

THE CEDAR FOUNDATION – TANZANIA

REPORT FOR THE STUDY ON PEOPLE WITH DISABILITIES AND CHALLENGES THEY FACE IN ACCESSING HEALTH SERVICES IN NYAMATONGO WARD OF SENGEREMA DISTRICT.



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i. Acknowledgement

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ii. Acronyms

CBR – Community Based Rehabilitation

CFTZ – The Cedar Foundation Tanzania

CHAWATA – Chama Cha Walemavu Tanzania

KD – Karumo Dispensary

NHC – Nyamatongo Health Center

PWD – People With Disability

SPED – Special needs Education

SPSS – Statistical Package for Social Scientists

NW – Nyamatongo Ward

1.0. BACKGROUND INFORMATION

The Cedar Foundation's overarching outcome framework operates through four major priority sectors; namely health, education, community empowerment and training & entrepreneurship. Therefore, all projects implemented by the organization are designed in a way that contributes in the aforementioned priority sectors. In this way, all project outcomes contribute towards achieving the organization's long term impact of fostering thriving communities, equipped for the future. The Community Based Rehabilitation project (CBR) is one of the organization's projects which aim to increase PWDs' access to quality health care services as well as increasing knowledge and awareness of their rights. Supported by Inter team, this two (2) year (March 2016 – March 2018) project is being implemented by Cedar Tanzania in partnership with Inter team, and CHAWATA. CHAWATA is an association of people with disabilities in Mwanza region. Involving them in delivering the project was seen as vital, as, it engages PWDs themselves in efforts to enhance their quality of life, but also enhances their capacity.

The CBR project is delivered alongside and integrates with the Special Needs Education Project (SPED), which also targets PWDs in terms of assisting them to access education; as another means for ensuring that PWDs' wellbeing is improved.

A formative study that was conducted by The Cedar Foundation in collaboration with CHAWATA revealed that disability is a phenomenon which is surrounded by myth and wrong cultural beliefs, hence resulting in barriers to PWDs accessing necessary social services such as health and education, which are also their basic rights¹. It was also learned that community members have a tendency of hiding PWDs and that people

¹ Cited from CBR project proposal

avoid discussing them². This not only contributes to preventing PWDs from accessing necessary social services such as health and education, but also poses difficulties when gathering information necessary for informing the design and delivery of services deemed apt for addressing the needs and challenges for each group of PWDs.

Disability has many facets; and different types of disabilities may be as a result of different types of and severities of impairments. This variation in degrees of impairment presents a range of barriers to PWDs. Hence a diversity of strategies to remove those barriers should be employed (Weir, 2016). Coming up with appropriate programs which are suitable for addressing particular challenges affecting a certain group of PWDs will require relevant information on which to base the design of those programs. For that reason, The Cedar Foundation embarked on a survey which involved the four villages of Nyamatongo ward (which together form 19 hamlets), so as to collect comprehensive, first hand information, provided directly from the PWDs themselves and their close guardians; information which will guide the overall delivery and design of CBR and SPED projects, as implemented by the organization in Nyamatongo ward.

2.0. Statement of the problem

Implementing organizations (Inter team & CFTZ) lack comprehensive information on which to base the design and delivery of appropriate social services (Health & Education services) for PWDs in Nyamatongo ward.

This study therefore covered 19 hamlets of the 4 villages of the Nyamatongo ward (NW). This is one of the 34 wards of the Sengerema district, and it has a total

² CBR Project proposal

population of 26,707 people, with 13,441 being male and 13,266 being female.

However, obtaining an accurate number of PWDs was a challenge even after consulting different stakeholders such as CHAWATA and others who involve themselves with helping PWDs. Therefore, the only solution to this challenge was to embark on a survey across the ward to identify and register PWDs based on their geographical distribution; prior to collecting other information about them.

A total number of 314 PWDs were identified and registered in all 19 hamlets of NW. This group was then split into two categories, whereby, the first category of 86 PWDs (male 59, Female 27) included all PWDs with age ranging within 0-17 and the second group of 228 (male 108, female 120) comprised of people with age from 18-60+. This was due to the study being designed to inform two projects targeting PWDs in the same geographical area. Therefore, information collected through the former age group category was for SPED, and information collected using the later group category was for serving the CBR. This report then includes information collected for the sake of informing activities under the CBR project.

3.0. Objectives of the study

Generally the study aimed to identify numbers of PWDs, their needs, and the challenges that face their accessibility to social services.

3.1. Specific objectives

- i. To identify the number of PWDs and who are PWDs

- ii. To ascertain challenges facing PWDs in accessing quality social services
- iii. To assess the community's support in relation to assisting PWDs to accesses available social services
- iv. To assess PWDs' awareness of their rights to access quality social services.

4.0. RESEARCH QUESTIONS:

- i. How many and who are PWDs?
- ii. What are the types of impairments existing in the ward?
- iii. What are the most prevalent causes for impairments in the ward?
- iv. How far are the services from PWDs place of domicile?
- v. What support do PWDs get from the community in accessing the existing social services?
- vi. Are PWDs aware of their rights to accessing quality social services?

5.0. THEORETICAL LITERATURE REVIEW

There are various models and theories which are used to look at and understand the concept of disability. This study examined issues affecting PWDs through the lens of the social model of disability; a model which views disability as a social phenomenon rather than as an individual or a medical phenomenon. This model supports that the challenges experienced by PWDs are institutionalized throughout society (Thomas, 1997); therefore, 'disability is the disadvantage or restriction of activity caused by a contemporary social organization taking no or little account of people who have

impairments and thus excluding them from the mainstream of social activities' (Yee, 1997).

In light of the above mentioned theory, this study was therefore designed to generate information which will form a basis for the design of initiatives which will not only guarantee equitable access to health care and education to PWDs, but will also go further into transforming the community's perception towards disability; perception which will eradicate the discrimination and social oppression which blocks PWDs' participation or inclusion in mainstream activities, and result into enhanced community support to PWDs. Community support to PWDs is necessary to lift socially created barriers which hinder PWDs' participation in social life, hence negatively impacting their general welfare. Supporting PWDs in accessing social services, such as health and education, is vital. Social services have the potential of presenting a lever towards full citizenship of PWDs, but only if they respond to the user's needs in an individualized way. This has to be both at the community level but also mainstreamed at the national level, enhancing the participation of all stakeholders to the service provision (DMI, 2006).

6.0. METHODOLOGY

The research team reviewed relevant documents to acquaint themselves with issues facing PWDs in different parts of the world and Tanzania in particular. Various models for explaining disability were referred to and in that way, the research team learned information which guided them in opting for an appropriate approach in looking at issues

pertained to disability and challenges facing PWDs.

The data collection process was done by five (5) enumerators from CHAWATA, an association for PWDs in Mwanza region. Basically, this institution acted as a bridge between The Cedar Foundation and PWDs in NW, and also fostered the environment of trust and openness during the interview sessions.

The study bears some capacity building elements where the capacity of CHAWATA was also enhanced. Five members of CHAWATA were involved in all stages of the study, and three additional days were used to train them on using mobile phones to key in responses from respondents during data collection process.

The field work was divided into three major phases, whereby phase 1 dealt with identifying PWDs and their distribution across the ward, and registering them based on their geographical location. It also involved setting up appointments with PWDs for the interviews. This was made successful with the help of CHAWATA and local government leaders in all of the four (4) villages that were surveyed.

The second phase involved a team of five (5) enumerators interviewing the identified PWDs in their locations (homes) using a structured questionnaire hosted by mobile phone technology called Magpi - a data collection software application.

The last phase involved uploading data from Magpi into ms excel, and then into the Statistical Package for Social Scientists (SPSS), for data processing, analysis and report writing.

7.0. DISCUSSION OF FINDINGS

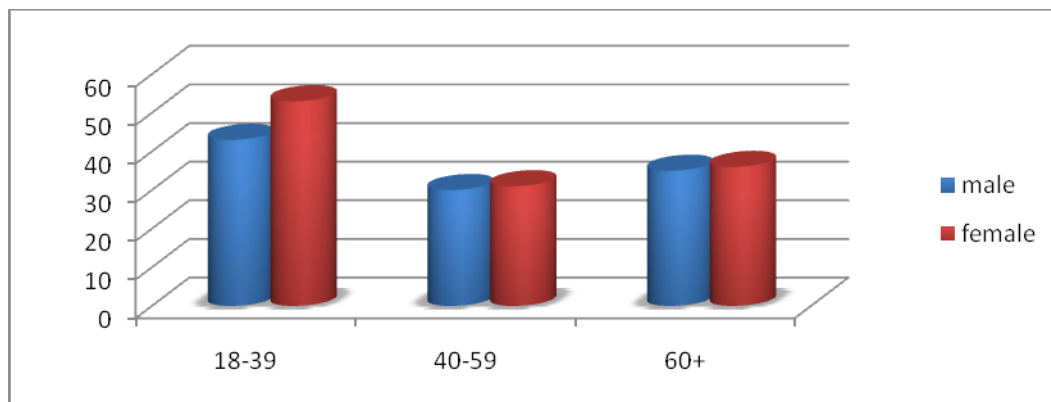
7.1. Identifying PWDs

Under this objective, the intention was to identify PWDs, their types of disabilities and causes for their impairment.

Sex and age distribution of respondents					
		Age			Total
		18-39	40-59	60+	
Sex	male	43	30	35	108
	female	53	31	36	120
Total		96	61	71	228

As seen from the table above; a total number of 228 PWDs were identified and reached during the survey. Out of these, 108 (47.4%) were male and 120 (52.6%) were female. This implies that there are more female PWDs in NW than their male counterparts.

The surveyed population was categorized into three major age groups; 18-39 (youth group), 40-59 (middle aged group) and 60+ (aged group). Analysis bases on these age categories revealed how PWDs are distributed in these age categories.



Still women appeared to be more numerous than men across all age categories; and more PWDs are found within the youth age group category (18-39). The number tends to decrease a bit in the middle aged group (40-59) and then increases slightly in the aged group category (60+).

This trend may be due to shortage or low use of health services; or delay in noticing an intervening disease and other issues that are potential in causing impairment, particularly in young individuals. Undetected symptoms then develop into infirmity causing disease, which is fully manifested during a person's younger years. Some also may not survive into their middle ages due to disease; a probable cause for the slight decline in that age category. But then those who do are joined by others who went through their *early, youth* and *middle aged* phases as people without disability, but then acquired disability after entering the aged group category due to illness that comes with age; hence, an increase in the aged group category.

This trend therefore, suggests that measures to improve health services, should go simultaneously with measures to improve uptake; through sensitizing people to cultivate the behavior of using available health services, as it will help to detect and mitigate earlier health issues which are capable of causing impairment.

7.2. Existing types of disabilities

Different causes may lead to different types of disabilities; therefore it was important to identify the predominant types of disabilities in the ward so as to be exact with the existing needs and challenges of PWDs in NW.

Type of disabilities prevalent in the ward

		Responses	
		N	Percent
	Deaf	36	12.4%
	Intellectual impairment	39	13.4%
	Upper limbs	53	18.2%
	Lower limbs	115	39.5%
	Visual impairment	43	14.8%
	Skin	1	.3%
	Autism	3	1.0%
	Albinism	1	.3%
Total		291	100.0%

Seven major categories of disabilities were identified, whereby; 39.5 PWDs appears to be having lower limbs disability. This is the highest, followed by upper limbs disability, with 18.2%; while skin disability and albinism seems to have affected the least number of people (0.3% each). The majority of PWDs in the ward might be experiencing challenges walking to health facilities, particularly when they get sick. Plus the inability to afford hired means of transport might also be another limiting factor for them to access the available health facilities.³

7.3. Major causes of disabilities

Failure to identify health issues and other factors which could potentially cause impairments increase the chances of acquiring a disability. Therefore, identifying major

³ Researchers are aware that identified through this study, are not the only types of disabilities in NW. This is due to the fact that, people who conducted this research are not professionals in identifying disability types.

causes of disabilities in NW would help to earmark areas in which to put more efforts in order to minimize chances of people being impacted by disability-causing diseases in the future. For that matter, a question was set to enquire on the currently prevalent causes of disabilities in the ward.

Causes of disabilities			
		Responses	
		N	Percent
	Birth	50	20.5%
	Accidents	49	20.1%
	Long term illness	129	52.9%
	Others	16	6.6%
Total		244	100.0%

On analyzing data from the surveyed population, it was learned that long term illness is a major cause of disability in the ward, with 52% of cases being as a result of long term illness of diseases such as boils, polio and convulsion. 20.5% of PWDs surveyed were born impaired, while 20.1% cases were acquired through accidents. Some of them linked their impairments to witchcraft. Other causes of disability and the toll it has on the rest of the surveyed population can be viewed in the table above. These findings continue to confirm the problem of accessing medical help; frequent checking of health could have helped in early recognition and mitigation of diseases which potentially cause impairments. The findings also continue to echo the importance of employing multiple strategies for improving the quality of health care services, accessibility and use of available health services.

7.4. Challenges facing PWDs in accessing quality social services

An opening question under this objective enquired whether PWDs were aware of the existing health facilities in their locality. Responses to this question, revealed the following:

Presence of health centre					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	200	87.7%	87.7	87.7
	no	28	12.3%	12.3	100.0
	Total	228	100.0%	100.0	

The majority of PWDs, 87.7% responded by saying YES, implying that they are aware of the existence of health facilities in the ward, while 12.3% said NO to this question, implying that they are unaware of the existence of any health facility in their vicinity. There are two health facilities in the ward, Nyamatongo Health Centre (NHC) and Karumo Dispensary (KD). However, the majority of PWDs aware of the presence of health facilities in the ward does not differentiate them from the minority who are unaware of the availability of those facilities. This is due to the fact that PWDs in general, rarely attend these health facilities. A health care professional, Steven Angelo who has worked at Nyamatongo Health Centre for ten years, is familiar with only one PWD who regularly attends at NHC for treatment. A similar account was given by another health care professional, James Mbilinyi of KD, who estimated providing healthcare to only eight PWDs per year. This finding therefore implies that PWDs barely use health services available in their localities, thus, suggesting more effort to be put on outreach services, including sensitizing PWDs to the use of health services which are found in their areas.

7.5. Distance to where health services are

The distance between PWDs' homes and the nearest health facility can greatly influence PWDs' health seeking behavior. A question was set to assess the distance from PWDs' domiciles to where health services are being offered. The time that PWDs spend to reach the nearest health facility was used as a proxy indicator to determine distance from PWDs' homes to where health services are being offered. A cross tabulation analysis was run, using two variables - *time spent* and the *means of transport used* - to examine how easy or difficult it is for PWDs to access services from the nearest health facility.

Time that PWDs would spend to reach to the health facility

Means of transport		Time Spent			Total
		Less than 30 min	30-60 min	More than 60	
	Foot	64	44	42	150
	bicycle	9	10	2	21
	tricycle	7	1	0	8
	motorcycle	34	5	1	40
	Car	4	4	0	8
	wheelchair	1	0	0	1
Total		119	64	45	228

From the findings above it was noted that 28% of PWDs could take less than 30 minutes to get to the nearest health facility by foot, although given their disabilities this time is likely to be arduous. It was also observed that 42% PWDs could take the same amount of time using a motorcycle. Overall, 52% would take less than 30 minutes to reach to the nearby health facility by foot or through the use of other means of transport as indicated in the table. 28.1% will use between 30 minutes to 1 hour and 19.7% will spend more than 60 minutes. This implies that most PWDs are within walking distance of health facilities, although their physical challenges might make it difficult for them to walk to the health facilities or ride a motorbike to seek medical help, particularly when

they get sick. Together with outreach services which are helpful in bringing health services to PWDs, community support is equally important in assisting PWDs to reach static health services. However more research is needed in terms of what influences PWDs' health seeking behavior.

A question was asked to enquire on how often PWDs visit health facilities for medical help.

Last time to attend health services			
Last time visited health facility	Frequency	Percent	Valid Percent
(0-3)month	32	14.0	14.0
(4-6)month	15	6.6	6.6
(7-12)month	24	10.5	10.5
More than12	157	68.9	68.9
Total	228	100.0	100.0

Findings indicate that 68.9% of PWDs paid their last visit to a nearby health facility more than 12 months ago; while the most recent visit paid was 3 months before the study (only 14% of the PWDs). More can be viewed in the table above. These findings support the two accounts given by health care professionals, Steven Angelo from NHC and James Mbilinyi from KD on the low attendance of PWDs at health facilities for medical help.

Another follow up question was posed to capture PWDs' general views on their health.

Findings were as follows.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very good	4	1.8	1.8	1.8
	good	56	24.6	24.6	26.3
	normal	101	44.3	44.3	70.6
	Bad	61	26.8	26.8	97.4
	Very bad	6	2.6	2.6	100.0
	Total	228	100.0	100.0	

44.3% of PWDs described their health as being normal; which means they experience alternating periods of falling sick and being well; while 26.8%, described their health as being bad, which means periods of being sick are longer than those of feeling well. 2.6% described their health as being very bad. Only 24.6% described their health status as being good and 1.8% described their health as being very good. Cumulatively, most of PWDs experience regular periods of falling sick, and some have extended moments of being sick. Even those who described their health as good still need reliable, high quality health services at their disposal, supported by interventions which are designed to foster a behavior of continuing to use the available health services.

7.5. The community's support in assisting PWDs to access available social services; if disability is socially created, then social support to PWDs is vital in improving their well being. A question was posed to enquire on who surrounds PWDs in their day to day lives.

Who PWDs lives with				
		Responses		Percent of Cases
		N	Percent	
	wife	44	14.7%	19.6%
	husband	37	12.4%	16.4%
	parents	45	15.1%	20.0%
	guardians	56	18.7%	24.9%
	alone	46	15.4%	20.4%
	children	71	23.7%	31.6%
Total		299	100.0%	132.9%

The table above shows that most PWDs live with close relatives, some even with dependants. Some unique cases were noted, whereby some female PWDs raise their

children as single mothers after being deserted by their partners. 15.4% also said they live alone. When PWDs were asked about the support they get from close relatives and the community at large - to access health services - a percentage of 71.9% felt like they get little support from people surrounding them, while 25% felt like they are getting no support. Only 3.1% felt like they are getting enough support.

Support obtained from the family/community in accessing health care service					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Enough support	7	3.1	3.1	3.1
	Little support	164	71.9	71.9	75.0
	No support	57	25.0	25.0	100.0
	Total	228	100.0	100.0	

The social model for explaining disability emphasizes the importance of society taking into account people who have impairments. However, discrimination and stigmatization towards people with disabilities are still problems amongst community members; probably community members still have little knowledge about disability.

Support needed;

Frequencies				
		Responses		Percent of Cases
		N	Percent	
Support needed	Supportive facilities/equipments	98	23.6%	43.0%
	Dietary support	100	24.0%	43.9%
	Surgery	33	7.9%	14.5%
	Exercise	56	13.5%	24.6%
	Others	129	31.0%	56.6%
Total		416	100.0%	182.5%

This question intended to determine from the surveyed population what support they think, if granted, will help to improve their health status. Findings for this research

question showed that; 23.6% of the respondents mentioned supportive facilities/equipments, with many mentioning facilities such as the provision of a white cane, glasses, a wheelchair and an amplifier. 24.0% mentioned nutritional support, and 7.9% mentioned surgery, 13.5% need exercises and 31.0% mentioned others which were not included in the list. The “*others*” variable was included to widen the scope for PWDs to mention what really matters to them without being limited and enumerators were instructed to jot down what was being mentioned. Amongst these, “*treatment*” emerged as the most needed support. However, it might be challenged that this response was influenced by PWDs being aware that the study is related to the construction of Kamanga Health Center; yet it should still not be ignored. Maybe it should prompt more probing on why PWDs’ attendance to the available health facilities is low, while they seem to be frequently getting sick and admit to be in need of medical help?

A question asked about how PWDs view the current health services provided may give some clue to the above question. PWDs were asked if they felt that the services provided through the available health facilities consider their needs. An analysis of the responses revealed the following.

Do the services offered consider the PWDs needs?

		Frequency	Percent	Valid Percent
Valid	YES	33	14.5	14.5
	NO	169	74.1	74.1
	I DON'T KNOW	26	11.4	11.4
	Total	228	100.0	100.0

As seen in the table above, 74.1% feel like services offered through the available health facilities do not consider needs of PWDs, while 14.5% said yes, they do consider their needs; and 11.4% said they did not know.

Further probing revealed that PWDs find the environment at the facilities to be unfriendly and that bad language is sometimes used by some of the health care practitioners. The health care professional, James Mbilinyi from KD agreed that the services offered at his work station are not tailored for PWDs. For example, they lack facilities such as wheelchairs to assist the PWDs at the centre, there are no specialized doctors and nurses for PWDs, some of the equipment like labor beds does not favor the PWD, and there are no outreach services for PWDs who cannot attend the dispensary. Hence there is much need for inclusive health care services and facilities which are supportive of PWDs.

However this raises another question – is the unsuitability of current services for PWDs the reason behind the low turnout of PWDs at existing health facilities, in spite of majority admitting their health is not good? Further study is needed to confirm this.

PWDs awareness of their rights

Knowledge of their rights				
		Frequency	Percent	Valid Percent
Valid	yes	36	15.8	15.8
	No	192	84.2	84.2
	Total	228	100.0	100.0

Through this question, researchers wanted to investigate if the PWDs knew their basic rights including getting the best health care services. 15.8% said YES they do know

their basic rights, but it was particularly surprising that the majority (84.2%) said NO. Most PWDs have no knowledge or understanding about their rights. Therefore there is a great need for awareness campaigns to raise the awareness of PWDs on their rights as per the Convention on the Rights of People with Disabilities (CRPD).

8.0. Conclusion and recommendations

Guided by the findings of this study as presented in previous pages, it is noted that PWDs form 1.18% of the total population in NW. However, the number might be higher than this, since, due to limited time, the data collection team could have probably failed to reach some of them. Researchers presume that, a population segment of such size (1.18%) can easily be overlooked by conventional development planners or public service providers who do not have the knowledge and skills on how to cater for PWDs; thus resulting to such groups being left out of the main development agenda. This calls for *advocacy* on the inclusion of PWDs in mainstream health care plans and other public services, together with interventions that will stir the community towards lifting barriers which lead to the sidelining of PWDs from the health system.

Since PWDs are experiencing physical challenges, then the majority of PWDs face difficulty in reaching existing health facilities. Furthermore they are given little to no support from community members, particularly when they fall sick. A health outreach service would significantly increase the chances of PWDs receiving crucial health care when they need it most.

Not being aware of their rights to health services, facing challenges in reaching services, and experiencing an unfriendly and sometimes hostile environment at health

facilities if they do reach them, are suspected to be amongst some of the factors which dissuade PWDs from attending available health facilities. Therefore, an improvement in the existing health facilities in the ward should entail campaigns for improving the relationship between health providers and PWDs, sensitizing PWDs on their rights to quality health services, as well as equipping health providers with the proper mindset for serving PWDs.

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