

Collecting Disability Statistics: A Participatory Strategy?

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SUMMARY

This chapter examines the background to disability statistics and introduces the WHO definition of disablement in the form of the International Classification of Functioning, Disability and Health (ICF) (WHO 2001). It argues, that utilising this classification system as a basis for collecting survey data on disability, provides a new and exciting opportunity to gather information that will be more meaningful and useful, than one based on impairment categories. The approach includes collecting data on levels of activity and functioning, participation and contextual factors. The problems faced in structuring the survey questions, training the enumerators and motivating the service providers to collect information, are examined. Accommodating different languages and cultural norms are discussed and some ethical issues are also considered. Recommendations are made, relating to a participatory approach to collecting disability statistics.

INTRODUCTION

Collecting statistics on disability has proved problematic, mainly due to the confusion surrounding the definition and parameters of disability. This lack of clarity has served to confuse both, those collecting and those interpreting the data. Data collected in different countries and in different settings are virtually incomparable from survey- to-survey, as different categories of disability are used with different cut-off points. The impairment categories that are used are not mutually exclusive, for example, speech or communication problems can be found in most impairment groups. This makes the data almost impossible to interpret.

Until recently, methods employed to collect disability data have been based on bio-medical definitions and impairment groups. Given the higher level of morbidity together with less developed medical facilities, researchers were surprised to discover that surveys showed a lower disability prevalence level in Less Developed Countries (LDCs), than in More Developed Countries (MDCs) (UN 1990). The explanation lies, in part, in the social and contextual construction of disability. There are other real differences that explain the higher prevalence rate in MDCs. These include higher levels of road and industrial accidents, longer life expectancy and better health services, which mean people survive traumas but are left with impairments. In LDCs, different criteria are used to define disability and impairment levels that may have to be much more severe, before communities consider members disabled. For example, many people with mild to moderate intellectual impairments in a rural, pre-dominantly illiterate setting, will not be considered disabled at all. Additionally, given poorer medical facilities, it is likely that many more severely disabled children may not survive. The higher incidence of certain diseases such as measles and meningitis, which relate to subsequent impairment (e.g. hearing impairments), are known to be higher in LDCs but this is not often reflected in the data collected, coupled with the fact that these children often die and do not survive as they would in MDCs. These factors help to explain the prevalence rates in the UN Disability Statistics Compendium (UN 2001). Their website (<http://esa.un.org/unsd/disability/>), currently reports a range in the

proportion of the population from 0.2% in India and Qatar, to 33% in Norway.

The advent of the new International Classification of Functioning, Disability and Health (ICF) (2001), replacing the WHO (1980) Classification of Impairment, Disability and Handicap (ICIDH), has provided a framework that has great potential for the collection of more meaningful disability data. The framework offers the opportunity to look at all aspects of functioning and disability, regardless of the nature of the impairment, or health problem information. The additional information it can provide, is about the person's capacity to participate and how this is affected by the environmental/contextual factors.

The ICF follows a bio-psychosocial model, integrating the medical and social models of disability. It is universal, as it considers disability on a continuum and not as binary categories of 'disabled' and 'non-disabled'. It is also interactive, as it accommodates the complexity and multi-layered interactions between the person, his/her health condition and environmental factors. It is cross-culturally applicable and takes account of the parity across different aetiologies (i.e. where two very different aetiologies have the same experience of disability) and it has a full life span coverage from children to elderly people.

The new classification considers disability as the outcome of an interaction between a person's health condition and contextual factors. This outcome of disability can be described at three levels. One, is at the level of the body, as an impairment of the body function or structure, the second, is the level of the person, which looks at activity limitations and is measured as capacity. The third, is at the level of society and looks at participation restrictions measured as performance. A description of the contextual factors, both personal and environmental, completes the picture.

For example, let us consider a person with a hearing loss. The hearing loss is an impairment caused by damage to the ear (for whatever reason). This is the body function level. This impairment makes it difficult for the person to listen and communicate (e.g. understanding conversation),

both activities engaging the whole person rather than just the hearing organ. This person will therefore have an activity limitation in listening and in communication. When this person is in his/her current environment, the interaction between the hearing impairment and activity limitations and the environmental factors, determine the person's experience of disability. If the person works in a noisy environment with poor lighting, making it difficult to lip-read people speaking, they will experience a high level of disability. Whereas, if the environment is quiet and there is good lighting making it easy to lip-read people speaking, the experience of disability will be much less. In the first situation the environment is full of barriers, whereas in the second, these are facilitated.

The new classification has been extensively field trialed in a number of regions of the world, including Europe, North America, Australia, Latin America, Nigeria and India. The ICF has now been developed and endorsed. It must now be implemented in different applications, from service provision, through to national survey data collection.

Problems associated with data collection

Survey research on levels of living conditions among people with disabilities in Namibia and Zimbabwe, carried out by SINTEF and funded by the Norwegian Federation of Organisations of Disabled People (FFO), involves Government and University departments, together with NGOs and people with disabilities. The studies are attempting to establish better base-line data, in order to get a more accurate and realistic indication of the true level of disability, so that there can be a more equitable distribution of resources. Household surveys on living conditions, are used together with detailed disability questionnaires and elements of the ICF, to collect this information. They aim to find out who is disabled, by asking what the person can do, what happens when they are in their usual environment and the environmental factors that make it easy or difficult for them to undertake the different activities. It aims to find out, where a person's needs are not being met, both at the national and community levels. Pilot projects have been completed in both countries and national surveys are now underway.

Capacity building at the local level has been an important element of the research project. Participants from Government departments, NGOs and representatives from organisations for people with disabilities, have attended seminars, discussed research methodology, how the data have been collected, and how it will be used, presented and interpreted with particular reference to disability issues. Efforts have been made to bring together managers, administrators and supervisors, in order to learn how to formulate questions in the most appropriate way, and to best identify the target population, namely, people with disabilities. Time must be taken, to train the enumerators and prepare them to handle situations unique to people with disabilities.

Two major problems face those interested in studying or determining the extent of disability in a population. One, is coming up with a definition for disability. There is no standard definition, and no standard test for disability, that is constant from one population or society to another. The other major problem encountered, is the choice of 'instrument' used, to measure disability. That is: what question(s) to ask, in order to capture the proportion of disability in a population. In the past, many African countries have reported disability prevalence rates in the order of 1-5% (or 1000 to 5000 per 100 000 population). This is far below the European rates of 15-20%. That is not to suggest that African rates should be as high as, or higher than those seen in western societies – but there is a real fear of under-reporting among African countries. What is needed is a standardised approach to the disability phenomenon, so that international measurements can be compared.

A recent workshop on Disability Statistics for Africa, held in Kampala, 10th-14th September, 2001, organised by the UN Statistical Office and attended by representatives from 13 African countries, discussed this actual problem. There was agreement that the figures reported for African countries reflected, for the most part, the most severe cases of disability in the population – and were in fact, similar to rates for severe cases of disability reported in western countries. But what about those with more mild degrees of disability, of those who, for example, need glasses in order to read, but do not have them or cannot get them. They experience

a real limitation in activities because of this disadvantage. We do not like to think of this as a true ‘disability’ – but this person is disadvantaged as compared to others who have, or do not need glasses.

The meeting in Uganda recommended the use of **global questions for the screening of disability in a population**. These questions are based on the following principles:

1. The approach taken to screening should be based on an **activity limitation** approach.
2. The elements of **severity, time** (chronicity, i.e. acute, accidental limitations should be excluded), and **cause** should be implicit.
3. The individual’s actual use of assistive devices/technology should be included.

The following Global Screening Questions were agreed upon

1.1 Does anyone in your household ever have any difficulty in doing day- to- day activities because of a physical, mental or emotional (or other health) condition?

1. Yes, often
2. Yes, sometimes
3. No

1.2 Has this difficulty lasted, or is it expected to last 6 months or more?

1. Yes
2. No

1.3 If YES to 1.1 and 1.2,

How would you describe your difficulty?

Seeing

Hearing

Speaking

Moving around

Learning/comprehending

Movement (reaching, gripping, holding)

Others (specify)

2.1 Does anyone in your household need assistance to do day-to-day activities?

1. Yes, a lot
2. Yes, a little
3. No

The questions are intended to capture as many people with disabilities as possible, while at the same time, exclude people without disabilities.

Question 1.1 takes an **activity limitation** approach (difficulty in doing day-to-day activities) and **cause** (because of a physical, mental or emotional (or other health) condition). It also includes **severity** (Yes, often/Yes, sometimes).

Question 1.2 includes the element of **time** (lasted, or is it expected to last 6 months or more). This should exclude the more short-term, acute cases and those due to accidents.

Question 1.3 was thought to be optional, since in a population screening exercise one would be more concerned with the amount of disability, rather than the type of disability.

Now, consider that a person with a disability may have lived his/her entire life with the support and protection of his/her family and have been able, despite his/her disadvantage, to be integrated and perform well in his/her society. This person may respond to the above questions in such a way that he/she would not be counted - i.e. he/she actually has no difficulty in performing day-to-day activities – but it would be said that he/she still has a disability.

By asking **Question 2.1**, which includes the use of assistive devices/technology, one would be able to capture those who do not experience activity limitations (within their environments) but may require help or assistance of some kind to fully participate in society.

It is important for everyone who is involved with disabled people, to collect data; it is not something that should just be left to enumerators. Service providers should not be frightened of collecting data, they are in a unique position to collect very valuable data, but first, they must set their priorities and then plan how they will achieve them. Research is essential for service development; it is not a mystifying process only understood by statisticians. It is important to remember that traditional impairment categories might not cover what local populations consider to be a disability, such as women's infertility, or men's impotence.

Factors which affect data collection

- In many countries, there are so many different languages and dialects, that efficient communication is very difficult and usually confounds national initiatives that often prove impractical. Additionally, many of the key words are problematic in themselves, e.g. disability. It is advisable to avoid such terms and elicit a description of the problem or need. For example, describe the difficulty walking; describe what is preventing you from participating, and so on.
- Cultural perceptions could also confound statistical interpretations. For example, it is usual for an African family not to want to tell anyone how many children they have; they do not want to be 'counted' because of fear that something bad might happen to the family. For other reasons, the poor communities expect assistance to follow the enumeration of the people in their community, such as supplementary feeding, or income generation projects. In CBR programmes in Uganda, counting people has raised a lot of anxiety and expectations. People, especially parents of disabled children and people with disabilities, often do not feel comfortable with the focus on disability. In the 1991 census in Uganda, people with

disabilities were identified, but other vulnerable groups were not included. For example, there were no special sections for women or youth. Some of the disabled people, who were identified, still hold their identification numbers and papers, in the hope that one day they will get some assistance! This would indicate that it might be better to start a service that attracts people and while providing the service, then one might want to count them. Delegates at the conference questioned why WHO was now promoting surveys? It was explained that information is needed if useful services are to be provided. The participants argued that it was important to develop a service at national and local levels and relate them to known problems. Up to now, data have not helped service providers develop services that relate to felt needs, because, the surveys have been looking at disabilities from a medical impairment perspective. There is a need to look at disability from both, the medical and social perspectives, if useful service information is to be gathered.

Cultural perceptions can often be accessed through local stories and proverbs. These have been reported by Kisanji (1995) and help to understand local concepts and beliefs which can be used to inform surveys. For instance, data from Zambia and West Africa indicates that disability is seen in different ways that cannot automatically be grouped together, since the stories do not have disability as a common theme. Studies in Uganda (Jacobsen 2000), indicate that disability is not a concept attached permanently to somebody, but more an observation relating to a specific situation. This is a point also underscored by the ICF, where the definition of disability as an outcome of an interaction, means that the experience is a feature of the changing environmental contexts, and not a static feature of the individual. A child can therefore be perceived as disabled at school, but not disabled at home. It is this information that should be used to inform surveys.

Experiences in Uganda show that the reality of collecting data before service is provided, has not resulted in the development of services, but has resulted in survey after survey, with very little

follow-up. It is suggested that one way around this is to provide service first and then count, or, to conduct a survey, which is part of a service development programme.

THE ETHICS OF SURVEYS

The justification for disability statistics is that they help to decide how resources should be distributed, but this does not address the ethical problem of what happens when there are NO resources. Perhaps, data is needed to compare the amount of resources used for collecting this data, with the resources available for the development of service provision. The question is, could there be a more equitable distribution of resources between service provision and data collection?

QUESTIONS ASKED AT THE SESSION IN KAMPALA

- How do you get ethical approval through the research ethics committees, for doing survey research as people are identified, but no service is provided?

The ethical considerations should be verified with PWDs or their organisations, even if projects have passed through funding bodies or the universities' ethical committees and got approval in these institutions.

- Are disabled people included from the beginning?

In Zimbabwe, this has been a thorny issue, where programmes meant to benefit the disabled people were planned for them, without involving them at the planning level. The National Council of the Disabled People of Zimbabwe (NCDPZ), as an organisation representing different PWD's organisations, is very vocal about research that does not include PWDS. As a result, there is now a strong relationship between government ministries and NCDPZ to include disabled people when planning research protocols and modalities, and also engaging disabled people as enumerators where it is possible. Good statistics help Governments and other interested bodies, such as academic institutions, to know the extent of the

problem and help them to formulate and test hypotheses and theories to understand better, the nature of the problem as a basis for further research.

RECOMMENDATIONS

1. Participation of PWDs and/or their organisations and parents of disabled children, from the beginning of the research or survey activities.
2. Ethical approval should be rigorous, 'no survey without service'. It is very important to encourage service providers to be accustomed to carrying out surveys, to make sure they are reaching the target group. The research institutions should foster a relationship with the service providers, to provide a complementary service to build a good database and enable them to monitor and evaluate their interventions.
3. Central Statistical Offices (CSO) in less developed countries, should put in place structures which guarantee that data will be analysed (Census in Kenya, data so far not been analysed). There is a need to collect information that is useable. For example, the 1965 census in Uganda (Uganda Government and ILO identified 650,000 PWDs). Until 1990, people were still coming to government offices and other service providers with letters and the expectation of getting assistance.
4. It is strongly recommended that a service should be provided first and people involved should be counted later.
5. There should be a democratic distribution of funds, between survey and service, with at least equal amounts for both.
6. Issues in data collection: Data are collected for many different purposes and at many different levels. Disability is no exception. Good data is needed to:
 - Plan an appropriate intervention programme for an individual.

- Develop and provide resources for services in a local area. The data could assist in deciding whether the focus should be on prevention of illnesses resulting in impairments, rehabilitation services, or changing the environment, or a combination of all these.
- Develop, implement and monitor relevant policies at national level. For example, if there is a much higher rate of unemployment among disabled people than the general population, then a policy and legislation on employment targets for disabled people could be developed. This can only be done with national level data.
- Compare disability rates and experiences internationally, which requires national level information to be collected across a number of different countries in the same way.

Even if there are all these different levels, they can use the same framework of data collection. If the framework is the same (e.g. using the ICF at different levels of detail, with the individual level having the most detail and the national and international levels having the least), the data can be compared, pooled and so on. This will save resources, as well as allow people to communicate with each other at different levels.

7. Build the capacity of the service providers to carry out surveys to monitor and evaluate the impact of their interventions.
8. Governments to collaborate with PWDs on how and what information is required to be collected, for the purpose of improving the welfare of disabled people. Censuses provide an ideal opportunity to involve PWDs about the information necessary to be collected by the CSOs.
9. Disabled men often leave out disabled women; therefore, it is important to make a deliberate effort to include women in surveys.
10. Parents of disabled children are another important group that is usually excluded by the PWDs and viewed as outsiders by PWDs' organisations; yet, the burden of looking after disabled children

rests solely in the hands of this group. PWD organisations are usually concerned with adults and ignore early intervention services, which are essential for children with disabilities, to reduce the progression of the disability, as the child grows.

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