DISABILITY DATA COLLECTION

IN NORTHERN UGANDA

Draft

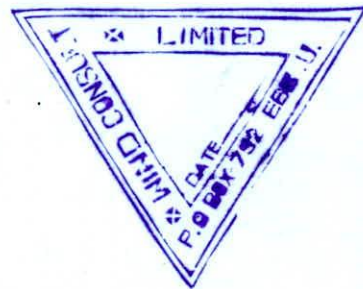## April 2005

Ministry of Health

AVSI

CUAMM

CCM

INDEX

1   CONTEXT

Disability has become in recent years a key issue in development. After getting over a long process made of dialogues, cultural changes, and also contraposition between the various actors involved in it, disability is nowadays considered as a multifaceted and complex element that cuts across many important dimensions of human life such as health, sociality, education, occupation, and leisure.

Both for the relevance of disability itself and for the complexity of the argument, data collection and statistics on this field is a very important issue. Like in any other field, intervention planning must be supported by accurate assessment of the problem. For many years studies and projects on this topic have been poor, because of the little relevance and thus resources disability found in the scientific and development world, and also because of the difficulty in understanding and exploring the matter. These difficulties can be referred to three principal factors. Firstly, the variety of aspects disability involves, as mentioned earlier, lead to a problem of classification and definition of terms: the different subjects involved with some aspect of disability may use a different system of classification and data collection (focus on functional impairment vs. health condition). Secondly, the disability phenomenon is in some cases context-dependent and it is not easy to find uniform systems to look at it. Thirdly, the nature of the problem itself forces us to look at the behaviour and life condition of a person as a whole despite of the disease or functional limitation he/she has and, being daily life influenced by many factors, it is difficult to "measure" this in a uniform way.

A great work has been made in the last 20 years by WHO developing the ICIDH (International Classification of Impairment, Disability and Handicap), matured and updated today in the ICF (International Classification of Functioning and Disability). This classification, although still suitable of critics and improvements, is the best we have at the moment in terms of scientific and cultural bases and of geographic spread, and is now being adopted by many countries.

Uganda, since its independence, has always posed an increasing attention to disability. Great concern has been shown by different parties, especially the people with disability themselves, and nowadays there are many actors, both on the government and non government side, dealing with it. Like in other countries the multidimensional physiognomy of disability, cutting across the health, educational and social sectors, is reflected in the services and policies put in place to deal with it. On the government side each of the three sectors has developed specific programs and activities: the Ministry of Gender, Labour and Social Development (MGLSD), with support of the Norwegian Association of the Disabled (NAD), has started in 1992 a Community Based Rehabilitation

Programme in 9 districts of Uganda, later on extended to many others; the Ministry of Health (MOH) established in 1996 a Disability and Rehabilitation Section (DRS), drawing a 5 years strategic plan on disability and rehabilitation, whose main goal was to increase access to better quality Medical Rehabilitation Services for Persons with Disability in Uganda; the Ministry of Education (MOE), besides the Universal Primary Education (UPE) policy, intervenes in the disability field through the EARS/special Education Programme (Early Assessment Resource Service) for the identification and assessment of children with disabilities in the schools, and through the Uganda National Institute of Special Education, which carries out training courses in special education and CBR. In 2001 the MOH and MOE have joined the MGLSD CBR program together with some NGOs and a national steering committee was established.

Regarding data collection, the various actors, although covering all together most of the country, have often utilised different systems and classifications so that uniform and comprehensive data on disability have never been produced. Taking this in account, the Disability and Rehabilitation Section has tried to create a format for data collection that could be adopted by all parties in the different locations. In doing this the DRS joined with some NGOs present in the field for testing the format and subsequently conducting a first census. In this way a pilot study has been carried out in the northern regions of Uganda, and specifically in the districts of Gulu, Kitgum, Arua and Nebbi, in collaboration with three Italian NGOs, namely AVSI (International Service Volunteers Association), CCM (Comitato Collaborazione Medica) and CUAMM (Collegio Universitario Medici Missionari), and some District Offices engaged with disability. These NGOs, each one with long time experience in these areas, are at present collaborating together in a consortium project (SCORE Project) of the Italian Ministry of Foreign Affairs on disability in those districts. This census has therefore been a good occasion for integration and collaboration between the projects of cooperation partners with the policies of the Ugandan institutions.

2   <u>CENSUS RESULTS</u>

2.1   Data management

Data from the paper forms were entered by AVSI and CUAMM in two respective excel files. The first step for analyzing the data was then to create a uniform file assembling all the data, and to clear possible errors. Afterwards data were imported in SPSS 10.1 statistics program and the following was computed:

- distributions of disability among various categories: age, sex, location, type of disability
- correlations between types of disability and some variables: age, sex, location
- correlation between two different types of disability

2.2   Distributions

The census covered a population of about 389,000 people and identified a total number of 19,696 PWDs, of which 9,244 were females and 10,427 males. Table 1 shows these data divided per age group and sex. The percentage of males is higher from 0 to 45 years, whereas females are more numerous above that age. It is noticeable also a high prevalence of children, with a percentage of 20,5% between 6 and 12 years and with 46,2% below 18 years. From table 1 it is also possible to notice a small percentage of missing or incorrect data (ns), both for the sex and for the age specification, due to procedural errors during the collection phase or the data entry; age missing could also be due to difficulties for elderly to report the exact age. However the percentage is very small and this shows a general good work performed.

Age group	Female n	% age	% sex	Male n	% age	% sex	ns n	% age	% sex	Total n	% age	% cum
0-5	885	9,6	43,7	1.136	10,9	56,1	3	12,0	0,1	2.024	10,3	10,3
6-12	1.815	19,6	45,0	2.210	21,2	54,8	5	20,0	0,1	4.030	20,5	30,8
13-18	1.303	14,1	42,8	1.739	16,7	57,1	1	4,0	0,0	3.043	15,4	46,2
19-30	1.288	13,9	45,8	1.520	14,6	54,1	3	12,0	0,1	2.811	14,3	60,5
31-45	1.332	14,4	46,6	1.525	14,6	53,4	1	4,0	0,0	2.858	14,5	75,0
46-59	1.119	12,1	52,8	1.001	9,6	47,2	/	/	/	2.120	10,8	85,8
60+	1.375	14,9	54,3	1.152	11,0	45,5	3	12,0	0,1	2.530	12,8	98,6
ns	127	1,4	45,4	144	1,4	51,4	9	36,0	3,2	280	1,4	100
Total	9.244	100,0	46,9	10.427	100,0	52,9	25	100,0	0,1	19.696	100,0	

Table 1: number of PWDs identified, divided per Age group and Sex

Table 2 shows the prevalence of PWDs over the total population, divided by sex and location. The total population number (2004) was estimated according to the last updated census (2002) and to the actual growing rate (3,7% - 4%). The 25 ns sex specification were redistributed between males and females according to the current trend. **5,1%** of the population in those areas result to have at least on disability, with respective values of **4,6%** for **females** and **5,5%** for **males**. For what concerns the location, Nebbi district reports the highest prevalence (5,7%) and Kitgum the lowest (4,0%), whereas at sub county level Oli River was the lowest (2,9%) and Rhino Camp the highest (7,3%). The distinction between rural and urban areas (Table 3) shows small differences of prevalence: for females the rate is higher in the urban areas (4,71% vs. 4,54%), for males it is higher in the rural areas (5,77 % vs. 5,28%), and as a total there is a major prevalence in the rural area (5,14% vs 4,99%).

	Female		Male		Total	
	Count	% on Total Population	Count	% on Total Population	Count	% on Total Population
Arua District	**2.113**	**4,2**	**2.248**	**4,7**	**4.361**	**4,4**
Arua Hill	295	3,5	282	3,4	577	3,5
Oli River	480	2,9	463	2,8	943	2,9
Rigbo	736	4,6	848	5,5	1.584	5,1
Rhino Camp	602	6,7	655	7,9	1.257	7,3
Nebbi District	**2.896**	**4,9**	**3.534**	**6,5**	**6.430**	**5,7**
Nebbi TC	795	6,0	847	7,2	1.642	6,5
Erussi	1.077	4,6	1.380	6,3	2.457	5,4
Jang-Okoro	647	5,0	846	7,2	1.493	6,1
Packwach	377	4,1	461	5,5	838	4,8
Gulu District	**3.193**	**5,1**	**3.475**	**5,8**	**6.668**	**5,4**
Bar-Dege	745	4,2	770	4,9	1.515	4,5
Laroo	751	6,4	822	7,5	1.573	6,9
Laybi	717	5,5	886	7,1	1.603	6,3
Pece	980	4,7	997	4,9	1.977	4,8
Kitgum District	**1.057**	**3,7**	**1.180**	**4,3**	**2.237**	**4,0**
Padibe East	241	3,2	301	4,2	542	3,7
Padibe West	421	6,1	388	6,1	809	6,1
Kitgum Matidi	202	2,9	247	3,7	449	3,3
Lagoro	193	2,6	244	3,5	437	3,0
Total	**9.259**	**4,6**	**10.437**	**5,5**	**19.696**	**5,1**

Table 2: prevalence of PWDs divided per sex and location

	Female		Male		Total	
	n	%	n	%	n	%
Urban	4.763	4,71	5.067	5,28	9.830	4,99
Rural	4.496	4,54	5.370	5,77	9.866	5,14
Total	9.259	4,63	10.437	5,52	19.696	5,06

Table 3: prevalence of PWDs referred to urban-rural areas

Table 4 reports the distribution of the different types of disabilities. As many people presented more then one conditions, this compute refers to the disabilities identified and not to the number of persons. In fact the total number of disabilities is 22,998, whereas the number of persons contacted is 19,696. The highest percentage regards "Difficulty in Moving" (1,42% of tot Pop. – 26,52 % of disabilities) and the lowest "Leprosy" (0,11% of tot Pop. – 2,13 % of disabilities). A relevant percentage (0,36 % of tot Pop. – 6,78 % of disabilities) refers also to not specific or other types of disabilities. Some differences are noticeable between males and females: these are better explained in the correlation analysis below.

	Female			Male			Total		
Total Population	200.038			189.055			389.093		
Disabilities	Count	% on Total Population	% within Disability	Count	% on Total Population	% within Disability	Count	% on Total Population	% within Disability
Difficulty in Moving	2.850	1,42	26,52	3.280	1,73	26,81	6.130	1,58	26,56
Difficulty in Seeing	2.530	1,26	23,54	2.644	1,40	21,62	5.174	1,33	22,42
Difficulty in Hearing	1.989	0,99	18,51	2.266	1,20	18,53	4.255	1,09	18,44
Epilepsy	1.090	0,54	10,14	1.312	0,69	10,73	2.402	0,62	10,41
Strange Behaviour	370	0,18	3,44	530	0,28	4,33	900	0,23	3,90
Difficulty in Speaking	446	0,22	4,15	655	0,35	5,35	1.101	0,28	4,77
Difficulty in Learning	281	0,14	2,61	330	0,17	2,70	611	0,16	2,65
Leprosy	229	0,11	2,13	226	0,12	1,85	455	0,12	1,97
Spinal Lesion	242	0,12	2,25	237	0,13	1,94	479	0,12	2,08
Others + n.s.	729	0,36	6,78	762	0,40	6,23	1.491	0,38	6,46
Total disabilities	10.756		100	12.242		100	22.998		100

Table 4: distribution of type of disabilities. NOTE: the count refers to the number of disabilities and not to the number of persons identified, as someone presented more than one condition.

Tables 5 to 9 report data regarding the specifications related to some type of disability. In fact the census format foresaw to specify the anatomical distribution of the problem for "difficulty in moving" (upper limb, lower limb, bilateral), for "difficulty in seeing" (partial, total, bilateral) and for "difficulty in hearing" (partial, total, bilateral). This information was quite accurate, even though

there have been some incorrect data, due to interviewers misunderstanding or to data entry mistakes. Table 5 shows how in very few cases (highlighted) there was a specification also for disabilities where this was not required and on the contrary the specification was missing for the three types mentioned above. Table 6 shows that in these three groups the specification was in few cases (highlighted) incorrect as not regarding the correct group. A particular note is for "partial + total" in "difficulty in seeing" (n=45) and "difficulty in hearing" (n=28). in this cases probably the person reported partial disturb on one side and a total on the other side. Tables 7, 8 and 9 report the selection of correct specifications respectively for "difficulty in moving", "difficulty in seeing" and "difficulty in hearing", divided by sex. Among "difficulty in moving" the highest percentage regards the lower limbs (71,7%), with 49,1 % for unilateral and 22,6 % for bilateral. Upper limbs account instead for 17,4% with 14,2 for unilateral and 3,2 for bilateral. There are then some mixed cases of upper and lower limbs (17,5%). No great differences are noticeable between males and females.

	Total number of disabilities	Presence of specifications				
		Yes			No	
		Count	%		Count	%
Difficulty in Moving	6.130	5.802	94,6		328	5,4
Difficulty in Seeing	5.174	4.316	83,4		858	16,6
Difficulty in Hearing	4.255	3.903	91,7		352	8,3
Epilepsy	2.402	56	2,3		2.346	97,7
Strange Behaviour	900	24	2,7		876	97,3
Difficulty in Speaking	1.101	72	6,5		1.029	93,5
Difficulty in Learning	611	29	4,7		582	95,3
Leprosy	455	12	2,6		443	97,4
Spinal Lesion	479	22	4,6		457	95,4
Others + n.s.	1.491	22	1,5		1.469	98,5
Total disabilities	22.998	14.258	62,0		8.740	38,0

Table 5: number of specifications among disabilities identified. The values highlighted are the errors.

Among "difficulty in seeing" the highest percentage was reported by "partial bilateral" (54,9%), followed by "partial" (29 %). The total visual deficit accounts for 14,4%. Among "difficulty in hearing" the highest percentage regards "partial bilateral" (52,5%), followed by "partial" (26,6%). Total hearing deficit accounts for 20,2% with 15,7% of bilateral cases.

Specifications	Difficulty in Moving	Difficulty in Seeing	Difficulty in Hearing
Bilateral	2	8	4
Lower Limb	2.739	8	8
Lower Limb + Upper Limb	459	2	
Lower Limb + Upper Limb Bilateral	2		
Lower Limb Bilateral	1.232	7	11
Lower Limb Bilateral + Upper Limb	10		
Lower Limb Bilateral + Upper Limb Bilateral	389	9	9
Partial	8	1.243	1.024
Partial + Total		45	28
Partial + Total Bilateral		17	15
Partial Bilateral	28	2.351	2.020
Total		288	172
Total Bilateral	35	330	605
Upper Limb	764	6	5
Upper Limb Bilateral	134	2	1
Ns	328	858	353
Total	**6.130**	**5.174**	**4.255**

Table 6: Categories of specifications reported in the three groups where it was required. The values highlighted are the errors.

Specifications	Female		Male		Total	
	Count	% Type	Count	% Type	Count	% Type
Lower Limb	1.267	47,6	1.470	48,0	2.831	49,1
Lower Limb + Upper Limb	226	8,5	232	7,6	516	8,9
Lower Limb + Upper Limb Bil		-	2	0,1	2	0,0
Lower Limb Bil	590	22,2	642	21,0	1.302	22,6
Lower Limb Bil + Upper Limb	4	0,2	6	0,2	50	0,9
Lower Limb Bil + Upper Limb Bil	187	7,0	199	6,5	441	7,7
Upper Limb	324	12,2	440	14,4	819	14,2
Upper Limb Bil	65	2,4	69	2,3	185	3,2
Total	2.663	100,0	3.060	100,0	5.770	100,0

Table 7: Specifications reported for "Difficulty in Moving"

Specifications	Female		Male		Total	
	Count	% Type	Count	% Type	Count	% Type
Bilateral	4	0,2	4	0,2	8	0,2
Partial	591	28,6	649	29,3	1.240	29,0
Partial + Total	20	1,0	25	1,1	45	1,1
Partial + Total Bilateral	10	0,5	7	0,3	17	0,4
Partial Bilateral	1.137	55,1	1.214	54,8	2.351	54,9
Total	127	6,2	161	7,3	288	6,7
Total Bilateral	174	8,4	156	7,0	330	7,7
Total	2.063	100,0	2.216	100,0	4.279	100,0

Table 8: Specifications reported for "Difficulty in Seeing"

Specifications	Female		Male		Total	
	Count	% Type	Count	% Type	Count	% Type
Bilateral	3	0,2	1	0,0	4	0,1
Partial	486	26,9	537	26,3	1023	26,6
Partial + Total	14	0,8	14	0,7	28	0,7
Partial Bilateral	971	53,7	1049	51,3	2020	52,5
Total	86	4,8	86	4,2	172	4,5
Total Bilateral	249	13,8	356	17,4	605	15,7
Total	1809	100,0	2043	100,0	3851	100,0

Table 9: Specifications reported for "Difficulty in Hearing"

Table 10 reports the distribution of PWDs according to the number of disabilities present. divided per sex. It is noticeable how relevant percentages present 2 and 3 disabilities (11,76 % and 1,9% respectively).

Number of disabilities	Female		Male		ns	Total	
	N	%	N	%	N	N	%
1	7,970	86,22	8,939	85,73	23	16,932	85,97
2	1,077	11,65	1,237	11,86	2	2,316	11,76
3	171	1,85	203	1,95		374	1,90
4	22	0,24	36	0,35		58	0,29
5	4	0,04	12	0,12		16	0,08
Total PWDs	9,244	100,00	10,427	100,00	25	19,696	100,00

Table 10: distributions of multidisabilities.

2.3 Correlations

Table 11 reports the correlation explored between the type of disability and some variable such as location, age and sex. These correlation do not indicate a relationship of cause-effect between the specific conditions and the three variables, but rather describe a phenomenon and give some hints for further research.

Location

For "Difficulty in Moving" and "Strange Behaviour" there is no difference between rural and urban area. For "difficulty in seeing", "Leprosy", "Spinal Lesion" and "others + ns" there is a higher prevalence in the rural areas; instead for the remaining conditions there is a higher prevalence in the urban areas.

Age

It is noticeable how some disabilities affect more the younger ages whereas other conditions relate to older people. Interestingly "difficulty in seeing" is more frequent above 46 years: this could indicate an improvement in the prevention or early treatment of visual problems occurred in the last years. The same could be said about "Leprosy". Differently from seeing, the "difficult in hearing" is related to 0-18 years and this could suggest to explore better the causes of this problem.

Sex

While "Difficult in Seeing" is related to the female group, "Strange Behaviour" and "Difficult in speaking" are more frequent in the male group: it would be interesting to know the reason of these gender difference.

		Location		Age		Sex	
		P Value	*major prevalence*	P Value	*major prevalence*	P Value	*major prevalence*
Difficulty in Moving	26,52	0,170	Equal	0,001	19 +	0,349	Equal
Difficulty in Seeing	23,54	0,001	Rural	0,001	46 +	0,002	Female
Difficulty in Hearing	18,51	0,019	Urban	0,001	0 - 18	0,757	Equal
Epilepsy	10,14	0,001	Urban	0,001	0 - 18	0,094	Equal
Strange Behaviour	3,44	0,163	Equal	0,001	6 - 18	0,001	Male
Difficulty in Speaking	4,15	0,001	Urban	0,001	0 - 18	0,001	Male
Difficulty in Learning	2,61	0,001	Urban	0,001	6 - 18	0,699	Equal
Leprosy	2,13	0,001	Rural	0,001	31 +	0,163	Equal
Spinal Lesion	2,25	0,001	Rural	0,001	31 +	0,129	Equal
Others + ns	6,78	0,006	Rural	-	-	-	-

Table 11: correlations between types of disability and three variables (location, age, sex). Pearson Chi-square test

Table 12 shows the correlation explored between "Difficult in Learning" and other conditions which could have some influence or relationship with the learning process.

Surprisingly there is a negative correlation with "Difficulty in Seeing" and "Difficulty in Hearing", that is the ones having problems with vision or hearing, more likely do not have learning problems and vice versa. This suggests a reasoning on the criteria of identification of "Difficulty in Learning". On the contrary with "Epilepsy" and "Strange Behavior" there is a positive correlation: this could induce to explore any cause-effect relationship between these conditions, as well as the possible diseases at the origin of both disabilities.

	Correlation with Difficulty in Learning	P Value
Difficulty in Seeing	Negative	0,001
Difficulty in Hearing	Negative	0,001
Epilepsy	Positive	0,001
Strange Behavior	Positive	0,001

Because of brain damage

Table 12: correlation between "Difficult in Learning" and other conditions - Pearson Chi-square test

3   WORKSHOP REPORT

Gulu St. Monica Conference CentreThursday 3ʳᵃ February 2005

3.1   Program

Time	Content	Presenter/participants
08:30	*Registration*	AVSI
08:45	*Welcoming and introduction*	MOC: DRO Gulu
	Opening remarks	DDHS Gulu
09:00	*Introduction/overview*	
	Introduction of workshop and objectives	D. Naggi (AVSI)
	Brief overview of SCORE program	"SCORE" Team
	Definitions and classifications of disability: ICIDH, ICF, MOH	G. Corti (AVSI)
10:30	Tea break.	
11:00	*Census result*	
	Method and procedures utilised	D. Naggi
	Frequencies of disabled people divided by sex age and type of disability	G. Corti
	Correlations between the above and other variables	G. Corti
	Reaction/comments/clarification from the participants	All participants
12:30	*Discussion/contribution on the data presented:*	
	Suggestions for possible intervention programs	Group work
	Evaluation of methodologies	
13:30	Lunch.	
14:30	*Presentation group work*	Group secretaries
15:00	*Plenary discussion*	All participants
15,30	*The importance of data in planning at district level*	District Planning Unit
16:00	*Way foreword*	D. Naggi G. Corti
16:30	*Closing Remarks*	Nokrach – MOH – Santini – It. Coop

3.2   Sessions

3.2.1   Welcoming and Introduction

The MOC Mr. Ocen Bernard welcomed all the participants and called them for self-introduction. The workshop participants hailed from MOH, Italian cooperation, partner NGOs (USDC,

UNICEF), NGOs of the consortium (AVSI, CUAMM & CCM) and focal persons for the SCORE project in all the seven districts (Annex1).

3.2.2 Opening remarks

The DDHS Gulu Dr. Onek asserted that disability is not considered a priority in the government institutions, as it is a commodity which is difficult to sell. Its budget is always small and often not functional. He called upon the governments at both central and local level to include disability in the mainstream planning and development process, and remarked that data on disability are strongly needed to back up the process.

3.2.3 Introduction of workshop and objectives – Davide N. (Annex2)

Davide Naggi illustrated the workshop objectives, underlying the importance of such a work and inviting the audience to an active participation and interaction.

⇒ To present the participants the results of the census conducted by AVSI, CUAMM & MoH

⇒ To identify, in the light of the data presented, some major areas of need and plan some more focused needs assessment and/or intervention programs

⇒ To highlight some key concepts about data collection method on disability

⇒ To make suggestions for improving the data collection system in the northern regions of Uganda

3.2.4 Brief overview of SCORE program - Davide N. (Annex2)

The Score Project (Support to Community Based Rehabilitation) was presented in its focal components.

3.2.5 Definitions and classifications of disability - Gustavo C. (Annex3)

Gustavo C. presented a conceptual framework on disability, highlighting the cultural and scientific development that took place in the last 20 years on classification and terms.

Any process of classification or data collection on disability is bound to some factors: the specific purpose for doing it, the international standards and guidelines, the local (national) policies and the cultural evolution.

At international level the main contribution came from WHO with the following documents:

⇒ Training in the community for people with disabilities (1989)

⇒ ICIDH (1980) International Classification of Impairment, Disability and Handicap

⇒ ICF (2002) International Classification of Functioning, Disability and Health

The ICIDH offered a first good innovation separating the disease dimension (impairment) from the functional one (disability) and subsequently from the social disadvantage (Handicap). In this frame work different diseases could determine the same disability or vice versa the same disease could determine different disabilities. The different services (health, rehabilitation, social support) act respectively at different levels.

However that system was still too much medical oriented and referred to the person with disability merely as somebody with "problems" in need of help, where these problems were just medical or functional limitations.

Over the years a new perspective, more social oriented, opposed to this one. The focus shifted to the participation and social integration of the person, despite his/her functional or medical conditions. Disability was conceived as a socially-created problem and not at all an attribute of an individual.

Then with the new ICF classification, a kind of compromise between the two tendencies has been found. "Disability is always an interaction between features of the person and features of the overall context in which the person lives, but some aspects of disability are almost entirely internal to the person, while another aspect is almost entirely external. In other words, both medical and social responses are appropriate to the problems associated with disability; we cannot wholly reject either kind of intervention" (WHO).

In parallel WHO developed in 1989 the "Training in the community for people with disabilities" manual for promoting CBR (community based rehabilitation) in developing countries. A kind of simplified classification is present also here, and it is the one that often is adopted in many countries. Even Uganda for its classifications and data collections referred often to it.

3.2.6   Census Results – D. Naggi and G. Corti

A. Methods and procedures utilised (Annex 4)

D. Naggi explained how the census was ideated and coordinated by a team including the MOH, AVSI, CUAMM, and key district offices dealing with disability and data collection like the District Rehabilitation Office (DRO) and the Municipal Planning Unit. Firstly a format was purposely designed for the census: this differentiates the disabilities by categories, making reference to the WHO Classifications (ICF and "Training in the community for people with disabilities"): disabilities were therefore divided in terms of impairment and difficulties (e.g. difficulties in moving) and not in terms of handicap.

Subsequently n data collectors form the 4 districts were selected by sub-county administrators and the Team members. Following selection, data collectors were trained on the utilization of the format and other information related to census activities.

Each data collector was in charge of one or two parishes according to the estimated total population living in the area. The census was carried out over five days. Four local supervisors supervised the exercise daily. Data collectors were guided by a person well acquainted with the distribution of the houses within their area. These guides were persons with disabilities (without difficulty moving), LC1 Chairpersons, or other local resource persons familiar with the area. A teacher with skills in sign language was on stand-by in case of any need to translate.

B. Results (Annex5)

G. Corti, after explaining the method utilised for analysing the data, presented some of the results of the census: prevalence of PWDs according to sex, age, subcounty and number and types of disability. Moreover some correlations between the type of disability and some variable like age, sex and location (rural vs urban) were presented.

This session saw a great participation of the audience in asking for clarifications or making comments and observation on the data presented. Some incongruence, due to typing errors, was also identified in the sex distribution between two different slides, which later on was corrected accordingly.

3.2.7 Group works

Utilising a 1-2 self counting the audience divided in two groups, which worked on two topics proposed by the moderators, starting form the results just exposed. After lunch then the groups presented their work to the all audience.

A. Suggestions for possible intervention programs

The greatest percentage of disability regarded "difficulty in movement", and therefore particular attention should be given to it with regard to projects and services. However, although there were some specification on the limb affected (upper/lower/bilateral), it is difficult to know from these results the specific type of movement problem the person has (walking, eating, dressing, etc.). Therefore some more specific enquiry in the movement area would be advisable.

B. Evaluation of methodologies

The strategies used in the census were good and relevant, as they implied a strict collaboration among stakeholders and a relevant involvement of the community. The data collection format was standard and included all the types of disabilities. However some questions were raised by the group with regards to these points:

- The "Leprosy" category belongs to the disease families and therefore differs from the functional criteria characterizing the other types of disability. Formerly this type of disability has sometime fallen under the "feeling problem" category, but this time it was decided to include it as Leprosy in order to differentiate from other feeling problems due to neurological traumas or disease.
- Difficulty in learning should be better defined as it looks strange that it reported a relative small percentage when other condition influencing the learning process were quite high (diff. seeing, diff. hearing, epilepsy).
- The real age should be recorded, and then classified in groups at a later stage.

3.2.8 Plenary Discussion

The data results and the group work presentation gave the audience arguments for a lively discussion. Besides the points mentioned above (4.2.7) the following were also raised:

- The census has been a good starting point as it put in evidence with objective data the entity of a problem: it created awareness and advocated for disability issues in the community. It also suggested for further research in the field
- The format should be incorporated at national level and, at the same time, shared at district level (i.e. district planning units). One possibility is to include it in the national census questionnaire. Government should streamline the guidelines for data collection and information sharing. Somebody should take the lead in commissioning a format which can be used for data collection on PWDs, as well as gathering all the data from the different districts: the MOH is a possible candidate.
- Format for data collection should not be frequently changed to enable comparing of data over time.
- Stakeholders should use a uniform the data entry procedure, and adopt a system for controlling errors.
- Pre-tests by data collectors be done after every training on data collection for quality assurance.
- In order to better understand the real need of the people identified a more specific assessment is needed. In case of high prevalence of a particular disability in a delineated territory, further research should be conducted.
- At the same time it was noticed that data collection raises people's expectation and therefore it should not be forgotten that the identified needs must find an answer.

- In order to face the needs showed by the data results the institutions should provide more resources in terms of personnel, facilities, drugs, training. This would improve accessibility to services for PWDs.
- Epilepsy revealed to be another great issue as it is above 10 % of all disabilities and it is a clearly defined condition, not a container for many different situation.
- PWDs should be exposed to both technical and financial linkages.

3.2.9 The importance of data in planning at district level (Annex 6)

The district planner stressed the importance of data for planning any intervention at district level. So far data on disability have been poor and not homogeneous. Now this census opens a new possibility also for the district.

3.2.10 Way foreword (Gustavo + Davide)

G. Corti recalled that working on disability data is not easy but is revealing to be very important. The present format, with small improvements could be adopted at national level. Great attention should be posed on methodological issues.

Naggi stressed the importance of the result reached with the present workshop and called for more cooperation in the future.

The data now available are a strong bases for presenting the disability issue to the institutions.

All the NGOs working in this field should continue to collaborate and share their information and technical resources. The Ministry of Health should take the leading role in this process, coordinating all the stakeholders and creating a central data bank.

3.2.11 Closing remarks – MOH, It. Cooperation, NUDIPU, CUAMM

4 **CONCLUSIONS**

This census, together with workshop held in St. Monica Centre, constitute a very important step in facing the issue of disability data in Uganda

For the first time a reliable estimation of prevalence of disability in the northern region of the country was obtained. In fact the census, carried out in 16 sub counties selected from the districts of Arua, Nebbi, Kitgum and Gulu, identified 19,696 PWDs among a population of 389,093, reporting a prevalence of 5,1% (4,6% for females and 5,5% for males). A relevant component (46,2%) regards young people (0-18 years), and the different types of disability is differently distributed in the different age groups. About 14% of PWDs present more than one disability. The condition most represented is "difficulty in moving" (26,56% of all the disabilities), followed by "difficulty in seeing" (22,42%) "difficulty in hearing" (18,44%) and "epilepsy" (10,41%). More specifically the movement impairments regards the lower limbs.

All these data are of paramount importance in showing the entity of the problem and in identifying the topics of major interest; the workshop stressed how the data now available are a strong bases for presenting the disability issue to the institutions, for conducting more specific research, and for planning better intervention in favour of PWDs. These findings can not depict the specific functional problems the single person has, but offer an indubitable starting point for further needs assessments.

The census and the consequent workshop revealed to be also a good opportunity for various stakeholders such as the MHO, the NGOs, the District offices, and the community workers, in practising and sharing experience with data collection and management, and for strengthening their collaboration in this field. Firstly it is to be remembered that the preparation and the implementation of the study implied a strict collaboration between these actors, both for preparing the format, and for collecting the data; for ONGs this was also a good opportunity for getting in contact and familiarizing with the communities included their respective development programs. Secondly, the workshop offered the possibility of analysing the methodologies adopted and proposing some improvements: this regards the census format, the collection procedures, and the data entry. Thirdly, it was recognised the importance of streamlining guidelines for data collection and information sharing, as well as coordinating all stakeholders at central level.

Actually the workshop has seen an active participation by all the members in discussing the procedures and the results, in asking for clarifications, and in proposing for improvements and future initiatives.

[...]

5   ANNEXES

Annex 1: Workshop - List of Participants

Annex 2: Workshop - Introduction of workshop and objectives (PPT) – Davide N.

Annex 3: Workshop - Definitions and classifications of disability (PPT) - Gustavo C.

Annex 4: Workshop - Census Results: Methods and procedures utilised (PPT) – Davide N.

Annex 5: Workshop - Census Results: Frequencies and correlations (PPT) - Gustavo C

Annex 6: Workshop - The importance of data in planning at district level (PPT) – District Planner