested to sustain interests of the parents in the rehabilitation of their CWDs. Most of them were poor and this has had negative effect on all rehabilitation programmes. In addition it was mainly mothers who were involved in the rehabilitation process as stated in Chapter 3.

b) One of the key challenges was that fathers of CWDs needed to be brought on board from their passive positions, to see the potential CWDs were endowed with and enable them understand that such potential could be developed and transformed into meaningful life with their active involvement.

c) There was inadequate clarity of direction, content and priorities in development of PSGs. There was need for a well-packaged and appropriate information kit on different forms of disability and how to cope and manage, in particular for parents. This was however, also affected by the low level of literacy and skills among parents.

d) There was still a need for more sensitisation on disability issues among parents for them to appreciate and be knowledgeable about.

e) The spiritual aspects in rehabilitation had not been captured adequately among parents in order to influence attitudes, behaviour and beliefs.

Institutional Weaknesses and Attitudes

f) The CBSD was weak, did not have clear terms of reference (direction) and lacked budgetary and obligatory support from national and district authorities.

g) Most of the CBSD (community services) staff were not trained in disability, e.g. sign language, how to make appliances and encouraging parents to manage CWDs. CBSD was supposed to work with all sectors but due to lack of leadership in coordination, there was no framework on exactly what should be done and how. The challenge was to determine the focus establishing clarity of programmes in education and health to fit in required roles for CBSD.

h) Departments requiring services of community development workers, went ahead and employed their own community workers, in the name of social workers, whereas these could be synonymous with community workers already employed by CBSD, who could be deployed to do community work for those departments. The impact on the disability sector, in general terms, was that the mainstreaming of disability concerns in community-based activities that cut across all sectors, had virtually failed.

i) The medical professionals felt that CBR was trying to dilute their work e.g. fixing artificial limbs. It was also learnt that medical professionals said that following people up and helping them to make appropriate appliances was not quite their work.

j) Due to the emphasis on medical rehabilitation without social rehabilitation, problems of disability tended to recur due to poor nutrition, negligence, etc. The challenge was one of conceptualising rehabilitation as social, medical, nutritional, educational and skills acquisition where all government sectors, CSOs, parents, etc must be involved. This required appropriate leadership role for MGLSD.

k) A major challenge was for each local government to acknowledge the importance of matching its resources for disability concerns to those of any donor by always providing for it in plans even if not immediately financed. This would build into the system of ownership in monitoring effectiveness of implementation, and ensuring that such activities had potential for continuity.

Total Communication

l) Creating an environment of total communication in order to establish two-way communication with the deaf, who were many in society, was a challenge.

Information on Disability

m) In order for concerns of disability to receive appropriate attention and be adequately addressed, the challenge was to obtain adequate data on the magnitude of disability in terms of types, numbers affected and the degree of the disabilities so that a correct picture was presented. This would challenge and move national and local governments to appreciate and come up with overall plans to address disability, particularly CWDs, for them to own the process so that they were in charge.

CHAPTER 8: INTER-ORGANISATIONAL RELATIONSHIPS IN SUPPORTING REHABILITATION OF CWDs

8.1 Introduction

Development interventions take place within institutional arena with many players and institutions of varied interests and values. In the social and medical rehabilitation of CWDs there were equally many actors involved, none of which individually could meet all the needs of any person or child with disabilities alone. According to Dorcas Robinson, et al[30], the different players related to each other in three major ways, namely through competition, co-ordination and cooperation.

The core of social and medical rehabilitation was in appreciation of what was the essence underlying and giving energy to the institutional arena, to decisions and practices surrounding the nature of relationships that evolved, and to apprehend the invisible patterns that governed existing relationships. It was important to understand the intentions of these relationships. This helped to deepen understanding of interventions into the heartbreaking nature of disability (the impairment and the stigma attached to it by the social environment) and in harnessing passion and commitment to appreciate it, hence work complementarily.

This Chapter assessed character of the relationships (different forms of cooperation, coordination, and competition) that emerged at three different levels. The Chapter highlighted the issues observed in the diversity of approaches in building inter-organisational relationships. At the government level the survey looked at inter-sector relationships and government to CSO relationships, including the coordination role of the government. The second level was the relationships among CSOs. The third level concerned itself with the relationship of CSOs to the beneficiaries.

8.2 Relationship among Government Sectors and Between Government and CSOs - Coordination Role

The relationships among government organs in social and medical rehabilitation of CWDs was observed at inter-ministerial levels, at the district local government levels, and in providing the coordination function to oversee and guide all operations in the rehabilitation processes. The study determined how holistic conceptualisation of the different organs of government was promoted to enable the different ministries and departments to perceive their roles as complementary to each other.

8.2.1 National level Relationships

The MOH; MOES and MGLSD played significant and vital roles in the social and medical rehabilitation of CWDs. Historically disability was the domain of the Community Development Department to the extent that at one time the orthopaedic workshops in hospitals belonged to the Department. Hence, history tended to perceive MGLSD as the lead ministry responsible for coordination of all ministries and organisations involved in working with and supporting rehabilitation services.

The MGLSD had evolved through various processes in ideas and approaches to address disability. In recent times the ministry adopted community based rehabilitation (CBR) approach to support P/CWDs within their homes, with the involvement of their families

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[30] Dorcas, Robinson, Tom Hewitt, John Harriss: Managing Development – Understanding Inter-organisational Relationships.

and local community members. The 'Guidelines for CBR in Uganda 1992'[31] acknowledged that an inter-sectoral approach and coordination was adopted for appropriate planning in the CBR because services to address disability cut across all sectors. In this context the Department convened meetings of all actors working with CBR to discuss the best approach to CBR. It discussed cooperation between and among the various actors, and their coordination.

The national Community Based Rehabilitation Committee (CBRC) led by MGLSD was formed composed of MOH, MOES and the Departments of Physical Planning and Housing with NUDIPU as the Secretary. The purpose of the committee initially was to coordinate CBR programmes nationally in all the districts. In practice, the structure was observed functional in supporting districts implementing CBR programme under the MGLSD with major funding from NAD. For example, the key individual interviews with the Project Coordinator showed that the Tororo CBR programme provided space for cooperation between government and private professional health establishments in outreach activities and in the hospitals. Such collaboration enhanced quality of service to P/CWDs.

Outside the NAD supported programme, the coordination function became invisible. Seemingly the MGLSD and the CBR Committee had not come out clearly on the essence of providing social and medical rehabilitation services under the CBR programme to attract, bind and guide all the actors. Embedded in this lack of clarity of essence was the rather unclear direction in what it entailed to rehabilitate CWDs, and how the leadership ought to have had national perspective to guide interventions to purposeful relationship of mutuality. The presumed lack of national perspective in leadership led to the apparent unclear role the government played at the national level. This resulted in the fact that government engagement with CBR remained limited to NAD support, as well as goverment's limited role in coordinating other actors engaged in rehabilitation activities, as discussed in more details below.

There were occasional efforts of MGLSD in steering collaboration among government ministries and CSOs to participate in providing legal and policy framework for disability. Lobbying by CSOs was a key characteristic in this process to influence legislation and policy on disability. One of USDC strategic objectives states:

> 'Increased policy advocacy and lobbying activities to influence official policiesand activities in favour of children with disabilities.'

Specifically, USDC lobbied to ensure inclusion and mainstreaming of issues of CWDs in policies and legislation. An example of USDC good practice in lobbying and advocacy was clear in USDC input into the process of developing the PEAP. However, the rather haphazard and political nature of participation still did not appropriately focus on the deep underlying issues, and more effective programmes of implementation at local government levels. For instance, the National Disability Council structures were formalised and put in place at district levels, requiring large sums of money to manage them, but without clear focus on coordination in supporting CWDs. This however, could

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[31] Guidelines for Community Based Rehabilitation Services 1992, The Department of Community Development.

become its undoing from being functionally effective. In addition, the Equalisation of Opportunities law was still in the making.

Government – CSO Relationship

At national level, a number of international and local CSOs engaged in supporting disability as mentioned in chapters 5, 6 7 and elsewhere in the report. A number of them implemented their programmes at district levels either directly or through the local government structures in rehabilitation of CWDs.

Government through its organs was the major service provider. CSOs came in to supplement efforts of the government where they were inadequate or limited. The initial relationship between a CSO and the government was based on the authority to operate either as an international or local CSO through the NGO Registration Law. The terms of cooperation and relationship were spelt out in the memorandum of understanding (MOU) the CSO signed with the different organs of the government, either at the national level with ministries or district level with the local governments. This entailed that the central and local governments provided effective leadership to draw the organisations to cooperate based on acknowledgement of the complementarities in their work. The leadership would provide coordination role to streamline the various programmes for maximum utilisation of resources and benefit. It was presumed that these agreements spelt out the role of the government in coordinating both national and local levels of interventions and also spelt out the monitoring role of the government and the CSOs collectively or individually.

As an example, at national level USDC worked with departments of MOH, MOES and MGLSD on concerns of disability. MOH stated that it was guided by the principle of collaboration and partnership with the public and private organisations in provision of health services. It acknowledged that its working partnership with NGOs and CSOs had enabled the government, through the ministry, to efficiently and equitably allocate resources to ensure equal access by all Ugandans to essential healthcare.[32] The MOH acknowledged that partnership with USDC in carrying out interventions for equalisation of opportunities for CWDs to access medical rehabilitation so that no one is left out. Medical rehabilitation was delt with in Chapter 5 of this report.

However, USDC efforts to enter into formal agreement with MOH and MOES to strengthen and increase the integration of services for CWDs in mainstream planning had so far been kept in abeyance by the respective ministries up to the time of the survey. The Principal Medical Officer in charge of Mental Health Services asserted that NGOs did excellent work, but on behalf of the government. Their effectiveness could only be seen if they made provision for the voice of the respective Ministries. This was true saying without any question. However, the findings in key informant interviews indicated that efforts of USDC at working with the ministries and local governments were marred by dishonesty; lack of commitment and apathy displayed by some of the government officials. Similar situation of agreements might have prevailed between the government and other CSOs, which could not be accessed by the consultants in depth.

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[32] Letter of acknowledgement from Ministry of Health in USDC Annual Review of 2003/2004

8.2.2 District level Inter-departmental Relationships and Local Government Relationship with CSOs.

While departments were observed to appear to collaborate in some activities, genuine systemic and holistic approach to cooperation did not exist at district level. For example, the DDHS of Sembabule and Kabarole districts acknowledged that sector departments tended to work in a closed manner. When prompted to collaborate or complement each other, they experienced resistance to ensure that such collaboration was short-lived. The Probation Officer in Sembabulre echoed this situation by reiterating that the departments worked in cocoons without recognition of the inter-linkages in professional input, yet these inter-linkages were necessary for more effective outcome of their work in their respective fields. He reiterated further that working together could only be understood if ministry officials went down to the districts as a team and demonstrated team spirit to make the DEO, the DDHS and Coordinator Community Based Services appreciated the importance and value of working together. For example, the Global Fund in the district was utilised by one DDHS department without recognition of the social healing relevant within an environment where negative attitude towards victims of HIV/AIDS prevailed. The CDO in Ntungamo affirmed that each department sat alone to make plans, which did not show any space for the involvement of other departments.

The conversation with the consultants acted as an awakening that prompted respondents to ponder about how the local governments had not promoted inter-departmental efforts to work together. The DDHS of Kabarole had an opportunity on the day of conversation with the Consultants to meet the education staff and promised to take up issues of authentic collaboration. It also pointed to the failure of the centre to provide leadership to inter-departmental cooperation in holistic and systemic way. For example, the function of community mobilisation, facilitation and involvement in identifying CWDs for rehabilitation and engaging the community to participate in the rehabilitation processes was recognised in the districts by Education, Health and Community Development departments as a necessary approach in social rehabilitation. It was an important complementary component to medical rehabilitation. However, Education and Health departments did not perceive this function as the domain of or a responsibility to be more effectively performed by the CBSD, for which the different departments should provide facilitation.

The central government maintained the Community Development department, probably, on the understanding of the important social role it should be playing. The Health department recruited its own social workers to play the function that the Community Development department would play in social healing. Yet the Health department could have trained the community development staff in the basics of knowledge they needed in health. The social worker structure was a creation of MOH at the centre without consideration for complementarities in its roles with MGLSD. Hence, the individual departmental efforts to work independently rendered the CBSD without active work until an NGO or donor funding came in. The Acting. Director of CBSD in Ntungamo admitted that without UNICEF supported activities, they would be redundant. The DRO in Apac lamemnted that they were basically inactive because the other departments did not provide facilitation to enable them work.

a) Relationships in USDC Programme Districts

One major difference between USDC and non-USDC programme districts was the efforts USDC programme districts made with USDC support, to establish linkages between and among departments and CSOs. USDC signed a MOU with each district it worked with spelling out its programmes of operation. The MOU was also a declaration that the terms of agreement were discussed and agreed upon and would be implemented in the spirit of good cooperation to ensure smooth and effective working relationship. In each district the USDC Field Coordinator represented USDC, while the office of the Chief Administrative Officer was represented by key departments of Planning, Health, Education and Community Based Services. The contribution of USDC and of the local government in the partnership were spelt out clearly with obligations

In practice USDC adopted a number of approaches of ensuring that the partnership worked out effectively. The key departments formed the CBR Committee in each district in the **review and planning meetings**, to interest the partners to work together in providing social and medical rehabilitative services to CWDs. Government interventions in such areas were assessed to determine intervention gaps, which USDC took up to support in line with its objectives. USDC worked through the departments using their staff to carry out activities in their respective fields, with financial and moral support from USDC. One respondent called it ***'doing a demonstrable work'***. USDC undertook activities that developed capacities of those who dealt directly with rehabilitation of CWDs in order to take services delivery nearer to the CWDs, as mentioned in Chapters 5 and 6. This was a good practice in drawing the departments to appreciate complementarities in their different functions.

The USDC strategy of lobbying and advocacy was an indication that the MOU did not automatically make the local governments fully committed to assume full responsibility to provide for CWDs. USDC engaged local governments through different types of meetings and fora. These meetings extended to consultative meetings with parents, community members, local leaders and PWDs to identify disability issues and influence them to advocate to the government to address them.

There were experiences of individual level collaborations among SNECOs, Probation Officers and Medical Professionals in making referral cases that needed medical services. Schools and Medical Professionals were reported to collaborate in order to have school children assessed and treated. For example, the PTA/SMC members of Paila, Alwi, Pangiet and Ley Primary Schools in Nebbi District in a joint meeting expressed satisfaction with the work of the Medical Professionals who checked children in these schools. This practice had led to the identification of serious hearing impairments and ear infections in the area, which had hitherto not been recognised.

In Jinja district, the consultants were told that there was an understanding between Spire Road P.S and Jinja Regional Hospital that enabled children with eye problems to be assessed and identified in the eye clinic before the children were enrolled in school. This enabled Medical Specialists to prescribe treatment and advice on the kind of education support such a child should be provided. Children with low vision were availed opportunities for print education, while total blindness could be subjected to Braille. In Buckley High School in Iganga district, there was a particular visiting doctor to the school. In Yumbe district, the Mecial Supertintendent said that Yumbe Hospital organised training of teachers (2 from each of the selected schools), on how to identify children with eye problems and send them for treatment. This activity was supported by Lions Club Norway.

It should be noted here that the scale of inter-relationships in all the USDC districts was minimal, presumably because of the lack of culture of holistic and systemic inter-relationships extended to the districts from the centre. For example, In Masindi, both the DRO and the Medical Professionals admitted that coordination between DRO and the rehabilitation medical team was lacking. They confessed that the three (health, education and community based services) had never sat down to discuss and streamline this situation. The Medical Professionals were of the view that the DRO should be drawing programmes for outreach activities and requesting the HSDs to facilitate. The DRO was responsible for coordinating them. Surprisingly, they were aware that there should be coordination but would not deliberately do something about.

A few CSOs discussed below demonstrated the nature of relationships that evolved with the local governments from the MOU and the leadership role governments' played.

Government Relationship with SSI

Sight Savers International (SSI) was a non-implementing organisation, but through CECS, it worked with the Chief Administrative Officers who assigned officers to deal with specific aspects of the programme. These were the Inspectors of Schools for EARS/SNE in educational rehabilitation of the blind; the District Rehabilitation Officers on facilitation of the community in taking up responsibility for managing treatment of *onchocerciasis* and the Medical Superintendent in eye care.

CECS communicated ceiling of budget and allowed each component to plan and budget for activities. The plans were approved and funded. There was a district Steering Committee (composed of the Chief Administrative Officer, District Heads of Departments, Head Teacher of St. Bernadette) intended to involve the district leaders in supervision and monitoring of implementation.

Government Relationship with CUAMM

In both Arua and Nebbi districts, CUAMM indicated that it was on the District Development Team engaged in planning district technical programmes. At the same time CUAMM was deeply involved in field operations in the respective districts, which kept it engaged and connected to particularly the health services and other sectors in what it called 'vertical and non-vertical programmes'. It was not clear how the position of one CSO engaged to the extent of CUAMM would mean for the local government in terms of its commitment with other committed CSO efforts. This seemed to be the source of some of the conflicts that existed mentioned below in inter-organisational relationship among CSOs.

Government Relationship with Disabled Persons Organisations (DPOs)

In every district visited there were DPOs, particularly the District Unions of Disabled Persons. The DPOs were represented on the District Local Council and on every lower local council by both male and female representations. Their representation was aimed at lobbying and advocating on issues of disability to ensure adequate mainstreaming into local government plans and budgets.

In an interview with the District Local Council Chairperson and the Chairperson of the District Union in Masindi, it came out clear that the Union was loud in demanding for budget allocation for celebrating Disability Day. It was not clearly demanding for mainstreaming of issues of social and medical rehabilitation of CWDs or other developmental issues for disability. In Jinja, the CAO said that the District Union of PWDs preferred to follow political lines rather than address disability issues technically with technocrats.[33] The problem seemed to rest on the low capacities of the Local Councils and representatives of PWDs to articulate issues of disability clearly and to engage the departments to understand how the concerns should be mainstreamed, as discussed in Chapter 7.

The findings showed that partners were supportive in the CSOs-implementing partners' relationship, especially their involvement directly in rehabilitative activities. The CSOs managed to get several things done with partial involvement of the government, although basically in terms of staffing. USDC active participation in government programmes within respective districts made the local governments build confidence in USDC as an organisation for CWDs. It was consulted and involved in strategic disability activities at the districts, such as being selected as CSOs representative on the Disability Council in some districts.

However, the partnership was challenged by the inadequacy with which the local governments seemed to play their agreed part. CSO presence seemed to relieve the local governments of their responsibility, because where the CSOs undertook rehabilitation activities in support of P/CWDs the local government tended to pull out completely. The consultants took note of a specific comment made in all the USDC districts to the effect that issues of CWDs were for USDC to address.

> ***'Disability is not at all an issue for the local government but an issue for NGOs headed by USDC'.*** One NGO representative in Apac commented

The Local Government – CSOs MOU were not cardinally specific about government contribution which would have made it binding for the local government binding in order to challenge its passions to respond responsibly. The government was already generally engaged in providing for rehabilitation. The issue was that government needed to strategically do more and MOU needed to be necessarily binding to get extra effort from the government.

b) Relationships in Non- USDC Programme Districts

Among the non-USDC programme districts, the example of such linkage was only mentioned in Moroto district. There was collaboration between primary schools with units for CWDs (such as Kangole P.S) and Matany Missionary Hospital. In the absence of a special unit for ENT in the hospital, deaf children were referred to Soroti Regional Hospital.

In general, in non-USDC programme districts, it was difficult to determine other areas of inter-departmental cooperation. The 'School health and child day visit to schools programme' under MOH (as stated by DDHSs of Kabarole and Kasese) in all the districts emphasised the traditional immunisation, health education, de-worming, T.T Immunisation, dental care and related services, without focus on hearing and visual impairments, mental health and physical disabilities.

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[33] Report of the Evaluation of Action on Disability and development

The lack of deliberate efforts at inter-departmental cooperation negatively affected opportunities for CWDs to access medical, educational and social care. For instance, schools with units or enrolment of CWDs did not link the children to access medical care. Parents of the majority of these children were neither concerned about, nor able to seek medical care for them. Hence, untreated disability conditions developed complications that led to further deterioration of the children's conditions, often in form of secondary disabilities, hindering their education. For example, Mpondwe Primary School with trained SNE teachers, did not link CWDs to close by HC III or to Bwera Hospital. The dropout rate among CWDs from the school was high asa mentioned in Chapter 7 due to complications that developed.

The consultants observed one boy who was said to have been very active in the school, but became paralysed (in the adjacent picture) and was wasting away without adequate medical treatment.

Another boy from Rukoki Primary School had reached the stage of mental disorder because his epilepsy situation was inadequately attended to. A number of children in Rukoki P.S and Sembabule Primary School in Sembabule district experienced ear problems without any attention from the hospitals that were nearby. Both Mpondwe and Rukoki Primary Schools were renowned for support of special learning needs. However, it would seem that although the teachers were trained in SNE, guiding and linking the CWDs to medical treatment was not part of their understanding of support to children with special needs for education.

The DEO Ntungamo district said, ***"A school like Rwera Primary School which is the only school with a unit in the district is not linked to any medical facility for medical rehabilitation and treatment of CWDs, yet this school has many CWDs. I had never thought of linking such a school to health services so that children get support. It would therefore be good for education and health sectors to collaborate so that the health needs of CWDs are met bearing in mind that many of them come from families that are too poor to afford the costs of treatment".*** The Head teacher of the school admitted that she had not thought that it was possible to make arrangements with the hospitals to help the CWDs.

The key issue illustrated by the haphazard nature of linkages was the absence of recognition and appreciation of the underlying holistic character of the different organs of the government. This led to failure to clearly articulate, portray and emphasise the inter-relationships and complementarities among government organs for effective functioning. The ministries or departments were essentially separately structured for effective functioning to serve people - one whole human life. However government organs did not show good example of acknowledging the complementarities and take initiatives to steer together in the area of disability. There was need for the central government to come out clear to comprehend the wholeness of human life and the underlying holistic character of the ministries and departments to deliberately emphasise the importance of adequate and systemic cooperation. The examples were probably merely a tip in the magnitude of the lack of knowledge and the will to understand and articulate disability as cross cutting, to be mainstreamed in various development activities collectively.

Furthermore, without the MGLSD coming out clearly on the essence of social and medical rehabilitation of CWDs, it was not adequately acknowledged as providing strategic leadership. The Ag Coordinator, Community Based Services in Ntungamo acknowledged that it was difficult to point fingers at other departments as being closed when his ministry or department had not clearly articulated the role it should play in other ministries/departments to make the departments recognise and appreciate it. He cited experiences where his departmental staff took initiatives to identify and refer CWDs to Itojo Hospital only to receive negative response. When the same children were referred to OURS in Mbarara, they were received positively, because of the different way in which OURS perceived its relationships in working with others in rehabilitation activities.

8.2.4 Government Coordination Role at District Local Government

Coordination, supervision and monitoring of staff of CSO programmes remained a challenge for the government to a great extent due to the unclear reason of appreciation of concerns for CWDs. The absence of good leadership denied opportunities to build a more conducive working environment to enable inter-organisational relationships to emerge and evolve in supporting the rehabilitation process. A few efforts at coordination were treated with minimal importance. For instance, USDC office in Lira reported that the Assistant Rehabilitation Officer coordinated activities of CSOs including issues of disability. A few specific cases of collective support had worked out well as good examples. Although coordination meetings started among NGOs, a proper system to ensure continuity of coordination of services was lacking.

In Nebbi and Arua districts CUAMM attempted to create or revive District Disability Coordinating Committees, which the districts claimed existed before, by calling meetings, providing venues, transport refunds and refreshments. A number of meetings were held and discussions started on CSO plans and activities, but not those for the local governments. This gave the impression of a CUAMM engineered structure. CUAMM efforts to shift responsibility for organising the meetings back to a neutral ground in the focal office (DRO) had not picked up well. The meetings had not discussed the need to perceive and collectively manage the development and support to P/CWDs holistically within clear government and CSOs relationship under an effective leadership of the local government. This would challenge and bind the local government to coordinate, streamline, supervise and monitor the respective programmes.

The USDC initiative to draw the relevant departments and CSOs to discuss work plans together in order to share information and plans was not embraced to be uplifted for a district coordination initiative. It could have left a bad taste. Neither USDC nor any of the other CSOs had direct control over the partners. The USDC/Local Government MOU put responsibility for coordination and monitoring on the local government. The consultants did not see the MOU between the local governments and the other CSOs. Basically, the CSOs dealt with focal persons appointed either by respective heads of department or the Chief Administrative Officer. This was the case with USDC, SSI, AVSI and CUAMM. The focal persons were expected to report to their respective heads of department for inclusion of CSO programme of activities in the departmental plans. The focal persons either built interest and team spirit among the professionals or discouraged them, unless the head of department or section supervised.

It should be noted fundamentally here that the cooperation agreements did not collectively define mechanisms of joint supervision, monitoring and evaluating both the commitment and achievements. This led to substantial absence in monitoring and coordination of activities to keep the MOU alive. On individual sense of responsibility, the MSs in Adjumani and Masaka Hospitals showed keen interest in managing the outreach programmes with USDC support and this was managed well. In the other districts, there was absence of effective leadership to link USDC supported outreach activities to that of the hospital or the office of the DDHS, or other departments as part of the departmental plans. For instance, the MS of Masindi was quoted as having said that there were neither work plans nor reports on rehabilitation activities hence any budget provisions.

The hospital community (Nurses, MS, etc) believed it was USDC doing rehabilitation work. The medical professionals were thought to account to USDC, while they knew that USDC had no authority over them. The medical professionals openly admitted that they did not make any reports to the MS despite the fact that they were local government employees under the MS. They felt no obligation to account to the MS, because they had never planned outreach activities in the area of disability with the MS. The same situation prevailed with the District Education Office in Masindi because it did not have evidence of linking USDC plans to its own. The situation was aggravated by the fact that government did not see disability as life threatening, in the absence of data to present the magnitude of the problem.

'Until Washington recognises the negative effects of disability in children and starts pushing money for it, the government is not in a position to provide resources. When polio was being funded, malaria killed many people and nobody cared, until Washington acknowledged the situation and started funding it' said the DDHS Masaka.

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and a statement that government ceded its responsibility for the plight of part of its population (disabled), unless Washington provided funds. The above situation probably contributed to government's inability to provide leadership to create a healthy environment of operation and for inter-organisation relationships to develop.

The absence of needs assessment and concrete data to provide authentic information to a great extent rendered the government largely uninformed about the extent of different types of disabilities and magnitude of the problem. It further denied individual districts clarity in creativity and uniqueness in addressing issues of disability. This was partially the reason for the government not to come out with strategic plans for disability to guide other actors, coordinate and streamline activities. The failure of the local governments to provide leadership was partly embedded in the absence of authentic information.

Duplication, dishonesty, competition and confl
+icts - experiences of lack of coordination led to duplication of resources, turned into unhealthy competition and unbecoming dishonest practices and conflicts as elaborated under CSO relationships section below for a clearer picture. The districts those were fortunate to have two external sources of funding for outreach activities did not maximize utilisation of the resources due to poor coordination. The said districts and source of funding were as bellow:

Chart 8.1 Examples of CSOs presence in USDC districts

District	Source of funding
Arua	USDC, SCORE (CUAMM)
Adjumani	USDC, MOH
Apac	USDC, SCORE (AVSI)
Lira	USDC, SCORE (AVSI)
Moyo	USDC

Arua and Adjumani provided examples of the results of poor coordination with the most extreme being Adjumani. Rehabilitation workers went to outreaches organised by both funding agencies. Each agency took the workers to their planned venue once a week. This resulted in rehabilitation workers being out of station for two or three times a week. In Adjumani, the physiotherapy unit was closed daily because of the outreach service and one of the Physiotherapists; the district focal person[*] for disability stopped hospital work altogether claiming to be coordinating rehabilitation services. As a result static services within the hospital suffered because in most instances the rehabilitation worker was alone with nobody to cover for him when he was out on outreach activities. In-patients were also neglected.

The impact of the services especially physiotherapy was not appreciated or felt by the hospital administration, which resulted in reduced resources. In the case of Adjumani, the MS was so frustrated that he closed the physiotherapy unit until further notice. Moyo had only one external funder, and the Physiotherapist seemed to concentrate on outreaches as evidenced by the redundant department, un-used equipment and few numbers of patients in his records. The large number of outreaches benefited the rehabilitation workers personally in form of allowances but killed the overall service.

However, the consultants' assessment of what seemed to be duplication and unhealthy competition was promoted and perpetuated to a large degree by the civil servants. While the local government staff appeared interested and committed in rehabilitation work, they took advantage of the situation and benefited in terms of allowances from different sources and therefore were not willing to disorganise the facility by being straight. They held monopoly of human resources and would go for the highest bidder while holding the least paying in abeyance. They received allowances from all donors for a single job done with duplication of reports. The professionals admitted that the same data they collected

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[*] One of the Standards in the Rehabilitation Package was for each district to identify a focal person for disability who would coordinate rehabilitation services and ensure they are mainstreamed in the district plans and budgets. This was an additional duty to his responsibility and not a full time job.

in each outreach activity was presented to and reflected differently by USDC, CUAMM, AVSI, SSI (whichever organisations supporting them with allowances), and the MS/DDHS through HCs.

The competitive rates of payment affected commitment of sector staff to USDC work. One Field Coordinator commented '***Often the professionals go to the field late even though they are given logistics the day before. Most times by eleven o'clock they have not gone and, at two o'clock they are seen back yet they want increased allowances'.*** In Masindi, the ENT person narrated his willingness to work until he cleared children who turned up for outreach clinic. This was however, hampered by the focal person who was the first to complain and pushed for them to leave before handling patients who had turned up.

Sometimes they took money but did not do the work. For example, a Physiotherapist, who took USDC motorcycle and allowance to provide home visit, reached the home, but when he was told that the child was at a school closeby, he promised the parents that he would pass there to attend to the child. Instead he rode away with a colleague and was seen in the town so early that the Field Coordinator decided to make a follow-up the following day and confirmed that no work was done on the child. The Chairperson of CBR, who was also guilty of having not adequately accounted for some other funding, would not take action to address such a situation. In another dimension, the DRO in Masindi acknowledged that he got support from SSI, USDC and the district local government in terms of allowances differently, for doing similar work. In practice he basically did his normal work but made similar reports to all.

From 2003, USDC supported the programme of CRCs and the education offices were implementing a similar strategy of working with school children through Child Friendly Environment (Peace) Clubs funded by UNICEF in districts like Masindi and Adjumani. The two programmes appeared similar in content and implemented in same schools. Good leadership and coordination would have enabled the local government streamline the programmes to benefit more schools.

These relationships affected the commitment and concentration of government employees engaged in professional support, on their paid local government work. It was not clear how much the top leadership was conscious about such conflicting situations. In Masindi, some staff did private business in the workshops constructed with USDC support. USDC efforts to discuss such anomalies with the MS resulted in promises to streamline work of medical professionals, which unfortunately had not materialised by the time of the study.

8.2.5 Coordination and Management of Continuity of CSO Programmes

At the local government level, the flows of the different programmes were not coordinated, again resulting in duplication of resources. For example, when USDC took over to provide short-term training of SNE teachers, the local government did not coordinate the departure of DANIDA with the coming in of USDC. Hence the same teachers received similar training twice.

It was mentioned above that **no district demonstrated how it planned and managed its resources to match with those of CSOs.** CSOs came in and engaged in any activity they wished to, sometimes driving the district local governments at will until they left.

There was no clear evidence the sector departments assumed full responsibility for initiatives started by CSOs. For example, DANIDA came in and invested heavily in supporting SNE. However, MOES did not take up adequate responsibility for SNE as a commitment to promote education of CWDs. The utilisation of the EARS/SNE Resource Centres left much to be desired about local government commitment to SNE.

The management of facilities constructed and equipped by USDC in hospitals were handed over to the local governments. The local governments did not yet demonstrate commitment to manage them effectively for the benefit of the P/CWDs. For example, the Orthopaedic Workshop in Masindi was built, equipped and handed over to the local government to manage. The local government employed an Orthopaedic Technologist to make appliances under the direct supervision of the MS. An Orthopaedic Workshop Management Committee was established to manage it. However, the Committee was not in control. Consequently, the Orthopaedic Technologist managed the workshop without supervision and proper financial management structure. It was not clear where the finances went and who took responsibility for them. Similar situations prevailed elsewhere.

The root of the inadequate commitment to mainstream CSOs programme of activities into local government plans and ensure continuity of the programmes was in the non-binding nature of the MOU in committing the local government. For example, the 2000 evaluation of the CBR pilot programme in the 10 districts mentioned under Chapter 7 showed that the local government did not own the programme. Hence, it did not invest much in them. Despite the MOU, the implementers saw these programmes as brought from outside although they were implemented right at the grass roots.

This state of affairs led other DPOs to express misgivings about USDC engagement in supporting government implementers. During KIIs, critics of USDC's method of implementation expressed the view that while USDC made substantial achievements, it did not commit the government to provide for disability. The critics said that USDC prompted the government to play its expected role of planning and finding resources to provide services to CWDs. When both government and USDC agreed that particular services were needed, the government said, '*Look for the money and do it*'. USDC did it with less push in advocacy such that the demonstrable work ceased to be an effective advocacy tool. The government took USDC for granted that it had money, and therefore could do all that needed to be done for CWDs. For example, when asked as to how the DDHS Sembabule managed the department's resources to match with those of CSOs like USDC, he simply said ***'When we know how much money USDC wants us to plan for, we make the plans and send to its headquarters. Money then comes and they pay themselves'***.

This did not provide the consultants with any clue of how much the local government provided as co-funding. According to one DPO, USDC had become bedfellows with the government without leaving it space for effective and more strategic advocacy. This made USDC less of a CSO, more of government, yet it was the only and strongest CSO that would steer the advocacy for CWDs. As a result, it was felt that despite its good intentions all services were stalling on account of USDC.

Probably, the issue was of whether USDC and the local governments shared the same ideas and passion for improving quality of life of CWDs and their families. The MOU fell short of reflecting on how USDC instilled in and shared with the local governments the essence underlying its support to improve the quality of life of CWDs. A Senior Orthopaedic Officer in Mulago Hospital who engaged in USDC supported surgical camps said; Government did not have in-depth understanding of the devastating effects of disability on CWDs arising from social rejection, hence was not seen to be preparing an alternative plan to USDC support to CWDs. It was contented that USDC did it. In this situation, if USDC pulled out or its programme ended (a situation like DANIDA support to EARS/SNECOs), the good work that it had done would not be sustained.

UNAB representatives expressed the view that USDC should remain in the background in the area of advocacy and provide resources through organisations like UNAB or other DPOs, to push for it. The consultants did not find UNAB and other DPOs on ground for strong lobbying and advocacy. For instance, UNAB did not pick on PWDs trained in advocacy to support them further to be more effective. It was also clear that where USDC remained in the background in working with local government staff, the identity of USDC was in jeopardy particularly when other CSOs were keen on winning publicity.

8.3 Inter-organisational Relationships among CSOs

Among the different CSOs working with children, CWDs and PWDs in general, different types of relationships were reported and observed as presenting different forms of cooperation, coordination, competition and indifference towards disability.

8.3.1 Cooperation

In some districts CSOs took initiative to create informal networking structures to work together. For example, USDC, Action Aid and other NGOs in Apac District working with children did a lot of joint advocacy to the district. USDC participation made the CSOs reflect consciously on issues of CWDs and included them in their agenda. Their purpose was to influence the local government to make purposeful provisions for children including those with disabilities in the district development plans. They submitted a petition to the District Council on issues affecting quality of education in Apac District. The advocacy seemed to have minimal influence on district planning. For instance, the district made meagre budgetary provisions to disability compared to 49% for finance and planning for the financial year 2004.

In Moyo/Adjumani, USDC developed initiatives to relate to ADEO and *Afrika A. Hilfe* (AAH), which were positive. In Gulu, SCORE programme said it withdrew from providing outreach support in order to work with USDC, which offered similar service. In Masindi district USDC was on FENU Executive Committee where it shared information on CWDs. They worked together in the global campaign for Education Week and during PEAP review process where children's views were sought on how to increase their participation. It shared resources such as vehicles with CCF and Action Aid. Occasional consultations were encouraged from within and without and yielded positive linkages. For example, Action for Children accepted to provide relief to a disabled child who had been raped and later delivered twins. During discussion with the CSOs working with children in Masindi district, they felt they had not been adequately informed and conscientised about CWDs and their special needs.

The above relationships were entirely ad hoc and remained rather haphazard. They were characterised by non-committal endeavours that made them not become binding to own responsibility to serve CWDs. Genuinely shared understanding and commitment to the value of working together to address issues of rehabilitating CWDs did not guide them. The question that must attract attention was how could such opportunities have been streamlined for healthy sustainable relationship? What conceptualisation of support to disability would best guide these relationships and win passions for deeper levels?

8.3.2 Competition, (Duplication, Conflict and Dishonesty)

The survey findings brought to light some relationships among CSOs, which were characterised by duplication, competition and simmering conflicts. CSOs in each district utilised services of the same government staff. As such, there were overlaps in demand for staff, facilitation and persons or communities targeted in outreach. There was overlap in catchments area and in some instances competition among rehabilitation workers. In districts where the funder was not directly present to monitor the outreaches, the statistics they received in reports might have been the same as that submitted to NGOs, thus implying double reporting. In the absence of effective leadership to coordinate, streamline, supervise and monitor, different forms of competition, conflicts and dishonesty emerged where more than one CSO operated in a district in the same field of disability. Here below were some examples of duplication, competition and conflicts in these relationships, which were rather obvious in a number of districts.

While USDC in Moyo sponsored the Orthopaedic Technician in Moyo Hospital to attend an orthopaedic workshop management and maintenance training in Gulu for 2 weeks, AVSI did later provide funds to him under the claim of meeting his cost for the same training. This was duplication and money paid by USDC was not refunded. Fears were expressed that CUAMM planned to move him to the Orthopaedic Workshop in Arua Referral Hospital without discussing it with USDC and the Moyo Local Government.

In Nebbi Hospital, USDC had shared with Nebbi District Local Government plans for construction of a physiotherapy and occupational therapy unit. CUAMM moved faster and in agreement with the district constructed one. The new plan was smaller in size and eliminated the office facility for USDC, which CUAMM had initially agreed to provide. The Community Development Department informed the consultants that CUAMM wanted to transfer the equipment available for physiotherapy (initially provided by USDC when it temporarily rehabilitated the minor theatre for use in physiotherapy and occupational therapy) to Gulu. To the consultants, CUAMM denied this and agreed that they would transfer the equipment to the new building and would only fill in equipment gaps.

CUAMM picked on three Sub-counties each in both Nebbi and Arua districts and trained former USDC volunteer facilitators as CBR workers, an approach originally implemented in the same districts by USDC. CUAMM picked on a former employee of USDC and placed him in a strategic position in Nebbi. The consultants learnt from the district that the former employee of USDC seemed to fuel conflicts and competition between the two organisations in terms of areas of operation and nature of activities to serve his personal interests, which situation marred any possible opportunities for cooperation by these interests.

In Apac USDC constructed and equipped a physiotherapy/occupational therapy unit and an orthopaedic workshop. AVSI partitioned the physiotherapy/occupational therapy unit with plywood in order to create a treatment room, and provided equipment to the orthopaedic workshop. AVSI put up a label, **'Physiotherapy unit constructed and**

equipped' which could give the impression that it was entirely constructed and equipped by AVSI.

In Arua, the hospital had a workshop building that was extended and rehabilitated by USDC during 1999 as an orthopaedic workshop and provided some equipment. CUAMM recently rehabilitated the same with extensions and provided additional equipment. At the time the consultants were in the region, CUAMM was in the air to commission the same, with a possible impression that it was entirely CUAMM work

In Hoima Hospital, AVSI constructed a workshop for maintenance of medical equipment, which remained under-utilised by the time of the study. There was equipment in that workshop which the consultants were made to understand could probably be used in the orthopaedic workshop constructed by USDC. The local government needed to make efforts to pull resources together for maximum utilisation for the benefit of the disabled.

SSI went to Masindi and Hoima districts while USDC was already working with CWDs including the visually impaired. Certainly SSI had more specialised and elaborate programme for the visually impaired. Both SSI and USDC were involved in training of SNE teachers, and in outreach programmes. Nevertheless, there was no deliberate move by the CECS programme to exploit the strength of properly designed relationships to pull resources for maximum and more effective implementation. After quite some time the two organisations were still exploring opportunities for working together.

As it could be concluded from the district examples, AVSI and CUAMM basically worked on CBR without age limit, while USDC focused on rehabilitation of CWDs and DRO was the focal organisation on the side of government coordinating the work. It was interesting these organisations had not discussed collaboration or complementarities. Both USDC and CUAMM separately acknowledged the importance of goodwill for bilateral relationship in terms of engaging in dialogue for collaboration and partnership.

The competitions were probably a symptom of the different values and commitment to rehabilitation and of differences in underlying motives of interventions. They competed for attention and recognition from the government. Sometimes they appeared confrontational as if to discredit the humble ones and win government attention regardless of magnitude of work done. They craved to assume strategic positions of visibility. Was it struggle for sphere of influence? Sometimes they appeared to demonstrate desire to appear to be 'the organisation' in the specific field in order to attract funds from their donors. A detailed understanding of the conflict left one with disgust.

The competitions adopted different methods of wining. For instance, they introduced competitive rates of paying allowances to the civil servants which affected commitment of sector staff to 'other's work and their own work. The plans for outreach activities for the least paying organisations often received secondary consideration. CECS paid Ushs.30,000/= as daily field visit allowances to MORAs; SNE Itinerary Teachers; steering committee members when they went out on filed monitoring visits and medical professionals. AVSI and CUAMM paid similarly. USDC, which was found on ground, paid Ushs.10,000/= to all the local government staff.

The beneficiaries suffered when there were conflicts. An experience to share was in Nebbi District where CUAMM mobilised children and adults with impairments for medical operations for which they had no plans. USDC support was limited to medical operations of children. The mobilised adults were not its area of jurisdiction. This put the beneficiaries in predicament. In a situation of cooperation CUAMM would have sought information about USDC activities and nature of support before mobilising the beneficiaries.

8.3.3 Coordination by Civil Society Organisations

There were opportunities for organisations providing rehabilitation services to be coordinated by those with character of network in specific sectors like education or health or disability movement. Such were efforts made by Forum for Educational NGOs in Uganda (FENU) and National Union of Disabled Persons of Uganda (NUDIPU). However, these relationships were marred by dishonesty, suspicion and lack of trust among the CSOs and the networks. For example, when CSOs met to discuss the Global Week on Education, they agreed to work together with FENU and FAWE. Donors made commitments to support this venture. Next, FENU was in the corridors of Parliament to follow up the process alone without the knowledge of others partners. This raised eyebrows, suspicion and was a sign of lack of trust.

The focus of NUDIPU oscillated between service provision and steering advocacy. Its membership was composed of the District Unions, Uni-disability organisations, and others. International CSOs recognised its role of bringing all organisations supporting disability to roundtable to engage in dialogue on how to collectively address disability. It would be expected to provide leadership that promoted horizontal learning and sharing – learning from colleagues or peers in the same sector. This would promote space for organisations to bring up ideas and experiences to share and learn from. It would have enabled them to act collectively and individually from their own and each other's experiences.

Organisations shared experiences and such sharing were in vain because NUDIPU would soon be seen taking up the issues for implementation alone, sometimes when not adequately discussed to enable effective implementation. NUDIPU presence in some districts was more of an implementer (competitor) rather than one steering collective movement, that encouraged those with more abilities and professional know to handle some areas for effectiveness.

8.3.4 Relationship of Indifference

Lack of trust, suspicion and fear within the disability movement blocked the opportunities to develop specific areas such as CWDs and garner resources from organisations with related interests. For example, there were organisations involved in supporting vulnerable children in general or disability organisations, which did not support CWDs. These included Save the Children, NACWOLA, Plan International, World Vision and UNICEF at national level. Although the definition of vulnerable children included children with impairment (disability), they operated in the districts without deliberate recognition of the specific needs of CWDs in their programmes.

The survey showed that Save the Children was one of the CSOs that targets vulnerable children. However, CWDs were not specifically focussed or identified and included in its programme, yet they were among some of the most vulnerable in society. Save the

Children was operating in the north of the country in Lira, Apac, Gulu, Pader, Kitgum and Arua. It also operated in the East of the country in Soroti, Kumi, Nakapiripirit, Kotido and Moroto. In the west of the country, it was active in Hoima, Kasese, Kyenjojo and Bundibugyo. It worked through partners and local government. Its main strategy was building the capacity of partners in order to reach a wider coverage of vulnerable children. Its main programme focus was HIV/AIDS education, children in armed conflict, social protection, and advocacy and emergency education. These sectors did not discriminate CWDs in principle. The categorization of vulnerable children did not discriminate CWDs who needed more input to bring them to the same level. Save the Children wth ample opportunities to support social rehabilitation of CWDs, did not make deliberate efforts to mainstream CWDs neither had it worked with USDC although it would like to network and share information in order to avoid duplication.

These were relationships of indifference despite having such children in the society. Genuine collective efforts would explore and ensure that these organisations developed deeper understanding of issues of disability in children. It would enable the organisations to give additional special attention to mainstream issues of CWDs in their various programmes for their survival and development.

There were also the various DPOs mentioned earlier. Although their focus was disability, they did not show sufficient evidence of working adequately for development of children, as if indifferent to it. They supported adults who were probably an easier terrain to deal with. In Chapter 3 it was shown that disability largely began in childhood. Genuine collective efforts would have charged DPOs with responsibility and clarity of how to address issues of children within their engagements. A number of these organisations looked to USDC to provide them with funding to engage in programmes to support children, yet none seemed to have any programme of action that could attract funding.

Both cooperation and coordination required substantial amount of respect and trust. The essence of why special attention should be paid to PWDs needed to be placed at the forefront. The deep inner hindrances, which underlay the predicament of disability, must be of concern to win passion. The Disability Movement seemed to have become more concerned with advocating for form[34] (laws, policies and structures). Seemingly, it was stuck with forms without giving in-depth thought to the underlying ideas and the essence of the Disability Movement. The forms narrowed focus on disability to peripherals like lack of capacity, skills and resources in the individual and the society. These apparent deficits were symptoms of the internal poverty in conceptualisation and management of disability. A focus on removing the outer, more visible hindrances could help to create space for political, social and economic conditions to free space and opportunities for development. However, they might serve to mask and perpetuate the deeper causes of continued disability, because the ideas/essence were dying away. The dying of the ideas rendered relationships and perceptions inside the Disability Movement itself not adequate to provide energy. CSOs supporting this area were mainly paternalistic, that they were doing it for PWDs.

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[34] An ideal archetype existing independently of those individuals or groups, which fall under it, supposedly explaining their common properties and serving as the only objects of true knowledge as opposed to deeper passionate feeling.

The consultants feared that USDC, the major recognised actor in the area of rehabilitation of CWDs, needed to appeal to the passions and conscience of the central and local governments/authorities, CSOs and communities to embrace the deeper understanding of the essence of rehabilitation of CWDs and lift high the spirit. USDC believed in the uniqueness and value of each child, and a people-centred approach to development, that should leave the P/CWDs in better position to control their future life. USDC could assume effective responsibility to keep the passion for disability alive with energy to engage processes in different organisations with resources, to focus on mainstreaming social and medical rehabilitation of CWDs in their respective programmes. Such attempts might bring insights into the absence of special provisions for CWDs. It would help to expose the absence of special provisions as segregation against a certain section of the vulnerable children where some of the CSOs did not consider CWDs in their programmes. In the absence of such challenges, USDC remained one player in the field of social and medical rehabilitation of CWDs, yet the needs were overwhelming against USDC capacity to handle in the absence of sufficient inputs from government and other players. This situation depicted USDC as **'one man holding a buffalo by the horns and struggling with it'**.

8.4 Relationships between CSOs and Beneficiaries.

The nature of relationship between CSOs and the beneficiaries, to a great extent depended on the motives and commitment of the CSOs, and clarity of conception of the meaning of their intervention. The children with impairment developed disability out of deprivation and hindrances imposed by the society. They had deep inner hindrances of oppression, rejection and denial that lay beneath the relationship between them and family members, between them and the society. This bred in them fear, self-doubt, self-hatred and other deep consequences of deprivation, oppression and abuse. The consultants were of the view that the primary purpose of any intervention for their sustenance and development needed to adopt approaches that helped the CWDs to be freed of these inner hindrances. Such interventions would enable the disabled become creative and make their own future. The parents, siblings and other family members, and the society equally needed to be freed of their attitudes, guilt and other hindrances in their relationships with CWDs. The findings highlighted a few issues that characterised these relationships.

8.4.1 Relationships of Learning and Empowerment.

Relationships of respect for experience, learning and empowerment were observed between USDC and parents and PSGs. USDC engaged in purposeful and open process of relationships with parents, whose responsibility for their own children provided the most powerful and natural motive, force or energy to engage in their rehabilitation. The USDC conceptualisation was that parents were in daily interaction with their children and therefore would be more effective in assuming full responsibility to help them regain functionality. In respect for the role of parents and in order to ensure continuity of rehabilitation process to the children, parents were facilitated to learn and own the learning and healing (rehabilitation) process of the child. For example, parents were given knowledge and skills to use local materials to make appliances for their children. They were given skills to teach their children life skills, and trained by medical personnel in providing after-care services for children who underwent operation.

This approach promoted peer engagement in horizontal relationship and learning with mutual understanding among parents and different PSGs. It liberated latent relationship of inter-dependence, self-reliance and generosity with USDC, with CWDs and among parents. For example, parents sensitised other parents about disability and helped them to identify CWDs. Parents advised each other to go to USDC and to hospitals for rehabilitation services of their CWDs. They supported each other as parents in many ways to strengthen each other to manage the burden of disability. The formation of PSGs was a way of reinforcing and sustaining the local support system. The PSGs helped the rehabilitation workers to learn from the experiences of their daily living collectively. Similar situation of learning and acceptability was encouraged between the 'able' and disabled children, where they grew to accept each other.

As an example, similar relationship of empowerment developed between Offaka Sub-county Epilepsy Support Group and USDC. USDC encouraged the Group to take responsibility for drugs by contributing to the cost. The Group testified that although CUAMM supplied drugs they continued to collect money meant to buy drugs so that they could use when CUAMM stopped. They had experienced drug shortages before and were taking charge to ensure they did not suffer such shortage in future.
Another empowering relationship was in the SSI programme approach to 'eye' problems in Hoima, Kibaale and Masindi districts. It was holistic, encompassing and involving the people themselves to take initiative and responsibility to understand *onchocerciasis*. The approach involved facilitating the community in taking up responsibility for decisions on how to implement the programme for their own benefit. CECS availed drugs, sensitised the community on the importance of using the drugs continuously and importantly the nature of continuity had to be managed by them. Such continuity was more appropriately managed through selection of persons they trusted who could handle distribution of the drugs to their benefit. The distributors were given knowledge and skills in standard measure of height – simple method of assessment for prescriptions. It trained the distributors in record keeping and supervised the implementation. The drugs were distributed either when the community gathered in one place or when the distributors made home-to-home visits. CECS avoided payment of incentives to the trained persons who carried out the distribution.

In another situation, UNAD trained community to communicate in sign language, trained facilitators to train community in supporting blind children in schools. Blind But Able (BBA) provided marketable skills in knitting and tailoring to beneficiaries for future use.

The key issue was that the approaches of respect, learning and empowerment built capacities to tackle disability in children, epilepsy, hydrocephalous, cerebral palsy, eye problems in a more effective way. The real work and success was in organically connecting people with each other in purposeful relationships of mutuality. It built commitment to eradicate diseases, fear of disability, leave the children with disabilities and adults with visual impairments socially adjusted with skills and understanding of the disease. The open processes enabled participation and involvement of local actors their families, local community members, and appropriate sectors of health, education, social services, and CSOs, as an effective way of linking services to the people and sustaining them. The involvement and relationship matured into inter-dependence. The CBR approach focused on supporting disabled persons within their homes focussing on improving the quality of life of P/CWDs to remove marginalisation and promote social integration.

8.4.2 Exploitative Relationships

Some CSOs engaged in relationships with beneficiaries 'sweet coated' as providing genuine support to disabled persons, but fraught with underlying exploitative tendencies. Often this depended on the underlying agenda of the CSOs that engaged in the relationship. For instance some CSOs exaggerate the numbers of beneficiaries they worked with to win donor funding and government attention. Such relationships focused on making impressive, projected and exaggerated impact, which did not exist in reality. For example in Masaka during FGDs, parents said they were tired of NGOs that came to them but never delivered services. It would appear they used them as a source of income through the sympathy of the society of the funding NGOs.

Their approach was material benefits- or handouts-oriented. Although in some incidences it gave beneficiaries hope, it was short-lived, on and off. It did not develop inner abilities, capacities and consciousness about understanding the oppressive hindrances or disability. Hence it did not enable them to take responsibility for managing their own situations in the future. The approach was not in the best interests of CWDs because it did not focus on beneficiaries being fully conscientised or informed about issues of concern to them. It remained relationships of dependence, and reinforced the oppressive hindrances or disabilities. For example in Nebbi, the consultants learnt that CUAMM mobilised PWDs including children for operations of impairment, but this was a false alarm. In this case the adults with impairment mobilised for operation were frustrated by failure of the 'operation'. The nature of CUAMM programme did not support operation of impairments, while USDC working in the same geographical area supported programmes of operation of CWDs only. CUAMM had registered numbers of people as those it reached regardless of whether they received the envisaged support fully or not. Such were situations that raised expectations of beneficiaries while the CSOs could not address the issues through collaboration.

Another key issue was that the interventions were linear without consideration for the holistic and complex nature of human development. For example, CSOs supported beneficiaries with drugs for epilepsy. This was important since many could not afford. However, where the beneficiary already developed ability and will to collectively contribute for purchase of the drugs, the system should have been strengthened to reinforce epilepsy treatment in another way. The supply of epilepsy drugs, blind or indifferent to such initiatives was linear in perception of epilepsy treatment, to development and therefore mechanistic. It disempowered the beneficiary and reinforced dependence.

The government-beneficiary relationship was characterised by indifference by its failure to take responsibility to raise awareness about existing problems, yet it had structures for information and sensitisation up to grassroots levels. The outreach programmes for information delivery could be channelled through these structures if they were conscientised enough to disability issues.

Parents also engaged in relationships of dishonesty by obtaining funds from CSOs for treatment of CWDs, but put them to other usage. For example, one parent came to Chegere PSG meeting because he expected the consultants to offer and start providing for the daughter. He neither educated any of his children nor provided for them.

Hence the underlying intentions of CSOs and beneficiaries needed to be understood to determine if they were genuinely beneficial to the beneficiaries or simply exploitative, thus entrenching inner oppressive hindrances. Somebody somewhere needed to take responsibility to ensure that beneficiaries were not exploited, which would be appropriately done by the government in playing its coordinating, supervisory and monitoring role effectively. The government also needed to have developed clear understanding of what it wanted to do to the P/CWDs and how the CSOs came in.

8.5 Challenges

a) The different actors had not adequately appreciated the interconnectedness and inter-linkages of processes of social and medical rehabilitation of disabilities at all levels, hence the complementarities of their services in holistic way.

b) MGLSD had not assumed visible effective leadership position with clarity of that it should do in social and medical rehabilitation of disability and why. It needs to assume responsibility to play its cardinal role in providing effective leadership to steer all other actors to assume collective responsibility for mainstreaming disability and collectively develop coordination, supervisory and motoring mechanisms and be embraced by all.

c) The Disability Movement faced the challenge of refocusing on the general lack of inner energy to stimulate the movement win passion, in the absence of clearly defined essence of the movement. The relationships, issues, ideas or essence and concepts need to be made more conscious, and allow new energy and passion to emerge instead of being stuck.

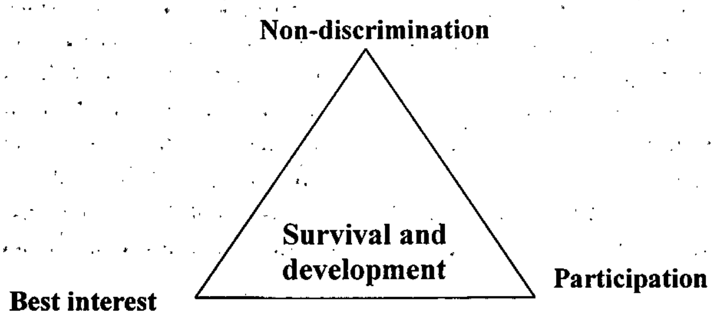
d) The lack of authentic data to establish the magnitude of disability in terms of types, numbers affected and the degrees of disabilities in order to gain a correct picture of the extent of disability. This would challenge and move governments to appreciate disability and come up with overall plans to address disability, particularly CWDs, and take charge to own the process

e) There was overlap in catchments area and in some instances competition among rehabilitation workers. In districts where the funder was not directly present to monitor the outreaches, the statistics they received in reports are the same as that submitted to other CSOs, thus implying double reporting.

CHAPTER 9: IMPACT OF INTERVENTIONS TO REHABILITATE C/PWDs

9.1 Introduction

This Section has dwelt on the overview of various presentations on interventions in social and medical rehabilitation of C/PWDs, answering the question, **'Are the actions at the intervention level leading to improvements in the lives of children (people) with disabilities at the lower levels?'** Rehabilitation interventions for survival and development of P/CWDs should centre on three pillars. At both policy and implementation levels, the service/intervention should ensure non-discrimination; enable P/CWDs participate in various aspects of life; and the actions were in the best interests of P/CWDs, as reflected in the triangular figure below..



In accordance with the TOR, the survey sought to determine the positive changes leading to trends in improvements in the lives of the children from four broad areas of assessment, namely, a) if levels of non-discrimination had been reached; b) if they were in the best interests of CWDs; c) if CWDs could be said to participate in various aspects of life, and d) if all was well for the survival and development of CWDs. The report focused on how these four areas of assessment featured in the different areas of intervention to determine the overall impact.

Non-discrimination in care and protection for CWDs assumed that there was a strong moral and political commitment by the government to take action for equalisation of opportunities for P/CWDs. This meant that the government was expected to ensure that processes and systems within families, society, government itself and the environment, were pro-disability. The government was expected to make information and documentation on disability and services available to parents and CWDs. It implied that the needs of CWDs were held in equal importance so that those needs were made the basis for planning in the family, society and all levels of government. It further implied that all resources were employed to benefit the CWDs equally as any other. Non-discrimination looked at whether children with different disabilities were supported without discrimination, benefited equally irrespective of type of disability, age, sex, creed, and ethnicity or origin at different levels of the society.

The best interests of CWDs meant that the interventions aimed at positively transforming the impairment and inner prohibitive hindrances into physical/medical recovery, learning abilities and social healing. It meant that results of the interventions contributed to an enabling environment and positive impact in the survival and development of CWDs so that they gained confidence and developed capacities to take control of their own future.

Participation focused on whether and how the CWDs and/or their parents were enabled to be fully involved in contributing to or influencing decisions made on issues concerning them. It focused on how they became actively involved in processes of the society which they were part of as equal members. It further focused on how resources were employed to enable them opportunity to participate equally as others with equal rights and obligations.

This Chapter risked repeating some issues already mentioned in various Chapters in the body of the report. However, it was felt appropriate to pull out and synthesise what appeared positive or negative changes and determine the extent and sustainability of such changes.

9.2 Family life of P/CWDs and Social Acceptance

Chapter 3 presented social rejection and scapegoat attitudes of parents who experienced frustration at failure to determine how to deal with the situation of disability in their children, and the society at large. They lacked knowledge of how to manage disability. This led to rejection. In one home one hearing impaired child said he was isolated and the family members said they did not understand him. In a few informed and knowledgeable homes CWDs were loved, given proper care, protection and stimulated equally to develop. For example, the hearing impaired interviewed in school said they were friends with family members, loved each other and cooperated with the hearing children. The hearing children learnt to sign and translate for parents.

9.2.1 Information to Families of CWDs and Change of Attitudes

Considering that information was light, strength and wealth, it was a measure to promote change in negative attitudes towards impairment and disability and the challenges of parenthood of CWDs, especially of girls with disabilities. Mentioned elsewhere, USDC through its Disability Information and Education strategy involved and engaged many actors in multi-disciplinary approach to reach P/CWDs, parents and the public with full information and documentation on impairment and disability, diagnosis of different types of disabilities, rights and services available, the value of rehabilitating CWDs in order vto develop their potentials to live self reliant life, hence cease to be dependant.,

Such information was presented in appropriate forms and technologies accessible to persons and children with different imapirment and their families' right from the grassroots levels. This was intended to create awareness and raise levels of consciousness to take responsibility to transform attitudes towards CWDs. Parents were informed about the social and medical rehabilitation services available and how they could be accessed. They were given information on how to manage disability instead of despairing. Medical professionals trained them in skills of home based management of different disabilities and post operative care guidance, so that they continued with rehabilitation and management of CWDs at home.

USDC developed booklets on some disabilities, specifically mental health and hearing impairment, for parents' and caretakers' consumption. It distributed the Convention on Children's Rights in Braille to enable the visually impaired access that information.

Information to parents was not discriminatory to the extent that all those who attended outreach clinics listened to and were sensitised on disability. Those who did not attend outreach clinics; those who could not read and those with visual or hearing impairment did not access such information unless provided in appropriate form. The blind missed out on details of such information they heard by not being availed any documentation for reading in Braille. While children with physical impairment (especially those with less severe disabilities) gained more from all information provided, there was no evidence of children with cerebral palsy, hydrocephalous and mental retardation being given specific information on their needs, using specific appropriate technology. In other words, apart from the few mentioned above, there was no evidence that children with different types of communication impairment and their parents were being provided considerations to access information and documentation on those specific impairments using appropriate technology.

SSI throughCESC sensitised people to understand that some causes of visual impairments could be dealt with by the community. It sensitised them on the importance of using the drugs continuously and of the importance of the drugs being managed by them. It organised outreach programmes to health centres and to schools to screen eye problems while informing them on what could be done about eye problems. It organised counselling and capacity building programmes intended to leave the people with visual impairments socially adjusted with skills and social understanding of the disease.

9.2.1 Strngthening of information flow through PSGs

USDC support to parents in the formation of PSGs created links among parents. PSGs informed and supported each other. Among parents or PSG and the wider community, it was informed about the existence of opportunities and services for rehabilitation of CWDs; such as outreach clinics and surgical camps and upcoming radio programmes on disability.

9.2.2 Impact of Access to Information

Respondents among parents and government officials affirmed that people were increasingly becoming aware of the need and opportunities to develop potentials of CWDs in order to involve them in social and economic processes. Parents received knowledge and skills, which enabled their attitudes to positively, change. The change enabled parents to manage the impairment and healing processes of their children. This attracted parents to be more involved in the rehabilitation process of their CWDs. The strengthened parents spoke for their children to ensure that CWDs were given equal opportunities in services. As a result more CWDs were accessing medical and educational services than before. This was in the best interest of the children because parents had crossed the level of resenting impairments and not knowing what to do about it, to assume responsibility to seek knowledge and support the children. They began to experience appreciation of the impairment in their children and potentials of the children that could be developed. The children received attention and experienced love, care as they observed the desire in their parents to make them benefit equally with other children.

An example of the transformation in attitude of parents as a best practice in the interventions to rehabilitate CWDs, and the impact on children was observed in Chegere Parents Support Group in Apac District. These parents come together to forge a way to cope with the challenges of disability. They came up with ways of overcoming difficulties associated with impairment. They created a basis through which their children could attain their needs and opportunoities in the community. They regularly collected epilepsy drugs on behalf of the group from Apac hospital. This reduced individual transport costs. They carried out lobbying meetings with sub-county officials to influence adequate allocation of resources for CWDs. They mobilised many children for assessment and corrective surgery better than the local authorities and the In-charges of health units did. They engaged in home visits and councselling. There was increased disability awareness among parents and better sense of responsibility for children's rehabilitation. Parents made efforts to change attitude among the community around them. This augmented acceptance. The group of about 44 members had initiated 4 other groups in the area.

The acceptance in both the family as equal participants and within the community, often with empathy, consequently built confidence in CWDs within families,. One pupil during focus group discussion with children said he felt touched that his brother had to go through painful experiences of epileptic attacks. He helped him to manage it.

Paula Angayika is Obeti's sister (same mother), aged 13 years and is in P3 at Ediofe Girls Primary School. She does not go to school together with her brother because he leaves very early due to his impairment. She assists him by drawing water for him to bathe and enable him wash his clothes himself.

The positive impact on the children was that many of them became better or were rehabilitated. The healing promoted full participation of PWDs in family life. Parents provided opportunities for the children to access education and to learn to write. In some homes the parents promoted communication through writing. Parents and children gained confidence to speak about the healing.

A parent in Chegere PSG operated on clib foot was proud to announce his daughter's healing which she had often been abused. He proudly asked her to stand up for all to see her. He went further to elaborate that she could go to the well to fetch water carrying a big jerrycan. She went to school and other children were amazed at her healing.

The above confessions are the evidence of how parents treasured the rehabilitated children and engaged in consciously planning for them. When the children were fairly improved they gained freedom of mobility. This coupled with the empowerment through PSGs and seminars, enabled parents support each other in supporting their children. It relieved parents from the bondage of attendant-care services for the CWDs. Parents engaged in socio-economic activities more freely. In different FGDs, parents said that they worked to see their children in perfect health, fully integrated as part of the society, accepted by the community and living married life while earning a living.

As the Director of Kampala School for the Physically Handicapped said, ***'Parents are the first in lives of CWDs. If they love them, they will be loved, but if they reject them, the CWDs will also be rejected by the society. When the parents love their CWDs, they will support their education'.***

For examples, a family in Arua provided ample support to their blind child by arranging things in the house for ease of his accessibility. They supported his education intensively. They paid for typing out textbooks for him in Braille. The blind boy was respected and treated with dignity within his neighbourhood, a sign that society came to accept children accepted by their families.

Self-esteem of CWDs stemmed from social acceptance which included support given to manage their environment. The provision of assistive devices and equipment (wheelchairs and white canes) according to the needs of CWDs was an important measure to achieve the equalization of opportunities. The development and supply of support services increased their level of independence in their daily living and to exercise their rights. The survey found out that it was parents' responsibility to provide assistive devises to their CWDs to enhance their mobility. These were not affordable by the majority of parents. This situation discriminated against majority of children with severe physical impairments from poor families, hence access to schools or health facilities or any other participation.

Viewing the information and documentation against the USDC strategic objective of ***"Increased awareness on disability issues among policy makers, professional staff and communities in order to promote more positive attitudes and better understanding of disabled children's needs"***, it could be said that the strategy contributed to creating awareness and raising levels of consciousness to cause change of attitude from what was described in Chapter 3. The transformation of parental attitude and its effect on the lives of CWDs stood out when comparing attitude and acceptability of CWDs by parents in PSGs with individual parents such as those the team met in Karamoja. The latter were extremely negative which led to very high mortality among CWDs. Of all the interventions assessed, thePSGs had the greatest impact in improving the lives of CWDs, even outpacing surgery and provision of assistive devices.

The change in the attitude and perception of parents had its limitations in social reintegration of CWDs. Although it was the most powerful tool for improving the quality of the lives of children, the dire poverty that many families lived in limited access to some of the social services that were important for full inclusion of the child. Among the most sited was the cost of transport for rehabilitation, medical care of the child and provision of basic needs. In Kasese a child wasting away could neither be taken to OURS in Mbarara nor to Fort Portal nor Kagando Hospital because of transport costs and fear of the minimal payment for services. There was inadequate evidence that children with all different types of communication disabilities and their parents were being given considerations to access information and documentation on those specific disabilities using appropriate technology.

9.3 Impact of Interventions in Rehabilitative Health Care

The assessment of the impact of interventions in medical rehabilitation looked at how the work of the state towards provision of programmes run by multidisciplinary teams of professionals or by CSOs for early detection, assessment and treatment of impairment had resulted in prevention, reduction and/or elimination of disabling effects. Such programmes should ensure full participation of CWDs and their families at the individual level. It looked at how any consistent rehabilitation improved quality of lives by accessing schools, as a sign of successful rehabilitation and inclusion.

9.3.1 Changes in Accessibility of Health Service

In Chapter 5, a number of CSOs, particularly, USDC, which focused on children, SSI, CUAMM, AVSI, the Churches and others, supported medical rehabilitation of CWDs in one way or other. USDC supported districts in ensuring availability of services in terms of infrastructure, facilities and equipment, availability of skills and knowledge at different levels of government, families and parents, geared towards attitude change. This led to more spontaneous referrals by parents, community leaders and frontline health workers. The USDC Field Coordinators said the awareness creation was transformed lives of CWDs and their parents through access to medical and educational attention. This was in agreement with the second strategic objective of USDC, i.e “**The second strategic objective is increased capacities within government, local organisations of PWDs and empowerment of parents and families enable them to participate in the rehabilitation of CWDs and integrate services for children within mainstream planning and development processes".**

USDC went to lengths to make provisions for what could heal and transform the life of the CWD.

A Senior Orthopaedic Officer at Mulago Hospital said that USDC had put money into structures, taking medical personnel to the people at the grassroots and brought CWDs out of the villages to receive treatment, visited CWDs in their homes and gave the parents/care givers skills in managing rehabilitation of disabilities. It provided transport, catered for upkeep; it built capacities, and so on.

Many CWDs in USDC districts were medically rehabilitated after receiving rehabilitative medical services through surgery, drugs and care. As more people were conscientised, more CWDs accessed medical services and the severity of their impairment reduced. This was particularly the case where Orthopaedic Workshops and Physiotherapy and Occupational Therapy units were put in place by USDC. CWDs such as those with cleft palate, clubfeet, and hydrocephalus were rehabilitated and were able to go to school.

The data in the Table 9.1 below collected during qualitative information gathering, showed that in USDC districts, many CWDs had been treated from different conditions of impairment in hospitals with the support of USDC and had either been ‘cured’ or were getting better (e.g epilepsy seizures reduced in number with treatment).

. **Table 9.1: CWDs Treated/Cured in USDC Districts**

District	2001	2002	2003	2004	2005	Total for 5 years	Comments
Moyo	39	23	15	13	19	109	Categories of cases not spelled out
Masaka and Sembabule							
- Orthopeadic surgery	40	52	45	35	30	202	
- Plastic surgery	25	27	30	20	25	127	
- Physiotherapy	120	140	125	103	154	642	Got better with exercises
-Mental Health from 8 health centres (Masaka)	-	-	302	264	266	832	Included epilepsy cases who improved with treatment
-Mental health from 4 health centres (Sembabule)			160	183	187	530	“
Apac						146	Cases for 5 years included
Hoima							Cases for 5 years included
-Orthopedic Surgery (club feet)						46	Successfully rehabilitated
-Cleft palate						53	“
- PPP (poliomyelitis)						20	Operated and given walking

							aids
Osteomylites (operated)						43	Treated, some still on treatment
Injection neuritis						49	
Rheumatoid arthritis						2	Operated
Erbs palsy						2	Given erbs palsy splints and physio exercises
Cerebral palsy						109	Assessed and therapy given, some still on treatment
Lira						80	All cases for 5 years included
Luwero						1914	951 successfully treated
- Corrective Surgery	40	35	32	36	29	172	
- Physical disabilities /physiotherapy	90	78	80	72	60	380	
-ENT cases	72	78	88	65	87	390	
Epilepsy*	120	98	77	89	66	350	Seizures reduced with treatment
Visual impairment	58	81	70	81	73	363	
Arua, Soroti , Nebbi and Masindi							Data not available

Annex 2, where access to rehabilitative health services by type of impairment 2002-2005 was presented with USDC districts separated from non-USDC districts, the numbers of persons with different disabilities accessing rehabilitative health services were much bigger in the USDC districts than in the non-USDC districts. A summary of the data is presented in Table 9.2 below.

Table 9.2 Type of Rehabilation services received by presence/absence of USDC

	Surgery	Treatment with Medicine	Assistive Device	Therapy
USDC Districts				
Adjumani	50	3326		74
Apac	1061	2422	423	1500
Arua	604	4036	102	4036
Hoima	331	22		
Jinja	274	4920	6	213
Lira				
Luwero	651	2193	671	2498
Masaka	2809	40264	1756	5465
Masindi	299	49		
Moyo		2912	9	
Nakasongola	32	431	23	58
Nebbi		1135		
Sembabule	963	1037		21
Soroti	9	280	8	6
Non USDC Districts				
Kabarole	1386	2814	780	1417
Kalangala	22	656	62	80
Kapchorwa	2241	130	10	
Moroto			207	652
Ntungamo		252		
Tororo	7	7082	428	1032

The lives of many CWDs were transformed by enabling them to go to school or engage in meaningful activities than before.

Table 9.3 Summary of access to Education by district by year by sex

	2002		2003		2004		2005	
District	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**
USDC Districts								
Adjumani					376	359	409	449
Apac				981	779			
Arua	1577	1427	1317	1242	1460	1285	1503	1353
Hoima			10	8			1498	1281
Jinja	727	626	754	737	800	734	1231	1214
Lira	1135	744	1252	879	1659	1178	2142	1544
Lwero	518	438	587	517	629	527	710	581
Masaka	746	675	828	938	1042	13947	1213	1102
Masindi	1393	1252	1748	1463	1841	1617	237	216
Moyo	299	245	247	217	289	267	310	258
Nakasongola	368	382	319	303	315	284	276	213
Nebbi	287	211	306	201	256	168	390	289
Sembabule	879	678	942	822	1024	899	1022	916
Soroti	20	18			249	253	425	402
Yumbe	50	35	10	5			112	99
Non- USDC Districts								
Gulu	73	46	103	61	141	95	164	94
Kabarole	224	149	489	330	448	328	501	326

Kalangala	265	238	289	266	305	303	303	275
Kapchorwa			751	640	496	484	954	851
Moroto			120	88	104	109	119	115
Ntungamo					366	255	14	14
Tororo	594	595	749	656	840	725	1110	939

Many parents were happy and openly rejoiced over the changes in the health conditions of their children. Comparing Table 9.3 summary of access to education with Table 9.4 on summary of access to rehabilitative health services, both tables indicated that in 2002, there was a trend of increase in access to education. This could be the result of the good number of people accessing rehabilitative health services.

Mothers in Kitengesa Good Samaritan School said their desperation that their children would not get education and would always be inferior had disappeared. They gained hope after the children got relief from treatment. There were visible examples of the rehabilitated children now living socially accepted lives.

The attitude of health providers who were sensitised towards CWDs changed a great deal. Talking to the focal person in mental health in Sembabule, the consultants thought he sounded and behaved as someone so committed that he would go to lengths to serve children with mental illness.

Table 9.2 is summary of access to rehabilitative health services obtained from the quantitative data in Annex 2. Access to rehabilitative health services affirmed in general that a good number of children accessed services and were rehabilitated. However, it indicated an extremely high figure for speech impairment that could be subjected to questions about credibility of data collection process. Mental illness, mental retardation and epilepsy presented large figures. As mentioned in the body of the report, qualitative information collection revealed that epilepsy was on the increase but not being adequately addressed. Epilepsy tended to lead to mental illness and mental retardation.

Table 9.4 Summary of Access to Rehabilitative Health Services by Year by Type

Year	speech	visual	Hearing	Epilepsy	Mental Retardation	Mental illness	Multiple disabilities	Physical disabilities	Total
2002	632	4762	2141	7483	902	4427	346	3875	**24568**
2003	462	2559	2369	6514	272	3910	419	5361	**21866**
2004	625	7661	1532	8222	521	2827	638	8760	**30786**
2005	503	4318	1881	9669	498	4000	355	4019	**25243**
Total	2222	19300	7923	31888	2193	15164	1758	22015	

9.3.2 Limitation to Access of CWDs to Medical Services

Due to the mismatch between the quantities of services providedand the very large burden, many CWDs did not access adequate medical services to enhance rehabilitation. This led to a trend of discrimination building up against full and equal accessibility to other services such as education. For instance, in situations where parents of CWDs sought help early but frontline health workers were not equipped to help, they were not provided rehabilitative services. Where the health units proved unhelpful, CWDs were tortured through alternative treatment with traditional healers. Parents were left in state of dilemma of missing out on health services while receiving inadequate management of healing by traditional healers. The struggle ate into family expenditure in seeking for cure which in some cases led to rejection of the children. Late identification of impairment led to development of secondary disabilities thus complicating the situation.

The district local governments were not adequately taking on responsibility of service provision for rehabilitation of CWDs. Disability services were viewed as special, vertical, expensive and a complicated issue that could best be handled by CSOs such as USDC. Districts that did not have additional CSO support to rehabilitation services appeared extremely under-developed in such services for CWDs. For example, districts like Kapchorwa and Moroto were decrying the lack of CSOs to bring in rehabilitation services.

Despite what appeared to be some levels of change in consciousness and awareness among the public evidenced in the spontaneous referrals, discrimination still occurred when it came to commitment of resopurce for tangible health services by both the public and majority of families.

Training of community workers to participate in areas such as early detection of impairments, the provision of primary assistance and referral to appropriate services faced challenges of who should provide for them. The number of community workers vis-à-vis resource limitations challenged USDC, SSI and CUAMM efforts to train community workers. Expectations of voluntarism in the face of rampant poverty had become void. Hence, it had not been possible to ensure that infants and CWDs were provided adequately with the same level of medical care within the same system as other members of society.

90% of medical and paramedical (front line) personnel were not adequately trained and equipped to give medical care to P/CWDs. They did not have access to relevant treatment methods and technology and they did not give appropriate advice to parents, thus restricting options for their children. Such training should have been an ongoing process and based on the latest information available.

The supply of epileptic drugs was either inadequate or inconsistent. This had maintained the status of epileptics (continuous fits), which eventually led to death. Mental retardation and movement disabilities developed as secondary disabilities. In many situations the result of poor coordination especially of outreach services, was that CWDs assessed did not receive further help. Many CWDs were still not reached due to overlap in some areas and no service in others.

The service provision for Occupational Therapy remained extremely low leading to CWDs not being trained in activities of daily living. They remained dependent on parents and siblings even if the sickness or impairment was rehabilitated to some degree. Parents were tied down to caring for the child, which in turn reduced income to family.

Little or no horizontal referral service existed between sectors. USDC encouraged linkage between schools and health services. This seemed to work effectively in some schools such as Paila Primary School in Nebbi District. In non-USDC districts there was little or no horizontal referrals in existence. At Mpondwe Primary School in Kasese, a CWD was wasting away while rehabilitative services in Kagando Hospital were accessible if the schools linked.

9.3.3 Re-thinking Care

The ideal approach to service delivery would be that of providing child focussed services that put the interest of the child and concerns of the parents first. The advances in expansion of CBR had not changed the approaches which still rotated around the best interest of the health worker and his/her perception of what was good for the child. The child with multiple disabilities was still passed from one specialist to another like a cog in a factory. Through these frequent referrals and lining up the child might get lost to care.

As mentioned earlier in Chapter 5, there was need to change the paradigm to service provisions so that a rehabilitation health worker with broad skills could manage the multi-impairments a child with cerebral palsy and refer only what was difficult. This required overhauling of both general and rehabilitation health workers training or creating a new cadre with a different outlook that put the child and parents before their own rehabilitation plan. One such example of this approach was the play ground which had been established for therapy in Nakaseke hospital by the Occupational Therapist but collapsed due to little understanding for its purpose by the hospital leadership.

9.3.4 Mortality and Improved Developmental Milestones

Most of the parents interviewed in the PSGs expressed satisfaction and in many instances happiness at the growth and development the children expereinced since identification and initiation of home-based programmes or surgery. The most excited were the parents whose children improved in cognition because the children's fits had been controlled. Simple home–based measures such as assistive devices, more complex interventions such as drugs provided at HCs to complex surgery all played an important role in stimulating development of CWDs.

This was in contrast to parents interviewed in Moroto to use an extreme example, where many deaths of CWDs were reported to the consultants. There was report on the death of two children with epilepsy due to neglect, starvation and abandonment leading to early death, within one month prior to the visit.

Provision of rehabilitation services not only improved the quality of life of the CWD but improved their development and chance of survival. When developing child survival programmes based on initiatives such as immunisation, management of fevers, child nutrition and child health days, it was important that issues that increase vulnerability of CWDs to early death, poor or no development should be addressed. The mainstreaming of CWDs in such programmes would underscore their right to life and promote positive support from the parents

To conclude impact of medical rehabilitation, one would say that there were great strides taken to build infrastructures and systems for improving access to CWDs, except this machinery was performing below expectations as demonstrated by the low access to services that still pertained even in districts with long standing rehabilitation services such as Tororo (GOU) and Nakasongola (USDC). There was therefore, need to get the system functioning, improve its effectiveness and expand to areas of severe need.

9.4 Impact of Intervention in Education

With sensitisation of parents and CWDs about disability and opportunities for rehabilitation of impairments so that their potentials were developed, coupled with positive policies, many children with different types and levels of disabilities enrolled in various schools.

9.4.1 Special Schools

Special Schools increased in focus, numbers and general attention. The special schools had adequate numbers of teachers with SNE training and skills able to provide quality teaching and support. The children studied in an environment with adequate educational materials and equipment to support learning and teaching. Efforts were made to provide the schools with friendly environment both social and physical, like walkways and gentle ramps were built and special latrines constructed so that some who had very severe physical impairments could access them. These schools could be considered to be non-discriminative. The positive attitude of care, protection, teaching and learning facilities to enable the children learn and move, and availability of teachers served the best interests of CWDs. The schools promoted participation among the CWDs and SNE teachers as they received quality education.

However, costs discriminated against the poor particularly those living in rural areas as the boarding schools were too expensive to be afforded in terms of transport to and fro and residential expenses, by most parents. They could not access the special schools. The schools were limited in enrolment by the space and facilities.

The children were further isolated by the fact that they did not interact with 'normal' children. For example in Kireka Home for Children with Special Needs, the CWDs did not get opportunities to interact with 'normal' children in the school just opposite. The same situation was found in Uganda School for the Deaf Ntinda, which was just separated from a mainstream P.S across the fence. The Head teachers agreed that they were denying the CWDs their rights to interact with other children. This was not in the best interests of the children, and did not promote equal participation on wider scale of relationships outside the CWDs and the teachers. Masindi Centre for Disabled Children made arrangements where the CWDs experienced some few exchange/exposure programmes with mainstream schools.

The concept and practice of special schools was discriminatory and disabling in that it kept the children from socialisation and being accepted by normal children for a long time during the essential prime years. While this situation was necessary for severe disabilities such as cerebral palsy and mental illness, there was need for efforts to limit separation as far as the hearing and visual impairments were concerned. Surprisingly more special schools were being built for the hearing and visually impaired who have potential to mix effectively in mainstream schools. The funds spent on putting up such schools could be sufficient to provide resource rooms with adequate materials and equipment in mainstream schools in order to enhance social inclusion.

9.4.2 Mainstream Integrated or Inclusive System

In Chapter 6 it was indicated that many more CWDs were enrolled in various mainstream schools with inclusive settings. Some integrated schools had some good amount of learning and teaching materials and equipment that enabled them to learn. Some did not have adequate materials and equipment required to enable them learn equally as 'normal' children in the mainstream schools.

Integrated schools like Rwera in Ntungamo seemed to have enough facilities like classroom space, dormitory and teachers with skills in SNE, while St. Bernadette PS did not have enough teachers. Sometimes the schools would have only one or two teachers with skills to teach different classes of CWDs. The few teachers trained in special needs education were at the same time full time teachers for the mainstream school. This posed challenges of over working and inadequate time to teach the CWDs.

Separating CWDs from their peers within the same school environment in different classrooms socially isolated them. They were denied opportunity to interact and share in learning from able children. An example was in St Bernadette PS in Hoima district, where four classes of CWDs (P1-P4) were taught separately in different corners in one classroom with the teacher moving from one group to another. The children would certainly feel discriminated against when their colleagues had large rooms and shared in all activities. When education materials were provided, they enabled the CWDs to participate normally like other children and they gained enthusiasm from full participation. Many of the schools tended to limit access because of location of the schools with such special units, similar to special schools.

The inclusive settings with resource rooms or annexes attending the same classes with 'normal' children had one or two teachers with SNE in charge of the special unit. The teacher/pupil ratio in mainstream schools with more than 100 pupils in class hindered opportunities to provide quality education. The CWDs did not receive adequate attention. The inadequate materials and equipment, such as Braille machines and reading materials, were cited in Chapter 6 as hindrances, hence discriminatory. They were discrimatory as long as they did not permit CWDs to receive adequate attention to allow them take thelearn at their own pace. This limited participation of CWDs the learning process.

For example, the Consultants were told in Ediofe that most times the blind children did not get notes in Braille from the teachers either before the lessons so that as the teaching progressed they followed what they did not read on the black board, or after. Teachers did not make notes for blind children; hence these children only listened to the teacher in class. Those who read what the teacher wrote on the blackboard and gave out in notes. The blind children did not have Braille to take notes as the teacher taught, nor did the hearing impaired hear. This limited participation of the children in both cases.

9.4.3 Confidence building through child rights clubs

Child rights clubs provided opportunities for mainstreaming and integration of CWDs in the same learning environment with non-disabled children. The clubs enabled the CWDs to learn about their rights and to go through confidence building exercises that prepared them for active participation in decisions affecting them.

It encouraged full participation with all children taking part in extra curricular activities such as sports, games, debates, music, dance and drama with a focus on children's rights. Vibrant children werte identified and invited to make presentations at public dialogues and on radio programmes to speak out about their rights, sensitise and educate the public and authorities further on impairment and their potentials that can be developed. It gave them power to shape both the process and outcome of activities and programmes set up for them.

A best practice in this area was in Luwero Boys Primary Schools where children of all abilities were brought to learn about children's rights and inclusion of CWDs. They interacted freely, were very supportive of each other and learnt to appreciate their differences, as they capitalised on each other's potentials, not disabilities. Each able-bodied child took responsibility of ensuring the welfare of his or her friend with disability. They acted as guides for hearing and/or visually impaired friends when crossing the road or moving on the school compound. They stood up for them when others tried to bully them. They took active role in supporting and encouraging their peer CWDs to feel accepted and start to participate fully in the life of the community around them.

9.4.4 Social Acceptance within School Environment

Some mainstream schools with facilities for CWDs provided environment of mutual acknowledgement of the need to support each other among mixed society of CWDs and 'able children. It offered them opportunities to interact, to play together; shared learning and other things with the 'able-bodied'. They were helped with work such as washing, collecting water and reading notes. These were schools like Kamurasi, Rukoki and St Peters and Paul PSs, where sensitisation of teachers and pupils was carried out regularly and the whole school learnt sign language to relate to each other. These efforts were done through enhancing communication with both visually and hearing impaired. The CWDs were given equal responsibilities as the 'able' children, such as making them prefects, which strengthened their esteem.

In Kamurasi P.S, one deaf boy was a great friend of a blind boy and the consultants observed them moving together hand in hand. The blind boy was a prefect and was flanked by his colleagues with disabilities. Asked as to how they communicated, the blind could not see the deaf and not make verbal communication to him. However, they both said they were fine and somehow communicated to each other.

The visual impaired boy felt proud of being a prefect and he was managing very well according to the children and teachers. Such acceptance of children increased further inclusion. Cases of abuse decreased where sensitisation was done. The deaf in Kitengeza Good Samaritan School in Masaka expressed joy that they knew, understood and communicated in sign language. They appreciated God for it because they felt the ability to communicate made them the same as those able to hear.

They said they preferred to be in the same class with all other pupils than be separated for classes, which to them would make them feel segregated. There was a strong desire to be treated like any other, in a strong sense of acceptance and responsibility towards each other, which was built within and around the school environment.

The was growing self-esteem and ability to talk and express themselves where there was free interaction. This was in their best interests because it provided them with opportunities to show their talents and make the public know they had potential to develop. The CWDs felt happy, socially accepted and were participating, while getting the feel of a sense of belonging.

Then there were mainstream schools which neither had any resource rooms nor any other materials and equipment. Due to the absence of what was needed for a child to participate, the CWDs lacked opportunities for educational development and growth. Such children felt they were discriminated against because they could not access quality learning and teaching as the normal children, hence denying them opportunities to participate in the learning process equally. They liked the school environment because it enabled them to play with other children.

The teachers in these schools were not sensitised about disability nor trained in SNE. The CWDs and the 'normal' children were equally not sensitive to disability. The CWDs were abused and discriminated against by both teachers and the 'normal' children because of their impairment. Teachers who would prefer to teach the 'able' children that did not require special attention discriminated against CWDs leaving them redundant.

The teachers shunned CWDs particularly as they had difficulties understanding how to manage them. For example, teachers would continue to teach a class with presence of hearing impaired oblivious of the fact that the visually impaired did not follow. Apart from Schools like Kamurasi and St. Peters and Paul that had programmes to train teachers (and parents) in sign language, and programme by UNAD in Kampala, no other considerations were given to regular programmes of education in sign language in the education of hearing impaired children in their families as well as among communities.

It was further noted that the school systems did not emphasise or provide for adequate and free interaction between parents and teachers in the educational development of the CWDs. There was growing interest and anxiety among informed and conscientised parents to monitor progress of the development of their CWDs. This was expressed by PSGs and was in the best interest of the children and parents as well as teachers (with concerns about progress of children they taught). Parents in Mitete in Sembabule expressed anxiety to visit schools to follow up on and build dialogue with class teachers and head teachers to support the educational process of their children. They lamented about difficult head teachers and class teachers who would not accept them when they went to the school.

Participation and effective learning of some children particularly those with physical impairment was also hampered by lack of physical accessibility. Very few schools had CWD-friendly ramps and special latrines that aided mobility and convinience of physically impaired children. The programmes to make the physical environment accessible by ensuring that architectural and construction engineers were involved in design and construction of the physical environment was still in vain. There were provisions of education standards for architectural and construction engineers to take measures to ensure that design of and construction works provided for and enabled CWDs to achieve accessibility. However, these had not been adequately implemented in the practice of constructing of classrooms, toilets and schools' physical facilities. There was need to provide information on disability and related policies to architectural and construction engineers.

9.4.5 Legal Framework and translation of Policies into Implementation

As quoted in Chapter 4, Article 34 of the 1995 Constitution of the Republic of Uganda provided for the rights of all children to be cared for by the parents or those entitled by law to bring them up, and the state. The care included basic education, medical treatment, or any social or economic benefit. The 1997 Children's Statute translated into Children's Act 2004 stated that all local councils had a duty to protect the well being of children in their areas. They were expected to ensure that all children were taken to school. They were expected to keep registers of all CWDs and help them grow like other 'normal' children.

In USDC strategic objective of:
'Increased policy advocacy and lobbying activitiesto influence social policies and activities in favour of children with disabilities........'

USDC made efforts to influence policy making processes in various bodies. It drew local government offices in review and plans to provide for CWDs. While at national levels USDC lobbying and advocacy had substantial influence in the disability friendly policies and legal provisions, the influence at implementation levels needs time to affirm as mentioned earlier in Chapter 8.

The implementation of these legal provisions was questionable. There was no evidence of family counselling of appropriate modules regarding disability and its effects on family life. The consultants did not come across any evidence to the effect that the state provided programmes to promote the rights of children to respect and dignity within the families to ensure that there was no discrimination against parenthood of CWDs. Neither the local councils nor the NCC came up with programmes to ensure that CWDs were equally provided for in the homes. For instance, CWDs and their families needed to be fully informed about taking precautions against sexual and other forms of abuse because they were particularly vulnerable to abuse in the family, community or institutions. Although the government structure of local councils and chiefs reached the lowest village levels, they were not trained to engage in providing the needed educational programmes on how to avoid the occurrence of abuse, recognize when abuse had occurred and report on such acts.
The majority of parents had no access to legal provisions on the rights of children and so they did not know how to advocate for them. Unfortunately, the provision of information and documentation for awareness creation among parents and children was basically done by CSOs. This was being done on a small scale due to resource limitations of the committed CSOs. The media, especially television, radio and newspapers were accessible to the hearing impaired during news casts and in a few other programmes mainly in USDC supported programmes of information provision. There were minimal efforts of other media in playing the role of encouraging parents to provide their children love, care and protection.

The **inclusive education policy** and related legal frameworks mentioned in Chapter 4 acted as a catalyst to interest both parents to send their children to school and for teachers, administrators and SMCs to accept CWDs and provide for their special needs. All teachers had responsibility of supporting the learners including those with special needs. The school and classroom environment should also have been adjusted to meet the learners' needs. Efforts should have been made to ensure that learners with special needs had equal opportunities to participate in all school activities, including extra curricular activities.

However, the enforcement of these policies in MOES, District Local Governments and in schools left much to be desired, leaving parents basically uninformed. Awareness creation was still limited to a small population of parents of CWDs and community. The laxity in enforcing implementation left pre-primary education for CWDs outside any provisions for education of CWDs, hence children born with impairment or those who received it early in their lives delayed or often started at a late age.

In view of the political window dressing character of the policies, SNE received inadequate budgetary provisions to re-train enough teachers and provide adequate scholastic materials and equipment for CWDs to access equal opportunities for learning and teaching. This was evidence that the education system in Uganda cared little about them and denied them opportunities to participate equally. Even where there were general policies like UPE, it did not empower CWDs to participate in decisions on how the money was spent. Hence, the schools management were discriminative in utilisation of the UPE funds. Although the categories of items spelt out to be purchased did not state that special requirements for SNE should not be included, the school management deliberately left them out, claiming that they were not on the list.

Finaly, poor economic conditions were a hindrance limiting a greater bulk of CWDs from accessing services, although it could be difficult to determine the exact numbers in the absence of accurate data on the extent of disability.

In conclusion one could say from the above that the survival and development of CWDs had been provided to some degree. USDC had demonstrated effort to ensure all CWDs had equal opportunities to medical, educational rehabilitation, and acceptance by the communities to enable them participate in community development activities which they were part of. All was well for a few CWDs who had been relieved of activity limitations and provided with necessary facilities and CWDs friendly environment. Thus, a section of the society had moved from dependence to inter-dependence after appropriate medical, educational and social rehabilitation and contributed to the national development.

Suffice that the CWDs were brought into mainstream inclusive schools with the implication that the individual child had to adapt to the available improved environment to fit in society. The adaptation was effectively possible only if facilities in accessibility such as latrines, ramps and other structures, teachers, materials and equipment were first put in place in their interests and to promote their equal participation with 'able' children. It also required the socialisation mentioned above in schools like Kamurasi. The information and documentation for awareness creation, the opportunities to rehabilitate the impairment, had resulted in large numbers of children enrolled in the mainstream inclusive schools. Schools which never used to receive CWDs were receiving them. Among the many examples were Kikonge Primary School in Masaka without any SNE teachers had 24 CWDs within a total of 421 children, Mitete Primary School in Sembabule had 50 CWDs with special learning needs. These children and their parents were frustrated by the absence of facilities to enable quality learning; and inadequate commitment by the government to provide for survival and development of CWDs.

There were still barriers to equalisation of opportunities for CWDs to contribute to the development of their communities and cease to be treated as dependants.

These concerns showed that the environment provided at schools and their learning was knit together. What was further required was allowing for curriculum flexibility, addition and adaptation; providing for quality materials, ongoing teacher training and support to teachers.

CHAPTER 10: QUANTITATIVE DATA ANALYSIS

10.1 Data Collection

Quantitative data was collected from 13 USDC and 8 non-USDC programme districts. General instructions for data collection were as reflected in methodology (Chapter 2) of this report. However, each district of the baseline survey had some unique experiences, which some of them documented in brief reports. A number of USDC programme districts were unable to submit such briefs, as it was not originally part of the instructions. Nonetheless, comprehensive reports were received from Adjumani/Moyo, Nebbi, Nakasongola/Luwero, Soroti, Tororo, Ntungamo, Kabarole, Kalangala and Arua.

Data collection in all districts was undertaken according to the instructions provided by the consultants and USDC head office. The only differences observed were in selection of sub-counties and then the subsequent coverage (selection) of educational and health institutions. In Kalangala district, all 7 Sub-counties were covered (100%). For the education component 17 Primary Schools and 4 post-primary institutions, 2 Health Centre IV and 3 Health Centre III (2 Health Centre III not involved) and 1 NGO, participated in the exercise.

In both Luwero and Nakasongola districts, all sub-counties were selected (23 for Luwero and 9 for Nakasongola), and 50% of the educational institutions were selected in each of the sub-counties and only Hospitals and Health Centre IV were covered under health institutions. In Nebbi district, only 30 schools out of 278 were selected for recording enrolment data for CWDs. In Ntungamo district, not all the selected schools made returns and there was an expressed difficulty in digging out data for earlier years. Secondly, it would appear that poor institutional record keeping affected timely returns.

In terms of contents, the district data collectors were able to describe the purposive selection process of sub-counties for using the instruments (Forms 1A, 1B, 1C, 2, 3A and 3B (Annex 3)) designed for quantitative data, the selection process of sub-counties as primary sample units, schools, health units and disability service providers, that completed the forms, the actual fieldwork or survey process, findings or achievements, challenges and recommendations, some of which are shared for purposes of the report. Table 10.1 below shows records of selection and coverage.

Table 10.1: Numbers of Selected Sub-counties, Educational and Health Institutions covered

District	Sub/Counties	S/Counties Selected	Primary Schools, etc	Number Selected	Health Units	Health Units Covered
USDC 1.Adjumani	6	3	84PS 18SS	42PS 2SS	1Hosp 5HCs	1Hosp 5HCs
2.Apac	22	11			57H/Units	11
3.Arua	37	15	349 (273 Govt., 76 Private)	71	4Hosp 4HC IV 17HC III 26HC II	14
4.Hoima	24	12	239	191	4Hosp 1HC IV 19HC III 13HC II	
5.Jinja	12	6				

6.Lira	29	14	323	123PS 3SS	1Hosp 6HC IV 12HC III 23HC II	1Hosp 6HC IV 2HC III
7.Luwero	23	23	166	83		
8.Masaka	23	13Health 15Educ.	240	116	3Hosp 8HC IV 22HC III	3Hosp 13HC
9.Masindi	14					
10.Moyo	8	4	78	39	1Hosp 8H/Units	1Hosp 8H/Units
11.Nakasongola	9	9	132	61		
12.Nebbi	19	11	278	30	57H/Units	20H/Units
13.Sembabule	7	6	140	68	2HC IV 6HC III	6HC
14.Soroti	17	8	99	49PS 5SS/VC		
15.Yumbe	8	8	130 (126 Govt., 4 Private)	16 (2005)	1Hosp 0HC IV 6HC III 9HC II	0Hosp 0HC III
Non-USDC 16.Gulu	23					
17.Kabarole	14	7	121	56	3	1
18.Kalangala	7	7	17PS 3SS	7	5	5
19.Kapchorwa	12					
20.Kasese	22	14	258	127		
21.Moroto	11					
22.Ntungamo	15	9	246	106PS 18SS		1Hosp 3HC IV
23.Tororo	17	9		96	2Hosp 3HC IV	2Hosp 3HC IV

Notes *PS – Primary Schools* *HC – Health Centres (IV, III)*
SS – Secondary Schools *H/Units – Health Units*
VC – Vocational/Tertiary Inst. *Hosp - Hospitals*

10.2 Analysis of the Information

The quantitative data determined the progressive support USDC and other organisations supporting CWDs, made in contributing to changes the CWDs were experiencing in accessing resources and opportunities to enable them achieve their full potential. It established a general picture of the different categories of CWDs, general levels of accessibility of services and information, highlighting issues of attitudes, knowledge, perceptions at different levels towards the categories of disabilities and social acceptance and integration of CWDs. It contributed to establishment of database, particularly on CWDs, levels of available services and gaps.

However, no attempt was made by the consultants to make estimates at district level using the data collected and analysed. This was deliberate because no comprehensive national or even district level data had been collected and analysed accordingly which would have been a good basis for making estimates. The only observable aspect of the information was to look at trends, such as in school enrolment as shown in Table 10.2 and Tables in Chapter 5 on health seeking patterns (rehabilitation) and other education related Tables in Chapter 6, over the period 2002 to 2005. For example, information on training of special needs teachers and medical professionals in disability were included in the respective Chapters.

Therefore, data for each of the baseline survey districts were summarised in the Quantitative Data Annex (Annex 2).

Table 10.2: Enrolment of CWDs in Primary Schools 2001, 2003 and 2004 and Enrolment from Baseline Survey 2002 - 20054

District	Gender	Enrolment from Education Abstract			Enrolment from Baseline Survey			
		2001	2003	2004	2002	2003	2004	2005
USDC Districts								
Adjumani	Male	712	885	677	..	..	376	409
	Female	492	736	557	..	..	359	449
Apac	Male	3,742	5,124	5,068	..	..	981	1,838
	Female	2,886	4,502	4,729	..	..	779	1,465
Arua	Male	7,734	11,787	10,404	1,600	1,317	1,443	1,499
	Female	5,978	9,602	8,735	1,409	1,242	1,265	1,366
Hoima	Male	1,273	2,388	2,116	..	5	..	1,498
	Female	998	2,002	1,798	..	4	..	1,281
Jinja	Male	1,016	1,663	1,440	727	754	800	1,231
	Female	881	1,513	1,296	626	737	734	1,214
Lira	Male	3,662	4,336	4,140	1,135	1,252	1,462	1,828
	Female	2,865	3,776	3,672	744	879	1,062	1,391
Luwero	Male	2,173	2,017	1,982	518	587	579	710
	Female	1,837	1,847	1,798	438	517	437	581
Masaka	Male	2,662	4,912	4,384	849	1,113	1,132	1,323
	Female	2,434	4,420	3,997	754	1,041	1,063	1,223
Masindi	Male	2,342	4,012	3,798	1,393	1,748	1,841	237
	Female	1,936	3,537	3,458	1,252	1,463	1,617	216
Moyo	Male	738	851	678	299	247	297	302
	Female	599	712	567	245	217	273	252
Nakasongola	Male	768	952	674	370	324	313	278
	Female	704	848	607	382	307	280	214
Nebbi	Male	2,527	3,025	3,426	308	285	256	390
	Female	1,920	2,454	2,859	222	190	168	289
Sembabule	Male	616	1,808	2,109	879	942	1,033	1,013
	Female	497	1,642	1,930	740	822	911	904
Soroti	Male	3,124	2,510	2,270	20	..	249	425
	Female	2,402	1,924	1,806	18	..	253	402

Yumbe	Male	936	2,147	1,049	50	10	..	112
	Female	607	1,763	719	35	5	..	99
Non-USDC								
Gulu	Male	2,704	3,385	3,118	73	103	141	164
	Female	2,187	2,926	2,684	46	61	95	94
Kabarole	Male	835	1,483	1,536	224	489	448	501
	Female	624	1,217	1,296	149	330	328	320
Kalangala	Male	170	304	246	265	289	305	303
	Female	155	268	200	238	266	303	275
Kapchorwa	Male	959	817	719	..	758	496	954
	Female	802	747	678	..	643	484	851
Kasese	Male	1,761	2,119	2,057	..	..	..	..
	Female	1,716	1,880	1,850	..	..	..	..
Moroto	Male	655	256	334	..	120	104	119
	Female	469	184	162	..	88	109	115
Ntungamo	Male	862	1,667	1,406	..	..	366	14
	Female	596	1,429	1,105	..	..	255	14
Tororo	Male	2,587	3,093	2,846	594	749	840	1,110
	Female	2,174	2,601	2,425	595	656	725	939

***Source:** Uganda Education Statistics Abstract 2001, 2003 and 2004 Ministry of Education and Sports and USDC Baseline Survey 2005*

Key: (..) Indicate figures not available.

10.3 Trends in Enrolments in Primary Schools

In general terms, three categories of trends emerged, **a) increasing enrolment, b) first increasing then falling enrolment and c) falling enrolment**. For baseline survey data, a category of **no trends** was added mainly due to lack of data over most of the years of the survey period, for observance of trends (as shown in Table 10.2). Data from the Education Statistics Abstracts showed that most USDC programme districts were in category b), while Apac, Nebbi and Sembabule were in category a) and Luwero and Soroti were in category c). Among the eight non-USDC programme districts, most were in category b), Kabarole in category a) and Kapchorwa and Moroto in category c).

The Baseline survey showed that most USDC programme distrcts were in category b), with Nakasongola district in category c) while Hoima and Yumbe districts in the category of no trends due to poor quantitative data records. Among the non-USDC districts, Gulu, Kabarole, Kalangala and Tororo districts showed increasing trends, Kapchorwa and Moroto were in category b), while Ntungamo and Kasese districts were in the no trends category due to incomplete and misplaced returns, in that order.

While the Education Abstract provides total coverage and therefore the figures are appropriately large compared to the baseline survey limited to few schools, the data on Arua is extremely large compared to the baseline survey. This raises questions of credibility of the data in the district. It is possible that schools with large numbers of CWDs were left out in the selection process as a prominent school such as Arua Demonstration School was left out. However, from observations during field work, the Arua figures can be challenged. Another unique situation is Kalangala district that presents higher figures for the baseline survey for selected schools compared to the total coverage in the Education Abstract.

In terms of gender analysis, the trend in both male and female enrolment for the baseline survey generally showed steady increase over the four years. However, the Education Abstract shows drop in enrolment for most distrits during 2004. This is strange because the baseline survey data was supported by qualitative information from parents and the public that successful medical rehabilitation enabled CWDs access schools. And the data on access to rehabilitative health services indicate increased access of CWDs to such services (Annex 2). All districts show lower female enrolment (both Education Abstract and the baseline survey) than males for every year; with the exception of slight difference in Soroti in 2004 baseline survey. Some of the explanations for the lower female enrolment is provided in the qualitative narrative.

10.4 Trends in training of Teachers

The survey data shows increase in training of teachers in special skills to teach and manage CWDs. There was also a growing trend in the types of training as shown in Table 6.3. The types of training give the impression that large numbers of training were being provided to teacher to provide appropriate education to CWDs. It is not clear if the different names of training mean the same or be similar in content. Could the different names be reflecting the difference in concptualisation by different CSO or donors? One wonders as to how coordination would help to streamline this any such duplication.

10.5 Trends in Access to Rehabilitative Health Services

Despite the lack of standardization in the collection of this data, there was an increase in the number of persons receiving services over the years as shown in Table 10.3 below. The total population of disabled people was not known; therefore we could not conclude that there was increased access to services although a greater number of PWDs were receiving services. Medical treatment followed by therapy (physiotherapy and occupational therapy) were the commonest services received. It was important to take note that data from Soroti, Nakasongola, Sembabule, Kapchorwa and Apac could be considered unreliable.

TABLE 10.3: ACCESS TO REHABILITATIVE HEALTH SERVICES BY DISTRICT BY TYPE OF SERVICE

			YEAR				Total
DISTRICT			2002	2003	2004	2005	
APAC	TYPE		1	1	1	1	4
		Assistive device	18	18	18	18	72
		Corrective surgery	19	19	19	19	76
		Therapy	21	21	21	21	84
		Treatment	20	20	20	20	80
	Total		79	79	79	79	316
ARUA	TYPE		10	11	13	13	47
		Assistive device	180	198	234	234	846
		Corrective surgery	190	209	247	247	893
		Therapy	210	231	273	273	987
		Treatment	200	220	260	260	940
	Total		790	869	1027	1027	3713
KABAROLE	TYPE				1		1
		Assistive device			18		18
		Corrective surgery			19		19
		Therapy			21		21
		Treatment			20		20
	Total				79		79
KAPCHORWA	TYPE			1	1	2	4
		Assistive device		18	18	36	72
		Corrective surgery		19	19	38	76
		Therapy		21	21	42	84
		Treatment		20	20	40	80
	Total			79	79	158	316
NAKASONGOLA	TYPE		2	2	2	2	8
		Assistive device	36	36	36	36	144
		Corrective surgery	38	38	38	38	152
		Therapy	42	42	42	42	168
		Treatment	40	40	40	40	160

	Total		158	158	158	158	632
SEMBABULE	TYPE		4	3	3	3	13
		Assistive device	72	54	54	54	234
		Corrective surgery	76	57	57	57	247
		Therapy	84	63	63	63	273
		Treatment	80	60	60	60	260
	Total		316	237	237	237	1027
SOROTI	TYPE			1	1	1	3
		Assistive device		18	18	18	54
		Corrective surgery		19	19	19	57
		Therapy		21	21	21	63
		Treatment		20	20	20	60
	Total			79	79	79	237

10.6 Key Issue

This was probably the first time a comprehensive baseline study of the disability area had been undertaken. There had been sectional studies or reviews undertaken by service providers to P/CWDs (e.g USDC study on Accessibility and Relevance of Education for Children with Disabilities in Uganda – October 2003) and mainly in the process of their respective work programmes. It was generally observed that most, if not all, programmes of services related to disability were prepared and implemented without background statistical information. The main reason for such kind of situation was the supply driven nature of such interventions (programmes). Some programmes implemented by agencies/CSOs such as UNICEF, Save the Children, World Vision, etc, targeted children in general and amongst them there was no indication of targeting CWDs in particular or as a component of such programmes.

CHAPTER 11: CONCLUSIONS AND RECOMMENDATIONS

11.1 Conclusions

Impairment caused a child to experience limitations in carrying out activities in a manner or to the extent that was expected of people without impairment. Such impairment could be medically addressed in order to heal and/or enable potentials in the child to be developed and realised.

However, the social environment understood and perceived disability as something unfortunate and fearful, the explanation of which cultural values and norms sought in the mystery of the underlying unknown forces beyond human capacity. This perception did not acknowledge human acts such as mismanagement of pregnancy period or early childhood sickness as causes of impairment. The activity limitation and the negative social perception and attitudes resulted in disability in the child with impairment.

Disability and the way it was perceived introduced another polarity in humanity. When a normal child was sick or lacked fees, efforts were made to provide medical treatment, fees or education and whatever the case may be at all costs. This was not so with the CWDs. Depending on the extent of impairment, the child was shunned. Disability exposed children with impairment to common yet real challenges of negative attitudes of parents, guardians, and community and service providers. Parents, particularly fathers, resented the extra efforts required and difficulties involved, which made rehabilitation efforts, appear a burden.

Viewed from deeper level, the child was a human being, with feelings for self and others, with desire and longing to be loved and cared for and enabled to grow and develop. Those feelings were dehumanised in response to the negativity received from the other human beings who treated them as lesser beings.

From available information, the government mainly provided policy environment by introducing a number of education and health related policies for social and medical rehabilitation of CWDs. Although government was the main provider of services, there was discrepancy between policy directives from the centre and implementation at national and local levels, between national perceptions of disability. Chapters 4, 5, 6 clearly highlighted the policies and discrepancies in provisions for CWDs.

At the local government levels the district and lower councils had not interpreted the Local Government Act appropriately into Ordinances and By-laws to support the disability generally and CWDs in particular, and bring it closer to implementation levels. The political emphasis on numerical representation of PWDs in District and lower Councils was weak as a result of their low education levels and therefore low capacity in articulation of disability issues. The seemingly democratic structures and policy fiormulation processes appeared highly politicised, presenting major window-dressing in practical plans and budgetary provisions for CWDs, from which they were increasing excluded.

The general health framework for supporting disability existed in all health units, including ordinary facilities, workers and in some cases budgetary resources such as in the PHC funds. However, those inherent attitudes and perceptions explained above made health planners, workers and administrators regard disability as a problem that was out of reach and could only be managed in a special manner, using special facilities, personnel, equipment and programmes.

It was an important lesson that the existing framework was not designed to address rehabilitation of impairment and disability, specifically of CWDs. Rehabilitation services were not easily available and when they were, they were not accessed on a regular basis for complete child development. When offered, the services were impairment oriented and did not take into consideration the whole spectrum of disability (impairment, difficulty in performing activity, limitations in participation, etc). Health services, especially outreach were poorly coordinated and allowance-oriented (inbuilt danger), hence were 'killing' static services where no allowances were paid..

USDC provided and demonstrated committed and an embracing approach in the social and medical rehabilitation of children with disabilities. It adopted a holistic approach in addressing social and medical rehabilitation and development of the CWDs. It focused on addressing negative attitudes and perceptions about disability within the social environment manifested in social rejection of CWDs. It provided for the health and education of the individual CWD, going to lengths to make provisions for what could heal and transform the life of the disabled child. It strengthened capacities of government staff and parents, drawing the parents together, to embrace their roles of caring for the lives and needs of their CWDs with parental love and commitment. It advocated to the central and local governments to mainstream issues of CWDs in the legal, legislative and policy framework and in plan and budgetary provisions. It was widely acknowledged by local authorities, communities, parents and CWDs in all the USDC districts that USDC did tremendous work in transforming the lives of CWDs.

Some other CSOs engaged with disability in general (not specifically focusing on CWDs) and on more limited scales as elaborated in Chapters 5 and 6. During the interviews, representatives of each of the three ministries, namely MOH, MOES and MLGSD ephasised collaboration and partnership with public, private sector and civil society organisations in provision of services. This was to say that services provided by the CSO were in partnership and therefore provided by the ministries. However, the CSOs approached lacked strong, clearly focused advocacy that should prompt government to own and demonstrate a sense of responsibility to provide rehabilitative services to CWDs. USDC approach left it to assume full responsibility for programmes of rehabilitation of CWDs without sizeable responsibility in terms of budgetary provision by the local governments to making adequate contributions for the growing needs of CWDs so that USDC and government would complement each other.

The above is a lesson learnt that unless the government both national and local, engaged sizeable budgetary input into rehabilitation services, the continuation of quality rehabilitation processes for CWDs at the level done by USDC and other CSOs, which elevates the CWDs to having ability to make choices for their growth in self-reliant life would cease, if the CSOs stopped supporting rehabilitation of disability, or specifically CWDs. Sustainable development could only be achieved through fighting social exclusion and promoting a tolerant and inclusive society that valued and appreciated the contributions of all its members. Howevwr, there were still barriers to equalisation of opportunities for CWDs to contribute to the development of their communities. The government needed to reach a higher level of consciousness to practically appreciate this fact and provide equal opportunities for CWDs.

Information and education about disability enabled people to increasingly become aware of the need and opportunities to develop potentials of CWDs in order to involve them in social development processes. The strengthening of PSGs built an understanding of disability in parents such that they were no longer ashamed of their CWDs. Many CWDs in USDC districts were medically rehabilitated after receiving rehabilitative medical services through surgery, drugs and care. The lives of many CWDs were transformed by enabling them to go to school or engage in meaningful activities than before. These changes contributed to social acceptance of children by parents and the society leading to increased inclusion. They are important to the nation when a sector of population that was dependent is made active self-reliant. The challenge was how to share this experience among parents nationwide!

The lesson here is that there is ample evidence that impairment can be rehabilitated rather that be socially rejected to cause disability. Both medical personnel and parents with these experiences had responsibility to expose the positive results to attract more parents, communities and authorities to become more involved in this process.

The consultants viewed rehabilitation as an imposition on deeply entrenched denial, rejection and social exclusion, such that many actors dealing with disability appeared to perceive it from the periphery, and with shallowness. People, structures and processes in government lived in the shadows of entrenchment of a long period of negative social perception of impairment and exclusion manifested in their lack of commitment to provide for rehabilitation of the CWDs.

The evident lack of commitment among government staff could be perceived as a manifestation of the fact that government policy pronouncement on CWDs might not be rooted in deep commitment and understanding of the devastating effects of the social rejection on CWDs. The consultants could not find strong evidence of MOH adequately advising the government on the fact that if disability was addressed during early childhood, it was either healed completely or reduced in effect so that such a child had opportunities to develop its potentials fully.

In education, MOES showed appreciation of disability by allowing some teachers train abroad in SNE, by working in partnership with DANIDA and USDC in setting up UNISE for training teachers in special needs skills, establishing resource centres at district level and resource rooms in schools and support in providing materials and equipment for CWDs. However, its commitment to provide for special learning needs of CWDs, did not in any way come close to equal recognition with other education needs. Many inadequacies were still hindering their access, retention and achievement. A good number of already trained teachers who took interest in acquiring knowledge and skills in providing children with special learning needs with quality education were not rewarded, leading to discouragement of more teacher efforts to go for SNE training.

The policy provisions for inclusive education was not supported with provision of adequate materials and equipment to teach and efforts to retrain as many teachers as possible to meet the demands of inclusive setting or adequate support for their further education in the post-primary institutions. Mainstream inclusive schools were the majority, offering good opportunities for enrolment of many more children. However, they lacked teachers with special needs skills, materials and equipment. In majority of the schools visited there were either no sign or inadequate activities to transform the physical environment to the needs of CWDs.

Furthermore, many of the CWDs were still in the communities, although the actual number of those out of school was not established. Those out of school included the pre-school (for whom there was literally no provision) and young CWDs of school going age. This was an indication that despite the existence of positive policies that gave all children rights to education, majority of CWDs were still not enjoying these rights. The consultants did not find evidence of specific efforts of government or MOES enoforcing the implementation of the policies and address the different challenges.

The lack of authentic data to establish the magnitude of disability in terms of types, numbers affected and the degrees to a great extent rendered the government largely uninformed and unappreciative about the extent of different types of disabilities and magnitude of the problem. It further denied individual district clarity in creativity and uniqueness in addressing issues of disability. The absence of authentic information on disability was partially the reason for the government not to come out with strategic plans for disability to guide actors in supporting social and medical rehabilitation of P/CWDs.

This further rendered the government unable to provide leadership to coordinate and streamline activities in rehabilitation. MGLSD did not assume its cardinal role in providing visible and effective leadership with clarity of what it should do in social and medical rehabilitation of disability and why. It did not have adequate energy to steer all other actors to assume collective responsibility for mainstreaming disability. Collectively, such drive required the ministry to develop coordination, supervisory and motoring mechanisms that could be embraced by all. The deep inner hindrances, which underlay the predicament of disability, were not concerns of the Ministry to win passion. Relationships, issues, ideas or essence and concepts were not made conscious, to allow new energy and passion to emerge.

Another consequence of lack of leadership and direction was that a number of organisations working with vulnerable children in general and DPOs in particular, did not come up to embrace responsibility to consider CWDs as a vulnerable group that required special focus and provisions with equitable opportunities to develop.

Although there were many good positive responses, the assessment of the respondents did not on the whole show that the levels of consciousness of all the people interacted with had reached maturity to the extent of being moved to do something for CWDs with commitment on their own. This presented challenges in the process of rehabilitating CWDs.

Government at various levels did not see disability as life threatening as malaria, HIV/AIDS, tuberculosis, etc. Yet impairment and disability had psychological effect of social rejection that ate up and devastated the affected persons. The number of people dying or deteriorating in the rural areas as a result of epilepsy was large, basically more so because of the psychological factor. Malaria was looked at vertically without consideration of study into possible reciprocal relationship with epilepsy. This meant that if current activities mainly undertaken by USDC ceased, it would be difficult for government to take over such investment in disability as its priorities do not directly address P/CWDs. Districts did not perceive disability as their responsibility neither did they see it as a priority.

Suffice to say that the different actors did not appreciate the interconnectedness and inter-linkages of processes of social and medical rehabilitation of disabilities at all levels, hence the complementarities of their services in holistic way. What appeared on the periphery as relationships of cooperation among CSOs, were entirely ad hoc and remained rather haphazard in character? They were characterised by non-committal endeavours that made them not become binding. Genuinely shared understanding and commitment to the values of working together to address issues of rehabilitating CWDs did not guide them.

There was overlap in catchments area and in some instances competition among rehabilitation workers. The competitions were probably a symptom of the different values and commitment to rehabilitation and of differences in underlying motives of interventions. In districts where the funder was not directly present to monitor the outreaches, the statistics they received in reports were the same as those submitted to other CSOs, thus implying double reporting.

The question that must attract attention was how could such opportunities have been streamlined for healthy, more enduring and beneficial relationships? What conceptualisation of support to disability would best guide these relationships and win passions for deeper levels of understanding and commitment? Both cooperation and coordination required substantial amounts of respect and trust.

The government bpth local and central and other stakeholders sincerely concerned about rehabilitation of the CWDs need to rethink the rehabilitation strategy. For example they need to rethink effectively about facilities in accessibility; teachers, materials and equipment; the socialisation mentioned above in schools like Kamurasi; to enable quality learning, equal opportunities for participation and survival and development of CWDs.

There were still barriers to equalisation of opportunities for CWDs to contribute to the development of their communities and cease to be treated as dependants.

11.2 Recommendations

For successful and sustained rehabilitation of CWDs, USDC needed to strategically think about approaches and strategies that send out strong advocacy to engage the government and other development partners with commitment to appreciate issues of disability in children to be addressed at early age and avoid or limit disability in future.

USDC needed to come out to redefine its approach to allow space for strong advocacy with the government and other CSOs supporting CWDs to specifically and clearly define their contributions to CWDs. USDC should take a firm stand and together with individual district authorities to identify what the district can do and what can be left for USDC to continue with or start.

USDC could overcome competition by going public on its mission rather than hide behind the government as partner, steering collaboration and coordination for/and effective implementation of programmes, particularly in advocacy for partnership building with other CSOs.

The Consultants reasoned that USDC should consider entering new districts with criteria that would take into consideration the dire need of CWDs (like Karamoja, Kapchorwa, etc), the readiness of the district to put resources into rehabilitation services (e.g Kasese), the need to continue services where previous support awakened the district but continuation was not possible (e.g Gulu, Kapchorwa, etc) and security of USDC and other staff is assured. However, such suggestions would challenge USDC capacity to handle new districts without dropping the current ones since the districts did not appear capable of sustaining programmes it started. Would it be effective to take on additional districts under the demands of the current strategy? Another alternative for USDC not to appear discriminative and therefore to take on more districts was to refocus its emphasis on areas that could be effectively managed on a wider coverage. The consultants made the following suggestions for such areas:

- USDC could focus on developing the capacities of and enhancing understanding and knowledge of parents in providing holistice support to the CWDs. This included enabling them communicate with and manage CWDs. It was a USDC best practice that deserved more input and wide coverage. Part of social acceptance was the ability to communicate with the children. Such capacities would therefore include learning sign language.
- USDC could focus on the development of the institutions surrounding disability in children (value systems). This included development of strong partnership and undertaking organisation development and strengthening of DPOs and other CSOs working generally with children, to strategically embrace and engage with support to CWDs.
- USDC needed to display or develop or acquire capacity and strength in programme development and advocacy in order to confront the challenges embedded in partnership and advocacy.

- Refocus and strengthen advocacy strategically to move government to assume its responsibility of strategising and engaging with social and medical rehabilitation of CWDs.
- There was also need for all stakeholders to consider aspects of rehabilitation that have been neglected, for example orientation and mobility for the blind, sign language training for families of deaf children, etc.

In response to the critical gaps and challenges identified in interventions in social and medical rehabilitation of CWDs under each Chapter above, the consultants made the following recommendations for the central government, local governments and CSOs/NGOs dealing in children, PWDs and CWDs in particular. Some of the recommendations might appear in one place, but had been considered essential for every aspect of rehabilitation of CWDs. It was hoped that engaging with these recommendations/suggestions would bring about social and medical healing for CWDs, and also bring social attitudinal transformation in the society to recognise, accept and appreciate CWDs and provide for their equitable development.

11.2.1 LAWS/LEGISLATION AND PLANNING

Laws/Legislation Interpretations for Compliance: Laws and frameworks put in place by government to support disability, be beefed up with more definitive legislation, and by practice in terms of implementation with appropriate guidelines provided to local governments. The national disability laws and policies needed to be properly interpreted into Ordinances and By-laws in order to bring them closer and prompt local governments to interpret into local situations and capture them into development plans consistently for effective implementation in addressing disability. The local and central governments together needed to ensure proper interpretation of Ordinances and By-laws, in order to ensure compliance. This would help strengthen the political will in Parliament and local Councils for disability by concrete support through legislation, advocacy and lobbying.

Data collection on Persons/Children with Disabilities: i) A framework for capacity building and coordinated and sustainable data collection on P/CWDs, analysis, storage and dissemination was needed to be developed. Impairment/disability should be documented by type/category and the extent of rehabilitation, to be able to make more informed decisions and initiate development in those areas for the central and local governments to embrace. All departments and interested stakeholders should contribute to this data collection so that the synergy produces authentic information that could be placed centrally for effective utilization.

Mainstreaming Disability into Plans and Budgets - Translation of the Human Development Pillar in the PEAP was not disability-friendly and the monitoring framework not clearly spelt out.
i) It was recommended that government, donors and CSOs needed to consider disability as a key intervention area.
ii) Local governments needed to adopt development planning based on adequate needs assessment which was broad-based. The plans should mainstream disability to eventually guide the central government.

iii) As a cross-cutting development focus, every department should allocate resources for disability so as to integrate it in every sector,
iv) Adequate budgetary allocations from the central government should be made to the local government departments/sectors managing disability and such funds be released on timely basis.

Central Government
i) More definitive legislation needed to be put in place to cater for the protection of the rights of CWDs, as existing Laws were so generalized under children,
ii) Existing guidelines and policies should be completed (such as health disability policy and rehabilitation package) and disseminated (such as the National CBR plan, guidelines for conditional grants for CBR, policy on disability, etc),
iii) MGLSD should specifically develop concrete guidelines for mainstreaming disability. Dissemination of such guidelines and policies should be education-oriented and not just sensitisation, especially for technocrats (such as DRO, DDHS, DEO and their respective departmental teams),
iv) Government should enact policies that were disability-friendly and such policies be consistently implemented,
v) A long-term education policy on CWDs that span pre-school, primary, secondary and tertiary education be prepared and implemented,
vi) Adequate budgetary allocations be made to the local government departments/sectors that manage disability and such funds be released on timely basis,
vii) Adequate monitoring and evaluation tools for monitoring disability specific interventions needed to be established.

Local Governments
a) Ensure proper interpretation of Ordinances and By-laws, in order to secure compliance,
b) Establish and ensure adequate systems of coordination for activities on disability, c) Carry out effective monitoring, review and evaluation of activities on disability.

NUDIPU/Other CSOs
a) There was need to provide updated data on disability, especially numbers by gender, age and disability categories,
b) There was need to share guidelines on disability projects with partner organisations to avoid duplication,
c) There was need to monitor, review and evaluate disability programmes in a consistent and coordinated manner,
d) There was need to focus more on lobbying and advocacy, in order to competently and sufficiently present disability issues.

USDC
a) USDC and other CSOs/CBOs need to develop and apply a stronger and coordinated strategy in the review process of the PEAP as their past inputs may not have been adequately prioritised and incorporated;
b) USDC needed to review its current advocacy and lobbying strategy in areas of policy influence in disability using a national approach.

11.2.4 HEALTH AND DISABILITY

Recruitment: The organs that recruited staff and especially rehabilitation staff needed advice during the recruitment process from rehabilitation professionals to avoid the situation where resources were wasted through redundant staff.

Prepare Medical Workers for Mainstreaming Health Services to CWDs: Mainstreaming of health services for CWDs within overall health services should be promoted. Hence, it was recommended that

i) The frontline health workers (nurses and medical assistants) needed to be trained on identification of CWDs, how to refer and how to support the parents to overcome the negative attitude within the family and community. This would widen the possibilities for early identification of CWDs,

ii) There was need to explore possibilities of drawing mental health nurses back to their original profession and perhaps widen their scope to include other disabilities,

iii) The staffing norms for rehabilitation personnel be reviewed to match the changes in the population and socio-political environment. Before this was done, a study by Public Service, Health Service Commission, Allied Health Council and district technical representatives should be carried out joint activity to assess the needs.

***Sustainable Rehabilitation Services in other Hospitals to be brought close to the community*:**

i) Consideration needed to be given to train Nursing Assistants/Health Assistants who were available in all HC IIIs and IIs to establish sustainable rehabilitation services as close to the community as possible and provide a resource for advice to parents when outreach teams (an aspiration of USDC) returned to the district centre, Their turnover was low and they were trainable,

ii) In order to sustain work at community level, engage Nursing Aid or Health Assistant to work with the PSGs in order that the medical skills and knowledge taught to parents might be actively delivered to other parents and the CWDs. Except for very common disabilities like epilepsy, it was not advisable to have single disability PSGs, as this would make meetings of the parent groups difficult,

iii) CBR programmes needed to consider adding the Environmental Officers to the cadres they train and deploy in order to reach P/CWDs with services, and

iv) The consultants supported the recommendation of the Ag. DDHS Arua, of considering reorientation and utilisation of the village health committee (VHT) to reach CWDs in a sustainable way.

***Help patients understand the difference between Physiotherapists and Occupational Therapists*:**

Health service managers needed to be sensitised about the different roles Physiotherapists and Occupational Therapists play in the rehabilitation process. For the immediate, separation of the services by having them in different locations in the hospital would help patients access and benefit from both services.

Strengthening Rehabilitation Services:

i) Kagando Hospital Orthopaedic Workshop needed to be strengthened in providing general orthopaedic assistive devices, as it was more accessible to people in Kasese than

the services provided in Fort Portal. Kagando already does provide such services. Persons disabled by leprosy and the elderly for whom the hospital catered were few, hence not fully occupying the hospital,
ii) For Karamoja region, either the government hospital in Moroto or Matany Mission hospital establishes an Orthopaedic Workshop to support the region and especially its own CBR programme.

Epilepsy condition to receive national initiative:
i) The condition of epilepsy should no longer be managed piecemeal in small projects but a national initiative driven by Government and WHO, supported by NGOs,
ii) In the short term, a study on the socio-economic burden of epilepsy and the cost/benefit of controlling fits for the family and community and nation at large be carried out and widely disseminated. The study would be an important advocacy tool for policy makers and development partners.

Recommendations on Hearing Impairment:
i) It was recommended that tertiary prevention services for deafness be systematically developed through linking with organisations of the deaf (UNAD), PSGs and the education sector,
ii) Hearing aids should be available to children with hearing impairment who were established to be able to use the aids effectively and criteria developed for deciding on who should get these aids. This was because their maintenance and repair was difficult and expensive,
iii) Special effort needed to be made at the national level to train communication specialists and made them available to children and parents,
iv) Secondary prevention (mainly treatment of ear infections) should be sustained and expanded until all HC III have a basic Ear Care Worker,
v) The provision of drugs for treatment of common ear infections should be the responsibility of the HSD and not CSOs such as USDC.

Recommendations on Visual Impairment:
i) There was need to identify the needs of blind children especially the pre-school children. No service was available for blind babies and toddlers,
ii) Cadres including teachers of the blind, Physiotherapists and Occupational Therapists should be given skills through basic and in-service training to enable them meet the needs of blind children. By having the skills for training in orientation and mobility widespread among as many cadres would increase the probability of a blind child and his/her parents receiving help. The provision of this service would also help the growing number of blind adults from various causes, ranging from chronic non-communicable diseases such as diabetes and glaucoma injury to those blinded by infectious diseases like HIV/AIDS,
iii) USDC and SSI strategically filled the gap of the absence of rehabilitation services for blind children. The efforts, however, needed to be expanded to include rehabilitation of the pre-school child and in school, provision of equipment needed to be expanded in number and the type of children supported extended to secondary school level.

Outreach Services:

i) All outreach should be coordinated with the rest of the district outreach activities in the Public Health Department of the hospital or through the office of the DDHS. NGOs should not be coordinating outreach services but as stakeholders, they should participate in the planning under the leadership of the DDHS. DDHS needed to assume this responsibility with commitment.

***Centrally placed Rresources for Outreach*:**

i) There was need to provide rehabilitation teams with resources, to reach HSDs to provide support to the sub-districts. These resources ought to be centrally placed at district headquarters until HSDs reached a level of consciousness and appreciation of the need for rehabilitation services,

ii) The same HSDs should be visited on a regular basis, for example monthly, so that regular follow-up of clients was provided,

iii) In planning for the outreaches, it should not exceed one day per week so that static and in-patient services were not marginalized.

***Guidelines for Outreach*:**

i) MOH needed to develop guidelines on outreach services and disseminate these to District Local Governments and CSOs,

ii) CWDs come from poor families and the district Local Governments should explore means of supporting the families reach hospital for definitive care.

***Re-open the Physiotherapy Unit*:**

The Disability Prevention and Rehabilitation (DPAR) Section of MOH needed to work with the MS of Adjumani Hospital to re-open the Physiotherapy Unit.

The Coordination of Orthopaedic Services:

These services needed to be strengthened at national level so that meagre services and resources were maximized to benefit the clients. The situation in the northwest, especially in Adjumani could have been averted by supervision and discussion of findings in an Orthopaedic Services Committee.

***Review of Personnel*:**

There was need for the MOH to explore available possibilities in the country and beyond to fill the gap between the specialised Clinical Officers, Nurses and Therapists and the community where the family lived. The exploration should include the potential of Nursing Aids and the possibilities of a new cadre of Rehabilitation Assistants.

11.2.5 EDUCATION AND DISABILITY

a) Ministry of Education and Sports

A long-term education policy framework on the learning process and needs of CWDs, spanning pre-school, primary, secondary and tertiary education, be prepared and implemented in order to provide CWDs with special requirements to meet their special needs for equitable education. This should include the following:

Planning and Budgeting

i) There was need for MOES to plan for education of young CWDs including the pre-school and those not able to go to school because of their disabilities,

ii) There was need for more funding to education of CWDs bearing in mind that more CWDs enrolled in schools as a result of UPE and the inclusive education policy and the fact that there were many inadequacies in the education system still hindering participation of CWDs,

iii) Remittance of subvention grants for schools with units/annexes for SNE should be more consistent and if possible increased to enable CWDs get better services,

iv) Documentation of all CWDs in schools including the mainstream schools with inclusive settings should be undertaken to facilitate the planning for it to be more informed.

Training more Teachers in SNE

i) Bearing in mind the increasing numbers of CWDs in schools especially those with inclusive settings and the shortage of teachers with skills in SNE especially in sign language and Braille, more teachers needed to be trained and those already in service oriented to help children with special needs learn. Government should challenge all teachers to go for further training in SNE including sign language and specialisation in Braille at diploma or degree levels. The government ought to plan for this and meet costs on behalf of the teachers.

ii) In the short term, the one-week sensitization should be extended to all teachers in all districts using specialists already in the field. These include SNE teachers and Inspectors in each district. This would enhance attitude change and consciousness about disability and the need to identify the CWDs to give them special treatment. This could be organised during holidays to ensure that learning was not interrupted,

iii) PSC and ESC should expedite the recognition of SNE qualifications so that teachers already qualified are motivated and others encouraged to train,

iv) MOES should strengthen linkages with districts in relation to the policies of teacher-pupil ratios and staff ceiling so that education of CWDs is not compromised,

v) MOES should train all PTC Tutors in Brail, Sign Language and in all that was required in SNE to enable them teach those subjects effectively.

Standards for monitoring/supervising SNE

i) In order to promote SNE nationally, the tool for national standards should be quickly reviewed and updated to ensure that SNE was incorporated. The tool should include the basic standards for SNE, as well as the provisions, facilities, materials and methodologies that were required in schools at different levels. Monitoring and supervision using SNE focused tools will enable identification of any inadequacies in the education system so that they were subsequently addressed,

ii) The tool used by Inspectors of Schools at district level should also be reviewed and updated to include standards for SNE.

Skills training in Teacher Training Curricula

The National ESA and SNE/Guidance and Counselling in MOES have a big role to play in this endeavour.

i) Bearing in mind that the SNE curricula at Kyambogo University and PTCs do not offer skills training in sign language, Braille and in handling children with mental impairment, the review process of the SNE curriculum in Kyambogo University currently ongoing be expedited but ensuring all skills were included. This would ensure that in future, the University would be able to train teachers who were skilled enough to teach sign language, Braille and handling of children with mental retardation. This would greatly contribute to improving SNE,
ii) Primary Teachers' Curriculum (PTC) should be urgently reviewed and updated to ensure inclusion of skills in sign language, Braille and in handling mentally impaired children,
iii) The PTC curriculum should be extended from 2 years to 3 years to give students enough time to acquire the needed skills.

Favourable Assessment System for CWDs

MOES in collaboration with UNEB should review the examination system to ensure that the needs and problems of CWDs particularly those with severe impairment are adequately catered for. Government should consider having a different assessment for CWDs with very severe cases of disability such as the deaf, the mentally impaired and those with severe physical impairment. Hence, the assessment system should be flexible and adjustable for such CWDs, to ensure fairness.

Post-Primary Institutions for CWDs

i) To supplement the existing institutions, MOES should identify and develop some post-primary institutions to absorb CWDs. These could include secondary schools such as Bwera in Kasese that are supportive or already had CWDs. Those with CWDs could be supported by training some teachers in SNE and providing educational materials and equipment such as Braille. The institutions to be developed as CWD friendly schools should be selected from different regions to reduce transport costs and problems associated with transporting CWDs,
ii) Construction of new secondary schools for CWDs should be expedited,
iii) New vocational institutions should be developed in different parts of the county to reduce distance of movement for CWDs.

Materials and Equipment for SNE

While government provided educational materials for children with special learning needs including CWDs such as text books and Braille machines, more were required to cater for the increasing numbers of CWDs especially in mainstream schools with inclusive settings. In the long run all schools even those with one CWD would be provided appropriate materials and equipment to learn.

Total Communication as a Medium of Communication in Schools

i) Government should come up with total communication as a policy in both primary and secondary schools so that there would be no communication gap between those who were hearing impaired and those not impaired among both teachers and pupils. Total communication would enable CWDs to be socially integrated in everything, as every communication would capture both the hearing and non-hearing,

ii) Sign language be taught to parents to enable them communicate with their deaf children,
iii) Official sign language be taught to deaf children if possible even before starting school, ensuring socialisation could effectively start in pre-primary schools.

Special School and Home Care for the very Severely Impaired/Mainstreaming of CWDs in Inclusive Set-up

i) Separate schools to be established for very severe cases of disability at regional level to bring CWDs closer to the home environment. The argument for special schools for very severe cases should not be watered down by turning them into ordinary special schools for such CWDs,
ii) Home-based care to be provided for by the MOES, for those too severe even to go to the special schools and find a way of providing for the education of these children so that the issue of poor family status does not become a hindrance to their education.

Emphasis on Socialisation of CWDs with Other Children

Separating CWDs hinders their early socialisation with the other children and also hinders appreciation of each others' values. There was need to mainstream CWDs to ensure that they have opportunities to interact with and learn from non-impaired children more often.

Provide more space in ordinary Primary Schools for Vocational Training

MOES needed to plan and develop well-structured schools which could form part of the mainstream primary schools to have vocational components (carpentry and joinery, block laying and concrete practice, tailoring, driving and mechanics) for CWDs to help them acquire parallel marketable vocational skills for self-sustenance.

b) Education and Local Governments/Districts

Planning and Budgeting for SNE

i) There was need for local governments to appreciate issues of CWDs and revisit the decentralization policy to establish their responsibility towards SNE, and make budgetary provisions for special learning needs of CWDs,
ii) In order to enhance ownership of SNE by both the MOES and local governments, there was need to change negative attitudes about disability and enhance consciousness among the leaders and technocrats.

c) Education and CSOs (USDC, DPOs, Parents and Other CSOs)

Influence Attitude Change through Advocacy and Sensitisation

i) In order to maintain the impetus for attitude change, CSOs such as USDC should be at the forefront in advocating for more involvement of districts in SNE,
ii) There was need to redefine issues of the rights of children in schools as a strategy in social rehabilitation. USDC should identify CSOs that would be willing to partner with on the cause of CWDs and work out strategies for networking and advocacy, for the central and local government ownership and improvement of SNE,
iii) CSOs needed to work together in advocating for mainstreaming of child rights clubs (CRCs) in all schools as an official policy of government.

Policy Change

i) Children with severe disabilities had different needs not reflected in the new government policy for OVC. CSOs should come out clearly on issues of severe disability to lobby government for support.

Policy Influencing

i) Although government was the main actor in the provision of education services to CWDs, therewais need for a roundtable to engage actors involving government and CSOs in the area of SNE to discuss and agree on areas of collaboration. This required clear MOU and regular reviews to ensure increasing input from Government,

ii) There was need for CSOs to focus more on lobbying and advocacy, in order to competently and sufficiently present disability issues.

11.2.6 SOCIAL REHABILITATION OF DISABILITY

a) Central Government

Social Rehabilitation:

i) There was need for MOH, MOES and MGLSD to come out clearly on conceptualising the rehabilitation of CWDs as social, medical, nutritional, educational healing and skills acquisition, where all sectors must be involved,

ii) The CBSD needed to articulate its role very clearly in steering social rehabilitation across/within the respective sectors and in different areas where it was supposed to be working. The clarity would help to promote consciousness about complementarities and sense of collective responsibility, and recognition for each other's professional contribution to joint efforts to rehabilitate CWDs.

Appropriate placement of Disability:

i) Disability needed to be put under Community Development to emphasise social rehabilitation and be made cross-cutting, instead of putting it under the Disability and Elderly sector of the MGLSD which had marginalized it,

ii) MOES, MGLSD and MOH needed to come out clear on the interconnectedness and inter-linkage within their professional areas and embrace the nature of collaboration, cooperation and complementarities that exist between their ministries through practice,

iii) MGLSD should specifically develop concrete guidelines for mainstreaming disability. Dissemination of such guidelines and policies should be education-oriented and not just sensitisation, especially for technocrats (such as DRO, DDHS, DEO and their respective departmental teams),

iv) Adequate M&E tools for monitoring, reviewing and evaluating disability specific interventions be established involving all stakeholders in monitoring processes in consistent and coordinated manner,

v) The CBSD should be strengthened through training and mentoring in knowledge and basic skills of mainstreaming cross-cutting issues such as disability, children and disability laws for it to become more innovative and facilitative in approach to stimulate community members to articulate their situations and also be innovative in addressing them.

***MGLSD to provide Comprehensive CBR in the Whole Country*:**
In order to address issues of social rehabilitation of CWDs, which focuses on parental and community attitudes and perceptions, thus manifesting in social rejection; the MGLSD needed to provide comprehensive CBR in the whole country. All CSOs working with P/CWDs needed to adopt it. This would enhance acknowledgement of a holistic approach to social and medical rehabilitation of P/CWDs with emphasis on interdependence among the key departments and partners.

***Continuous process of reorientation in articulating and mainstreaming of issues of disability*:**
There was need for a continuous process of reorientation of different structures and processes (both civil society and government) in articulating and mainstreaming issues of disability and of setting up a process of continuous monitoring of the disability issues so that disability was perceived and approached as part and parcel of ordinary life that must be provided for with specific emphasis within the normal activities.

b) Central and Local Governments, CSOs/USDC
i) There was need to widen the advocacy agenda to include other CSOs, donors, UHRC, NCC, etc. USDC could identify/devise strategies to facilitate the partners to enhance their capacities to articulate the areas of collaboration in rehabilitation of CWDs,
ii) PSGs were a good medium of disability management and for gathering disability information at community level and should continue to be utilized to provide community mobilization,
iii) The PSGs strengthening processes needed to be anchored in a firm place in the CBSD to ensure a sense of ownership and sustainability. This would involve co-ordination and linkage of PSGs with local government structures, although USDC would continue to work with them to incorporate and facilitate them in the area of strong advocacy and lobbying for disability,
iv) PSGs was a best practice that USDC needed to continue focus on developing capacities of parents; enhance their understanding and knowledge in order to build partnerships among them and other stakeholders in supporting their CWDs as best practice. It should be extended to other districts in management of disability among children,
v) USDC, ACDOs and medical professionals needed to come up with programmes to drill parents in rehabilitation activities so that it would become their first priority,

11.2.7 INTER-ORGANISATIONAL RELATIONSHIPS

Local Governments:
i) Local governments needed to provide strategic and strong leadership through adequate systems of coordination for activities on disability. This would create a more conducive working relationship more beneficial to the districts. The absence of adequately coordinated relationships affected the beneficiary community, education and health workers commitment and their concentration on their paid local government work,
ii) Local governments needed to acknowledge the importance of matching their resources to that of CSOs by providing counterpart funding. This built a sense of responsibility for monitoring effectiveness of implementation and ensuring that such activities had potential for continuity.

ANNEX 2

BASELINE SURVEY QUANTITATIVE DISTRICT DATA

A. PRIMARY EDUCATION ENROLLMENT 2002-2005

USDC DISTRICTS

ADJUMANI

	2002		2003		2004		2005	
Disability Type	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**
Physical Disability					38	32	45	38
Speech Impairment								
Visual impairment					88	92	108	90
Hearing impairment					147	144	135	177
Epilepsy					1	1	1	3
Mental retardation					10	5	56	70
Mental illness					45	34	26	21
Multiple disability					13	25	11	20
Other					34	26	27	30
Total					376	359	409	449

APAC

	2002		2003		2004		2005	
Disability Type	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**
Physical Disability				160	123			
Speech Impairment				118	66			
Visual impairment				294	275			
Hearing impairment				260	222			
Epilepsy				55	43			
Mental retardation				54	25			
Mental illness				5	8			
Multiple disability				27	14			
Other				8	3			
Total				981	779			

ARUA

	2002		2003		2004		2005	
Disability Type	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**
Physical Disability	264	188	223	163	336	143	286	224
Speech Impairment	94	80	62	40	140	111	90	46
Visual impairment	270	259	272	229	270	279	285	257
Hearing impairment	346	277	294	277	289	275	344	307
Epilepsy	22	62	24	46	29	43	40	59
Mental retardation	449	436	338	343	297	330	353	351
Mental illness	34	59	45	79	18	26	34	52
Multiple disability	20	25	20	17	17	13	32	23
Other	78	41	39	48	64	65	39	34
Total	1577	1427	1317	1242	1460	1285	1503	1353

HOIMA

	2002		2003		2004		2005	
Disability Type	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**
Physical Disability			5	4			248	178
Speech Impairment			2	2			102	55

Visual impairment							553	512
Hearing impairment			1				282	269
Epilepsy			1	1			48	41
Mental retardation							157	120
Mental illness			1	1			23	22
Multiple disability							63	52
Other							22	32
Total			10	8			1498	1281
LIRA								
	2002		**2003**		**2004**		**2005**	
Disability Type	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**
Physical Disability	282	218	322	266	393	331	458	339
Speech Impairment	179	92	188	105	230	133	314	153
Visual impairment	248	158	280	180	374	271	499	367
Hearing impairment	194	130	210	163	307	216	439	352
Epilepsy	76	49	80	52	132	86	148	108
Mental retardation	101	68	105	70	137	89	181	145
Mental illness	20	13	28	18	27	23	30	30
Multiple disability	29	16	29	20	42	25	61	41
Other	6		10	5	17	4	12	9
Total	1135	744	1252	879	1659	1178	2142	1544
LUWERO								
	2002		**2003**		**2004**		**2005**	
Disability Type	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**
Physical Disability	70	56	94	66	88	65	95	63
Speech Impairment	46	31	58	49	67	41	76	42
Visual impairment	75	60	69	64	60	62	81	74
Hearing impairment	90	61	97	95	96	96	106	103
Epilepsy	35	29	33	32	41	32	31	30
Mental retardation	162	160	177	172	216	171	233	187
Mental illness	29	27	38	22	34	30	43	36
Multiple disability	10	12	16	16	22	23	38	35
Other	1	2	5	1	5	7	7	11
Total	518	438	587	517	629	527	710	581
MASAKA								
	2002		2003		**2004**		**2005**	
Disability Type	**Male**	**Female**	Male	**Female**	**Male**	**Female**	**Male**	**Female**
Physical Disability	155	125	190	188	193	161	208	176
Speech Impairment	75	67	111	95	125	120	234	165
Visual impairment	168	142	173	248	209	229	246	230
Hearing impairment	105	118	115	182	244	170	178	166
Epilepsy	24	19	25	28	204	51	48	41
Mental retardation	183	171	182	157	25	13154	212	236
Mental illness	12	8	14	15	29	27	26	29
Multiple disability	21	21	18	19	13	26	38	27
Other	3	4		6		9	23	32
Total	746	675	828	938	1042	13947	1213	1102
MASINDI								
	2002		2003		**2004**		**2005**	

Disability Type	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**
Physical Disability	196	132	224	141	219	156	24	10
Speech Impairment	135	104	185	121	199	138	12	8
Visual impairment	461	462	565	510	590	539	103	107
Hearing impairment	320	298	366	321	447	448	67	58
Epilepsy	62	56	93	74	105	84	10	10
Mental retardation	162	164	243	247	220	198	7	15
Mental illness	13	10	15	15	17	24	2	1
Multiple disability	39	22	40	22	34	20	12	7
Other	5	4	17	12	10	10		
Total	1393	1252	1748	1463	1841	1617	237	216
MOYO								
	2002		**2003**		**2004**		**2005**	
Disability Type	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**
Physical Disability	59	47	48	44	50	45	58	44
Speech Impairment	6	7	10	5	11	5	4	3
Visual impairment	55	52	56	50	64	65	69	66
Hearing impairment	110	73	69	58	101	82	88	85
Epilepsy	15	18	19	21	20	27	22	21
Mental retardation	45	46	37	34	35	32	62	36
Mental illness	5	1	4	4	3	3		
Multiple disability	4	1	4	1	4	6	7	3
Other					1	2		
Total	299	245	247	217	289	267	310	258
NEBBI								
	2002		**2003**		**2004**		**2005**	
Disability Type	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**
Physical Disability	43	33	47	36	45	30	58	53
Speech Impairment	32	20	36	12	52	21	47	21
Visual impairment	96	73	98	73	72	48	107	74
Hearing impairment	88	55	81	51	50	38	122	83
Epilepsy	14	11	15	13	16	20	15	16
Mental retardation	11	11	19	10	7	5	33	27
Mental illness			2		10	1	4	7
Multiple disability	3	7	8	5	4	4	4	7
Other		1		1		1		1
Total	287	211	306	201	256	168	390	289
SEMBABULE								
	2002		**2003**		**2004**		**2005**	
Disability Type	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**
Physical Disability	184	144	200	161	221	189	225	193
Speech Impairment	118	112	120	111	137	124	137	107
Visual impairment	108	95	152	146	145	120	130	125
Hearing impairment	143	57	147	135	145	137	136	108
Epilepsy	45	31	33	31	45	39	69	68
Mental retardation	239	206	254	206	261	237	259	255
Mental illness	25	22	21	24	44	28	34	31
Multiple disability	17	10	15	6	24	21	29	25
Other		1		2	2	4	3	4

Total	879	678	942	822	1024	899	1022	916
SOROTI								
	2002		**2003**		**2004**		**2005**	
Disability Type	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**
Physical Disability	2	1			32	25	58	37
Speech Impairment					58	52	89	74
Visual impairment	3	1			100	80	138	117
Hearing impairment	9	8			33	49	64	96
Epilepsy		2			15	20	19	26
Mental retardation	4	5			6	11	44	34
Mental illness	2	1			1		7	8
Multiple disability					3	9	5	2
Other					1	7	1	8
Total	20	18			249	253	425	402
YUMBE								
	2002		**2003**		**2004**		**2005**	
Disability Type	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**
Physical Disability	8	9	2				27	24
Speech Impairment	4	5	5				14	4
Visual impairment	8	3					23	28
Hearing impairment	9	10	2				22	14
Epilepsy	3	1	1	5			3	9
Mental retardation	17	5					10	2
Mental illness	1	2					4	11
Multiple disability							8	3
Other							1	4
Total	50	35	10	5			112	99
NAKASONGOLA								
	2002		**2003**		**2004**		**2005**	
Disability Type	**Male**	**Female**	Male	**Female**	**Male**	**Female**	**Male**	**Female**
Physical Disability	66	48	68	28	60	53	47	28
Speech Impairment	12	9	12	18	20	18	19	17
Visual impairment	76	107	71	90	68	57	39	25
Hearing impairment	94	109	80	83	87	72	58	49
Epilepsy	4	11	9	12	10	8	10	11
Mental retardation	104	88	55	51	51	49	72	47
Mental illness	7	8	10	13	11	14	16	24
Multiple disability	5	2	14	8	8	13	15	12
Other	2		1		2			
Total	368	382	319	303	315	284	276	213
JINJA								
	2002		**2003**		**2004**		**2005**	
Disability Type	**Male**	**Female**	Male	**Female**	**Male**	**Female**	**Male**	**Female**
Physical Disability	148	108	117	85	131	90	208	176
Speech Impairment	22	14	24	10	32	21	52	37
Visual impairment	230	229	257	288	281	320	465	522
Hearing impairment	148	153	160	182	161	162	222	242
Epilepsy	16	6	11	4	11	14	15	22
Mental retardation	152	98	165	151	156	111	214	159

Mental illness	1	1	2	2	5	2	17	13
Multiple disability	5	5	7	6	14	9	20	20
Other	5	12	11	9	9	5	18	23
Total	727	626	754	737	800	734	1231	1214

NON USDC DISTRICTS

GULU

	2002		2003		2004		2005	
Disability Type	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**
Physical Disability	5	4	9	6	11	5	13	8
Speech Impairment								
Visual impairment	30	14	47	23	45	44	50	26
Hearing impairment	35	27	40	27	82	32	86	46
Epilepsy	3	1	1	1	1	11	3	2
Mental retardation			6	4	1	3	10	11
Mental illness							2	
Multiple disability					1			1
Total	73	46	103	61	141	95	164	94

KALANGALA

	2002		2003		2004		2005	
Disability Type	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**
Physical Disability	16	11	14	12	14	14	19	15
Speech Impairment	6	5	5	2	10	12	4	3
Visual impairment	26	24	41	48	38	40	58	54
Hearing impairment	37	32	40	38	42	46	45	39
Epilepsy	12	5	8	6	9	6	5	5
Mental retardation	160	155	169	152	182	178	126	127
Mental illness	7	4	6	3	4	3	29	18
Multiple disability	1	1	5	3	5	3	4	5
Other		1	1	2	1	1	13	9
Total	265	238	289	266	305	303	303	275

KAPCHORWA

	2002		2003		2004		2005	
Disability Type	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**
Physical Disability			161	123	102	77	178	172
Speech Impairment			56	48			121	59
Visual impairment			192	157	142	141	234	226
Hearing impairment			141	158	106	129	156	144
Epilepsy			21	18	4	2	30	32
Mental retardation			139	104	116	110	166	161
Mental illness			14	11	1	7	29	29
Multiple disability			26	19	11	8	35	23
Other			1	2	14	10	5	5
Total			751	640	496	484	954	851

NTUNGAMO

	2002		2003		2004		2005	
Disability Type	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**
Physical Disability					131	100	8	7
Speech Impairment					28	10	2	2

Visual impairment					55	30	2	1
Hearing impairment					100	82	2	1
Epilepsy					11	8		
Mental retardation					12	9		
Mental illness					20	13		2
Multiple disability					6	1		1
Other					3	2		
Total					366	255	14	14

TORORO								
	2002		2003		2004		2005	
Disability Type	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**
Physical Disability	185	139	189	123	218	151	258	200
Speech Impairment	57	35	81	43	102	60	142	57
Visual impairment	95	112	107	122	107	120	159	182
Hearing impairment	142	161	210	195	207	189	251	241
Epilepsy	24	45	27	53	16	50	41	51
Mental retardation	71	73	94	70	132	91	197	131
Mental illness	2	5	9	10	19	15	11	13
Multiple disability	9	11	21	22	30	32	39	38
Other	9	14	11	18	9	17	12	26
Total	594	595	749	656	840	725	1110	939

KABAROLE								
	2002		2003		2004		2005	
Disability Type	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**
Physical Disability	71	39	126	87	101	77	138	83
Speech Impairment	27	8	53	26	43	19	62	17
Visual impairment	31	38	103	90	93	86	104	97
Hearing impairment	33	29	94	69	95	85	86	61
Epilepsy	3	2	7	5	9	4	11	6
Mental retardation	33	22	70	38	72	39	75	41
Mental illness	3	2	3	1	1	1	3	5
Multiple disability	20	9	20	11	26	13	16	8
Other	3		13	3	8	4	6	8
Total	224	149	489	330	448	328	501	326

MOROTO								
	2002		2003		2004		2005	
Disability Type	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**
Physical Disability			44	29	38	33	36	33
Speech Impairment			7	5	8	5	7	7
Visual impairment			17	19	22	17	18	17
Hearing impairment			33	17	19	19	28	25
Epilepsy			11	9	6	15	13	14
Mental retardation			2	3	3	9	3	8
Mental illness				2		5		5
Multiple disability			6	2	8	4	13	4
Other				2		2	1	2
Total			120	88	104	109	119	115

D. ACCESS OF P/CWDs TO REHABILITATIVE HEALTH SERVICES BY DISTRICT BY SEX

DISTRICT	YEAR	MALE 0-18	FEMALE 0-18	MALE 18+	FEMALE 18+	Total
USDC						
MASAKA	2002	3832	3249	2114	2761	11956
	2003	2429	2087	1550	1809	7875
	2004	597	3811	4228	4205	12841
	2005	4062	2805	2153	2750	11770
Total		10920	11952	10045	11525	
HOIMA	2002	48	32	2	2	84
	2003	41	12	6	2	61
	2004	60	47	4	11	122
	2005	48	37	4		89
Total		197	128	16	15	
LUWERO	2002	782	704	184	152	1822
	2003	669	588	206	192	1655
	2004	675	579	195	191	1640
	2005	261	218	116	116	711
Total		2387	2089	701	651	
MASINDI	2002	1	2			3
	2003		3	7	4	
	2004	92	63	85	71	311
	2005					
Total		93	68	92	75	
JINJA	2002	1366	1369	634	549	3918
	2003	858	667	399	356	2280
	2004	1075	759	437	450	2721
	2005	697	446	196	222	1561
Total		3996	3241	1666	1577	
LIRA	2002	62	69	23	39	193
	2003	71	70	33	34	208
	2004					
	2005					
Total		133	139	56	73	
ADJUMANI	2002	1		1	1	3
	2003	2	2	6	7	17
	2004	12	10	21	22	65
	2005	942	763	638	706	3049
Total		957	775	666	736	
MOYO	2002	981	807	345	205	2338
	2003	770	627	364	318	2079
	2004	645	515	291	255	1706
	2005	535	457	374	307	1673
Total		2931	2406	1374	1085	
NEBBI	2002	171	107	44	64	386
	2003	199	89	39	80	407
	2004	104	25	39	18	186

	2005	122	87	66	70	345
Total		596	308	188	232	
APAC	2002	15	18	29	26	88
	2003	340	470	101	127	1038
	2004	650	614	513	464	2241
	2005	454	447	382	303	1586
Total		1459	1549	1025	920	
ARUA	2002	323	351	218	272	1164
	2003	241	195	203	266	905
	2004	200	229	152	231	812
	2005	108	89	169	153	519
Total		872	864	742	922	
NAKASONGOLA	2002	60	38	2	3	103
	2003	59	57	7	3	126
	2004	40	36	6	1	83
	2005	46	54	7	4	111
Total		205	185	22	11	
SEMBABULE	2002	78	92	26	16	212
	2003	87	108	46	56	297
	2004	369	396	79	109	953
	2005	409	450	74	109	1042
Total		943	1046	225	290	
SOROTI	2002					
	2003			8	8	16
	2004	10	23	44	22	99
	2005	10	23	33	32	98
Total		20	46	85	62	
NON USDC DISTRICTS						
TORORO	2002	719	338	155	263	1475
	2003	867	643	432	490	2432
	2004	1174	791	388	502	2855
	2005	799	654	425	613	2491
Total		3559	2426	1400	1868	
GULU	2002	18	4	3	2	27
	2003	379	347	310	258	1294
	2004	286	275	194	137	892
	2005	418	231	360	306	1315
Total		1101	857	867	703	
KALANGALA	2002	27	16	8	9	60
	2003	60	57	43	43	203
	2004	74	51	42	46	213
	2005	123	82	67	60	332
Total		284	206	160	158	
NTUNGAMO	2002					
	2003	4	9	17	44	74
	2004	16	31	29	31	107
	2005	23	26	16	16	81
Total		43	66	62	91	

MOROTO	2002					
	2003	132	73	147	54	406
	2004	47	35	76	48	159
	2005	62	49	162	100	373
Total		241	157	385	202	
KABAROLE	2002					
	2003					
	2004	503	617	2618	2513	6251
	2005					
Total		503	617	2618	2513	
KAPCHORWA	2002					
	2003	91	98	86	70	345
	2004			40	36	76
	2005	525	792	237	291	
Total		616	890	363	397	

E. ACCESS TO REHABILITATIVE HEALTH SERVICES BY TYPE OF IMPAIRMENT 2002-2005

YEAR - 2002									
DISABILITY									
DISTRICT	Physical Disability	Speech Impairment	Visual Impairment	Hearing Impairment	Epilepsy	Mental Retardation	Mental Illness	Multiple Disabilities	Total
USDC									
Adjumani	1				2				3
Apac	123							35	158
Arua	150	7	562	4	867		277	86	1953
Hoima	158								158
Jinja	831		269	295	1919		692		4006
Lira	21		73		79		12		185
Luwero	1539	46	27	66	374	75	121	40	2288
Masaka	361	450	2601	502	4307	810	3524	217	12772
Masindi	4								4
Moyo	28		893	757	559				2237
Nakasongola	38	2					101		141
Nebbi			161	91	50		7		309
Sembabule	45	8					179	7	239
Soroti									
Total	3299	513	4586	1715	8157	885	4913	385	
Non USDC									
Gulu	5		5	5	5		3		23
Kabarole									
Kalangala	6		18	8	10		3	2	47
Kapchorwa									
Moroto									
Ntungamo									
Tororo	173		579	281	127		31	19	1210
Total	11		23	13	15		6	2	
YEAR - 2003									
DISABILITY									

DISTRICT	Physical Disability	Speech Impairment	Visual Impairment	Hearing Impairment	Epilepsy	Mental Retardation	Mental Illness	Multiple Disabilities	Total
USDC									
Adjumani					15		2		17
Apac	548	37	122	223	28		151	201	1310
Arua	174		256	3		45	572	117	1167
Hoima	98								98
Jinja	40	9	440	297	828		396	6	2016
Lira	25		80		76		19		200
Luwero	1588	21	23	45	288	30	32	57	2084
Masaka	1114	264	901	680	2723	153	1819	253	7907
Masindi	8						9		17
Moyo	50		493	701	805				2049
Nakasongola	18						112		130
Nebbi			124	120	87				331
Sembabule	27	9	53	51			153	14	307
Soroti	4	5	8	4			25	5	51
Total	3694	345	2500	2124	4850	228	3290	653	
Non USDC									
Gulu	587		8	8	456	60	331		1450
Kabarole									
Kalangala	27	16	40	49	41	10	28	4	215
Kapchorwa	24		96	211	19		10		360
Moroto	569								569
Ntungamo			9		71		3		83
Tororo	419		298	317	1067		248	23	2372
Total	1626	16	451	585	1654	70	620	27	
YEAR - 2004									
DISABILITY									
DISTRICT	**Physical Disability**	**Speech Impairment**	**Visual Impairment**	**Hearing Impairment**	**Epilepsy**	**Mental Retardation**	**Mental Illness**	**Multiple Disabilities**	**Total**
USDC									

Adjumani	16		1	13	38	1	4		73
Apac							1131	656	1787
Arua	128	7	346				441	62	984
Hoima	175								175
Jinja	86	50	515	414	1054		298		2417
Lira									
Luwero	1504	48	25	55	320	39	37	59	2087
Masaka	4972	440	5736	1020	3983	395	1924	470	18940
Masindi	1				291		19		311
Moyo	63		468	429	761				1721
Nakasongola	22						83	0	105
Nebbi			25	23	120				168
Sembabule	15			6			331	39	391
Soroti				4			62	49	115
Total	6982	545	7116	1964	6567	435	4330	1335	
NON USDC									
Gulu	34		8	26	477	52	266		863
Kabarole	2047	76	2890	470	81		612	150	6326
Kalangala	11	4	46	48	37	12	37	6	201
Kapchorwa	26		55	25			10		116
Moroto	284								284
Ntungamo	1		9		73		22		105
Tororo	645		560	328	1002		176	15	2726
Total	3048	80	3568	897	1670	64	1123	171	

YEAR - 2005									
	DISABILITY								
DISTRICT	**Physical Disability**	**Speech Impairment**	**Visual Impairment**	**Hearing Impairment**	**Epilepsy**	**Mental Retardation**	**Mental Illness**	**Multiple Disabilities**	**Total**
USDC									
Adjumani	493	12	218	26	1686	73	631	25	3164
Apac							783	558	1341
Arua	24	7	89	11	11		484	32	658

Hoima	133								133
Jinja	14		422	305	445		103		1289
Lira									
Luwero	187	2	143	33	371	2	24	11	773
Masaka	878	292	1753	507	4864	339	2601	195	11429
Masindi									
Moyo	12		758	416	615				1801
Nakasongola	12						113		125
Nebbi	3		15	138	134		40		330
Sembabule	10						1039	12	1061
Soroti	4			15			62	41	122
Total	1770	313	3398	1451	8126	414	5880	874	
NON USDC									
Gulu	32	2	388	8	389	32	301		1152
Kabarole									
Kalangala	82	19	37	30	79	30	47	14	338
Kapchorwa	89	11	180	1522	40		56	3	1901
Moroto	583								583
Ntungamo			5		62		11		78
Tororo	634		403	242	958		198	22	2457
Total	1420	32	1013	1802	1528	62	613	39	

F. ACCESS TO REHABILITATIVE HEALTH SERVICES BY TYPE OF SERVICE BY DISTRICT 2002-2005

USDC DISTRICT	YEAR	SURGERY	TREATMENT	ASSISTIVE DEVICE	THERAPY	Total
MASAKA	2002	644	11346	154	1099	13243
	2003	228	6618	248	1198	8292
	2004	1934	11703	1340	2091	17068
	2005	3	10597	14	1077	11691
Total		2809	40264	1756	5465	
HOIMA	2002	83	7			90
	2003	61				61
	2004	110				110
	2005	77	15			92
Total		331	22			
LUWERO	2002	164	738	204	801	1907
	2003	139	511	254	825	1729
	2004	139	569	201	805	1714
	2005	209	330	12	67	618
Total		651	2148	671	2498	
MASINDI	2002	2	1			3
	2003	5	14			19
	2004	292	34			326
	2005					
Total		299	49			
JINJA	2002	222	1166		213	1601
	2003	9	1102	6		1117
	2004	43	1397			1440
	2005		950			950
Total		274	4615	6	213	
LIRA	2002					
	2003					
	2004					
	2005					
Total						
ADJUMANI	2002		3			3

	2003		12			12
	2004		73		1	74
	2005	50	3238		73	3361
Total		50	3326		74	
MOYO	2002		506			506
	2003		786	9		795
	2004		807			807
	2005		813			813
Total			2912	9		
NEBBI	2002		312			312
	2003		331			331
	2004		168			168
	2005		324			324
Total			1135			
APAC	2002	19	20	18	21	
	2003	19	20	18	21	
	2004	19	20	18	21	
	2005	19	20	18	21	
Total		76	80	72	84	
ARUA	2002	190	200	180	210	
	2003	209	220	198	231	
	2004	247	260	234	273	
	2005	247	260	234	273	
Total		893	940	846	987	
NAKASONGOLA	2002	38	40	36		
	2003	38	40	36	42	
	2004	38	40	36	42	
	2005	38	40	36	42	
Total		152	160	144	168	
SEMBABULE	2002	76	40	72	84	
	2003	57	40	54	63	
	2004	57	40	54	63	
	2005	57	40	54	63	
Total		247	160	234	273	

SOROTI	2002					
	2003	19	20	18	21	
	2004	19	20	18	21	
	2005	19	20	18	21	
Total		57	60	54	63	
NON USDC						
MOROTO	2002					
	2003			76	203	279
	2004			37	169	206
	2005			94	280	374
Total				207	652	
NTUNGAMO	2002					
	2003		76			76
	2004		109			109
	2005		67			67
Total			252			
TORORO	2002		1047	121	4	1172
	2003	7	2054	128	172	2354
	2004		2061	130	392	2583
	2005		1920	49	464	2433
Total		7	7082	428	1032	
GULU	2002	3	22			25
	2003		1003	388	60	1451
	2004	11	974		52	1037
	2005	17	1023	217	32	1289
Total		31	3022	605	144	
KALANGALA	2002	2	48		1	51
	2003	12	159	23	21	215
	2004	2	190	8	16	216
	2005	6	259	31	42	338
Total		22	656	62	80	
KABAROLE	2002			19		

	2003					
	2004	19	20	18	21	
	2005					
Total		19	20	18	21	
KAPCHORWA	2002					
	2003	19	20	18	21	
	2004	19	20	36	21	
	2005	38	40		42	
Total		76	80	72	84	

G. SUMMARY BY TYPE OF HEALTH TRAINING BY DISTRICT USDC PRESENCE/ABSENCE

Type of Training	District Type USDC Districts	 Non USDC Districts	Total
Capacity building on disability		2	2
Eye Care (Opthalmic)	17	6	23
Nursing	1	5	6
Physiotherapy		6	6
Occupational therapy	1	2	3
Orthopaedics	5	11	16
General Surgary		1	1
Opthalomology	6	10	16
Psychriatry	11	7	18
Senstisation on disability		13	13
Hearing Impairment	48	4	52
General Medicine		1	1
Clinical Officer		2	2
Visual	6		6
Mental Health	64	16	80
Workshop management	1		1
UCFP	2		2
SBEB Production	1		1
TB	2		2
CBR	1	1	2
Leprosy	1		1
Shoes	3	19	22
Total	170	106	276

F. SUMMARY OF HEALTH TRAINING BY DISTRICT BY LENGTH OF TRAINING

District	Length of Training 1 week - 1 month	 2 - 5 months	 6 - 11 months	 1 Yr	 2 yr	 3 yr	 above 3 yrs	Total
Tororo			3	3	2	5	2	15
Kasese			16	1	3	6		26
Masaka	27							27
Sembabule	17							17
Kabarole		2			4	7	2	15
Ntungamo		1		2		6		9
Moyo	24	3						27
Adjumani	13	1	1	1	8	4		28
Moroto		2	1		2	2		7
Jinja	26							26
Arua	3	7	2	1		2		15
Kapchorwa	19			1	1	1		22
Hoima	1							1
Luwero	12				1	16		29
Kalangala		2	1			3		6
Gulu	1					4		5
Total	143	18	24	9	21	56	4	275

H. SUMMARY BY TYPE OF QUALITIFICATIONS IN REHABILITATIVE HEALTH BY DISTRICT

	Type of Qualification						
	Certificate	Diploma	Degree	None	Postgraduate Diploma	Attendance Certificate	Total
Tororo	9	5		2			16
Kasasa	19	5	1		1		26
Kabarole	5	8	2				15
Ntungamo	2	7					9
Moyo	27						27
Adjumani	19	9					28
Moroto	4	3					7
Jinja	26						26
Arua	11	4					15
Kapchorwa	20	2					22
Hoima						1	1
Luwero	12	17					29
Kalangala	4	2					6
Gulu	1	4					5
	159	66	3	2	1	1	232

I. SUMMARY OF TYPE OF REHABILITATIVE HEALTH TRAINING BY QUALIFICATION

	Type of Qualification By Qualification						
	Certificate	Diploma	Degree	None	Post gratuate Diploma	Attendance Certificate	Total
Capacity building on disability				2			**2**
Eye Care (Opthalmic)	17	6					**23**
Nursing	2	4					**6**
Physiotherapy		6					**6**
Occupational therapy	1	2					**3**
Orthopaedics	4	12					**16**
General Surgary			1				**1**
Opthalomology	6	9			1		**16**
Psychriatry	4	14					**18**
Senstisation on disability	13						**13**
Hearing Impairment	18	5					**23**
General Medicine			1				**1**
Clinical Officer	1		1				**2**
Visual	6						**6**
Mental Health	60	5					**65**
Workshop management	1						**1**
UCFP	2						**2**
SBEB Production	1						**1**
TB	1	1					**2**
CBR		1				1	**2**
Leprosy		1					**1**
Shoes	22						**22**
Total	159	66	3	2	1	1	**232**