

# CARE FOR PEOPLE LIVING WITH DISABILITIES IN THE WEST NILE REGION OF UGANDA: EX-POST EVALUATION OF A PROGRAMME IMPLEMENTED BY DOCTORS WITH AFRICA CUAMM

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## ***Abstract***

*Disability is a common occurrence in many countries and a subject of much discussion and lobby. People with disability (PWD) are frequently segregated in society and by-passed for many opportunities. Stigma hinders their potential contribution to society. Doctors with Africa CUAMM, an Italian NGO, started a project to improve the life of PWD in the West Nile region in north-western Uganda in 2003. An orthopaedic workshop, a physiotherapy unit and a community-based rehabilitation programme were set up as part of the project.*

*This ex-post evaluation found that the project made an important contribution to the life of the PWD through its activities, which were handed over to the local referral hospital for continuation after three years. The services have been maintained and their utilisation has been expanded through a network of outreach clinics. Community-based rehabilitation (CBR) workers mobilise the community for disability assessment and supplement the output of qualified health workers in service delivery. However, the quality of care during clinics is still poor on account of large numbers. In the face of the departure of the international NGO, a new local NGO has been formed by stakeholders to take over some functions previously done by the international NGO, such as advocacy and resource mobilisation. This is an example of a local resource facilitating the sustainability of good initiatives.*

*Among other things, this paper recommends that the CBR programme be strengthened and expanded to cover the entire region. It also recommends that outreach clinics should be planned in a better way in order to reduce the workload of the health workers and improve the quality of care. It also recommends that the local NGO should be supported to fit into the shoes of the more experienced but exiting international NGO.*

## **Background**

In August 2003, Doctors with Africa CUAMM, an Italian international NGO which has been in Uganda since the late 1950s, initiated a project in Uganda's West Nile Region to promote the development of a basic package of services for people with disability (PWD). The project was designed in coordination with the Disability Section of the Ugandan Ministry of Health and in collaboration with local stakeholders, mainly: Arua Regional Referral Hospital, the administrations of the then Arua and Nebbi districts and local associations of PWD. The West Nile region, with a projected total population of 3.1 million people in 2010 (about 10% of Uganda's national figure) has a high population of people with disability. The major causes of disability

are limb loss and other sensory loss. The region has experienced five major waves of armed conflict since 1978. Many people, especially the civilians, suffered physical injuries due to the violence, especially from anti-personnel landmines which were one of the main weapons used indiscriminately. Although most local fighting had ended by 2005, the region remains under threat of eruption of armed conflict due to its geographic location, being ensconced between the zones of operation of the Lord's Resistance army in Uganda to its east, Sudan People's Liberation Army to its north and the unstable Ituri Province of the Democratic Republic of Congo to its west. Between 2006 and 2010, close to 200 people from the region had a limb amputation at Arua Regional Referral Hospital

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for various reasons (general trauma, gunshots, disease, congenital problem and animal bites), but with violence being a leading contributor. Apart from war-related injuries and other causes of physical disability such as birth trauma, the region also knows a high prevalence of epilepsy although no population-based study has been conducted to establish the actual prevalence and incidence. However, the pattern of high prevalence of onchocerciasis in certain areas of the region seems to overlap too conveniently with the distribution of a high incidence of epilepsy to be ignored.

Therefore, the CUAMM project had five main areas of commitment and intervention, namely, the creation *de novo* of an orthopaedic workshop in Arua Regional Referral Hospital for the production of assistive devices for people with mobility impairment (especially focusing on lower limb prostheses); strengthening of the physiotherapy unit of the hospital; the creation of a network of epilepsy clinics to ensure diagnosis, treatment and follow-up of patients with epilepsy; the establishment of a network of community-based rehabilitation (CBR) workers to handle CBR activities and to act as contact persons between the communities and the health services; and the provision of supportive means to facilitate the access of PWD to the health services provided in Arua Regional Referral Hospital (especially the orthopaedic workshop, but also the periodical orthopaedic and plastic surgical camps). Advocacy for PWD was not ignored, but was looked at as a component to be built over time, based on the experience to be gained by project staff (DwA CUAMM, 2007a).

The project, co-funded by CUAMM, its support groups in Italy and the Italian Cooperation (the international development cooperation arm of the Italian Ministry of Foreign Affairs), was completed in July 2006. By then, the orthopaedic workshop had been established and was producing prostheses. The physiotherapy unit was well-facilitated and operational. Epilepsy clinics had been established throughout all the then six districts in the region and access to anti-epileptic treatment had increased (DwA CUAMM, 2008c; Odaga et al., 2008). A network of twelve trained CBR workers had been set up in the region. They operated in two sub-counties of Arua District (Rigbo and Rhino Camp) and three sub-counties of Nebbi District (Jango-Okoro, Erussi and Pakwach). The CBR workers operated at administrative parish level. In Arua District, there were two CBR workers per parish, while in Nebbi, one CBR worker was responsible for several parishes. The CBR workers helped to identify patients with epilepsy and disability for medical or surgical attention and to follow up of those who needed to attend regular

clinic days. The project was handed over to the district administrations as the lead local stakeholders at the end of 2006. Since then, Doctors with Africa CUAMM has continued to support the districts to sustain the activities started by the project, albeit from aside and at a lower scale of financial commitment from the NGO. Financial assistance from CUAMM comes directly from community support groups in Italy, some of which developed direct partnerships with the local stakeholders. The main areas of support during this post-project phase comprise of support to the CBR workers, the epilepsy clinics, the orthopaedic workshop in Arua Regional Referral Hospital, and support to the physiotherapy units in all the other hospitals of the region. Support is also given to activities of community sensitisation and mobilisation to use the services, which is done by several stakeholders such as the sub-county authorities, and the Arua District Union of Persons with Disabilities (ADUPED), the umbrella organisation which unites all organisations of PWD and which is local branch of the National Union of Disabled Persons of Uganda (NUDIPU) (DwA CUAMM, 2007b). The support currently offered mainly comprises of assistance with means of transport to outreach sites (CBR workers were also given bicycles), ensuring the availability of medicines and supplies, air-time for radio and telephone communication, and data management.

The orthopaedic workshop in Arua Regional Referral Hospital has produced a wide range of assistive devices since its inception in 2006, particularly the lower limb prostheses, crutches, corsets, cervical collars, splints and, more recently, wheelchairs (DwA CUAMM, 2008g). In the period January-March 2009, the workshop provided a total of 42 items, of which 6 were lower limb prostheses and 22 corsets. Its staff also trains patients on the use of prostheses and crutches, as well as providing physiotherapy. Other rehabilitative services offered by the hospital, such as primary eye care, and ear-nose-and-throat (ENT) services have piggy-backed on the existence of this activity and expanded their reach too. Despite some facilitation from the NGO for the transportation and accommodation of patients when they come for care in Arua Regional Referral Hospital, the observed utilisation of these services has been lower than the estimated need in the West Nile Region. This apparent under-utilisation of the services may have different causes. The causes most commonly mentioned by the stakeholders are the unavailability of means of transport for patients from distant and remote villages and the financial constraints for securing transport to and accommodation in Arua for the patients and their attendants (DwA CUAMM, 2007b; DwA CUAMM, 2008a). However, there may be other factors. For example, in a village not far away

from the hospital, where distance was clearly not a problem, many people needing operation for cataract had never come for treatment. Despite the use of social media like the radio to announce the availability of the services, lack of awareness about the services and the attitudes of families, communities and local leaders towards PWD and their needs may play a role and still be a valid explanation for the non-use of the services. These aspects, especially the latter two, have received limited attention and are not well investigated and documented.

During the project period, clients in need of rehabilitation services were obtained passively through snowball information by hospital staff and former clients, and later through the trained CBR workers. In total, the project trained 20 CBR workers who are now active in three sub-counties of Nebbi district and in six parishes of two sub-counties in Arua district. After the introduction of the CBR workers, PWD from their sub-counties were referred for the services at Arua Regional Referral Hospital. PWD from other sub-counties were only identified and referred by hospital staff whenever they did outreach activities into their areas for other purposes. Both these were ineffective approaches because they did not yield many clients, in spite of good cooperation with the local health units. In the new approach employed by the local stakeholders after the official end of the project, outreach activities for identifying PWD are organised by health staff. They advertise clinic days and hold radio talk-shows about the services using public media and go out to the health units in search of clients. Many PWD turn up and those with correctable problems are identified. Building on this experience, systematic outreach visits have become the established strategy to identify PWD since the beginning of 2009 (DWA CUAMM, 2009). Three such outreach visits were done in the first half of 2009. There is an outreach activity every three months organised in a different sub-county every time. After thorough information of village leaders and consensus on the best date and venue for the identification visit, information is sent out to the general population using public media and through community leaders. A multi-disciplinary team of health workers from Arua Regional Referral Hospital comes to the selected health unit and registers all candidates for treatment and follow-up of epilepsy, assessment and review of clients with motor disability, visual and hearing impairment, and other related problems is done to determine the need for surgery, prosthesis, wheelchair, crutches, and any other support. It has been observed that when public media e.g. radio, are used for mobilisation, people come from much farther away than the target areas, even from beyond the target districts. It has also been observed

that announcements linked to this project attract more clients than those from other organisations providing a similar service, suggesting that the project was well known and trusted. Radio talk-shows have increased the awareness and also gave an opportunity for people to ask questions about the diseases and the services.

Community-based rehabilitation (CBR) has been advocated internationally for more than 30 years as a core strategy for improvement of the quality of life of PWD. Among other stakeholders, it is promoted by WHO (WHO, 1994; ILO/UNESCO/WHO, 2004) and endorsed by African countries. The Government of Uganda took up the CBR approach in 1994 (Ministry of Health Uganda, 1999). Standards were developed for three levels of local administration, the community, the sub-county and the district, with a framework of staff and services that should be available at different levels of administration and health care services. CBR is implemented by government structures as well as by several non-governmental organizations. Over the years, the concept of CBR has evolved. It started as a strategy for provision of rehabilitation services close to home but has evolved into a community development programme that addresses all factors influencing quality of life of PWD, with increased emphasis on human rights and full participation of disabled persons in society (WHO/SHIA, 2002). An evaluation of CBR programmes in several countries showed that they have had a positive impact on raising the awareness of human and political rights of PWD, on increasing education opportunities for children with disability, on social rehabilitation and counselling, thus resulting in better self-image, self-determination, self-reliance, empowerment and social inclusion. Initiatives for income generation and maintenance are among the most successful and appreciated interventions. Yet CBR programmes have been less successful in providing good medical assistance, physical rehabilitation and assistive devices. In most countries, PWD do not gain access to the medical care they need. The main reasons are lack of competence for diagnosis and treatment at first line health facilities, the financial barriers to acquire care provided at referral level, and the unavailability of appropriate technology and required expertise.

This paper looks at the situation of rehabilitative services before the outreach activities were started and compares it with the period after they started. It also reports on how some local stakeholders have planned to sustain the services after the withdrawal of the external support from the NGO. The study focused on documenting the successes and challenges of the project, and the process it went through at all its stages. It is hoped that lessons learnt from these

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stages could be used in other similar circumstances to avoid and or overcome similar challenges. The success of the outreach programme is measured in terms of increased utilisation of the services, rather than other outcomes of care.

### **Objectives**

The overall objective of the study was to provide relevant information and understanding of factors affecting access to and utilization of existing medical and rehabilitative services for people with disability and epilepsy in the West Nile region of Uganda. Such information, it was hoped, could enable the stakeholders to develop effective and appropriate strategies to improve quality, access to and utilisation of such services as well as increasing commitment among stakeholders to responding to the needs of PWD and epilepsy. The specific objectives of the study were to describe the rehabilitative needs of people with disabilities and epilepsy; to determine whether the project had responded to the needs of people with disabilities and epilepsy; to document the strategies used to reach people with disabilities and epilepsy in the West Nile region; and to identify strategies for maintaining and mainstreaming the programmes for PWD and epilepsy in the region after the end of the project.

### **Methods**

#### *Approach*

The overall approach of the study was qualitative. The main methods for data collection were informal, semi-structured and in-depth interviews, group discussions, direct observation, and review of available activity reports, study reports and routine data from the health management information system. The overall study design was developed during a consultative meeting with some key local stakeholders, especially the manager of the CUAMM-funded project who was still in the area. We attended outreach activities which took place during the data collection period to enable the study team to observe the process of care, to have access to the PWD, health workers, other key informants and the general population.

#### *Study population and sampling strategy*

Respondents included all categories of people concerned by the project activities: people with disabilities, their caretakers, the general population, focal persons having a political or administrative responsibility in providing services to PWD at district and sub-county levels, health care providers and health workers either in the hospital, lower level health units and CUAMM staff linked to the project. The main selection strategies for the respondents were purposive sampling for the key informants and the disability type groups, and convenient sampling for the

individual respondents once at the outreach site. We decided to include respondents from all the disability groups (persons with epilepsy, with visual impairment, with ENT disabilities, people with motility disability and people with leprosy), but once at the outreach site, we interviewed whichever client was available and willing to respond. The sites for data collection at sub-county level were purposively selected to ensure that the study covered two major aspects of the project, namely its outreach activities and its support to community-based rehabilitation workers. The research team participated in two systematic assessments of PWD and follow-up of clients (Pajolo and Bileafe sub-counties) and follow-up outreach activities in sub-counties with active community-based rehabilitation components (Rigbo and Rhino Camp).

Some clients were interviewed before they received services and others afterwards to evaluate the quality of services received. A precise sample size was not determined. We planned to reach at least 100 PWD and/or caretakers, a figure that was amply exceeded. Generally, we adapted the number of respondents according to issues observed during the outreach activity.

For interviews with members of the general population, two research assistants went into the villages around one outreach site (Aroi) and selected respondents by convenience, with an overall purpose to include respondents of different age groups, mixing men and women equally.

For key informants, our objective was to interview the focal persons for PWD in each sub-county: technical officers responsible for PWD affairs (the sub-county chief, the Community Development Officer), political leaders and representatives with specific responsibility for PWD (LC III chairman, LC III representative for PWD, LC III councillor representing women or LC III Councillor representing youth); and the health staff of the local health unit. However, whenever they were not present during the assessment, no further steps were undertaken to contact them later. In addition, any other relevant community resource person could be interviewed. Health workers interviewed included staff from Arua Regional Referral Hospital and community-based rehabilitation workers. They were interviewed during the outreach activities or at the regional hospital.

#### *Data collection and analysis*

For the PWD and their caretakers, we used interviewer-administered questionnaires with open-ended questions. A guide for probing was developed with specific questions for each disability sub-group. The interviews

were conducted by research assistants who were trained before the data collection exercise. Key respondents were interviewed using a topic guide. We used informal interviews, mainly with the project manager and the health workers involved in the project, to clarify issues and fine-tune the questionnaires and topic guides. The interviews were not recorded. Each interviewer took the notes of all the answers to the interviews he/she conducted. Notes were directly taken in English and completed after every interview.

Group discussions were held when the opportunity presented itself, especially when a group of people showed eagerness to participate in interviews and when it was felt that individual interviews would spoil the momentum. This occurred twice when groups of community members showed keen interest in discussing the topic. Another group discussion was organised with people with leprosy, who had been wrongly informed that there would be services for them during the follow-up outreach activity in Rigbo sub-county and were happy to discuss their concerns with the research team. In such cases, the questionnaires originally meant for individual interviews were used as the discussion guide during the group discussions. Each research assistant took his own notes for the group discussion. The discussion with people with leprosy was conducted by one research assistant while notes were taken by two observers. Notes were reviewed and completed immediately after the discussions.

Direct observation of procedures was mainly used to evaluate the implementation of the outreach activities. It also guided the selection of specific sub-groups of respondents for interview to document apparent challenges in implementation.

The documentary records pursued included the estimates of the number of beneficiaries and potential beneficiaries (through surveys of PWD in the project area, people reached by medical rehabilitation services) and a

description of the services provided to PWD, strategies used, achievements, challenges and the resources used. The records consulted include project activity reports, financial expenditure reports, assessment reports and records of medicines dispensed to epilepsy patients.

Transcription was done during the data collection period either on the very day of data collection or on the second day thereafter. Data collection took four days. Analysis was done by the principal researchers. Preliminary results were discussed among the researchers and a preliminary submission was made to the local CUAMM project manager and other CUAMM hierarchies. Publication comes after approval of the final report.

## Results

### *Respondents*

A total of 240 respondents were interviewed or participated in group discussions. Respondents comprised of 141 PWD, 43 caretakers, 23 community members and 33 key informants (Table 1).

Of the PWD and caretakers, 123 were individually interviewed and 18 people with leprosy participated in a group discussion. Of the community members, eight were interviewed individually and 15 took part in two group discussions of six and nine community members. The ten key respondents from Arua Regional Referral Hospital were people who regularly participated in the outreach activities. The others were community-based rehabilitation workers, health workers of the local health units, and ten key persons with a political or technical role in providing services to PWD at sub-county level (the chairperson of the Arua District Union of People with Disabilities is included in this group). Two persons were included on the basis of being considered as local opinion leaders

### **Rehabilitation needs as assessed by health workers**

Records about the number of disabled persons were not easy to come by in the West Nile region, despite a

**Table 1: Number of respondents by location**

Place	PWD	Caretakers	Community members	Key respondents	Total
Pajulu	41	23	0	5	69
Aroi	21	2	0	5	28
Bileafe	22	6	23	4	55
Rhino	25	8	0	3	36
Rigbo	32	4	0	5	41
Arua Regional Referral Hospital	0	0	0	10	10
Union of Disabled	0	0	0	1	1
<b>Total</b>	<b>141</b>	<b>43</b>	<b>23</b>	<b>33</b>	<b>240</b>

wider assessment in 2004. However, we managed to retrieve the following from various sources, carefully triangulating to avoid double counting (table 2).

to May 2009, a total of 2,470 PWD were served in 5 sub-counties (table 4).

**Table 2: Summary of the hand written files compiling data about PWD provided by the ADUPED**

Year of data collection	Sub-county	Estimated population*	Number of PWD	%	Description of type of disabilities	Observations
2006	Ogako	16,700	176	1.1%	Arm, leg, eye, head, ear	- About half have physical disability - Information of 1 parish is missing
2008	Offaka	21,900	195	0.9%	Physical, mental, deaf, dumb, eyes	eyes not included for 1 parish
2008	Aroi	25,132	19	0.8%		Data not reliable

\* Population projections are for 2008 based on the 2002 population census

Data from the Planning Unit of Arua District (table 3) differed from those obtained from ADUPED.

**Table 3: Estimates of the number of PWD by sub-county, census 2002**

Range	Sub-counties
1241-1525	Adumi, <b>Ogako</b>
891-1240	Dadamu, Logiri, <b>Offaka</b> , Vurra
731-890	Okollo, Pajulu
561-730	Ajia, Manibe, Oluko, Rigbo
311-560	Arivu, Oliriva Division, Rhino Camp
129-310	Aroi, Arua Hill, Uleppi

Source: Adapted from UBOS, 2002: Uganda Population and Housing Census 2002.

A comparison of the available figures for Ogako and Offaka from the two sources confirms the difficulties of getting reliable data. The numbers estimated in the census were much higher than the numbers compiled by the ADUPED. In addition, the numbers obtained from the CBR workers were much smaller compared to the figures of the census. However, all in all, project records show that PWD are very many in the region. For example, during the three months of March 2009

During the study, we encountered many people who came for disability assessment. They had different types of disability and, for some, their conditions could not be classified as disability yet, but rather chronic conditions of illness e.g. stunting and chronic otitis media. For example, of the respondents interviewed, the recorded disabilities were as reflected in table 5.

**Table 5: Disabilities of respondents**

Type of disability	Number	%
Mobility	67	34
Epilepsy	47	24
Leprosy	25	13
Visual Impairment	23	12
Hearing impairment	11	6
Mental Disorders	6	3
Cleft lip	2	1
Cerebral palsy	3	2
Others	12	6
<b>Total*</b>	<b>196</b>	<b>100</b>

NB: Several PWD had more than one disability

#### Rehabilitation needs as perceived by the clients

Rehabilitative needs identified by the PWD and their caretakers include assistive devices and appliances

**Table 4: PWD who received rehabilitative services, March-May 2009**

Department	2009			Total
	March	April	May	
Orthopaedic workshop department	24	7	40	71
Ear, Nose and Throat Department	135	19	211	365
Mental Health Department	126	0	242	368
Orthopaedic department	91	13	78	182
Primary Eye Care Department	471	0	607	1,078
Physiotherapy Department	169	29	208	406
<b>Total</b>	<b>1,016</b>	<b>68</b>	<b>1,386</b>	<b>2,470</b>

Source: Project records. NB: March and May 2009 were outreach months. April was a routine service month.

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(wheelchairs, crutches, tricycles, spectacles, shoes for people with leprosy). In addition, they had other social and emotional needs (respect and love, sense of belonging, support from community members, support from groups, parental support for disabled children); livelihood needs (money, loans, skills training, material support for the poorest); and an environment adapted to the needs of the disabled persons (e.g. special education). Other basic needs, such as shelter, food or assistance in fetching water, were not mentioned as needs because they are currently addressed by their community. Key informants mentioned the need for mobility aids and other assistive devices (mentioned 12 times), education (9 times), economic needs (6 times), basic needs (4 times) and care or assistance in daily life (2 times). All these needs are well summed up by one opinion leader, involved in activities for PWD for the last ten years who said:

*“In our sub-county the PWD are the poorest class of people. For this matter they cannot meet their basic needs. I can say they have two major forms of needs i.e. disability-related needs and social needs. These needs are interrelated. The disability-related needs aggravate the social needs. Disability-related needs include walking aids like crutches, wheelchairs for the crippled, white cane for the blind, the deaf lack sign language to communicate with their people. Social needs include lack of education. The disability-related needs hinder access to education and transport to school.”*

Other than assistive devices, medical services such as prevention of disabilities, physiotherapy, pain management or other intervention to improve the physical condition of PWD were not mentioned. Only one of the key informants observed that people with epilepsy do not get their medicines at times. This does not mean that PWD do not seek medical assistance to improve their conditions. Indeed, many PWD go to great lengths to find treatment and many mothers try everything within their means to seek improvement for their disabled children.

### **Knowledge and utilisation of existing medical and rehabilitative services**

The question of whether they had ever sought treatment before was asked to 36 PWD or caretakers. Only 8 said that this was their first time to seek medical services before; 28 had sought medical services from lower level units, hospitals and outreach services. Reasons for not seeking treatment earlier included long distance from their home to health facilities offering the required services, the opinion that their condition could not benefit from treatment, lack of information about the

existence of medical support for disabled persons, fear of the cost of treatment and of accommodation in the hospital, and the difficulties of staying away from home for a long time. For example, one man who had had one leg amputated would have liked to get an artificial limb, but when told that he had to come to the hospital to take the measurements, he refused, saying that it was impossible to leave his family for the entire time it would take him to get the device.

The key informants confirmed these views. As expressed by one local health worker:

*“We do not offer special services for disabled people. The disabled are referred to the hospital for specialised services. However some of them do not go because they have no caretaker to go with them, no money for transport and upkeep in the hospital. In the hospital they do not get the attention of health workers. Sometimes patients have to find money for medicines or for investigations like X-ray. These expenses stop them from going to the hospital.”*

Those who sought treatment faced similar problems of distance, cost of transport and accommodation in the hospital, and the considerable time spent away from home. One caretaker, for example, said that she was unable to continue to take her child for rehabilitation because she had other responsibilities at home. Those who sought treatment also lacked knowledge about what is available, what is helpful and what is not. They do not receive enough information about their condition, possible treatment or solutions, and outcomes. On the one hand, households spend much time and energy – and money – in unhelpful health seeking that could have been avoided if they had been properly informed earlier. Others, on the other hand, have not been seeking treatment in time but only much later when it is too late to correct the disability.

### **Support provided to PWD by other levels and agents**

The PWD and their caretakers did not know of other providers of medical services or other services addressing the needs of PWD. In health facilities were not mentioned by who were asked if they knew of any specific programmes addressing the needs of PWD. Only two members of the general population mentioned the Uganda Red Cross which had, some time earlier, trained PWD in income-generating activities and distributed seedlings and blankets. The local sub-county was also mentioned to have distributed wheelchairs but the respondents did not know the allocation criteria or the application process for the wheelchairs.

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When asked whether they had heard about the local Union for Disabled Persons and its roles, 4 out of 8 PWD had not heard about it. Only two could mention some of its activities: that the Union engaged in distribution of assistive devices (wheelchairs, crutches), in agricultural activities and in mobilising funds through proposal writing.

Key respondents said that not much is done for PWD at sub-county level:

*“In this sub-county there are no programmes for PWD both from government and non-governmental organisations. This activity today is the first of its kind to reach out to PWD. Our office has not reached the PWD to know from them what their problems are.”*  
[key informant, Pajulu sub-county]

This view is perhaps too negative, since the same key respondents mentioned a number of existing programmes and activities for PWD: activities related to the political process of greater inclusion of PWD:

*“We have a new government programme for planning, which is the bottom-up process of planning. The PWD are involved in the planning. Their priorities are integrated in Sub-county development plan.... There is a radio programme... that sensitizes the community on disabled people. Some of the areas discussed include rights of PWD, their economic empowerment and opportunities for rehabilitation like corrective surgery for children.”*

In addition, he mentioned specific attention for PWD in some schools:

*“In Pajulu sub-county we have one school for special needs education: Ediofe Girls Primary School. This school has boarding facilities that cater for girls.... All teachers in primary schools are sensitized on special needs education. The schools are followed up to make sure the teachers are implementing special needs education.”*

Within the West Nile region, there are also initiatives to improve the economic situation of PWD. Most mentioned was the Ocoke Rehabilitation Centre, which trains PWD in specific skills. Sub-county administrations have made an agreement with the Centre to finance the training of two PWD per sub-county every year at the school. A second initiative – or tendency – is to promote the formation of groups that can then request financial support for income-generating activities from national programmes such as the Northern Uganda Social Action Fund (NUSAF) and National Agricultural Advisory Services (NAADS).

Most key informants suggested that PWD should form their own groups; some suggest integration into existing groups. So far, five groups of PWD have been formed by the ADUPED. Finally, key informants mentioned several one-off donations of mobility aids, especially wheelchairs, by organisations e.g. ADUPED and the Rotary club of Arua, individuals like the local Member of Parliament and institutions like the African Development Bank (AfDB).

The major impediment for the sub-counties to do more for PWD is the lack of funding:

*“Currently the annual budget for PWD is small: about UGX 300,000 (about US\$ 150). The only activity funded by the sub-county is transport for PWD to participate in the national day celebrations. This financial year, no one from this sub-county was sent for training [in the Ocoke Rehabilitation Centre].”* [sub-county chief]

Suggestions from key informants on what could be done to improve the situation of PWD consequently concentrated primarily on funding. They felt that different levels could have different duties as far as PWD are concerned. For example, they felt that the political and administrative levels of the sub-county should identify the needs of PWD, include PWD in priority-setting, promote social action to empower PWD, improve their social inclusion in planning and implementation of sub-county programmes, promote adequate education and skills training for PWD, and identify opportunities for the economic empowerment of the PWD. District level authorities were expected to provide the financial resources to realise these actions. NGOs are expected to bring funds and material resources:

*“Let them bring services to the health units like walking aids, medicines and provide sewing machines; give cows, pigs, and bee-keeping”* [key informant]

NGOs are also expected to improve medical and rehabilitation services that can be provided through the existing health system or independently, and to connect more NGOs to the community. The government of Uganda is expected to organise programmes for economic empowerment to which PWD groups could then submit grant proposals.

### **Do PWD use the existing medical and rehabilitation services sufficiently?**

This question, which was valid at the inception of this study, seemed to have been answered with time after the introduction of planned and systematic outreach activities. Nevertheless, we still considered the question and inquired whether the respondents knew



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of any PWD who had not come to the outreach activity and why. About half of the 46 PWD and caretakers at the assessment site in Pajulu sub-county and the follow-up services in Aroi sub-county did not know of any PWD who had not come on the outreach day. The others knew one or several people who had not come. The main reasons suggested for not coming were long distance and lack of transport (9/23). Other reasons were: sickness (3/23); had already received assistive devices (3/23); not interested (2/23); did not have family support (1/23) and probably did not get the information (1/23). In Rhino Camp and Rigbo sub-counties where they have active CBR workers, the reasons given for not coming were similar: long distance, lack of transport or being engaged in other activities. Others did not turn up for treatment because the waiting period at the site was too long:

*“People normally get very hungry as getting treatment takes long and departure is always late in the evening.”* [CBR worker, Rhino Camp]

Because of the distance to the service point, one of the CBR workers has developed the habit of taking the medicines to three epilepsy patients who are unable to reach the monthly clinic because of the distance. Transport and long distance were also the reasons most frequently mentioned by the key informants. However, they doubted the possibility that the concerned people did not get the information about the outreach visits. One category of PWD may however be less represented at the outreach site than others, namely those with mental disability. Respondents felt that most of this type of patients is not brought to the outreach sites and that activities should be extended to them at household level.

A common comment was that children with disabilities often did not go to school. The key reasons given for this were poverty and not being able to pay the school fees, difficulties to get there physically, and, in some cases, parents not giving their children with disability this opportunity.

Stigma as a reason for poor utilisation of rehabilitative services was only mentioned by key informants in the case of epilepsy, mental illness or possibly ‘cerebral palsy’:

*“Epileptic people do not access services because of many reasons. .... Some people in the community do not see them as important human beings so they do not take them for treatment..... Some disabled like those with mental problems lack the support of family members”.* [Group discussion in a sub-county with no CBR workers]

There were also some reports of PWD who are abandoned or of children who are neglected by their parents. However, the study team felt that, generally, PWD are well integrated in the community. Most PWD themselves said that they felt they were treated well, although they cited occasional incidents of insult and abuse.

#### **Needs expressed by community members**

While community members said PWD are well integrated, they felt that some forms of disability hamper full integration: deafness and mental illness make communication difficult; the blind need help for some tasks; the *“crippled can’t carry heavy loads and therefore do not participate much in society duties”*. Needs of PWD expressed by community members also included assistive devices, attention so that children with disabilities can go to school, financial support for the poorest among them or assistance to improve their economic situation: such as business skills, access to saving and credit organisations, and creating groups to access project and government support. In addition, community members mentioned some very practical needs in daily life e.g.: water sources should be close to PWD; latrines in places where a PWD uses hands for crawling should always be clean etc. Others suggested that PWD should also engage in games and sports and address their social needs such as a sense of belonging, love and parental support.

Community members expressed willingness to support the PWD among them and proposed various ways of doing so. Loving and respecting PWD stood out strongly, as well as providing basic needs, involving them in leadership and decision-making, giving spiritual support and counselling, and ensuring access to assistive devices. When asked what PWD themselves can do to improve their situation, community members suggested that some could work harder to improve their lives, to become self-reliant. PWD should *“change their attitude of saying they are poor”* and *“use the opportunity that they have got to improve their situation”*. To achieve that, they should *“accept their situation”*; *“learn to be positive, to accept their condition instead of pitying themselves”*.

However, key informants at sub-county level, although aware of the government guidelines on integration and participation of PWD, seemed more patronising than general community members. One political leader was of the opinion that *“they can work individually to meet their individual and family needs, however to work in groups they need able-bodied people to mobilise them and run their programmes”*.

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### *Summary of the main findings on access and utilisation of the findings*

In this study, stigma did not seem to be a cause for not seeking medical and rehabilitative services for the great majority of PWD in the West Nile region. On the contrary, many PWD found the gathering of peers, a tradition started by the CUAMM project, quite stimulating. Whereas epilepsy and leprosy are prone to a greater level of stigma than other disabling conditions, due to the activities of this project, stigma against the sufferers of the two conditions in the region has reduced. The majority of people with epilepsy were very positive about the project activities, especially the medicines that make such a difference in their lives. Instead, the main reasons for not seeking medical services were distance, cost (of transport, of services and drugs, of accommodation in the hospital, of time spent away from home and work) and insufficient awareness of what should and could be done and when it is being done. The outreach activities, which significantly eliminate these problems, have been able to reach more people and could be considered a reliable solution. However, currently, during these outreach visits, the workload is too much for the health workers and most PWD are often referred to the hospital after assessment. Therefore, the need to go to the distant hospital and meeting the costs attendant to such a visit has not been fully eliminated by the outreach activities. As a result, many referred PWD still do not go. Whereas sometimes referral cannot be avoided, often it could, with good equipment, more supplies, extra personnel and less workload. It is important to reanalyse the details of the outreach activities in order to improve on the quality of services offered, and to increase their responsiveness to the needs and expectations of PWD.

### **Observed and perceived quality of services during outreach activities**

#### *Communication of outreach days*

The mobilisation of PWD and their caretakers for the outreach activities was done through political structures, religious networks, opinion leaders such as teachers, radio announcements, and through community activities like meetings. However, some key actors who should be involved in the rehabilitation of PWD, such as the nearby health facilities, the Union and representatives of PWD, and Village Health Teams were not involved. In addition, the quality of the message sent out left much to be desired. Most people came because they were told to do so, since the purpose of the outreach was rarely communicated :

*“I came because I was told that all people with disability should come here. I was not given any other reason. I got the information*

*from the church on Sunday from the priest. I wouldn't have come, but they told me it's a must that every person with disability should come”.* [PWD in a group discussion]

Others came to get free drugs and they appreciated the outreach. Particularly, the epilepsy patients appreciated the outreach because they did not have to go to Arua Regional Referral Hospital for medicines for the rest of that month.

#### *Clients' Expectations*

Some respondents were aware of the full range of services available and expected to receive all of them. Some caretakers even expected that their patient would be operated on the spot. Many others expected financial aid and food assistance. At the end of the day, therefore, it was not surprising that only about one third of the respondents (10/27) interviewed at one site felt that their expectations had been met. Two thirds (17/27) were not happy because their expectations were not met. These included those who did not receive medicines, those who were referred to Arua Regional Referral Hospital, those who expected free imported crutches, those who were told to wait for surgery at another date, those who were promised assistive devices at another date yet they had expected to get them on the spot and one who had wanted to be examined with a machine.

#### *Observed quality of services*

The services provided were in many cases not to the required or affordable standards of quality care. For some services, like eye care, this was largely because of the heavy workload. Health workers tried to expedite the examinations in order to attend to all the clients. For ENT clients, the health workers did not have the right equipment and facilities to do proper examination and treatment. For epilepsy, the clinical skills of the health workers in handling such patients were poor. No investigations were done and no counselling was done for epilepsy. In some cases, the treatment was inadequate or even not appropriate. Health education was either not provided or of poor quality. No single person was counselled about the anticipated outcome of their condition during the period when we observed the interaction between the clients and health workers.

#### *Workload during mass assessment*

The number of people present at the assessment venue was too high. Although this is a sign of effective mobilisation, it is bad for correct assessment of the patients' condition. Health workers tried to rush in order to attend to all who had reported, which has negative consequences on the quality of services. For example: during the assessment on day 3 (Bileafe) there

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were still 128 patients waiting for eye and ENT clinics at 3.30 pm. Due to the immense workload, testing for reading glasses, for example, was done too fast and glasses were very easily issued or recommended. Orthopaedic services and the distribution of crutches suffered from a similar weakness of great numbers. Beneficiaries of crutches were not allowed the time needed to get used to the crutches and to ensure that they were fixed at the right height.

#### *Equipment and medicine availability*

Whereas the ENT unit in the hospital may be sufficiently equipped, the outreach services lacked diagnostic ENT equipment for screening patients. On one day, the ENT staff had hardly any equipment to serve a large clientele and simply recorded their particulars and referred them to Arua Regional Referral Hospital. Most were referred even without any examination done at the assessment site. On another day, the ENT staff had to use private diagnostic equipment.

#### *Explaining the condition and the treatment to each individual patient*

Patients received little counselling about their condition. The diagnosis, cause, treatment, side effects, behaviour change required and prognosis were never explained for all the patients. Even when patients attempted to ask these questions, it was clear from the body language of the health workers that their intervention was not welcome due to the workload. Therefore, they would quickly keep quiet and only listen. Several left frustrated or in doubt and scared about what would happen to them. There were regrettably many missed opportunities for giving the correct information and reassurance. Other PWD for whom nothing much could be done were still referred to the hospital, which entails useless expenses for the household. It gave the impression that health workers are reluctant to inform PWD that their condition cannot be improved.

#### *Prescription habits and explaining the prescription to the patients*

In the ENT outreaches, the treatment prescribed was often inappropriate, as almost all the patients got antibiotic ear drops. Even in the eye clinic, nearly all eye patients received eye drops. We were informed that this was the only available preparation. Patients walked away with medicines but without clear instructions on how to use them and their possible undesired effects. During the exit interviews, we observed that many patients did not know how to apply eye drops or ear drops. No demonstration had been done by the dispensers. Several times, medicines which are not locally available in the district were still prescribed for very poor patients. Most patients had a prescription

recorded in their notebook with no explanation given to them, and yet their treatment was not available. The treatment had to be obtained elsewhere but this was not explained to them. Moreover, the handwriting was illegible and so it was certain that the patients would not receive the treatment from anywhere. The prescriptions were perfunctory and for the satisfaction of the health workers, not to the benefit of the patients. Although the health workers staff worked with much dedication to clear the long queues of patients, unfortunately they did not think much about the effectiveness and benefit of their effort for the patients.

#### *Quality of services as perceived by the clients*

Despite the observed gaps in the services received by the PWD, all of them and their caretakers said that they were satisfied with the services provided. All (27) people asked about whether they would come back for services showed the willingness to come back, some because they had hope that their unmet expectations might be realised during next visit.

#### *What else should the rehabilitation programme provide?*

While the key informants clearly emphasised that rehabilitation staff should provide the medical and rehabilitation services and leave the other stakeholders to deal with the political, economic and social service needs of the PWD, the PWD themselves and members of the general population simply wanted “the Project” to meet all these requirements. They did not seem to realise that the CUAMM-funded project had ended and the services were being provided by the government and local staff with minimal direct involvement of CUAMM. They even expected the services to be extended to a wider area.

#### *Integration of outreach activities into the referral system*

Although most outreach activities took place near health facilities, outreach activities were conducted exclusively by staff from Arua Regional Referral Hospital. Health workers from the nearby health units played little or no role in the screening and follow-up activities yet they were often involved in referring and mobilising patients for the outreach days. From the staff of the regional hospital, they received no data or feedback in terms of patients seen during the assessment, patients referred to the health unit with prescriptions, patients who needed follow-up in the community etc. Although the outreach activities were still in an experimental phase, cooperation with the health workers of the local health units and their integration into the services was not being given much attention. Moreover, many health workers in the lower

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level health units did not have the knowledge and skills needed to manage PWD at that level and to ensure proper follow-up. In one health unit, for example, the staff in charge was a nursing assistant, expected to manage antiepileptic medicines and treat patients. In a neighbouring unit, the enrolled nurse in charge did not know how to initiate treatment for epilepsy. Antiepileptic medicines were provided to the local health units, but the record-keeping was poor.

### **The Community-Based Rehabilitation Programme**

Community-based rehabilitation (CBR) workers exist in two sub-counties in Arua District. Their area of responsibility is the Parish. Their main roles are: informing communities about the different conditions of disability and the available rehabilitation services; advocacy for the rights of PWD in the sub-counties; identification of PWD in the parish and referring them when they have conditions that need specialised services (e.g., they are trained to identify cataract and refer cases to Arua Regional Referral Hospital); follow-up of patients after surgery; mobilisation of PWD for scheduled services or assessments; participation in monthly clinics for epilepsy; making assistive devices using appropriate technology and local materials, e.g. parallel bars, corner sheets, standing frames, helmets for epilepsy patients, gloves for persons affected by leprosy, toilet seats, axillary crutches. etc.; training of local artisans to make these devices; home visits and counselling of PWD and their families; assisting technical staff in follow-up activities and; compilation of monthly reports which are sent to Arua Regional Referral Hospital and the CUAMM office.

When asked about their work, most CBR workers started by describing their activities in the epilepsy clinics because it is the most frequent condition on which they work and where they can easily see their positive contribution. This great success rate keeps them motivated. When asked about his achievements, one CBR worker was happy to announce that “*fits are disappearing out of the community*”. The second condition they mention is leprosy, but this time mainly for their little action. There are other organisations which target people with leprosy and it was decided that the only activity to be officially included in the scope of the CBR workers is the mapping out of the patients’ feet and ordering for adapted shoes from the workshop in Kuluva Hospital, also in Arua District. In reality, however, the CBR workers do much more than that. They collect and distribute Vaseline and medicines from the health facility; identify those with active leprosy and refer them to the health unit; make devices to protect patients from burns, such as gloves and handles for lifting hot saucepans; connect leprosy patients to other

programmes such as adult literacy classes for women, programmes that make stoves without open fires; and give health education. People with leprosy also have many unmet needs and are quite demanding of the CBR workers’ time. The CBR workers reported that leprosy patients repeatedly expressed that they are not happy to be excluded from the activities of the project and would like to be considered like other PWD whom they feel are getting better services.

As positive outcomes of their activities, CBR workers listed mainly the provision of epilepsy medicines and mobility aids (crutches, leg prostheses and wheelchairs) and improvement of vision through referring clients for spectacles and cataract surgery. However, they also reported unmet needs, mainly concerning specific appliances that needed to be tailored to the individual client e.g. a high shoe for one client with a shortened leg, surgery for club foot etc. The link between the health system and cases with special needs required strengthening. From the NGO, the CBR workers received a monthly allowance, monthly supervision and meetings, information sharing on available services, financial support for refresher courses and transport refunds when they accompanied PWD to the hospital (DWA CUAMM, 2009). It was also acknowledged by CUAMM staff that supervision of CBR workers could be further improved, but this would require more financial and human resources than the NGO could offer at the time of the study. For example, CBR workers were not very skilled in keeping records of their activities and of the number of the PWD they follow. Since January 2008, efforts had been made to improve reporting by introducing a new reporting form, but progress was slow (DWA CUAMM, 2008d). CBR workers would have liked to have a higher financial reward for their efforts, but they also recognised and appreciated their other benefits. They appreciated the training they receive and the variety of skills they had acquired through the programme. Some had combined several community services and become comprehensive community health workers: one CBR worker had earlier been a Guinea Worm Eradication Programme (GWEP) supervisor, and was a family planning agent, a HIV/AIDS peer educator, and acted as a referral agent for accidents and deliveries. For each of these roles, he had received training from the district health office. CBR workers generally felt respected in the community but some were frustrated by the negative perceptions about them held by some PWD who think the CBR workers use PWD for personal gain. Others expected financial handouts and continuously demanded material aid from the NGO. CBR workers would also have appreciated greater recognition from the government authorities but it was yet to come.

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CBR workers still saw some unmet needs for their work, which suggested that they were well informed about the true needs for their work and could guide potential donors to be effective with their assistance. They highlighted the lack of surgery for cleft lip, lack of protective wear e.g. gloves for leprosy patients, better health education to leprosy patients, more home visits to find people who are not coming for services, training for teachers on how to give first aid to epileptic school children, better collaboration between the stakeholders and the need to create more outreach posts in other areas.

The PWD, for their part, registered appreciation for the CBR workers and cited their key contribution as being provision of medicines (7/13), provision of assistive devices and adapting facilities in the homes of PWD (5/13), starting outreach posts in rural settings, health education and counselling, home visiting, physiotherapy, and HIV counselling and testing. The CBR programme was also appreciated for facilitating the formation of epilepsy associations, such as the Buniababa Epilepsy Association which had started in 2005. Such associations were appreciated for helping to improve access to anti-epileptic medicines and the socio-economic status of the patients.

#### *Integration of the CBR programme, outreach activities and intersectoral collaboration*

The technical staff involved in the outreach activities for disability saw the existence of a CBR programme and the outreach activities as an opportunity to improve the management of disabilities in the region. CBR workers were believed to be best placed to inform the population about the services available and to mobilise people for outreaches. They felt that CBR workers should screen patients and select who should come to the outreach site on a given date, in order to avoid over-booking. CBR workers also followed up those who needed close watch and informed those whose assistive devices were ready. Alignment of the outreach and CBR programmes would, therefore, also provide room for more professional involvement by specialists within the community e.g. home-visits could be organised as part of the outreach activities. Moreover, professional staff would address knowledge gaps in the CBR workers by training them on the spot. An example cited of where integration could help was in the case of Tropical Ataxic Neuropathic Syndrome (TANS), a condition common in the region, which is caused by cyanide in cassava which is a staple food of the area. Brain poisoning with the cyanide results in problems of balance and patients present walking on the tips of their toes, or develop spasticity of arms and legs. When it affects several people in a household,

this can have catastrophic results for their survival and CBR workers are often called in to assist and to invite health workers or to refer the patients to health facilities. Traditionally, people know how to treat the cassava to reduce the cyanide, but when there is famine, they do not take the time to do it. Professional staff helps to confirm the diagnosis, manage the cases and advise the people on how to avoid the problem. They could also help to train the CBR workers to recognise the situation early and to differentiate it from other forms of disability. Intersectoral collaboration could also lead to the introduction and use of non-poisonous cassava varieties.

#### *Integration of the CBR programme into activities of local health facilities*

CBR programme activities brought relevant services to PWD that did not exist before. There was good interaction between CBR workers and health centre staff when PWD fall sick. CBR workers also managed the epilepsy clinic, but health workers felt that new cases should first be managed by qualified health workers before being maintained by CBR staff.

#### **Epilepsy clinics**

Improving the management of epilepsy was one of the core interventions of the project since 2004. This raised the profile of epilepsy in the region and implied that health units running epilepsy clinics should include antiepileptic medicines in their quarterly orders for medicines. The district took the responsibility of ensuring that their supply is regular. To ensure quality of care, a simple clinical protocol was developed for the assessment and management of epileptic clients, to guide health workers in the peripheral health units. Personnel from the mental health unit of Arua Regional Referral Hospital were also involved to supervise the peripheral epilepsy clinics periodically (DWA CUAMM, 2007b; DWA CUAMM, 2008c). Since 2007, CUAMM support has involved supervision and monitoring of the clinics, technical advice, data collection and analysis, continuous advocacy with the district and health sub-districts to ensure that drugs are available, procurement of antiepileptic medicines in case of drug stock-out, and attending health sub-district meetings for sensitisation and updates on epilepsy (DWA CUAMM, 2008c).

#### *Magnitude of epilepsy*

Despite the records of CBR workers being inaccurate and health workers at health unit, health sub-district and district levels being reluctant to release HMIS data on epilepsy, the available information demonstrates that epilepsy is a considerable health problem in the West Nile region. By March 2009, the number of epilepsy

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cases on record for receiving treatment monthly was 669 in Arua district and 447 in Nebbi (with data from both districts incomplete because not all units had reported). We did not obtain data from the other districts of the region due to shortage of time. However, the data show that at least 1,116 epilepsy patients received treatment monthly, thanks to the project (DWA CUAMM, 2009).

#### *Availability of medicines*

Although some sub-districts had a regular supply of antiepileptic medicines, the overall availability of medicines in the clinics was a constant challenge. This was due to, first, delays and stock-outs in the National Medical Stores (NMS), poor ordering practices, poor supply and untimely deliveries, and poor dispensing (DWA CUAMM, 2007a; 2007b; 2008a). However, even when the sub-districts were willing to provide the necessary antiepileptic medicines, they may be defeated in the long run because the increasing number of epilepsy patients implies increasing cost. Sub-districts must, therefore, reduce supplies of medicines for the other diseases. At the time of the study, the health sub-districts provided some antiepileptic drugs, and relied on the NGO as just a backup (DWA CUAMM, 2008e). For example, between January-March 2009, the organisation provided an emergency additional 66,000 tablets of Phenytoin, 11,400 tablets of Carbamazepine and 38,000 tablets of Folic Acid to 6 health units (DWA CUAMM, 2009).

#### *Management of the epilepsy clinics*

Many clinics were entirely run by epilepsy support groups or CBR workers. The involvement of qualified health workers was minimal. On clinic days, they first gave health education and then gave the treatment for a month and an appointment date. They also registered new patients in the programme. Although in some places the new cases were seen by qualified staff, this was not always the case. CBR workers have been trained to take history of the illness, assess the patient and prescribe treatment. They can correctly prescribe four different medicines: phenobarbitone, phenytoin, carbamazepine and folic acid. They know the side effects of each medicine and are able to counsel patients and caretakers correctly. In our opinion, this community-based strategy has good results in terms of continuity of treatment. Although there were patient drop-outs from the treatment schedules, they were few and CBR workers followed them up quickly. Most drop-outs occurred in the early months of treatment. Once the patients felt better, some did not come back, thinking that they have become cured. It is when the fits started again that they understand that they need to take the drugs permanently.

Among the epileptic patients interviewed, nearly all (23/24) reported that the fits had reduced in number and frequency. Many noted other positive changes such as feeling better, ability to do house work, or becoming “*normal like other people*”; “*I used to stay in the house to monitor fits but since I started treatment I can go out to do work*”. However, not all their physical problems are solved and many of those experiencing side effects of treatment did not know what to do about them.

#### *Should the NGO hand the programme over to the government fully?*

Given the financial constraints of the district health system, our opinion is that it may not be reasonable to hand over the epilepsy clinics fully to the public health sector soon. Epilepsy does not seem to be their top priority currently and this could have consequences on the availability of medicines. The continuation of the clinics was still heavily dependent on the additional drug supply provided by the NGO and the supportive environment kept the CBR workers and volunteers motivated. Stakeholders felt that the project had been valuable and that it was truly worthwhile for its activities to continue and expand even after the project had ended. To do this, the local stakeholders needed funding. The project had provided quality services at low cost to PWD, a population group that is generally neglected. A proper exit strategy, therefore, needed to be thoroughly planned with the involvement of all the stakeholders.

#### *A local NGO rises to sustain the support for PWD*

In the wake of plans by Doctors with Africa CUAMM to fully exit the West Nile region, there were concerns about the future of the PWD. However, the former staff of the disability project have risen to occasion and spearheaded the formation of a local NGO to take up the mantle of offering disability rehabilitation services in the region. Community-Based Rehabilitation Intervention for Disability (COMBRID), whose pet name is “*Friends of Disability*”, has registered itself formally as a non-profit organization with a vision of a fully restored quality of life for the PWD, and the mission to provide rehabilitative, medical services and foster socio-economic initiatives among the PWD (COMBRID, 2009). It promises to, among other things, raise awareness about disability; promote community involvement in disability rehabilitation; develop local capacity for the medical and social management of PWD; provide psychosocial support to the PWD and their families; build networks for the support of PWD and; develop environment-friendly income-generation skills among PWD.

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## Discussion and recommendations

### *Quality of data*

It was difficult to get reliable data about the prevalence of disability in the region since HMIS data did not often mention epilepsy and even the results of previous disability assessments were not available. In addition, significant disparities were noted in the data from different official sources. This also implies that the dissemination of data about disability rehabilitation services in the region was poor. It may also be an indicator that the status of the health management information system in the entire W. Nile region is poor. Without reliable data about disability, it is difficult to plan appropriately for the services. Case definitions of the various disabilities and their causes were not harmonised between the different data sources. Nevertheless, analysis of the available data showed that PWD resulting from cerebral palsy were under-represented in the reports, suggesting potential neglect of people with mental disability. A fully-fledged household survey for disability, strengthening the data collection activities of Arua District Union of People with Disabilities, and strengthening the work of CBR workers might improve the reliability of the data. This would require some training of qualified health workers and CBR workers, and the implementation of the use of standardised case definitions for each type of disability.

### *Access Barriers*

Despite heavy workload in the clinics, the study revealed some under-utilisation of the rehabilitative services. Some patients are not yet enrolled into the rehabilitation programme due to lack of awareness about the availability of the services and their potential for improvement in the quality of life, and the long distances and cost (direct and opportunity cost) involved. Therefore, broadly speaking, the reasons for under-use of the services are of two kinds: first, lack of knowledge about possible treatment and rehabilitation for disability; and second, cost (including opportunity cost). For the first problem, the answer is better information which is well disseminated through appropriate channels. For the second, the decentralisation of medical and rehabilitative services through outreach activities is the right approach. Both approaches have been embarked upon and the efforts are commendable and should be supported by all stakeholders. Stigma is not a reason for under-use of services in the study area. On the contrary, PWD are well integrated in the community and people want to assist them. However, they can only do what they can afford, and there is need for external help to develop social services at community level.

### *Outreach activities as a solution*

The early experience with outreach activities suggests an appropriate way forward for the rehabilitative services. However, they need to be organised better in order to improve their quality and effectiveness. Below, we discuss four areas in which improvement is necessary and achievable: the number of people per outreach clinic day; the communication with PWD; the quality of services and; the organisation of systematic follow-up.

### *Number of PWD on outreach clinic days*

The number of PWD present at the assessment and follow-up visits was too high, which had negative consequences for the quality of services. Outreach activities should be small-scale and more focused. One good option is to invite PWD in sub-groups e.g. people with specific conditions or people in different sex or age-groups to come on different occasions. Specifically, inviting people of the same condition together is the best option because it would improve the understanding of the purpose of the clinic day. It would allow the health workers to do detailed health education and align expectations with services provided. In all cases, the numbers of clients would be smaller and allow for good two-way communication between the health workers and clients. Another option to keep numbers manageable is to invite from defined and smaller geographical areas. Reduction of numbers would increase the cost of the exercise though, because more clinics have to be held, and it goes against the famed spirit of integrated clinics. However, the trade-off in terms quality of care outweighs the other costs and should be supported.

### *Communication about outreach activities*

The mobilisation of the PWD was certainly effective for many people turned up. Several channels were used. However, the quality of the message was poor. Many PWD said they were obliged to come although they did not know why they had been called. There was evidence that the correct information was given to the leaders but it was not passed on correctly to the population. The strategy for informing people for initial assessments needs to be revised. Where CBR workers are operational, they should play a major role in correctly informing the population the purpose of each outreach session and who are the target audience. Where CBR workers are not yet active, the local leaders should be made aware of the correct information, preferably by use of written messages, for transmission to the population. Another approach could be through a network of PWD. Use of radio messages needs to be carefully controlled. Radio messages need to be repeated several times to ensure that they are heard by

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many people. All those who have heard the messages correctly may then correct those who the messages wrongly.

#### *Quality of services*

The quality of the services during outreach activities was sub-standard in many cases. Yet, the quality of services is essential for the service to be attractive and to reach as many PWD as possible. Good quality care during the assessment is important to motivate patients and caretakers to come back for follow-up. Good quality care during follow-up sessions shows PWD that their situation can be improved, and they feel motivated to keep coming. Overall, good quality care at all phases motivates the entire population to report illness early before disability occurs or while the disability is still amenable to correction. Therefore, no effort should be spared to improve the quality of care. Qualified staff needs to be allocated for the rehabilitative services. Their knowledge and skills, especially in clinical methods, communication, drug selection, quantification, ordering, prescription, dispensing and management, need to be strengthened through refresher training and continuing medical education. Essential equipment, medicines and supplies need to be available to ensure accurate diagnosis and treatment. Medicine supplies need to be monitored very closely to avoid unnecessary stock-outs. The need for better planning of the services to avoid overcrowding of the outreach sites cannot be overemphasised. Every session, whether at the outreach or fixed site, needs to have a manageable number of PWD, in order for good quality care to be offered.

#### *Integration into the district health services and effectiveness of care*

The project initially opted to conduct outreach activities in collaboration with the public health facilities, with the aim to promote its integration into the routine activities of the public services. This practice has persisted even after the end of the project. Currently, outreach clinics are held in the existing public facilities, occasionally with the staff of those units, but more often by the staff of the regional referral hospital and the CBR workers. Our observation revealed little actual involvement of the staff of the lower level health units in the conduct of outreach services. Where the staff of the lower level units participates, there have been no efforts to improve their prescription practices. For example, the staff does not often question themselves as to whether the patient will get the medicine and take it. There are frequent medicine stock outs but the prescribing staff is not always aware of this. However, they also often knowingly prescribe medicine, crutches and other supplies that are out of stock. They do not reflect

about the effectiveness of their prescriptions because reflective thinking is not a common practice among Ugandan health workers. Therefore, efforts need to be taken to improve the quality of medical prescriptions, at least within the scope of the rehabilitation services. In addition, the health workers need to be trained to do reflective thinking, to enable them to always consider the effectiveness of their actions.

#### *Communication with patients and being effective as a professional attitude*

Many health workers did not pay attention to ensuring good communication with the clients. Yet, this is crucial to gaining the patient's confidence and subsequent adherence to instructions and health education. Giving information to clients can be about minor issues, such as warning before applying painful eye drops before an eye test, or explaining the condition and treatment to each individual patient. Good communication shows the health worker's interest in effectiveness and respect for the client. Listening carefully to a client's problem before prescribing treatment is equally important. Communication can also make all the difference between taking treatment adequately or not. Yet, it is often ignored. In this study, some clients with epilepsy had questions about drug reactions, about explaining and demonstrating how to apply eye and ear drops, about where they could purchase the prescribed medicines which were out of stock etc. Yet, they did not have opportunity to ask because the health workers were not listening. Communication with PWD should also be open and truthful, especially about the possibility of recovery, likelihood of persistent pain or deformity, loss of performance, treatment options available, complications and other possible outcomes. Such an exchange would require sufficient time, a good and quiet environment, good listening skills and good communication skills. However, most of these requisite conditions were found lacking in this study. We recommend that health workers should be trained in various communication skills, especially in listening, communicating bad news, counselling etc. This would enhance their effectiveness as providers of care, especially as they also serve as role models for the CBR workers. Proper planning of the clinics would reduce the numbers and allow sufficient and quality interaction time between the PWD and the health workers. Recruitment of a qualified counsellor is another option to be considered.

#### *Organising follow-up*

Most disabling conditions need sustained follow-up and care. However, it must be well prepared for. Such preparations must begin at the assessment stage. Health workers must take – and have – the time to explain to



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the patients their condition, their treatment options, and especially, to discuss the next steps at each phase in their management. Clear appointments must be made. A good opportunity for follow-up of clients with mobility problems might be to start a prosthesis repair outreach. During that outreach, which can run alongside the assessment outreach, health workers would discover what works and what does not work. Similar arrangements could be made for other forms of disability. Every person for whom treatment is started should be followed to ensure that the services given are effective. However, when follow-up cannot be ensured in conditions where lack of follow-up may compromise the outcome, the usefulness of starting a treatment should be questioned.

#### *Scope of services*

Whereas some categories of PWD can be helped very effectively in the current scope of services offered, e.g. people with epilepsy and people with some types of mobility disorders, some others cannot be helped. There are substantial additional investments in terms of time, training, funding and infrastructure needed to assist some PWD meaningfully e.g. those with visual impairment and those with deafness. As a result, the services currently offered for the other disabilities are minimal (e.g. Braille equipment, training and social support for school children) and yet the community mobilisation raises a lot of hope. We recommend that mobilisation for these conditions should be cautious and investment in rehabilitation for these services be expanded. For some other conditions, the effectiveness of intervention is questionable since they already have advanced disease and have serious complications, or develop complications after intervention due to poor follow up. Otherwise, they could be dropped from the list of services offered, at least for some time while the capacity develops. Some PWD would be temporarily excluded, but it is fairer to give effective services to some defined prioritised disabilities, instead of less effective services to all as is the case now. Our recommendation in that case would be to focus on mobility disabilities and on epilepsy. In order for all health workers, political leaders and PWD to know what to expect, these priorities would have to be widely communicated to avoid the current confusion and disappointment.

#### *Record keeping, analysis and use*

The study revealed poor record-keeping, characterised by incompleteness of data from any single source, inconsistencies in the data kept in different sources and ignorance about the data by the stakeholders. Successful follow-up of patients and of the services in general requires good record keeping, keeping track

of success or failure rates. For example, important indicators of success such as the proportion of people who use crutches out of those who receive them, is crucial. Yet, there are no data about it. It is hard to know the reasons behind use or non-use of prostheses and protective equipment provided. Such reasons would enable the staff to address them and improve the benefit for the population.

#### *Prevention of disability*

Much disability could be avoided if people were better informed. Whereas primary prevention of disability is addressed in the general health system, secondary to avoid specific disabilities or to avoid deterioration could be handled by the rehabilitative service. Many PWD and caretakers were quite ignorant about their disability, its origin or ways to keep damage minimal. It would be useful to do specific, well prepared and well organised information campaigns, e.g. preventing chronic otitis media, timely treatment of cataract, enhancing mobility among children with club foot, promotion of school attendance by disabled children, preventing burns in epilepsy patients, preventing the chronic consequences of leprosy etc. Each campaign should focus on only one selected message. It should be organised, implemented and evaluated thoroughly before starting a similar process for another message.

A good follow-up of patients will give ideas for prevention and messages to communicate to the communities. Organising such communications should become one of the pillars of the project, because good knowledge about diseases and disability will help PWD a lot. For example: everybody should know that club feet can be corrected when treated as soon as possible, but that the child will be disabled if nothing is done; where the project avails drugs for epilepsy, more could be done to improve understanding of and attitudes towards the disease in a population that has such a high prevalence.

Communicating such messages is more or less done, but it could be organised in a more systematic and effective way. Active communication about the disease could be organised in schools and communities.

#### *Medical aid or comprehensive aid for PWD?*

The study showed that the needs of PWD are multiple and comprehensive, some beyond the scope of the health sector. Medical needs, such as assistive devices and appliances were high on the agenda. However, there were others like adaptation of the environment to needs of disabled persons, and social and emotional needs, education of children with disability, special needs education, life skills training, assistance for basic needs

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such as fetching water, and economic needs. For the organisation of the response to these needs, we agree with the political leaders and other key informants that different aspects should be handled by different organisations. For this to happen, good and extensive networking is required from the district level, sub-county level, community level and other stakeholders, especially the NGOs and unions for PWD.

#### *Community-based rehabilitation*

The application of CBR, in combination with the use of outreach sites, seems to be yielding important successes in utilisation of the services. We recommend that as a strategy, CBR workers should be facilitated to make them more effective and accurate in their work, and to expand the strategy to all parishes in the region. However, we also recommend the improvement of the competence and capacity of first line health services to make early interventions, correct diagnoses, treatment and referrals. CBR workers need to be supported by systematic outreach done by qualified health workers. The strategy still requires fine-tuning to improve the quality of the services and to define what is manageable for effective service delivery. We believe that this combination of CBR workers in the community, regular outreach assessments and services, technical back-up and referral care at the referral hospital have higher chances of providing early and adequate interventions than any one of them applied singly.

#### *Financing of rehabilitative services*

Currently, the rehabilitative services are poorly funded and can be considered a neglected component of health services in Uganda. As long as the government does not have the required resources to be allocated to services for PWD, or as long as it does not prioritise the needs of PWD, these services will have to be funded by other sources and, most likely external donors, since PWD and their families may not afford to meet the required demands. A public-private partnership on disability seems a more effective option of providing the services than aiming at a full take-over by the public sector at this time. Therefore, we urge for further coordinated involvement of the private sector in the provision of rehabilitative services.

#### *Advocacy for and visibility of the needs of PWD*

There is need for strong advocacy for the interests of the PWD at all levels, especially for those which are not immediately considered as their rights e.g. income generation. Society, especially opinion leaders and decision-makers, have to be sensitised on the building of inclusive societies. Such advocacy needs to come from a wide range of stakeholders such as PWD unions, health workers, CBR workers, local and international

civil society NGOs etc. Advocacy and visibility will make resources available for the provision of the required services. The emergence of a new local NGO, COMBRID, interested in sustaining the campaign and work for disability rehabilitation may be a good opportunity to be supported by all stakeholders. In particular, Doctors with Africa CUAMM needs to consider introducing this NGO to other networks as a worthy exit strategy from the region. However, the NGO needs to re-evaluate its proposed scope of work, given its current capacity.

#### **General conclusion**

The project kick-started a process which has raised the awareness of the population of the West Nile region about the presence, extent and effects of disability in their area. It started services essential for meeting the needs of the PWD such as an orthopaedic workshop and the production of prostheses. It has raised the people's awareness about epilepsy in the region and offered crucial assistance to this category of people who have a usually stigmatised condition. Such awareness has helped to reduce the stigma and given people with epilepsy an unprecedented level of acceptance in society. At the end of this study, we conclude that although it was good for the project to hand the services to a local operator, there is still need for external intervention in providing financial support and equipment in order for the services to meet the needs of the PWD.

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