PWD's

NATIONAL COUNCIL FOR DISABILITY
P. O. Box 26080 Kampala, UGANDA.
NCD

REPORT ON ACCESSIBILITY OF HEALTH CARE SERVICES TO PERSONS WITH DISABILITIES IN ISINGIRO, MUBENDE, MBALE AND GULU DISTRICTS

Conducted by:

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Acronyms

PWDs:	Persons with Disabilities
NGOs:	Non governmental organizations
CSOs:	Civil society organizations
DPOs:	Disabled peoples organizations
UNCRPD:	United Nations conventions on the rights of persons with Disabilities
NHP:	National Health Policy
NUDIPU:	National union of disabled persons of Uganda
NHS:	National Health Systems
AIDs:	Acquired Immune Deficiency syndrome
HIV:	Human immune deficiency Syndrome
PMCT:	Prevention of mother to child transmission
WHO:	World Health Organization
UNHS:	Uganda National Household Survey
UBOS:	Uganda Bureau of statistics
HSSP:	Health Sector Strategic Plan
DHS:	District Health Services
IDI:	In-depth interviews
FGDs:	Focus group discussions
KII:	Key informant interviews

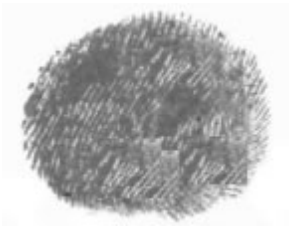
Foreward

This report is the product of a study commissioned by the National Council for Disability (NCD) as one of the documents generating feedback in our effort to monitor the implementation of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). The subject of concern is enshrined in Article 25 of the Convention, stipulating the right to health care for all.

The purpose of the study was fourfold, namely:Identifying factors affecting equitable access to health care services by Persons with Disabilities (PWDs);Establishing awareness levels on disability management and service provision for PWDs by health personnel;Identifying existing interventions that facilitate equitable access to health care by PWDs; Designing strategies for strengthening the capacity of service providers to better offer inclusive services.

Government and non-government actors working in the health sector are urged to utilize the findings and recommendations in this report to provide better health services to disabled women, men and children. The disability movement a like needs to identify areas of evidence-based advocacy within this report for more effective engagement with service providers. I take this opportunity to thank Government of Uganda for its effort towards improving the standards of living for PWDs. The Government has tried its best to mainstream disability in its commitment to the right to health in the NHP II and the HSSP III, to ensure that strategic planning is guided by human rights standards and principles in order to cater for vulnerable groups.

Despite numerous government efforts in providing accessible health care services using the decentralization approach however, a lot is still desired in order that PWDs can be fully served. For this to happen, there is need for inclusive planning, improved physical and communication access, increased budgetary allocations and releases, unwavering political will, and a lot more. I applaud Council for the commendable work done to collect data and document this report. Special thanks are extended to the study participants in the districts of study, who willingly provided invaluable information to this protracted undertaking.



Ms. Kyozira Esther

Chairperson, National Council for Disability

Acknowledgement

This report is a milestone in our monitoring and policy influence work for better service delivery for PWDs and the entire population. Needless to say, the NCD is Uganda's lead public institution charged with monitoring the impact of legislation, policy and programmes of Government and non-government actors on the lives of PWDs. This immense duty tantamount to serious engagement in disability coordination and networking, research, investigating cases of human rights abuse against PWDs, policy advocacy and monitoring. It is in this light that the NCD carries out and/or commissions its research so that all interventions are evidence-based. Access to health care services in particular, has been a subject of special interest to PWDs from time immemorial.

With this product, the NCD wishes to extend its appreciation to the Government of Uganda for the continuous financial, moral and technical support, part of which led to this research project; but which has also kept the Council on an even kneel since inception in 2003.

More specifically, special thanks goes to the Research team for the commendable work done in generating, analyzing and documenting the study findings, as well as disseminating this report. I am also honoured to thank all disability leaders and their organizations, as well as other NGOs for having tirelessly served PWDs and enthusiastically participated in this research process. Study participants are of special mention as this report would not have been without their invaluable information, shared freely and with keenness.

The sample districts of study deserve an obviation for providing a conducive atmosphere to the research team during data collection. All other districts should emulate this so that meaningful impact in the lives of PWDs is realized and recorded.

Join hands with the NCD! Let us all invest in more research for informed advocacy, planning and service provision.

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Mr. Kamya Julius

Executive Secretary

National Council for Disability

Introduction

Disability: Tterms of functional limitations experienced by a person because of environmental (physical, mental and sensory impairments) and social barriers. A disabled person is any one who has or has had an impairment causing a long term adverse effect upon his or her ability to perform daily activities.[1]

Inclusiveness: Trying to ensure that those groups often marginaliszed by and excluded from mainstream society – get equal and equitable benefits from their citizenship

Health system: All activities whose primary purpose is to promote, restore or maintain hHealth. Health actions and nNon-hHealth actions within and outside the hHealth sSector that lead to desired health results.

Human rights Laws: Tthey are legally guaranteed human rights laws, protecting individuals and groups against actions that interfere with fundamental freedoms and human dignity.

[1] www.cda-adc.ca/icda

Getting Started

Introduction and Methodology

This study documents the established mechanisms to increase equitable access to health care services to Persons with Disabilities in the Districts of Isingiro, Mubende, Gulu and Mbale. National Council for Disability conducted a study in 2010, a total of 117 respondents were interviewed, and there were 67(57.3) male respondents and 50 (42.7) female respondents. Data was collected through literature review, key informant interviews, in-depth interviews and Focus group discussions.

Key Findings

Factors affecting equitable access to health care by PWDs

It was observed that, it takes more than ramps to achieve accessibility to health care services by PWDs. In Uganda, health care delivery is not structured to provide patient centred care for PWDs; they are looked at as any other person who can struggle in the line and get the services. Though there is a policy for free health care access by all Ugandans. PWDs require therapies that are not provided in health centres for instance in PWDs reported their grievances on the demolition of the orthopaedic workshop at Mbarara regional referral hospital.

Barriers to movement and communication in the physical environment prevent PWDs from enjoying the same rights, privileges and opportunities as other members of society. Medical workers expressed their views to have experienced inadequate understanding of patients' history mostly the deaf, hard of hearing, deaf-blind and those who have challenges in speech and mental illnesses.

PWDs are inadequately reached with HIV/AIDS messages. Some are unaware of the symptoms of HIV/AIDS, and do not understand well the implications of these symptoms, should they appear. Many who depend on others for transportation or sign language interpretation reported delays in seeking testing or care even after symptoms appear because of reluctance to disclose personal sexual relations and the entire sexual histories/ background information.

Transport modes and health centres are inaccessible to people with moderate, severe and multiple disabilities. Many disabled women and men with physical disability, persons with intellectual, speech, hearing, visual disabilities and mental illness need helpers to travel with, and therefore required to pay transport costs for two people.

Lack of ramps, proper lighting, modified seating and overcrowding of vehicles combined with indifferent attitude of transport staff also forces many PWDs to only go out homes to address health and/or emergency needs. As a result, most of them do not participate in education, employment and social activities and are thus, often isolated and tend to be poor.

Hygiene conditions in most health centres are alarming more especially the restrooms (toilets) which are in most cases unclean with no running water. This poses a great challenge to the PWDs who crawl and wheelchair users.

Women with disabilities have reported challenges of accessibility often when they go for delivery or antenatal care in health centres. The examination/labour beds used in health centres are raised and not adjustable, they are hard to climb. In health centres visited in Isingiro district, its only one health centre that had an adjustable bed.

Poverty is a challenge to PWDs in accessing health care. Government health centers are always short of drugs and medical workers spend much of their time in private practice. PWDs being the poorest of the poor cannot afford to buy medicine in pharmacy neither to go to private clinics where the little you can pay for medical care is not less than 15,000=.

In Uganda**,** there are only 28 psychiatrists for a population of 33 million. There was a report in New Vision April 2010 that mental cases constitute 12% of the global disease burden and are projected to reach 15% by the year 2020. The report said that most of the work is being done by clinical officers and nurses since specialists are few in the country. This poses a bigger challenge to people with epilepsy and mental health cases.

Awareness of health care staff on disability management and service provision for PWDs

Uganda's health system offers a number of specialized services for PWDs through rehabilitation health services that ought to provide assistive devices. However, it was observed that assistive devices are not provided at all levels. Rehabilitation services are provided in regional referral hospitals, moreover inadequate, as the occupational therapy and physiotherapy department is understaffed. PWDs particularly those with severe disabilities find it difficult to go to the referral hospitals that are always located far from the communities.

Respondents were asked if there is provision for early detection and intervention services in the districts that were visited. 21% of the respondents said there is only detection, 24% said both detection and intervention, and 19% said only detection and 36% said neither of the two services is provided in their districts.

The services which are offered in health centres and hospitals in Uganda in relation to disability include general care, treatment of epilepsy, mental health care, orthopaedic care, eye care and ear, nose and throat care. However, those services at times are not provided due to lack of professionals because most health professionals spend their time carrying out private work in private hospitals and clinics. Another reason for not offering services is inadequate supply of medicines in government health care centres.

Existing interventions that facilitate equitable health care for PWDs

Health workers were asked to describe how they deal with patients that have different types of disabilities like physical, hearing, visual, mental, epilepsy and deaf blind. 41% of patients with physical disabilities were referred from the nearby health centres to National Referral Hospitals for medical attention. During the course of data collection, it was observed that orthopaedic and physiotherapy care is at National Referral Hospitals and non-governmental hospitals not found in remote areas. Other lower-level health care units do not offer the services.

Health workers were asked to list health trainings they received in relation to disability. 30% reported none, implying that they are not aware of any service they provide that is relevant to disability. Other health workers reported as follows; 25% said they were trained in community-based rehabilitation,18% trained in management of common disabilities, 13% trained in mobility and sight training, 8% trained in mental health care, 3% were trained in eye care and ear nose throat respectively.

Health workers attend to all patients that come for health care in the health units. However, PWDs have peculiar issues that require special attention from specialised service providers. For instance, people with sensory impairments need keen observations and support to communicate. During this study, health workers were asked the services they specifically offer to PWDs. 41% said they keep on referring patients with disabilities starting from health centres at parish level, health sub-districts and then to referral hospitals. The main reason given for the referrals is that services needed by PWDs are not available or the health workers are faced with the challenge of communication to the deaf and deaf-blind patients.

Non-Governmental Organisations reported by PWDs and key informants that are involved in providing health services specific on disability

1. NUMAT (Northern Uganda Malaria, Aids and Tuberculosis Programme) constructed laboratories at health centre

111 and made sure accessibility for PWDs was given a priority. Laboratories were built with ramps in the health centres of Bobi, Cwero and Patiko. Those health centres are supported by NUMAT to conduct VCT and HCT services. NUMAT has a partnership with Gulu deaf association and managed to train 20 persons in sign language from Lango and Acholi regions.

Ramp constructed at Health unit in Isingiro District

2. Cure-International is a hospital in Mbale specifically helping children with hydrocephalus, cleft palate, clubfoot, spinal deformities, and crippling orthopaedic conditions.

3. AVSI (Associazione Volontari per il Servizio Internazionale) built the Gulu Regional Orthopedic Workshop, the only orthopedic workshop in a region that is struggling to recover from 19 years of war in Northern Uganda. The field office in Gulu has been developing and supporting Mine Risk Education (MRE) and victim support activities.

4. Kataremwa Cheshire Home is an NGO that work on surgeries and rehabilitation of children with disabilities. It offers medical services which include orthopaedic therapy, physiotherapy, occupational therapy, orthopaedic and plastic surgery, assessment clinics, nursing, x-ray services, laboratory tests and other general medical services.

5. CoRSU (Comprehensive Rehabilitation Services Uganda) is another Non-Governmental Organisation that is operating a fully equipped Rehabilitation Hospital and Rehabilitation Centre on Entebbe road, providing orthopaedic and plastic surgery plus rehabilitation and other specialities. CoRSU has a community-based rehabilitation program which identifies, refers and follows up children with physical disabilities in Kampala and Wakiso districts. Its operation is still around central region, it needs to spread out to reach many PWDs in the rural areas who are in need of the services.

6. Red-cross International, this is based in Mbale hospital and its providing orthopaedic services for PWDs, before it opened its operations in Mbale, it was operating in Buhinga hospital-Fort portal offering similar services to those that are in need of orthopaedic services. The services are not purely free at times it requires payment of a small fee.

Strategies for strengthening the capacity of service providers to offer inclusive services

Facilitation of PWDs with income generating activities will improve their income levels thus use the earned incomes to pay the health care bills. In most cases, government health centres lack medicines and patients are referred to private pharmacies to buy the drugs.

They also said that health facilities should employ sign language interpreters or train their health workers in sign language to ease communication with the deaf and deaf-blind communities.

Other interventions suggested include:

- Ensuring regular supply of drugs,
  Constructing ramps on all health care centres to facilitate easy movement by wheelchair users,
  Train PWDs themselves as health workers since they know the challenges they face better.
  Giving priority to PWDs by serving them first before queuing for health care services.

Continuous advocacy and awareness campaigns about key health issues and concerns of PWDs.

Health information systems should be revised to ably capture issues of disability. In the due course of the research, it was observed that Form (A) for the hospital does not ask if a patient in question has any form of disability. If this is worked on, it will be easy for the administrators and planners to analyse the information and plan properly.

Capacity building and sensitisation about PWDs issues and concerns should be done at grass-root levels. It was observed that most Disabled People Organisations (DPOs) that normally carry out advocacy capacity building and sensitisation work in easy to reach areas (towns and urban centres). Rural areas where the masses stay are neglected yet they are the ones facing much of challenges in accessing medical care services.

Collect and monitor disaggregated data on women with disabilities in health and reproductive health programs. This will be helpful to register the total number of PWDs that access health services in health units, in particular access to services which can prevent HIV/AIDS, maternal and child mortality.

There is need for increased research and dissemination to enrich information in relation to equitable access of services by PWDs. Assessing the experience of PWDs access to health service may be a good way of probing the effectiveness of the overall public health system. This can be done by intensive qualitative exploration of experiences

of service users, non-users and providers in different contexts. Ethnographic Framework should be used which include in depth interviews, observations and facility reviews.

Also extensive quantitative exploration of epidemiology, living conditions, contextual and systems factors for PWDs should be carried out via household survey.

Rehabilitation and enabling technologies should be availed at all health centres and through outreach programs, so that many PWDs have access to these services that enhance their quality of life.

Review and analysis of health policies in Uganda in order to meet the standards set in the UN Convention on the Rights of Persons with Disabilities. The policies ought to be practical and popularised to benefit many Ugandans.

There is need to have many players working towards provision of better health services for PWDs. This should be done by re-forming the National Health Policy to respond to the needs, concerns and expectations of PWDs. Health institutions need to be well organised, streamlined, facilitated, and regulated to adequately serve the purpose for which they were set up to.

Health workers should stick and exercise their ethics by accepting PWDs as part of the wider humanity by avoiding discriminating and stigmatising them. To efficiently provide goods and services, health workers must be respectful of medical ethics by being sensitive to the needs of vulnerable people, protecting privacy and confidentiality of their clients.

Enforce a rights-based approach to improving the lives of PWDs. This involves using human rights as a framework for health development, assessing and addressing the human rights implications of any health policy, programme or legislation, making human rights an integral dimension of the design, implementation, monitoring and evaluation of health-related policies and programmes in all spheres - political, economic and social.

There is need for increased transparency and accountability in the health care system at all stages of service delivery in Uganda.

Health care management teams should have a representative of PWDs who can always front issues of disability in the health committees.

Review the health care programs to meet the needs and aspirations of PWDs. There should be guidelines specifically addressing mainstreaming of PWDs in the health care system and tailored to serve the needs of all kinds of PWDs.

Improving coordination of social and health care is needed to meet individual health promotion needs. For persons who are able to manage their own health and health care, there is a growing industry of self-management programs

available for different conditions and target populations. Many PWDs, however, may not feel that they have the expertise to take health care decisions even if their personal health choices are within their own control. Thus the question of assisting PWDs in making choices about health care and health promotion remains a challenging issue that requires innovative management care solutions.

Public health interventions should be put in place directed mainly at primary prevention of disability. Community-based strategies that address the problems of people with disabilities require a public health partnership to be well-formulated and coordinated. The same principles of cultural competency relevant to programs apply to all prevention and health promotion policy for people with disabilities. Prevention policy should focus on promoting equal access to primary health care and preventive services.

Incentives are needed to promote change in health promotion policies for PWDs. Economic incentives and disincentives need to be examined as possible arenas for promoting health. For instance, financial support for construction of ramps, provision of adjustable examination beds by government in all national and local health centers could help to promote access to health care services.

A ramp contructed at Bobi health centre 111-Gulu District.

Health workers should also be trained on how to handle all forms of disability more especially communicating with deaf-blind patients using tactile methods. Also refresher courses should be provided to health workers in sign language. This issue should be keenly followed since it is unique and requires attention of all service providers.

Community based rehabilitation programmes should be well staffed, allocated enough resources and equipment to cover the entire country in order to raise awareness on issues of disability and to manage disability.

Introduction

Uganda implemented a series of health sector reforms in the 1980's to make services more accessible to the entire population. The government went a head to abolish user fees, introduction of public-private partnership in service delivery and decentralisation of health services to district and lower local government levels. An empirical assessment was made of the impact of these reforms in terms of changes in utilization of health services that have occurred among poor and rural communities between 2002/3 and 2005/6. The NUDIPU report 2007 indicated that there is poor enforcement on the requirements of health centres to build ramps and other facilities to ensure accessibility for PWDs. This gap required further investigations and this research was conducted to establish mechanisms to increase equitable access to health services. National Council for Disability and the entire disability movement keeps receiving reports from PWDs about the inequalities that are faced in health care service delivery at all levels that has resulted into conducting this study. Patrick D (1997) urged that PWDs rarely receive the range of health promotion and preventive services they may need or want. This happens due to lack of accessibility to physical environment, information and difficulties in communication.[1]

Neri M.T and Kroll.T (2002) urged that constrained relationships with families, friends and colleagues as well as modifications to existing social roles, and limitations in societal participation has increased the barriers to health care access by PWDs.[2]

The World Health Organisation (WHO) estimates that disabled people make up 10% (about 650 million) of the world's population. Eighty percent of PWDs live in developing countries, according to the current report by UBOS. UBOS also estimates 19.8% of the population in Uganda have a disability. More than 40 % of the older persons in Uganda have a disability (Uganda National Household Survey 2005/2006). Sixty percent of PWDs in Uganda do not receive any kind of rehabilitation[3]

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The Constitution of the Government of Uganda (1995) provides among its social and economic objectives that the State shall ensure that all Ugandans enjoy rights, opportunities and access to education, health services, clean and safe water, work, decent shelter, adequate clothing, food security, and pension and retirement benefits. However,

[1] Patrick D: Rethinking prevention for people with disabilities, Part I: A conceptual model for promoting health. *American Journal of Health Promotion,* 1997.

[2] Neri. M.T and Kroll. T. (2002): Understanding the consequences of Access barriers to health care: Experiences of adults with disabilities, NRH centre for health and disability research , Washington, USA.

[3] Uganda National Household Survey 2005/2006

the right to health is not incorporated among the operational articles. The Constitution includes provisions against discrimination and provisions relating to specific marginalised groups, such as the rights of women, children, PWDs and minorities.[1]

About 400 million people in developing countries live with moderate or severe disabilities. Only a portion of them have access to health care and rehabilitation. Disability is no longer a medical issue as it was regarded in previous decades. Today, disability is understood as an issue of equal rights, dignity and participation of PWDs in all matters of life rather than charity. However, the health sector still has a key role to play in prevention and rehabilitation of PWDs.

Prevention of disability happens every day in the health sector when children are immunised, when chronic conditions are prevented or ameliorated, when nutrition and hygiene programmes are carried out well, and when injuries and emergencies are managed properly. Rehabilitation of PWDs can take many forms and rehabilitation services can be offered in national and regional hospitals, or in primary health care facilities and with various links to NGO and community- based initiatives. It may involve more or less specialised medication, surgery, physiotherapy, fitting of assistive devices among others.

Though it's a government responsibility to give medical care to all the citizens, PWDs have been neglected. However, Article 25 of United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)[2] talks about health and it states; Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

(a) Provide Persons wWith Disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;

(b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimisze and prevent further disabilities, including among children and older persons;

(c) Provide these health services as close as possible to people's own communities, including in rural areas;

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[1] The Constitution of the Government of Uganda ,1995

[2] UCRPD, 2007

(d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;

(e) Prohibit discrimination against Persons with Disabilities in the provision of health care, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;

(f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

Also PWDs Act 2006 recognises the right of PWDs to enjoy the same rights with other members of the public in all health institutions including general medical care. Furthermore, the Act makes reference to promotion of "special health services" required by PWDs, including reproductive services, in line with the Convention. The absence of general health legislation, however, represents a challenge in the implementation of the right to health of PWDs[1]
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To have good health care services in Uganda requires policy makers and implementers who are conscious of the needs and aspirations of PWDs. We shall achieve this by granting equal accessibility to health care by sensitively including PWDs and all citizens of Uganda. Uganda ratified the UNCRPD that provides for among other human rights, the right to health. Therefore, it is the responsibility of government and all actors to improve the quality and access of health care services to PWDs in Uganda.

PWDs represent 10% of the world's population, yet they are among the most underserved groups[2]
. Many of them lack access to preventive, curative, or rehabilitative services which is supposed to be their right.
"***The right to health does not mean the right to be healthy, nor does it mean that poor governments must put in place expensive health services for which they have no resources. But it does require governments and public authorities to put in place policies and action plans which will lead to availability accessible health care for all in the shortest possible time. To ensure that this happens is the challenge facing both the human rights community and public health professionals.***"[3]

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[1] The PWDs Act 2006

[2] Frye, B.A. (1993). Review of the World Health Organization's report on disability prevention and rehabilitation. Rehabilitation
Nursing, 18(l)

[3] Mary Robinson, 1999, United Nations High Commissioner for Human Rights.

Persons with physical impairments often lack opportunities to engage in preventive health care activities and do not have adequate access to primary health care, hospital care, and long-term care services[1]
. This is a common challenge to PWDs who use wheel chairs or have locomotive challenges. In the due course of the study, it was observed that 80% of constructed health centers in Uganda have no ramps. Those that have ramps have small corridors that can not be used by wheel chair users. Entry doors are also not standard; the wheel chair users are forced to crawl in order to enter the clinicians' rooms. This has increased reluctance of PWDs to seek medical care.

Mental health care is a challenge in health sub-districts and lower health centers because of lack of specialised medical personnel. For example in the entire Isingiro district, there are only three health workers who are trained to manage mental illnesses. Barton (1992) suggests that there is usually an insufficient caseload in general hospitals to warrant full-time staff for psychiatric emergencies, a shortage of trained personnel to respond to this type of crisis, and frequent failure to seek treatment for mental health problems due to lack of resources[2]

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[1] DeJong G, Batavia AI, Griss R. America's neglected health minority: working age persons with disabilities. Millbank Quarterly 1989;67 (Suppl 2, part II):311-351.

[2] Barton, G.M. (1992). The practice of emergency psychiatry in rural areas. *Hospital and Community Psychiatry*, 43(10), 965-966.

Health care policies in Uganda

The National Health Policy (NHP) 1999 and the Health Sector Strategic Plan II (HSSP II) 2005/2006 – 2009/2010 constitute a common strategic framework for all stakeholders. The role of government in health service provision continues to be vital for the foreseeable future, and full integration of the private providers into the National Health System is an important policy objective that seeks to provide equitable access to health care in Uganda. One of the policy objectives is to develop mechanisms to ensure equity in access to basic services for the most life- threatening health problems, particularly to avert pregnancy and birth-related deaths and the childhood killer diseases.[1]

The NHP provided for setting up the following functional structure as the national standard:

1. Ministry of Health and other National Level Institutions
2. National Referral Hospitals (27,000,000 population)
3. Regional Referral Hospitals (2,000,000 population)
4. District Health Services (District level, 500,000 population)
5. Health Sub-District
6. Referral Facility - General Hospital (District level - 500,000 population) or Health Centre IV (Country level - 100,000 population)
7. Health Centre III - (sub-country level - 20,000 population)
8. Health Centre II - (Parish Level - 5,000 population)
9. Health Centre I - (village health team - 1,000 population)

The Ministry of Health finalised the National Health Policy II and the Health Sector Strategic Plan III with the participation of development partners in the health sector and Civil Society Organizations (CSOs), including human rights and gender equality advocacy groups. The NHP I and the HSSP II referred to rights in relation to specific health issues. The HSSP II also expressed a commitment to build individuals' and communities' awareness of their rights. Stakeholders have noted the importance of explicitly confirming Uganda's commitment to the right to health in the NHP II and the HSSP III and to ensure that strategic planning is guided by human rights standards and principles in order to cater for vulnerable groups.

[1] The National Health Policy, 1999

Statement of the problem

PWDs represent a large and growing sector of the population that needs health care services. While 19.8% of Ugandans have been identified as being disabled, the true number of PWDs is unknown since there is no clear definition of disability and the statistics keep on widely varying from one study to another. At some point, almost everyone experiences a disability as they age. Though PWDs have many issues that require medical attention, many PWDs do not seek out or obtain quality health care because of different reasons. Often, health care facilities are not accessible or do not have the equipment needed to serve PWDs. Also, PWDs are often embarrassed because their disability requires them to obtain additional assistance from helpers, requiring them to surrender some of their independence and privacy.

The promotion of health and well-being among PWDs is a significant public health concern since health care providers discriminate PWDs due to failure to communicate, negative attitude and lack of effective materials that are favourable to PWDs. Basing on the health care providers' perspective, limitations in the physical environment, such as lack of appropriate equipment, may cause doctors and other professionals to forego, omit, or not recommend procedures or portions of procedures for PWDs that would otherwise be necessary. Increasing accessibility at health care facilities will encourage more people to seek for services, thus increasing client bases as well as the general health of individuals with disabilities and reduce on disabilities.

PWDs in Uganda were estimated at 19.8% by UBOS in 2009[1]. Having a disability limits PWDs participation in activities of their daily life and puts them at a higher risk of acquiring diseases than the general population. There is need to promote health care programs that may benefit PWDs greatly. PWDs are at a high risk of contracting communicable disease due to challenges with access to information. The fact that they are disabled, for instance those with physical disability and blind, makes them prone to accidents and hygiene related infections. The inadequate access to information has also led to health-compromising behaviours that increase their vulnerability to HIV/AIDS. This is strongly related to increased rates of anti-social behaviour, higher levels of depression and anxiety, and decreased life satisfaction. PWDs are among those living in extreme poverty; unable to afford transportation to testing sites, let alone the cost of testing or medical care. Many health professionals, unaware that individuals with disability may be sexually active, do not offer to test them or provide services, under the assumption that they are not at risk.

Most health centres in Uganda are located far away from communities and those that are closer to them may not have the required drugs or lack medical specialists to handle complicated cases. This study establishes the distances between health centres and communities. Furthermore, the study also establishes the accessibility of

[1] Hellen Nviri (2009) Presentation to a work shop on "Towards better Disability measurements and statistics in Asia and the pacific" .

structures at the health care centres. Disabled persons are faced with double tragedy of inaccessible physical barriers and poverty.

Objectives of Study

1. To identify factors affecting equitable access to health care by PWDs,
2. To establish awareness of health staff on disability management and service provision for PWDs,
3. To identify existing interventions that facilitates equitable health care for (PWDs),
4. To design strategies for strengthening the capacity of service providers to offer inclusive services.

Research Quesions

5. To what extent are PWDs accessing health care services and facilities in the four districts?
6. What challenges do PWDs face in accessing health services?
7. What interventions exist to facilitate equitable health care for PWDs?
8. To what extent are health service providers aware of disability management and conscious service provision?

Rationale of Study

The study was conducted to assess how PWD are accessing health care services, challenges they face, causes of challenges, and come up with recommendations to help health care professionals ensure equal use of the facility and services by all their patients. The information that was gathered gives health care providers a better understanding of how to improve not only the physical environment, but also their personal interactions with patients who are PWDs. It will also be used by policy makers to come up with new policies or review some of the current policies, reporting and design standards established through laws such as the PWDs Act, 2006, UNCRPD and the Constitution of Uganda (1995), that health care professionals need to know.

Methodology

Research design

The study was conducted in four districts, one in each of the four regions of Uganda. Data was collected using semi-structured questionnaires and interview guide. The study was conducted using quantitative and qualitative methods. The sample population was selected using simple random sampling to select PWDs and purposively for key informants. The target population included PWDs, opinion leaders, local political leaders of PWDs, Disabled Peoples Organisations and health workers. Secondary data was also used.

Study population and sampling

The total study population is 159 respondents, 117 were persons with disabilities and 42 respondents were key informants in the four districts. The districts include Isingiro from Western region, Mbale from Eastern, Gulu from North and Mubende district from Central. Simple random sampling was used to select the respondents according to the above stipulated categories. In Isingiro district 33% of the respondents were key informants, Gulu had 17% key informant interviews, 16.7% key informant interviews in Mbale and 33.3% key informant interviews in Mubende district. The table below indicates PWDs that were interviewed in the four districts;

Table 1: PWDs that were interviewed per district

District visited	Number of respondents	Percentage
Gulu	26	22
Isingiro	38	33
Mubende	27	23
Mbale	26	22
Total	**117**	**100**

Source: Data collected from the field

Data analysis

Information obtained was analysed using statistical packages that include SPSS and EPINFO and coding was used to analyse qualitative data that was obtained from Focus Group Discussions.

Discussion of findings

Demographic Characteristics of Respondents (PWDs)

Table: 2 Showing Demographic Characteristics of PWDs

Characteristics	Frequency	Percentage
Sex		
Male	67	57.3
Female	50	42.7
Total	117	100.0
Age Group		
Under 20 yrs	8	7
20 - 29	31	26
30 -39	25	21
40 - 49	19	16
50 -59	24	21
60+	10	9
Total	117	100.0
Household Size		
<4	33	29.1
5	19	16.2
6+	64	51.7
Total	117	100

Characteristics	Frequency	Percentage
Marital Status		
Single/Never married	35	30
Married	66	57
Divorced/Separated	9	8
Widowed	6	5
Total	117	100.0
Education Level		
No Schooling	16	13.7
Primary	56	47.9
0-Level	24	20.5
A-Level	5	8.5
Tertiary	5	4.3
Total	**117**	**100**

As shown in Table 2 above, there were 67 male respondents and 50 female respondents. Of the total respondents, 7 % were below 20 years, 26% between 20 - 29 years, 21% between 30 – 39 years, 16 % between 40 - 49 years, 21% between 50-59 years and only 9 % above 60 years.

With respect to household size, only 29.1% of the households comprised of less than four4 persons. The majority of the households (51%) had six persons, while 16.2% of the households had five persons.

Regarding education, 13.7 % of PWDs had no education at all, 47.9% of the respondents completed primary education, 20.5% completed O-level, 8.5% A-level and only 4.3 % of PWDs interviewed had received tertiary education Data on the respondents' marital status, on the other hand, indicated that 30% were single/never married and 57 % were married, 8 % of PWDs were divorced or separated and 5% widowed.

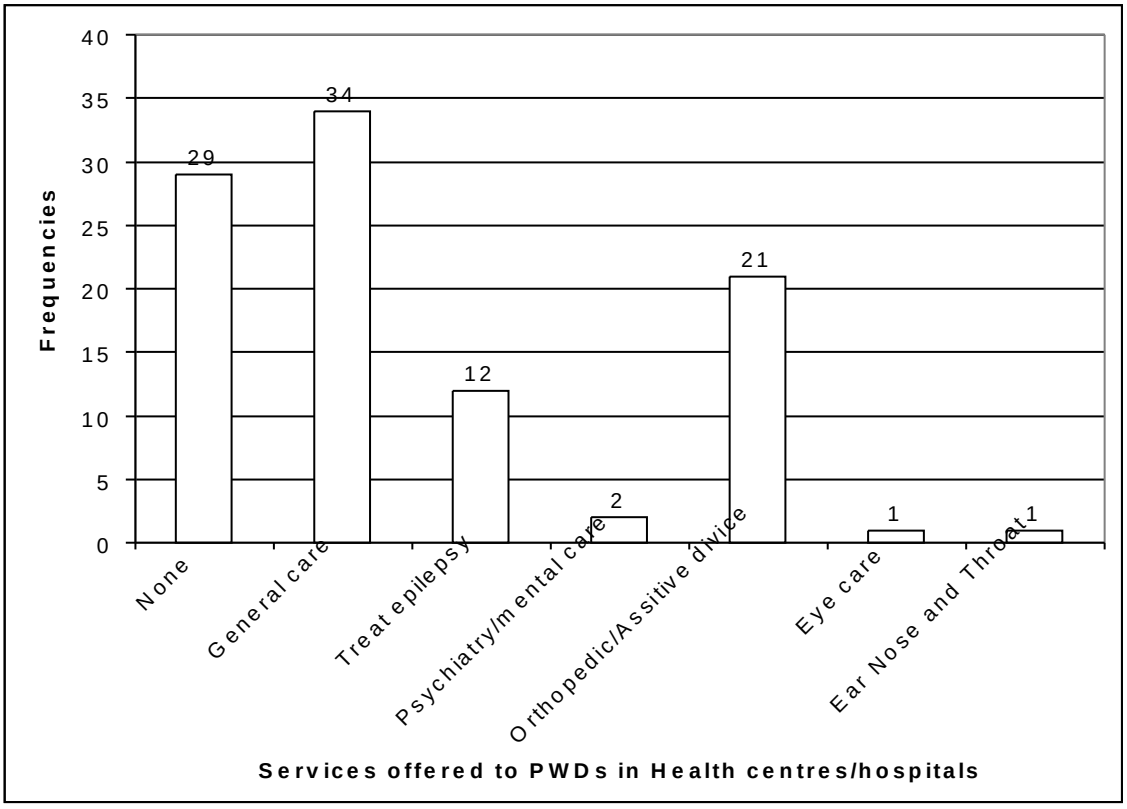
Factors affecting equitable access to health care by PWDs

In the due course of the study, it was observed that, it takes more than ramps to achieve accessibility to health care services by PWDs. In Uganda, health care delivery is not structured to provide patient centred care for PWDs;, they are looked at as any other person who can struggle in the line and get the services. Though there is a policy for free health care access by all Ugandans, PWDs are often unable to get the care they need due to the following reasons.

PWDs require therapies that are not provided in health centres. Health units in Uganda are most often running short of drugs and yet PWDs can not afford to buy medication. They therefore end up failing to get medication at all. ; Some of the PWDs have resorted to using herbal medication, off counter medication and self- medications. ***"Inclusion – that is what development is all about – to bring into society people that have never been a part of it."*** *James Wolfensohn, World Bank*. The graph below indicates the services offered in health centres PWDs visit in their respective districts;

In Isingiro district, PWDs reported their grievances on the demolition of the orthopaedic workshop at Mbarara regional referral hospital. The hospital started construction of buildings for hospital use and decided to close the workshop which has been supplying orthopaedic services to the entire western region. There was an out cry to government to make sure the orthopaedic workshop is put back to operation immediately.

Graph 1: Services offered in health centres accessed by PWDs in their districts



Source: Data collection from the field

Basing on the graph above, health units offer general care for malaria, headaches, flu and other infections not

specific on issues of disability as reported by 34 respondents. and 221 of the respondents suggested that orthopaedic/assistive devices be provided in the health centres. However, health centres that offer orthopaedic and assistive devices charge a fee which PWDs reported to be costly for them. This has caused health inequities that have put disadvantaged groups at further disadvantage with respect to health and diminishing opportunities to be healthy.

Barriers to movement and communication in the physical environment prevent PWDs from enjoying the same rights, privileges and opportunities as other members of society. Medical workers expressed their views to have experienced inadequate understanding of patients' history mostly the deaf, hard of hearing, deaf-blind and those who have challenges in speech and mental illnesses. A deaf person from Gulu district said ***" Whenever I go for medical care, health workers fail to understand what I explain to them and end up giving me wrong prescription due to wrong diagnosis. I have decided not to go and waste my time on long queues.; I go to pharmacies and buy medicine whenever I feel sickly".***

This is risky to the health of patient as it may lead to drug resistance or death. Another deaf person from Gulu also argued that **"D*ue to communication barrier, we write to the medical workers as a form of communication but at times they never understand us. When they are giving us medicine, we never get adequate explanations. We end up taking over- dose. Also at times we miss doses especially injections due to miscommunication and misinterpretation. In voluntary counselling and testing centres, deaf persons miss out on counselling".***

PWDs are inadequately reached with HIV/AIDS messages. Some are unaware of the symptoms of HIV/AIDS, and do not SAunderstand well the implications of these symptoms, should they appear. Many who depend on others for transportation or sign language interpretation reported delays in seeking testing or care even after symptoms appear because of reluctance to disclose personal sexual relations and the entire sexual histories/ background information. There is evidence from many countries of individuals with disability coming to clinics with full-blown AIDS only days before death; many others die without diagnosis or care. However, in Uganda, some districts have benefited from NUDIPU–HIV/AIDS program that have worked to increase availability of appropriate information and awareness on transmission of HIV infection among PWDs.

The districts that have benefited from the HIV/AIDS project of NUDIPU include Masaka, Soroti and Gulu. The said districts benefited from the project in the following ways;

i. Information Education and Communication Materials customized to respond to HIV information needs of

PWDs that is in large prints, braille, posters and audios.

ii. Re-fresher trainings to six peer educators and trainers per district.

iii. Increased awareness raising on HIV prevention, condom use, PMTCT services

iv. Developed communication strategy to guide disability and HIV/AIDS programs

v. Promoted integration of PWDs in Post Test clubs in the three districts

vi. Promoted dialogue on HIV/AIDS to reduce stigma amongst PWDs.

Beyond this, accessing medical, social, or legal services is often beyond the capability of ailing individuals with disability who have inadequate education, communication skills, and support networks. Where access to AIDS medications treatment or health services are not sensitive to human rights considerations and are prioritiszed in terms of "quality of life" or "contribution to society," individuals with disability are too often placed at the bottom of the list since its always survival for the fittest to get on the list.

It was found out that transport modes and health centres are inaccessible to people with moderate, severe and multiple disabilities. Many disabled women and men with physical disability, persons with intellectual, speech, hearing, visual disabilities and mental illness need helpers to travel with, and therefore required to pay transport costs for two people. Being the poorest of the poor, it's hard for PWDs to afford the transport fees for two, thus failing to attend medical care at all or delays in visiting the health centres. This worsens the sickness and may result into deaths.

Disabled people also rarely travel because of high cost incurred to hire vehicles. As a result, most people travel by public means as the transportation costs are lower. ,Nevertheless, the attitude of taxi/bus operators to PWDs is discriminatory and they normally charge them highly or leave them by the road side, arguing that PWDs occupy more space than the able-bodied persons. The PWDs appliances like wheelchairs and crutches also need more space and they are most often made to pay extra charges for the appliances. To move comfortably, people need to hire cars for personal use because they need more space to accommodate their aids/appliances and helpers, as they also find it difficult to reach the stages where they can get taxis from, or reach their destinations from where taxis/buses drop them.

Lack of ramps, proper lighting, modified seating and overcrowding of vehicles combined with indifferent attitude of transport staff also forces many PWDs to only go out their homes to address health and/or emergency needs. As a result, most of them do not participate in education, employment and social activities and are thus, often isolated and tend to be poor. The distance from health units to their homes at times is challenging as indicated in the table below:

Table 3: Distance from home of PWDs to health facilities

Distance from household to health centre/hospital	Frequencies	Percentages
1/2km	15	14
1/3km	4	4
1-2km	28	26
3-4km	25	24
5km and above	34	32
Total	**106**	**100**

Source: Data collected from the field

The table above indicates the distance PWDs have to move to seek medical care., 32% of the respondents travel for 5km and above compared to 14% who travel for ½ km to get health care services. This is a challenge to PWDs and they end up remaining at home with out medical attention because the longer the distance the higher the expenses for transportation and the delays faced on the way means they will reach when the clinics are closing thus missing the health personnel.

The study also found that most government health centres which offer free medical care are inaccessible. No preference is given to the disabled in these centres. Therefore, persons with severe disabilities rarely visit them.

Table 4: Easy accessibility for patients with disabilities to move freely in the health facility

Free movement in health facility	Frequencies	Percentages
Yes	12	66.7
No	24	33.3
Total	**36**	**100**

Source: Data collection from the field

Caregivers are supportive to disabled persons' health needs but, due to factors like high transport cost and health centres being in far distances, persons with moderate, severe and multiple disabilities are treated at home or through locally available medical services. They are only taken to health care centre during emergencies or when the patient is ill. Some parents and caregiver neglect their children with disability because of resentment A youth with disability narrates a story of his colleague: "***A boy suffering from malaria hated her mother for***

mistreatment when he was hospitalised and the mother never took good care of him due to stigma. The boy later hated the mother and refused to eat her food, till fellow youth with disabilities got to know about it and took care of him. The boy confessed that since the mother never cared about him, he feared her food suspecting her of intensions of poisoning him."

Table 5: Period PWDs last visited a medical worker for medical care

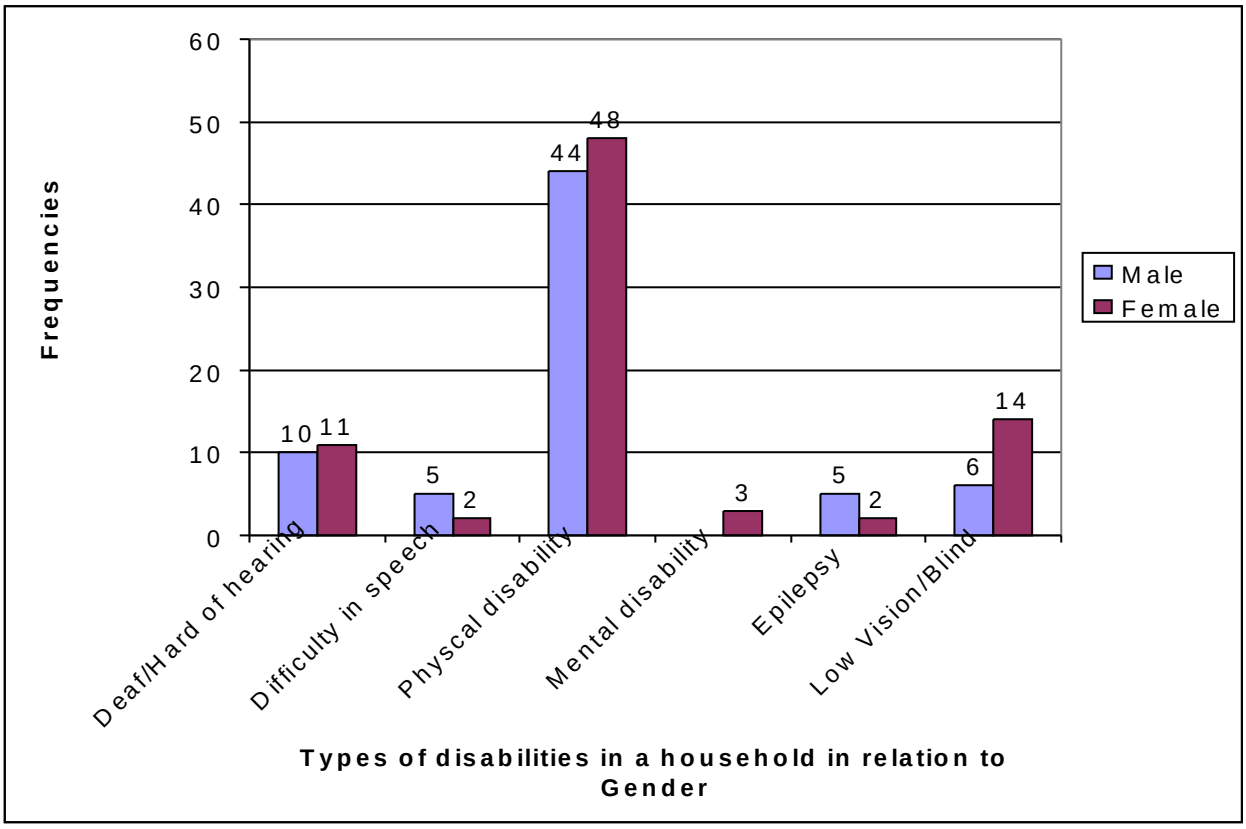
PWDs who have done general medical examination	**Frequencies**	**Percentages**
Within the past year	21	18
Within two years	11	9.4
Within past 5 years	5	4.3
5 or more years	8	6.8
Do not know/not sure	2	1.7
Never	70	59.8
Total	**117**	**100**

Source: Data collection from the field

Hygiene conditions in most health centres are alarming more especially the restrooms (toilets) which are in most cases unclean with no running water. This poses a great challenge to the PWDs who crawl and wheelchair users. ***"Accessibility audit teams went out and realised that there are no toilets that are friendly to PWDs.Access to physical buildings is a problem. Windows where drugs are dispensed from are too high for PWDs who are crawling and those in wheel chairs"*** Santos Dokwa, -Gulu.

Women with disabilities have reported challenges of accessibility often when they go for delivery or antenatal care in health centres. The examination/labour beds used in health centres are raised and not adjustable, they are hard to climb. In health centres visited in Isingiro district, its only one health centre that had an adjustable bed. That is Nyarubungo Health Centre Three. The table below indicates the number of women with disabilities that are in a household.

Graph 2: Types of disabilities in household basing on gender distributions



Source: Data collection from the field

Also, the lack of awareness of some of these issues on the part of AIDS advocates. There is little outreach efforts to disabled populations by AIDS organizations exist at any level, from grassroots to global. The importance of including individuals with disability in general AIDS campaigns or designing disability-specific interventions is largely unrecognized. This gap is well illustrated in a comment from a South African disability activist: "***I see AIDS educators going door-to-door, inviting all adults to AIDS meetings. They walk by and wave to the woman sitting in her doorway in a wheelchair watching her children, but they do not invite her to come."***

PWDs themselves often know little about health issues like HIV/AIDS. In some societies, individuals with disability believe that, since they have one disease, "God would not give them another". Due to communication barriers iIn deaf communities, there is widespread reported cases of misinformation about HIV/AIDS due to inaccurate information passed on sometimes by sign language interpreters. The information is at times

misinterpreted. For example, some deaf individuals believe that "HIV+ is a good thing" because the (positive sign) ordinarily indicates something good. A deaf person said; ***"At times we communicate with medical workers through writing. It's hard for those who do not know how to read and write to communicatee. Deaf members at times miss out on medical services when they fail to notice that they have been called to meet the health service provider. Nurses often call out the name of person in queue to see the doctor and the deaf cannot be able to know that you have been called. You end up spending a full day at the health unit and leave without getting care.***"

PWDs and their caretakers often bear the added burden of lack of money to pay health care bills, alarming rates of irregular supply of drugs in government hospitals and health centers and persistent shortages of medical workers. A blind person in Mbale lamented:; ***"I was called with other blind people to Mbale hospital for eye surgery. We spent two days lining up and never received any service, and I decided to go for an operation in Jinja in a Chinese hospital***."

Understaffing in government health centers/hospitals was reported as an issue that is affecting accessibility to the services. Patients come to the unit, line up for a full day and go home un- attended too. A physiotherapist in Gulu hospital reported: ***"In the physiotherapy department, we have three staff out of which one went for further studies, one is on leave and it is only me on duty. We have shortage of man power which may lead to some patients leaving without receiving services .A patient is supposed to be worked on for a minimum of 30 minutes. AVSI- Gulu work in partnership with CURE international hospital Mbale, where we refer patients."***

Materials used in physiotherapy sessions in Gulu Hospital

In Uganda**,** there are only 28 psychiatrists for a population of 33 million. There was a report in New Vision April

2010 that mental cases constitute 12% of the global disease burden and are projected to reach 15% by the year 2020. The report said that most of the work is being done by clinical officers and nurses since specialists are few in the country. This poses a bigger challenge to people with epilepsy and mental health cases.

A newly constructed phsychiatry department in Mubende hosptital

Poverty is a challenge to PWDs in accessing health care. Government health centers in Uganda are always short of drugs and medical workers spend much of their time in private practice. PWDs being the poorest of the poor cannot afford to buy medicine in pharmacy neither to go to private clinics where the little you can pay for medical care is not less than 15,000=. Alanyo Grace (-Paranga IDP camp Bobi sub-county, Gulu) said: ***"I stay in the camp because I cannot afford to build a house to resettle. I am poor and have no source of income yet I have to look after four children of my late brother."***

Table 6: Challenges faced by PWDs in getting medical care

Challenges PWDs face in getting health care	**Frequencies**	**Percentages**
Communication barrier	8	7
Irregular supply of drugs	21	18
Negative attitudes of health workers	9	8
Stigma	7	6
Discrimination	13	11
Inaccessible structures	16	14
Un hygienic environment/sanitary utilities	5	3
Long queues	8	7

Poverty/expensive services	14	12
Transport	16	14
Total	**117**	**100**

Source: Data collection from the field

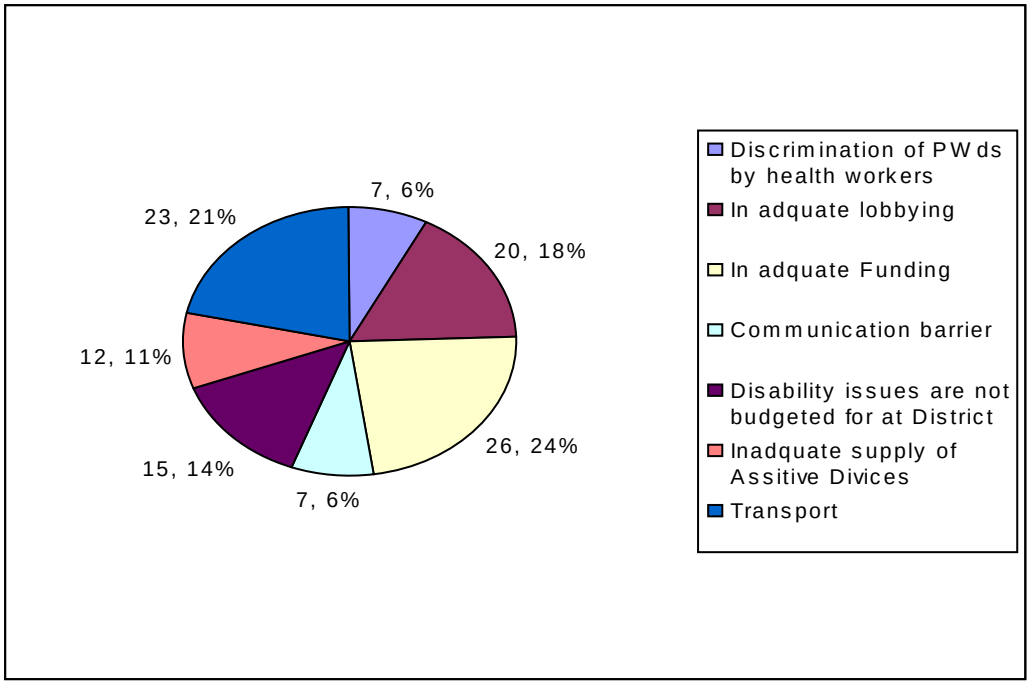
According to the table above, the major challenge that affects PWDs while seeking medical care is irregular supply of drugs (18%).This is a cross- cutting issue affecting every patient that goes to the government health units for medical care. This is caused buy corruption, sale of drugs by health personnel and delays in supply by Uganda Medical Stores. 16% of the PWDs reported transport and inaccessible structures to be other challenging issues affecting their health care access.

Health workers' attitudes towards PWDs is a another factor affecting health care access by PWDs. Women with disabilities and their spouses reported negativity from health workers mostly when expectant mothers with disabilities go for deliveries or antenatal care. Violations or lack of attention to human rights can have serious health consequences. A mother with disability said: ***"When ever I am pregnant and I go for antenatal care, nurses ask me to climb the examination bed. If I fail they say how come I managed to climb the bed where I was impregnated."*** Such stigmatising language has led to increased home deliveries that has in turn led to increased maternal and mortality death rates.

Health workers and other district staff also expressed challenges they face in providing services to PWDs. 24% of the health workers and those who plan and make budgets for the districts reported inadequate funds as a major challenge that hinders their service delivery,21% reported transport, 18% inadequate funding and 14% said that issues to deal with disability are not budgeted for at district level. The issue of budgeting for disability issues is undermined by district planners, thinking that they are catered for directly from central government.

PWDs suffer on long queues, as one lamented: ***"We are out competed in the lines and end up spending a whole day at the health unit. We even fail to be treated because , the time of closing is normally early and medical workers go before they attend to us."*** This challenge has led to negative attitudes of PWDs towards seeking medical care. Another participant reported: "***In some places we have no health centre 111's. , For example ,government is still constructing a health unit in Lelaobaro and PWDs are suffering with long distances to get medical care. Maternity wards and examination beds are inaccessible to women with disabilities, here at Bobi health centre IV. We have no labour beds that are adjustable, and the ones available are very high for us women with disabilities."***

Pie-chart 1: Challenges faced by medical workers while providing health care to PWDs



Source: Data collection from the field

Table 7: PWDs that experienced unfriendly or unhelpful attitudes from medical workers or support staff in health centres

Unfriendly or un helpful attitudes from Health workers	**Frequencies**	**Percentages**
Always	31	26
Usually	7	6
Some times	48	41
Never	28	24
Do not know/not sure	3	3
Total	**117**	**100**

Source: Data collection from the field

PWDs were asked how often they receive unfriendly or unhelpful attitude from health workers, 41% of the respondents said some times, 26% said always and 24% have never experienced unfriendly or un helpful attitudes from health workers. PWDs reported that health workers are rude or they pay pass them with no care at all, women who come for antenatal care at times are laughed at and asked how they got pregnant, some times they are not helped to climb on examination beds which were non adjustable in some health centres like Bobi health centre in Gulu, Nyamuyanja and Kaberebere health centres in Isingiro Districts.

Examination bed in Kabingo health centre-Isingiro District

Awareness of health care staff on disability management and service provision for PWDs

Uganda's health system offers a number of specialiszed services for PWDs through rehabilitation health services that ought to provide assistive devices. H, however, it was observed that assistive devices are not provided at all levels. Rehabilitation services are provided in regional referral hospitals, moreover inadequate, as the occupational therapy and physiotherapy department is . PWDs particularly those with severe disabilities find it difficult to go to the referral hospitals that are always located far from the communities.

Ministry of Health has been planning to mainstream CBR in the national health care system through early identification /assessment/screening, diagnosis and management of disability. Management and development of health services has been decentralised in order to take appropriate services closer to the people and to ensure that the rights of the most disadvantaged groups, including PWDs are observed. However, the health sub-districts and health centres at parish and sub-county level hardly provide special services for PWDs. The table below indicates key informants who reported to offer rehabilitation services in their districts., 51% of the key informants reported to offer rehabilitation and 48% do not offer any at all while 1% of the key informants are not sure if the service is existing in their area.

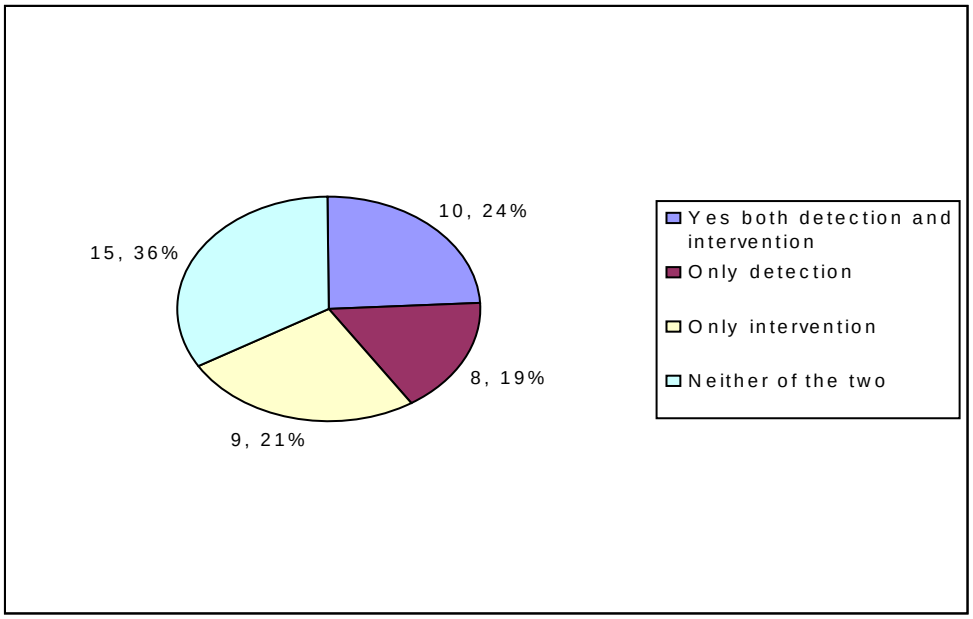
Table 8: District offering rehabilitation services to PWDs

District offering rehabilitation services	Frequencies	Percentages
Yes	20	51
No	19	48
Not sure	3	1
Total	**42**	**100**

Source: Data collection from the field

During the course of the study, respondents were asked if there is provision for early detection and intervention services in the districts that were visited. 21% of the respondents said there is only detection, 24% said both detection and intervention, and 19% said only detection and 36% said neither of the two services is provided in their districts. Without early detection and appropriate intervention in children, disability prevalence in Uganda will continue to go up. The Community Development Officer for Isingiro District reported: ***"Since in service training, there has not been any sort of training for community development workers in early detection and identification of disability which has been a challenge in executing our duties."*** The pie chart below indicates the respondents' views on early detection and intervention in the four districts that were visited.

Pie chart 2: Detection and interventions done by the district

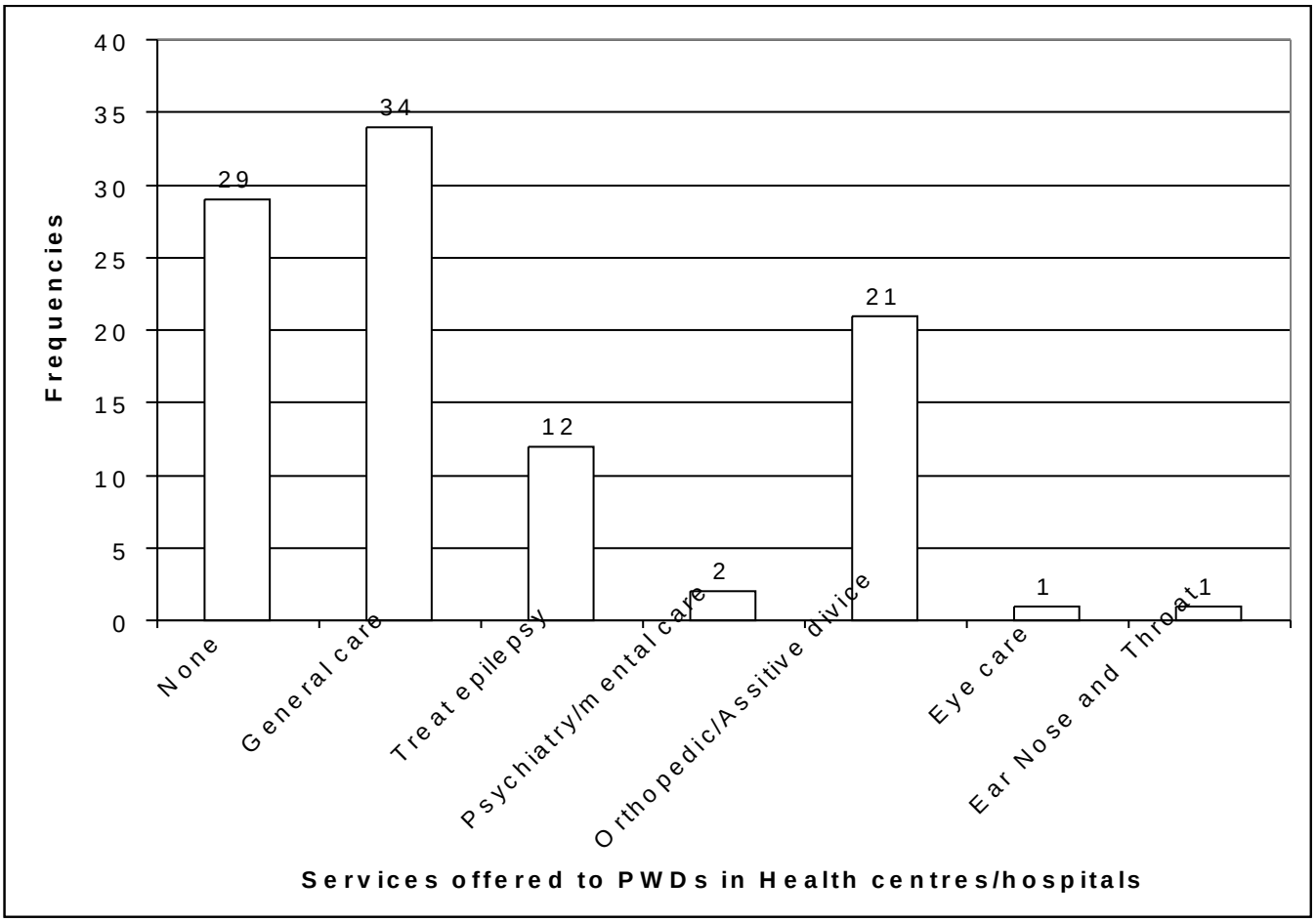


Source: Data collection from the field

The services which are offered in health centres and hospitals in Uganda in relation to disability include general

care, treatment of epilepsy, mental health care, orthopaedic care, eye care and ear, nose and throat care. However, those services at times are not provided due to lack of professionals because most health professionals spend their time carrying out private work in private hospitals and clinics. Another reason for not offering services is inadequate supply of medicines in government health care centres. The graph below indicates the services offered in district health centres.

Graph 3: Services offered to PWDs in the district health centres/hospitals



Source: Data collection from the field

Existing interventions that facilitate equitable health care for PWDs

Health workers were asked to describe how they deal with patients that have different types of disabilities like physical, hearing, visual, mental, epilepsy and deaf blind. The table below indicates the responses according to the type of disability.

Table 9: Table indicates how health workers, leaders and NGOs deal with patients that have a disability

Type of disability	Care given by health worker	Frequencies	Percentages
Physical	Assistive devices	9	26
	Treat general illnesses	7	21
	Referrals	14	41
	Counselling and advice	4	12
Sub-total		**34**	**100**
Hearing Impairment	Treat general illnesses	6	35
	Referrals	1	6
	Hearing aids	10	59
Sub-total		**17**	**100**
Visual Impairment	Provide white cane	3	12
	General treatment	3	13
	Referral	15	62
	Counselling and advise	3	13
Sub-total		**24**	**100**
Epilepsy	Treatment	20	61
	Counselling and advise	3	9
	Referral	10	30
Sub-total		**33**	**100**
Mental illness	Referral	18	53
	Treatment	13	38
	Counselling/advise	3	9
Sub-total		**34**	**100**
Deaf/blind	Not sure	3	11
	Referral	17	63
	Never seen any	7	26
Sub-total		**27**	**100**

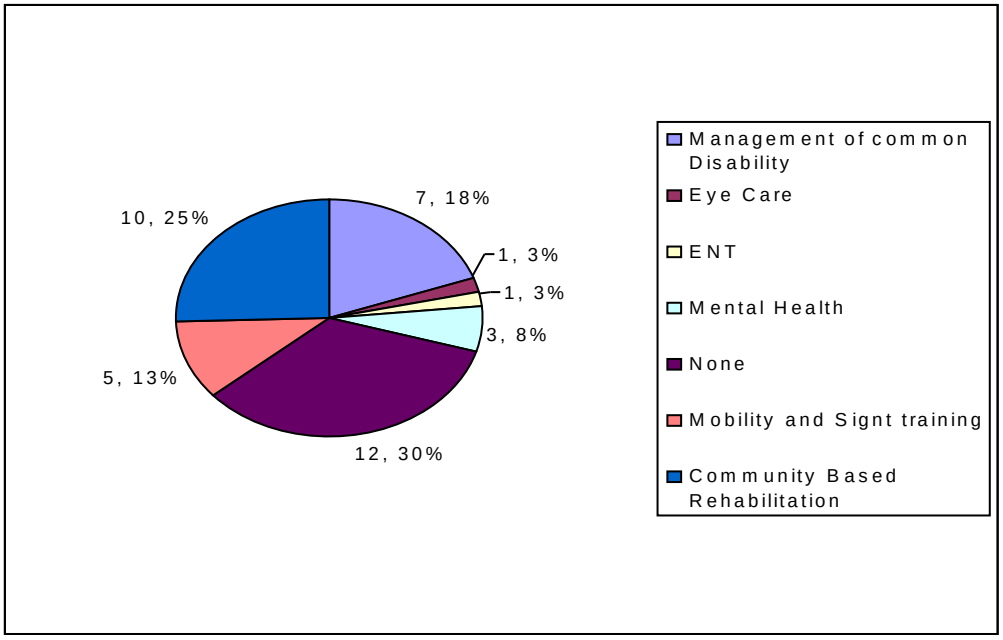
Source: Data collection from field

According to the table above, 41% of patients with physical disabilities were referred from the nearby health centres to National Referral Hospitals for medical attention. During the course of data collection, it was observed

that orthopaedic and physiotherapy care is at National Referral Hospitals and non-governmental hospitals not found in remote areas. Other lower-level health care units do not offer the services. Referring to the table above, patients with disabilities are commonly referred other than being attended too. A person with disability said that due to challenges with transport, they end up not going for treatment in far places.

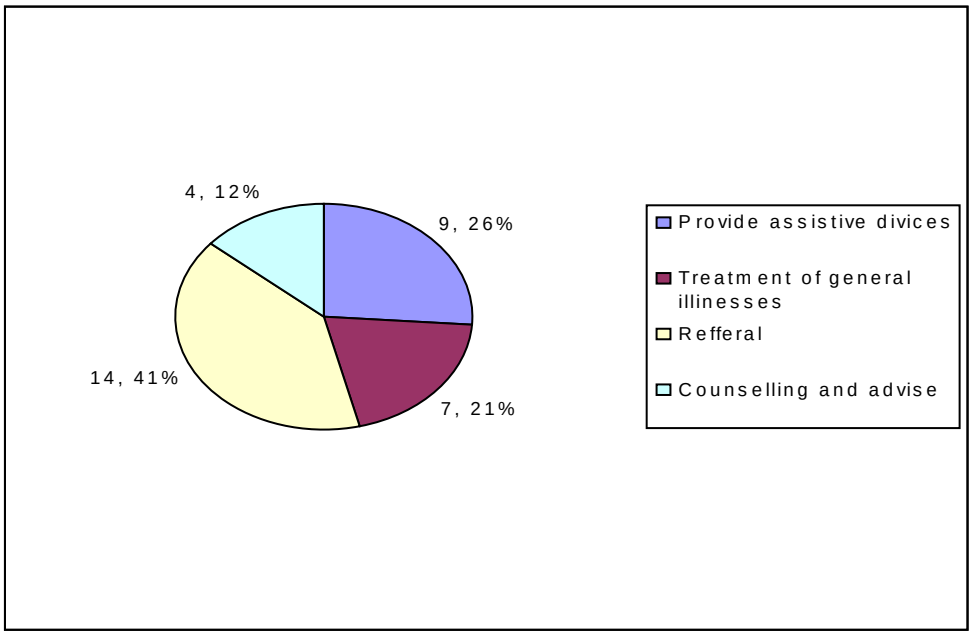
Health workers were asked to list health trainings they received in relation to disability. 30% reported none, implying that they are not aware of any service they provide that is relevant to disability. Other health workers reported as follows; 25% said they were trained in community-based rehabilitation,18% trained in management of common disabilities, 13% trained in mobility and sight training, 8% trained in mental health care, 3% were trained in eye care and ear nose throat respectively.

Pie chart 3: **List of health training received in relation to disability**



In general, health workers attend to all patients that come for health care in the health units. However, PWDs have peculiar issues that require special attention from specialised service providers. For instance, people with sensory impairments need keen observations and support to communicate. During this study, health workers were asked the services they specifically offer to PWDs. 41% said they keep on referring patients with disabilities starting from health centres at parish level, health sub-districts and then to referral hospitals. The main reason given for the referrals is that services needed by PWDs are not available or the health workers are faced with the challenge of communication to the deaf and deaf-blind patients. The pie chart below indicates the percentages as follows:

Pie chart 4: Services in place for PWDs



Non-Governmental Organisations reported by PWDs and key informants that are involved in providing health services specific on disability

Non-Governmental Organisation have collaborated with government to improve on accessibility to health care by PWDs. For instance, in Gulu District, NUMAT constructed laboratories at health centre 111 and made sure accessibility for PWDs was given a priority. Laboratories were built with ramps in the health centres of Bobi, Cwero and Patiko. Those health centres are supported by NUMAT to conduct VCT and HCT services. NUMAT has a partnership with Gulu deaf association and managed to train 20 persons in sign language from Lango and Acholi regions.

1. NUMAT (Northern Uganda Malaria, Aids and Tuberculosis Programme has a plan to send facilitators at the grass-root to sensitise PWDs at sub-county level. A pilot training was so far done in three sub-counties to map out people with hearing impairment. NUMAT is in the processes of mobilising funds to continue with the activity to integrate PWDs in its programs.

2. Cure-International is a hospital in Mbale specifically helping children with hydrocephalus, cleft palate, clubfoot, spinal deformities, and crippling orthopaedic conditions. The hospital offers good services but it is under utilised by the community surrounding it. The reason is that the services are costly to PWDs in the areas due to their low income. For instance, hydrocephalus surgery is at 700,000= Ugandan shillings, which is very high for parents

who have children with such a condition. The high number of clients who come for services in Cure hospital comes from other regions of East Africa, including Republic of Congo, Kenya and Tanzania.

3. AVSI (Associazione Volontari per il Servizio Internazionale) built the Gulu Regional Orthopedic Workshop, the only orthopedic workshop in a region that is struggling to recover from 19 years of war in Northern Uganda. The field office in Gulu has been developing and supporting Mine Risk Education (MRE) and victim support activities. AVSI's risk education program operates at a number of levels and through a variety of mediums. It also supports land mine survivors through outreach programs and at the Orthopedic Workshop in Gulu Government Hospital. However, the funding to the hospital reduced and the services now are inadequate. The physiotherapy department is understaffed with only three staff out of which there was only one on duty when the study was carried out. The second one was on leave while the third one had gone out of the country for further studies. The staff member reported overwhelming numbers of patients whom he could not adequately serve.

4. Kataremwa Cheshire Home is an NGO that work on surgeries and rehabilitation of children with disabilities. It offers medical services which include orthopaedic therapy, physiotherapy, occupational therapy, orthopaedic and plastic surgery, assessment clinics, nursing, x-ray services, laboratory tests and other general medical services. However, parents of children with disabilities living in rural areas are not aware of the institution, and therefore, there is need for increased awareness about the Home so that more people could come and benefit from the services offered.

5. CoRSU (Comprehensive Rehabilitation Services Uganda) is another Non-Governmental Organisation that is operating a fully equipped Rehabilitation Hospital and Rehabilitation Centre on Entebbe road, providing orthopaedic and plastic surgery plus rehabilitation and other specialities. CoRSU has a community-based rehabilitation program which identifies, refers and follows up children with physical disabilities in Kampala and Wakiso districts. Its operation is still around central region, it needs to spread out to reach many PWDs in the rural areas who are in need of the services.

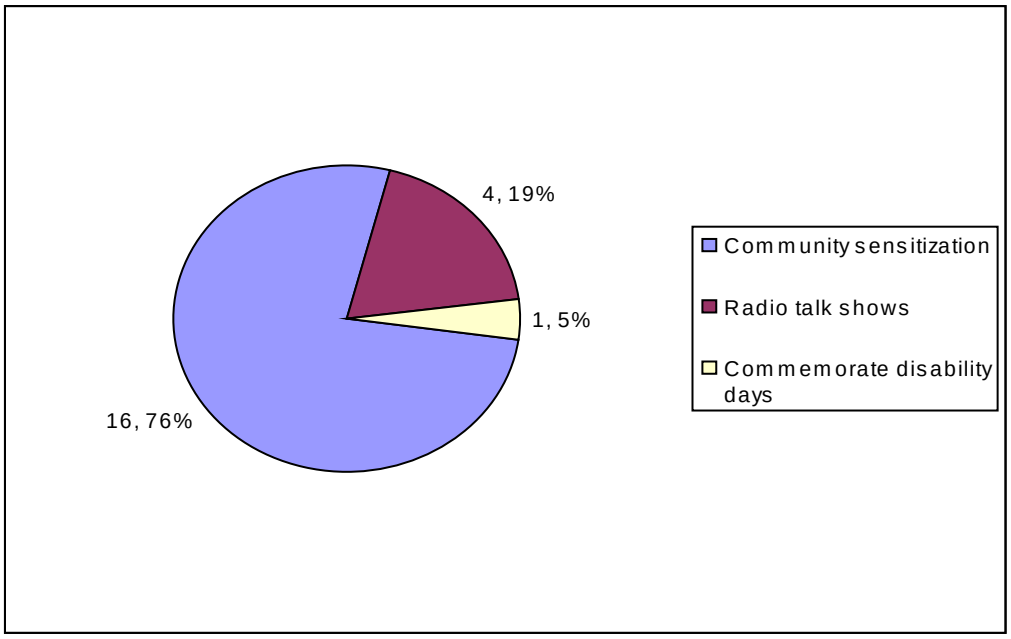
6. Red-cross International, this is based in Mbale hospital and its providing orthopaedic services for PWDs, before it opened its operations in Mbale, it was operating in Buhinga hospital-Fort portal offering similar services to those that are in need of orthopaedic services. The services are not purely free at times it requires payment of a small fee.

There are more organizations involved in rehabilitation of PWDs which have not reached a wider coverage and need extensive awareness-raising so that their services can be accessed by PWDs.

Strategies for strengthening the capacity of service providers to offer inclusive services

For PWDs to enjoy health care like any other person in the community there is need for community sensitisation as reported by 76% of the respondents. It's very necessary to make the community aware of the special health issues affecting PWDs while seeking medical attention. Also radio talk-shows and commemorating disability days are good areas for disseminating information both to government and to the wider community.

Pie chart 5: Health promotions initiatives



Source: Data collection from the field

There is need for increased delivery of clinical preventive services to PWDs and collect information on the delivery of recommended services by PWDs, health care providers and health planners. This information will allow health care providers and administrators to identify the services and groups of PWDs where the biggest gaps exist in receiving needed health care services.

To achieve access to health care services, PWDs suggested the following:

Facilitation of PWDs with income generating activities will improve their income levels thus use the earned incomes to pay the health care bills. In most cases, government health centres lack medicines and patients are

referred to private pharmacies to buy the drugs.

They also said that health facilities should employ sign language interpreters or train their health workers in sign language to ease communication with the deaf and deaf-blind communities.

Other interventions suggested include:

Ensuring regular supply of drugs,

Constructing ramps on all health care centres to facilitate easy movement by wheelchair users,

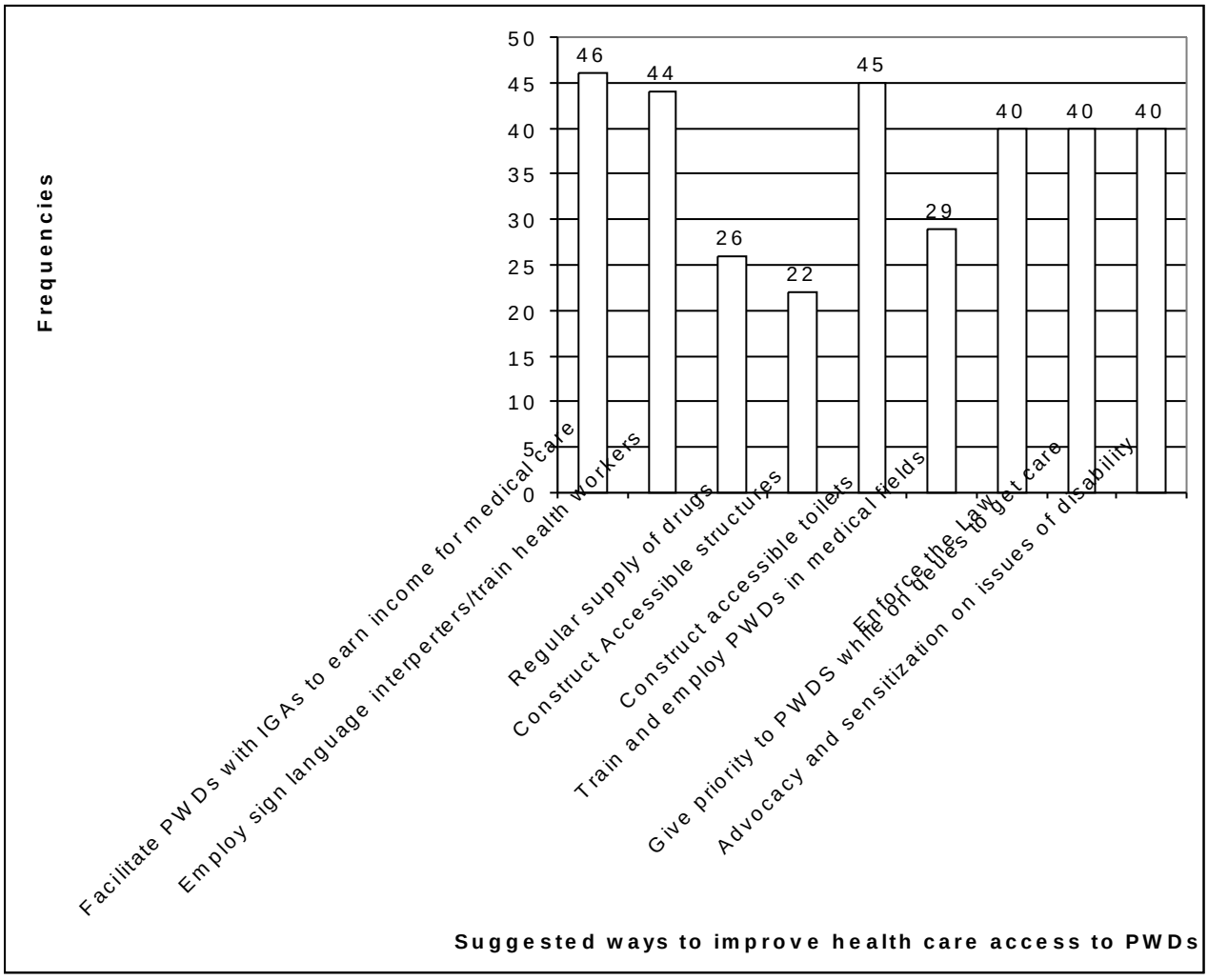
Train PWDs themselves as health workers since they know the challenges they face better.

Giving priority to PWDs by serving them first before queuing for health care services.

Continuous advocacy and awareness campaigns about key health issues and concerns of PWDs.

The graph below elaborates the above views.

Graph 4: Ways on how the challenges of accessing health care can be solved



Source: Data collection from the field

Health information systems should be revised to ably capture issues of disability. In the due course of the research, it was observed that Form (A) for the hospital does not ask if a patient in question has any form of disability. If this is worked on, it will be easy for the administrators and planners to analyse the information and plan properly.

Capacity building and sensitisation about PWDs issues and concerns should be done at grass-root levels. It was observed that most Disabled People Organisations (DPOs) that normally carry out advocacy capacity building and sensitisation work in easy to reach areas (towns and urban centres). Rural areas where the masses stay are neglected yet they are the ones facing much of challenges in accessing medical care services.

Collect and monitor disaggregated data on women with disabilities in health and reproductive health programs. This will be helpful to register the total number of PWDs that access health services in health units, in particular access to services which can prevent HIV/AIDS, maternal and child mortality.

There is need for increased research and dissemination to enrich information in relation to equitable access of services by PWDs. Assessing the experience of PWDs access to health service may be a good way of probing the effectiveness of the overall public health system. This can be done by intensive qualitative exploration of experiences of service users, non-users and providers in different contexts. Ethnographic Framework should be used which include in depth interviews, observations and facility reviews.

Also extensive quantitative exploration of epidemiology, living conditions, contextual and systems factors for PWDs should be carried out via household survey.

Rehabilitation and enabling technologies should be availed at all health centres and through outreach programs, so that many PWDs have access to these services that enhance their quality of life.

Review and analysis of health policies in Uganda in order to meet the standards set in the UN Convention on the Rights of Persons with Disabilities. The policies ought to be practical and popularised to benefit many Ugandans.

There is need to have many players working towards provision of better health services for PWDs. This should be done by re-forming the National Health Policy to respond to the needs, concerns and expectations of PWDs. Health institutions need to be well organised, streamlined, facilitated, and regulated to adequately serve the purpose for which they were set up to.

Health workers should stick and exercise their ethics by accepting PWDs as part of the wider humanity by avoiding discriminating and stigmatising them. To efficiently provide goods and services, health workers must be

respectful of medical ethics by being sensitive to the needs of vulnerable people, protecting privacy and confidentiality of their clients.

Enforce a rights-based approach to improving the lives of PWDs. This involves using human rights as a framework for health development, assessing and addressing the human rights implications of any health policy, programme or legislation, making human rights an integral dimension of the design, implementation, monitoring and evaluation of health-related policies and programmes in all spheres - political, economic and social.

There is need for increased transparency and accountability in the health care system at all stages of service delivery in Uganda.

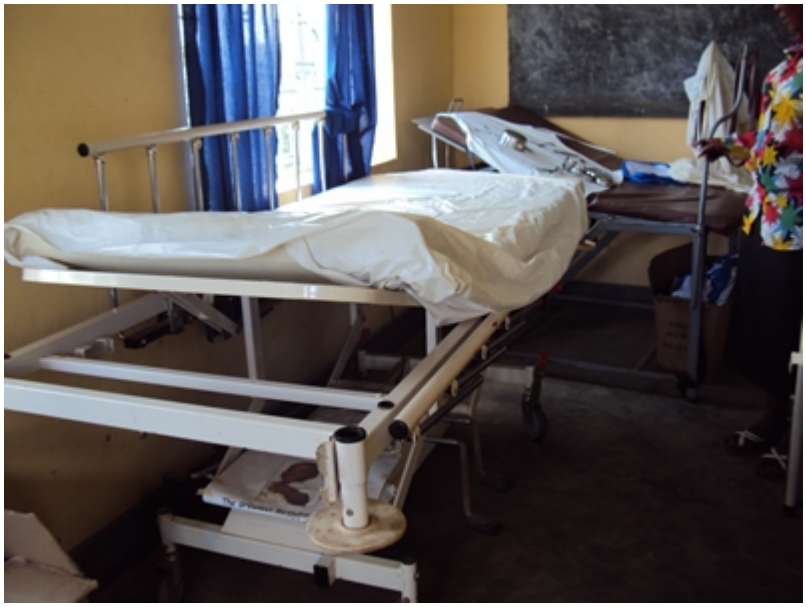
Health care management teams should have a representative of PWDs who can always front issues of disability in the health committees.

Review the health care programs to meet the needs and aspirations of PWDs. There should be guidelines specifically addressing mainstreaming of PWDs in the health care system and tailored to serve the needs of all kinds of PWDs.

Improving coordination of social and health care is needed to meet individual health promotion needs. For persons who are able to manage their own health and health care, there is a growing industry of self-management programs available for different conditions and target populations. Many PWDs, however, may not feel that they have the expertise to take health care decisions even if their personal health choices are within their own control. Thus the question of assisting PWDs in making choices about health care and health promotion remains a challenging issue that requires innovative management care solutions.

Public health interventions should be put in place directed mainly at primary prevention of disability. Community-based strategies that address the problems of people with disabilities require a public health partnership to be well-formulated and coordinated. The same principles of cultural competency relevant to programs apply to all prevention and health promotion policy for people with disabilities. Prevention policy should focus on promoting equal access to primary health care and preventive services.

Incentives are needed to promote change in health promotion policies for PWDs. Economic incentives and disincentives need to be examined as possible arenas for promoting health. For instance, financial support for construction of ramps, provision of adjustable examination beds by government in all national and local health centers could help to promote access to health care services.



ADJustable exaination bed in Kabingo health centre-Isingiro

Health workers should also be trained on how to handle all forms of disability more especially communicating with deaf-blind patients using tactile methods. Also refresher courses should be provided to health workers in sign language. This issue should be keenly followed since it is unique and requires attention of all service providers.

Community based rehabilitation programmes should be well staffed, allocated enough resources and equipment to cover the entire country in order to raise awareness on issues of disability and to manage disability.

Ethical considerations of research

Participants in the study were informed about the purpose of the study, allowed them make a voluntary choice to participate or not to participate. They had a right to withdraw from the interview at any time without penalty. Participants were assured of their right to confidentiality and privacy.

Balancing benefits and risks: The benefit of the study was all about knowledge; there were no direct benefits.

Obtaining informed consent: Informed consent was obtained and participants had a right to change their mind and stop the interview at any time. Participants also had a right to ask questions where they did not understand without penalty.

Risk considerations

- ✓ Time frame: The study was given a short time to be conducted that was not enough to have a big representative sample.

  Making appointments with medical officials and other technocrats was challenging given the limited time.

  Resources in terms of finances and human were not adequate to conduct a comprehensive study.

Conclusion

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