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**Original article**

# The Prevalence of Impairments and Disabilities in the North West Region (Cameroon)

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*Prévalence des incapacités et handicaps dans la Région du Nord-Ouest du Cameroun*

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## ABSTRACT

### **Purpose**

This project addressed the lack of disability prevalence data in the North West Region of Cameroon.

### **Methods**

A multi-stage cluster design was used, and included urban, semi-urban and rural areas. In the first stage, the team screened 3,933 households, representing an estimated screening sample of 18, 878 individuals. In the second stage, structured interviews were conducted. The interviews included the International Classification of Functioning, Disability and Health (ICF) Checklist to confirm disability status and determine the nature of disability.

### **Results**

A total sample of 1,233 individuals screened positive for having a disability. According to this study's cluster design the prevalence of screening positive for disability in this region was 6.9% (95% CLs 5.7-8.2%) and the population prevalence of disability was 6.2% (95% CLs 5.2-7.2%). Of the individuals who screened positive for disability, 1,106 (89.7%) of them had a participation restriction or activity limitation which was of moderate severity or greater, suggesting that the screening tool was useful for identifying many persons living with moderate or severe disability but not very sensitive at identifying people with minor disabilities.

### **Conclusions**

Although certain limitations in the study's methods must be taken into account, these results can be used to justify the need for, and inform the design of, programming for individuals with disabilities in this region.

### **Keywords:**

Cameroon - Disability prevalence - International Classification of Functioning, Disability, and Health.

## RÉSUMÉ

### **Objectif**

L'étude visait à remédier au manque de données quant à la prévalence des incapacités dans la Région du Nord-ouest du Cameroun.

### **Méthodes**

Un échantillonnage par grappes à plusieurs degrés a été utilisé et incluait les zones urbaines, semi-urbaines et rurales. Au premier degré, l'équipe a identifié 3 933 ménages, représentant un échantillon d'environ 18 878 individus. À la deuxième phase, des entrevues structurées ont été menées. Les entrevues comprenaient le questionnaire de la Classification Internationale du Fonctionnement, du Handicap et de la Santé (CIH2) afin de confirmer la présence et le degré d'incapacité.

### **Résultats**

Un échantillon total de 1 233 individus a été identifié avec une incapacité. Selon l'échantillonnage par grappes retenu au cours de cette étude, la prévalence des incapacités dans cette région était de 6,9% (les intervalles de confiance à 95% étant de 5,7% - 8,2%) et la prévalence des incapacités dans la population était de 6,2% (5,2% - 7,2%). Parmi les individus qui ont été identifiés avec une incapacité, 1 106 (89,7%) avaient une restriction de participation ou une limitation d'activité de gravité modérée ou plus. Cela suggère que l'outil de dépistage a été utile pour l'identification de plusieurs personnes vivant avec une incapacité grave ou modérée, mais peu sensible pour l'identification des personnes avec des incapacités mineures.

### **Conclusions**

Bien que certaines limites de la méthode utilisée dans cette étude doivent être considérées, ces résultats peuvent être utilisés pour justifier le besoin, et guider le développement, de programmes pour des personnes vivant avec une incapacité dans cette région.

### **Mots clés**

Cameroun - Prévalence des incapacités - Classification internationale du fonctionnement, du handicap et de la santé (CIH2)

**INTRODUCTION**

The World Report on Disability [1] emphasizes the importance of disability prevalence data to “improve efforts to remove disabling barriers and provide services to allow people with disabilities to participate” [p. 21]. Recommendation 8 of this report is “Improve Data Collection” [p.267], a clear indication of the lack of data, and the priority nature of research. Similarly, UNICEF’s State of the World’s Children Report [2] emphasizes the importance and complexity of data collection related to disability.

To reflect new understandings of the social contexts related to disability, the global community has developed the International Classification of Functioning, Disability and Health (ICF) classification system to gather information about impairments and disability [3]. The ICF is based on health, functioning, and social conditions, (not only impairments) as causes of disability. Previously disability and health were viewed as separate entities; now the ICF perspective focuses on a person’s level of health, participation, and inclusion in society, not solely on body impairments. This system is organized into domains that describe body functions and structures, and what a person can potentially do in a ‘standard’ environment (level of capacity) and what they actually do in their usual environment (their level of performance) [3]. It provides a common language for considering health and functioning, engagement in activity, social participation, and the environmental factors which influence functioning and disability. There are three domains: i) body functions and structures, and ii) activities, and iii) participation [3]. The ICF system provides a way to consider the integration between health (health condition, disease, or disorder) and environment (contextual factors including environmental and personal factors) [3]. Table 1 illustrates these dimensions in terms of functioning and disability. Notice that the term 'disability' in the ICF refers to all three dimensions taken together. From this perspective, an individual with an impairment is not automatically considered to be disabled.

**ICF LEVELS OF FUNCTIONING AND DISABILITY**

Dimensions of Functioning	Dimensions of Disability
Body Functions and Body Structures	Impairments
Activities	Activity limitations
Participation	Participation restrictions

(WHO, 2002)

The ICF framework has been used in several studies internationally. In Africa, ICF studies have looked at disabilities experienced by people living with AIDS receiving home based care in Zambia [4] and collecting

disability related information at the household level in South Africa [5].

The North West Region of Cameroon is one such jurisdiction in which disability prevalence is largely unstudied. The region has a population of approximately 1.8 million inhabitants [6]. According to the 2010 census extrapolation, the region’s population is 58% rural [6, p.8].

In response to the lack of research about disability in this region, an existing research partnership opted to include a disability prevalence component as part of a larger study carried out in 2010 [unpublished]. The partners included: 1) a research organization focusing on disability issues, 2) a major rehabilitation service provider, and 3) a working group from a North American university. The specific objective of this component of the larger study was to establish the prevalence of impairments, activity limitations, and participation restrictions in Cameroon’s North West Region.

This paper describes the approach used; presents an estimate of the prevalence of impairments, activity limitations, and participation restrictions in the region; and concludes with some discussion about the implications of this study.

**METHODS**

During the initial phase of the study, which lasted several months, we prepared the proposal using an inclusive process appropriate to the context, and which included people with disabilities as contributors. Ethical permissions were obtained from the University of Toronto, and from the Cameroon Baptist Convention Health Board. The Regional Governor was informed of the study and provided written endorsement. Divisional Officers were informed of the study through personal meetings by members of the research team. Due to resource availability, the study focused on people living in four divisions of the eight divisions of the region.

The larger study used a mixed methods approach to examine the prevalence of impairments and disabilities and the impact that they have on quality of life in the North West Region of Cameroon. A core component of this study was an enumerator-assisted household survey using a multi-stage cluster design. The survey collected both numerical and qualitative information. The broader study also incorporated meetings with local traditional leadership to obtain their perspectives on how many disabled people were living in their areas, and how they were integrated into the communities. In this paper we emphasize the quantitative results from the household survey. A full study report is available from the authors.

### ***Methods and tools for assessing disability – the ICF***

As described above, there has been a significant shift in understandings of disability and impairment over the past several decades. The ICF framework was chosen as a guiding framework for this study.

The study team included co-investigators from each of the three partnering organizations, a research project coordinator (RPC), and fourteen RAs who were local to the area (three of whom were assigned to be team leaders). Research assistants were either university graduates or had at least a secondary school education with considerable experience in health and disability issues, including three who self-identified as having a disability. The RPC led two weeks of training for the RAs.

This training included active discussion about disability issues, the data collection process, ways of dealing with challenging and ethical issues, and how to follow the research project as planned. Input from the RAs was encouraged throughout the training period, as they brought varied expertise and experience; their contributions were seen as a valuable component in order to improve and refine the process. The survey materials were translated from English to the widely-spoken local language of Pidgin by the study team during the training in order to facilitate their use in the field. A physiotherapist with advanced training in epidemiology joined the team at the data analysis stage.

The study used a multi-stage cluster design in order to select households. Clusters were purposively selected to include urban, semi-urban and rural areas, and a variety of socio-economic strata. The specific households were chosen using a standardized process, whereby a given number of households was approached in each cluster according to the *a priori* sample size calculations. In each selected household a research assistant (RA) approached the head of household to explain the study and to seek informed consent to participate in a disability screening interview.

If consent was granted, the RAs would ask the head of household to enumerate each of the individuals living in the household and to identify if any of these individuals had an impairment or disability by using a screening tool which asked: Is there anyone in the house who has any form of disability or handicap? This question could also be asked in Pidgin English: Any person dey dis house whey na disable or handicap? Handicap is a word commonly used in the community to indicate impairment or disability and so was chosen as one word to use as part of the screening process. Recognizing that disability does not have the same meaning for everyone, RAs were trained and encouraged to have conversations with the household

heads explaining the broad purposes of the study, answering any questions that came up, and providing examples of several types of impairments and situation that could be included (e.g. sensory functions such as hearing or seeing, mobility impairments, and cognitive impairments).

The RAs then approached those individuals who were identified as having a disability for their individual informed consent to participate to additional interviews. Children age 18 and under were not asked to complete the additional interviews themselves, but instead the RA would seek out an available parent, guardian, or caregiver in order to complete the survey on the participant's behalf. The RAs used this same process for adults considered to have significant cognitive impairments and therefore unable to provide informed consent (e.g. significant dementia or significant intellectual disability).

If consent was granted, the RA conducted a structured interview with the individual (or proxy respondent). This interview included the International Classification of Functioning, Disability and Health (ICF) Checklist [7] to determine the nature of the impairments and disability, as well as additional questions for other parts of the larger project in which this disability prevalence study was embedded. Participants each received a tablet of soap as a token of appreciation.

After data collection, the original paper copy survey forms were returned to a central office where data were entered into electronic databases. Despite attempts to check as data as it was being returned from the field to identify process errors, during data entry (after the teams had left the field) it was discovered that some survey items had been left blank. The paper surveys were scrutinized for additional information that could confidently indicate the appropriate entries, and this was possible in many cases. After data entry, the databases were then screened for implausible entries and key demographic information was double-checked for consistency with the paper copies.

Because the available data was only related to a) the individuals who screened positive for disability and b) the number of households screened, it was then necessary to calculate the number of people who were effectively part of the sample. To do so, the Cameroonian average of 4.8 residents/household [8, p.20] was multiplied by the number of households screened, to provide an estimate on the total number of people screened. Data analysis was conducted using Epi Info 3.5.2 [9]. The Complex Sample Frequencies function [10] was used for all descriptive and prevalence calculations due to the cluster design of the study.

## RESULTS

### A. Quantitative

The survey team screened 3933 households for the presence of people with disabilities, representing an estimated screening sample of 18,878 individuals. According to the screening instrument used in the study, 1245 of these individuals were considered to have an impairment or disability. Data was missing for 12 of these individuals, leaving a total sample of 1233 individuals who screened positive for having a disability.

According to this study's cluster design the prevalence of screening positive for disability in the North West Region of Cameroon is 6.9% (95% CLs 5.7-8.2%). The research assistants did not specify or record on the screening tool the terms that resonated with the heads of household when first approached; 6.9% is thus the prevalence for responding affirmatively to any indication that impairment, a disability-like situation, or altered way of functioning was present in at least one member of the household.

The mention of any impairment or disability-like situation by a head of household provided an opportunity for the interviewer to probe further, in essence to verify the intention of the screening tool. RAs reported that they often went into discussion with the household head to ensure that understandings of disability were broadly understood. However, they also noted that there were some households whose members might have had an impairment but were not identified as being relevant to the study (e.g. someone wearing corrective eyeglasses) or the household head would not grant permission to conduct an interview.

The demographic, educational, and occupational characteristics of those who screened positive for disability are presented in Table 1. The ICF Checklist is a tool that does not use the word disability directly; rather disability in this framework is understood to be the experience of a combination of factors leading to activity limitations and participation restrictions. In this study, 6.2% is the prevalence of having at least one participation restriction or activity limitation that was "moderate," "severe," or "complete" according to the ICF checklist.

**TABLE 1 – CHARACTERISTICS OF INDIVIDUALS SCREENING POSITIVE FOR DISABILITY IN THE NORTH WEST REGION OF CAMEROON**

Characteristic		Proportion	95% Conf Limits	
Age	0-4	3.1	1.4-4.9	
	5-14	8.5	6.6-10.4	
	15-49	31.7	29.1-34.4	
	50-69	27.0	23.5-30.5	
	70+	29.7	27.8-31.5	
Gender	Female	56.7	52.0-61.4	
	Formal education	None	47.3	43.2-51.5
		Primary only (1-6 years)	23.1	19.7-26.3
Secondary or more (7+ years)		29.6	23.2-36.1	
Occupation	Homemaker	9.4	5.3-13.5	
	Non-paid work	1.0	0.4-1.6	
	Paid employment	3.4	2.3-4.5	
	Self-employment	21.2	18.1-24.3	
	Retired	13.4	10.5-16.3	
	Student	11.2	8.8-13.7	
	Unemployed (health reason)	24.2	18.3-30.0	
	Unemployed (other reason)	2.5	1.5-3.6	
	Other	13.7	10.7-16.7	

Therefore, according to this interpretation of disability as being a composite of factors, the population prevalence of moderate to severe disability in the North West Region of Cameroon is 6.2% (95% CLs 5.2-7.2%). The population prevalence of selected impairments from the ICF checklist is presented in Table 2. The analysis of capacity and performance was difficult to do given the information which was collected, and is beyond the scope of this paper. More details related to demographics and other results are included in the full report of the study, which is available from the authors.

**TABLE 2 – POPULATION PREVALENCE OF SELECTED IMPAIRMENTS IN THE NORTH WEST REGION OF CAMEROON**

Impairment	ICF code	Percent	95% Conf Limits
Intellectual	b117	0.9	0.5-1.2
Seeing	b210	2.3	1.6-2.9
Hearing	b230	0.9	0.7-1.2
Pain	b280	2.8	2.2-3.5
Upper limb	s730	0.7	0.4-1.0
Lower limb	s750	2.3	1.7-2.9
Disability <sup>1</sup>	NA	6.2	5.2-7.2
Screened positive for disability	NA	6.9	5.7-8.2

<sup>1</sup> A person was considered to have a disability if he or she reported a participation restriction or activity limitation that was "moderate," "severe," or "complete" according to the ICF checklist.

The analysis of capacity and performance was difficult to do given the information which was collected. Despite the attempt to orient the RAs to the ICF framework, the concepts of capacity and performance, (which are key aspects of the framework), and of how facilitator and barriers should have been recorded, some shortcomings in data collection were evident when the data analysis was carried out. Our analysis led us to believe that the RAs and many of survey respondents did not fully grasp the notion of the interplay between capacity, performance, and environmental factors which are part of the ICF framework. We make a “general observation” from reviewing the collected data that environmental factors were often left blank on the paper copies, and when filled in they were generally without the necessary directional sign of positive or negative that was required. We therefore do not feel confident on reporting this data. However, we collected and analyzed valid data on the conditions of interest, presented above, which provided some insight about how the ICF is not intuitive to community members (including PWDs) in this setting. Our main finding with respect to environmental factors is that they are complex notions to ask participants about, using the tools we had selected. In future, additional attention should be paid to approaches for collecting data about environmental factors.

#### ***B. Learning about doing disability research***

Debriefing with the team, including the RAs, occurred regularly throughout the study. Team leaders debriefed with the RAs at the end of each day, and reported results to the central office weekly. Several full team debriefing discussions were held when information was being collected in the field, and again at the end of the data collection process. These meetings were valuable to assist the study team to understand more about the challenges and successes of the project.

RAs noted during the debriefing sessions that many participants were very agreeable to provide information and several wanted to give their entire life story, often going far beyond the questions that were asked. It seemed that for many people, this was the first time they had a chance to share their experiences related to disability, and they very much appreciated having someone take an interest in their lives.

All of the RAs reported that they saw a wide range of living conditions encountered in the different areas. One team reported that it was especially difficult to access the homes of the persons who appeared to be of higher income, those who lived in the GRA (governmental residential area), and in other high income areas, as often these people did not like to accept people into their compounds or the household head was not available and others did not have the authority to allow the researchers in. Several household heads asked many questions about the legitimacy of the study, reflecting the history of illegitimate studies which has occurred in the area generally. The RAs

carried many official documents related to the study with them, and this did allow improved access in many instances.

One RA had mobility impairment and used crutches to walk. She reported that many of the people she encountered were supportive of her involvement in the study, while some were not, because they perceived that it was too difficult for her to get around (many areas have difficult terrain). Because of these concerns, and despite her explanation that she was doing the work by choice, she reported that some potential participants would not answer the questions from her. In those cases, she turned to her team members to collect the information.

In this region there is also a culture of financial payment for participation in what is perceived as NGO (non-governmental organization) as well as governmental projects. The RAs reported that some participants initially did not want to participate because they were not paid in money. Most of these people did agree to participate when they understood more about how the study was being carried out.

Recording of births was not common in many parts of the region until recently. Therefore, obtaining accurate information about age and date of birth were sometimes difficult, when respondents did not know their exact ages. RAs would talk with the participant to obtain a “best guess” for age or date of birth when possible.

Some participants appeared to be reluctant to share information about their activities and social involvement; RAs suspected that at times it had to do with feelings of shame or marginalization. Qualitative comments in the interviews, not reported in detail in this paper, reflected these impressions from the RAs; many participants reported experiences of discrimination, lack of access in their communities (e.g. in schools and churches), and feelings of not measuring up to social expectations.

#### **DISCUSSION**

This was the first study that we are aware of which calculated the prevalence of impairments and disabilities in the North West Region of Cameroon based on interviews with people living with those impairments and disabilities.

Using these results and the region’s population it is possible to estimate the number of individuals who have impairments or disabilities according to this study’s definitions. For example, using the prevalence of 6.2%, it is probable that there are approximately 112,000 individuals with a participation restriction or activity limitation of at least moderate severity in the North West Region of Cameroon. This is a significant number of people, many of whom are likely to benefit from rehabilitation services. It is thus expected that these results will be valuable in the planning of service, policy, and advocacy activities in the region.

Among the impairments selected from the ICF Checklist [7] for analysis, impairments of at least moderate severity in seeing (b210), pain (b20) and the lower limb (s750) were the most common. The occupational and educational participation of persons with disabilities in North West Cameroon is also remarkable with less than a quarter (24.6%) involved in income-generating activities and nearly half (47.3%) with no formal education. Although these findings may seem alarming, some contextual factors must be remembered, namely that this study produced no comparison data for individuals who screened negative for disability, and that more than half of those who screened positive were 50 years of age or older. The age distribution of those screening positive for disability thus undoubtedly confounds educational and occupational variables that are strongly influenced by cohort and life-course effects.

Since the time that our study was carried out, Cameroon's National Institute of Statistics (CNIS) has released a report which includes prevalence of disability information in Cameroon, including the NWR [11]. In the CNIS study, the head of the household completed the interview on behalf of the person with a disability. The authors report that a series of questions was used to identify household members with a disability, motor disability, sensory disability and / or people with behavioral disorders. Despite the differences in categories and methods of the two studies, the results regarding impairments are similar. Tchamgoue and Nantchouang [11] report that 5.4% of the Cameroon population lives with a disability, and 6.6% in the North West Region. These results are similar to our findings; further analysis could be done to compare the two studies in more detail. Future research studies could also benefit from learning from both of these studies about methods, including language and approaches, used to assess prevalence of impairments and disabilities in Cameroon.

We must address the discrepancy between the results of this study and the trends reported more globally, such as the estimated 15% worldwide disability prevalence quoted in the World Report on Disability [1, p.27]. To account for this we refer to the tools used in this study and the results that they provided. More specifically, the fact that of the 1233 individuals who screened positive for disability, 1106 (89.7%) of them had a participation restriction or activity limitation of at least moderate severity, suggests that the screening tool is not very sensitive at identifying people with disabilities, particularly those with minor disabilities. Although it was conducted using a different tool, in a disability prevalence study in Zambia the prevalence of moderate disability (8.5%) was reasonably similar to the prevalence reported here [12].

This study provides some information about the challenges and considerations to engaging in

prevalence studies such as this one in the Cameroon context. The research process was planned in consultation with several people who were familiar with the local customs and potential challenges. It was strongly believed that the "head of the household" had to be approached first to provide permission for data collection, and that a clear description of the study should be provided. The screening tool used in this study was simple: essentially just a few questions to the head of the household asking whether any of the individuals identified as residing in that household had impairments or disability. Experiences with simple "yes/no" questions from national censuses in Africa have yielded very low disability prevalence estimates [11]. Those experiences have caused some to hypothesize that "yes/no" questions more closely reflect the prevalence of severe disability in a country [11]. In this sense the low screening prevalence and very low frequency of detection of individuals with mild disabilities reported in this study is less surprising. We did not collect detailed information about the wide range of living conditions evident in different areas. A previous study by Reidpath, Allotey and colleagues, [13; 14], explored the living conditions of people with disabilities, and documented the challenges which are faced by many. From the qualitative comments of both the respondents and the RAs in our study, it would appear that there is a need for more studies about the impact of living conditions as facilitators and barriers for people living with disabilities, and about the widespread loneliness, isolation, and lack of social involvement and inclusion.

Including the RAs in planning process, three of whom were people with disabilities themselves, was an important part of this project. The RAs who lived with disability brought important insights and credibility to the study. It would be valuable to follow up regarding attitudes and discrimination toward visible and non-visible disabilities in the region.

Readers must take additional factors into consideration when interpreting the results of this study. The purpose of this part of the study was to provide some evidence about prevalence of impairments, activity limitations, and participation restrictions, which we have been able to do. We make no claims of absolute precision: in a region where there are few studies and little evidence of robust data, this study provides data. Our team has worked hard to be forthcoming about how this data reflects the reality of the study situation and the challenges we encountered in carrying it out.

This study was an ambitious project for local organizations responding to an identified knowledge gap with limited funding and experience with this approach to research. There are few established health or disability researchers in the region, and recruiting members of the team was challenging.

Key lessons learned also relate to the need to financially prepare for contingencies when planning

the study, ensuring that the scope of the project matches the resources available, and creating a team that values the contribution of all members but can continue to proceed smoothly with the departure of any one of those members.

## CONCLUSION

Through a local partnership and with minimal funding, this study was able to estimate the prevalence of disability and various impairments, of moderate severity or greater, in the North West Region of Cameroon. The study had many strengths, including the large and diverse geographic area covered, the use of the ICF as an internationally recognized theoretical framework to assess disability, the involvement of many local researchers on the research team, and the detailed results obtained. Doing research related to disability and rehabilitation issues which is locally appropriate and respectful as well as rigorous is very challenging, requires adequate financial and human resources, and a willingness to be reflective and learn from experiences. Although certain limitations in the study's methods must be taken into account when interpreting these results, the results can be used to justify the need for, and inform the design of, and programming for, individuals with disabilities in this region.

## CONFLICT OF INTEREST

The authors declare that they have no conflict of interest related to the submission of this manuscript

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