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Disability Prevalence: Challenges for Measurement

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Abstract

This article attempts to examine the methodological intricacies of measuring prevalence rate of disability through a population based survey using the Capabilities Framework, developed by Amartya Sen and others. After considering various conceptual frameworks, from the medical and the social model of disability to the ICF approach, it presents the example of the methodology used in the NDSA. The authors argue that prevalence can be considered in terms of a defined threshold on a continuum of well-being, which is measured through answers to a set of questions combined to provide scores, even when no qualifiers are used. The article concludes that whatever the conceptual framework adopted, theoretical choices that might be made in order to conceive a survey methodology and tools selected will invariably have policy implications and methodological shortcomings that need to be addressed. Finally, setting the threshold for disability prevalence rate is most often a political decision.

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Introduction

Researchers, policy makers and persons with disabilities themselves usually agree that there is a need for a scientific basis and valid conceptual framework in establishing disability statistics. Yet, the collection of information on disability remains particularly complex in terms of measurement. The difficulty lies in the multiplicity of conceptual paradigms: the definition of a common framework on one hand, and its adaptation to various contexts on the other are major challenges. Assessing, or measuring disability empirically is a perilous exercise not only because it is a complex, multidimensional concept, but also because of the difficulty to choose among alternative paradigms. These make the elaboration of a survey instrument difficult. The various models, theories and definitions propose different perceptions of the phenomenon, ranging from the extremely medical to the very social. Over the last decade however there have been major steps taken to reconcile the various approaches by looking at the disabling condition, or the interplay between the individual situation and the collective resources (and limitations) that may make an individual impairment, a social disability. Two such frameworks that will be referred to in this article are the International Classification of Functioning, Disability and Health (ICF) defined by the World Health Organization, and the Capabilities Approach that has been elaborated by Amartya Sen and others. Efforts have been undertaken to improve and standardise the measurement of disability in population-based surveys based on the ICF. The use of the Capabilities Approach is rather an innovative way of assessing disabling situations. The focus has shifted towards looking at the individual within a context, a community and society as a whole.

The present paper argues that prevalence rates can only be relevant and valid when considered in line with the objectives of the measurement exercise, the cultural and social context as well as policy implications. As a result, what is included within the definition of disability will depend closely on a number of factors and will be considered valid for a given time and context. The tendency to over-focus upon these rates mainly comes from the need to order and compare data across countries. The article will further argue that to

give exaggerated importance to the prevalence rate and to define programmes and policies based on this number will invariably lead to serious concerns in terms of human rights. More importantly, from a research perspective, this will lead to ignoring the ever-changing reality of a dynamic phenomenon, which is by no aspect stable. Looking at disability as the ability (or inability) on a continuum also allows for taking into account the way a given society evolves over time.

1. Various Approaches, Various Measures

The first aspect to take into consideration is the approach that is being taken to look at disability as a comprehensive phenomenon. The choice undertaken closely depends upon the context and the objectives of the assessment, but also on the theoretical definitions and models that are considered relevant as the basis for designing the measurement instrument. As a result, not only will these measures shape the way the assessment of disability is carried out, but will also define the types and conditions of inability or difficulty to function that are included and excluded from the research process.

1.1 Models Considering Disability as a State: Implications for Measuring Prevalence

The conceptual framework underlying the measurement construct has implications for the estimation of prevalence. The individual or medical model is based on the concept of disability being a distinction from the physical norm. In this conception, disability is a (physical) condition intrinsic to the individual which reduces her/his quality of life and participation in society in comparison to a “normal” functioning (Amundson, 2000; Marks, 1999; Pfeiffer, 2001). In this model, the measurement of prevalence is based on evaluation of the number of persons within a series of categories of impairments, considered as limitations in health condition across a range of basic functions and structures of the body. Persons with disability fall neatly into a few categories with clear boundaries: the deaf, the blind, the paraplegic, the mentally ill...

Very low rates of prevalence are found when the questions asked are focused only on health limitations. The main reason for this is the negative implications

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of the model which foresees disability as being a deviance from the norm.

Surveys based on self-reporting respondents, questions that are perceived as stigmatising lead to reluctance to answer and underreporting.

The social model is based on a very distinct paradigm. It does not absolutely reject the idea of health limitation, which is considered as the impairment, but rather considers a person to be differently able. This view, which has been put forward by a number of disabled persons' organisations, tends to look at the barriers that exist within the social context and that prevent a person from achieving the same level of functioning than a non-disabled person. In this perspective it is society that needs to be redesigned in order to take into account the disabled persons' needs (Olivier, 1995). Mainstreaming disability concerns is a progressive and sustainable way of redesigning society in order to include people with disabilities. Yet, the advocates of this model consider that the physical limitation becomes a disability because society does not accommodate the difference; society is not adequately structured. However, the social model has implications in addressing the issue of measuring prevalence. Questions based on this model will not be oriented only on physical limitations or differences but will include the identification of barriers of the social environment.

In both models, impairment is understood as a state different from a situation considered as being a "normal" state of health, although they do not draw the same conclusions as per their approach of disability. Still, another approach might consider that this normal or perfect health situation is an ideal that most people do not experience. In a continuum of health states, each individual presents some deficiency in some dimensions of functioning. The ICF model is based on such an approach (WHO, 2001).

1.2 The International Classification of Functionings, Disability and Health (ICF) and the Capabilities Approach: Considering Disability as a Continuum

The WHO has defined an International Classification of Functioning, Disability and Health, known more commonly as ICF. The ICF looks at disability as a combination of individual, institutional and societal factors that define the environment within which a person with impairment evolves. Disability having

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several dimensions or levels, the ICF is composed of various domains of activities and participation that correspond to the body, the person, and the person-in-society. It looks at disability as a combination of these different types of factors that influence the environment within which persons with disability evolve. "In the ICF, the term functioning refers to all the body functions, activities and participation, while disability is similarly an umbrella term for impairments, activity limitations and participation restrictions" (WHO, 2001).

This definition is limited to 2 main concepts:

- Body functions and structures,
- Activities and participation.

This system contemplates an assessment of two kinds of factors:

- Environmental factors, including the physical environment, the social environment and the impact of attitudes,
- Personal factors which correspond to the personality and characteristic attributes of an individual.

This view is based on the assumption that functioning is an important measure of outcomes, regardless of its determinants. Thus, using the ICF in a population-based survey implies a different approach to the measurement of disability. The ICF consists of a scale of reference: its domains codes require the use of qualifiers, which identify the presence and record the severity of the functioning problem on a five-point scale (e.g., no impairment, mild, moderate, severe, and complete). To take full advantage of the coding however requires that a large amount of information be collected: information about activity or participation in sufficient detail to assign ICF domain codes¹, information about the use of personal assistance and assistive technology, and assessments of five levels of difficulty in both the current environment and

¹ Users of the ICF can code domains as Activity, or Participation, or both Activity and Participation. One list of domains and detailed classes within domains is used whatever code is chosen. The same code number is assigned to a detailed class whether it is coded as Activity, or Participation, or both. A literal prefix indicates "a" for Activity and "p" for Participation; or if the user chose not to make the distinction between A and P, the generic prefix "d" for Disability can be substituted.

within standardised environment. None of the question sets currently used or recommended by international organisations covers the entire range of information needed to assess all the qualifiers of the ICF. The complexity of disability as a social phenomenon leads to various ways of operationalising the concepts and to a large range of types of question that can be used or created (Altman, 2001).

Based on the ICF, WHO has developed a common survey instrument for measuring disability. The World Health Organization Disability Assessment Schedule II (WHODAS II) is a tool of measurement that aims to be compatible with the ICF and covers all types of disabilities: physical, mental, sensorial... It attempts to be usable cross-culturally, in different countries, languages and contexts. WHODAS II is composed of different versions consisting of 89 items, 36 items, 12 items or 6 items. The 36-item instrument is composed of groups. Each group consists of a series of questions about specific activities in the different domains.

The capabilities framework offers a general theoretical framework for disability studies that encompasses the social model (Burchardt, 2004, Mitra, 2003). This approach places the definition of disabilities within the wider spectrum of human development and enhancing freedoms. This view is based on “beings and doings that an individual has reason to value”, thus shifting the focus from the specificities of the disabling situation, to how to look at establishing equality in terms of possibilities and choices. Amartya Sen’s capabilities approach to human development provides broader insights into the issues related to disability since it proposes to look at not what a person actually does (functionings) but at the range of possibilities that he/she chooses that specific functioning from – this is the capabilities set (Sen, 1999). The fact that each individual is asked to assess the level of difficulties faced on each dimension helps assess the situation in a comprehensive manner. This approach covers the full range of the disability experience, shifting the focus away from limited views in terms of types of impairments only. This perspective looks at the interplay between individual characteristics and social restrictions and proposes to measure outcomes in terms of the expanding of people’s choices, and thus, freedoms. Limiting the definition to merely a

quantitative, or income and institutional access would be ignoring the dynamics that exist between the individual and the community (Bakhshi and al., 2006a).

There are evidently similarities between these various approaches of disability, the emphasis being on the interplay between the individual and the collective. Within the human development perspective, the definition of disability devised for the NDSA needed to take into account these diverse aspects: the individual's potentialities, the possibilities of "being" what she/he wishes; her/his vulnerabilities, the risk measured as the probability of falling to a lower state of well-being; the opportunities offered by the environment the individual lives in, the agency role of the individual or communities, which looks at the extent to which the person (or the group) considers him/herself as the main actor and decision maker in his/her own life. The definition utilised for the survey draws on the aims of the survey, the capabilities framework and the Afghan context: "Disability is thus the condition that results from the interaction between an individual impairment in functioning and the community and social resources, beliefs and practices that enable or prevent a person from participating in all spheres of social life and taking decisions that are relevant to his/her own future".

1.3 Beyond the Conceptual Framework, Other Factors that Influence Prevalence

Various studies have clearly shown that estimates of prevalence of disability in a given population are not only related to the conceptual framework that is the basis for the measurement instrument, but that these rates are also a "function of the specific survey conditions under which the measurement occurred" (Mathiowetz, 2001: 125). These conditions range from the specificity of questions used to measure disability, the context of the interview, the source of the information (person answering herself versus proxy response given by another person in the household), the variations in the approach of the interviewer, the method of data collection, and the management of the data collection effort. Furthermore, terms such as impairment, disability, functional limitation, and participation are often inconsistently used, resulting in different and conflicting estimates of

prevalence. Attempts to measure not only the prevalence but also the severity of an impairment or disability further complicate the measurement process.

1.3.1 Beliefs and Expectations of what these Rates Should Be

There are very strong beliefs of what these rates should be on the part of the various partners working on the field as well as donors and international agencies. It is interesting to note that, at the international levels, there have been attempts to set a standard for prevalence rates, which have so far been unsuccessful. In 1990 UN/WHO studies estimated that on an average 10% of national populations are disabled (Mitra, 2005). However, these estimates were modified to 4% for developing countries and 7% for industrialised countries. The discussion still continues worldwide on which statistics are acceptable and which are not.

1.3.2 Definition of Disability and the Extent of the Disability Experience

Developed countries often show high prevalence rates for disability. This is partly explained by the inclusion of various forms of disability, as well as a large array of questions that relate to mental and psychological disabilities. The social beliefs and stereotypes related to disability also vary, not only in terms of the culture but also depending on the level of awareness and visibility of different types of disability. Lastly, the decision to include certain forms of disability is also closely linked to diverse aspects of policies that are being implemented. This impacts on non-physical types of problems such as dyslexia or haemophilia, which are considered as disabilities in “developed” countries. As a result, some surveys find very high prevalence rates since they include various forms of chronic illness in the definition of disability. The frameworks used in the NDSA screening tool, a combination of the ICF and the capabilities approach include impairments, but also the activities and participation of individuals in order to understand the disabling experience. This does narrow the definition used in this context. In the survey, the conditions that prevent an individual from taking part in all spheres of life were taken into account.

1.3.3 Wording of Questions

The differences in rates of prevalence can also be influenced by the manner in which questions are asked (Mathiowetz, 2001, Mitra, 2005). Mitra (2005) asserts that prevalence rates may vary greatly based on whether the questions are impairment-based or activity-based: "Indeed, individuals are more likely to identify activity restrictions because they immediately connect with daily experience; whereas an impairment may only be vaguely familiar, and its nomenclature may be unknown" (Mitra, 2005: 8). The author goes on to illustrate this point with case of Turkey where two surveys carried out by the State Institute of Statistics the same year, 2002, gave a prevalence rate of 2.58% when the questions were based on impairment and a rate of 12.29% when they were not.

According to UN guidelines for the development of disability statistics (UN, 2001), the way in which questions are formulated can greatly affect the results. Experience from various countries shows that results could be affected by several factors: (i) whether the questions were generic or specific in trying to elucidate a difficulty; (ii) absence of ambiguity in the questions; (iii) and finally inclusion of too many items within a single question. The NDSA questionnaire design tried to take these shortcomings into account.

1.3.4 Under-Estimation of Mental Disability in Developing Countries

If detecting disability within the household is a difficult task, then finding people who have a mental disability is even more challenging, especially without proper training for data collectors and adapted tools. Surveys that are aimed at providing information regarding disability, more often than not, largely under-estimate the rate of mental forms of disability.

This can be explained by various reasons. There is a lack of knowledge regarding these forms of disability, which reflects a lack of visibility within society. Mental disabilities are often surrounded by lay beliefs and superstitions. This is closely linked to the inability to identify a specific cause. As a result it is believed that there is some mysterious or divine intervention or influence. In traditional cultures, mental disability is often viewed as a punishment that a person had to endure for his/her acts. The common

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language often uses negative, stereotyped terms to refer to these forms of disability (often the equivalent of ‘mad’ or ‘crazy’), which further carry stigma and lead to prejudice. Like disability that results from congenital causes, mental forms have an effect on the image of the family and can have serious consequences on the marriage of siblings, for instance. Therefore, a family may under-report a disability due to shame or fear of being stigmatised by the community.

All these reasons result in household members hiding the presence of a person who suffers from mental forms of disability.

2. Prevalence for the National Disability Survey in Afghanistan: Dilemmas and Solutions

One main dilemma in the measurement of prevalence and identification of persons with disability related to the person who provides information for the survey. During the training on the field in Afghanistan, the authors realise that limitations in ability due to age were reluctantly reported by surveyors, as old age is considered as a “natural” process that cannot be assimilated to a disability. Long explanations were necessary to convince the team of data collectors that all limitations in well-being, whatever the cause might be, had to be gathered according to the questions in the tool used. Similarly, as persons with disability themselves might consider their disability as a curse of God, often ignoring the cause for it, the interview must be carried out with tact to avoid underreporting.

Even if one considers that disability is a continuum, it might be seen as necessary to set a threshold of disability that establishes a cut-off within a population between persons with disability and the non-disabled to analyse the phenomenon and eventually to target a sub-population for specific public action. This must however be done considering the definition adopted and the goals to be achieved and decided through a consultative process with the persons with disability themselves. Unless public action is really based on mainstreaming and prevalence measurement is not a major goal for the users of the data collected...

2.1 Major Challenges in the Afghan Context

For the NDSA, several issues have to be considered: the definition adopted for disability, the difficulty of data collection, and the sample distribution.

As outlined earlier in the present article, the NDSA used a strict definition of disability and a questionnaire using multiple specific questions. The screening tool aimed at identifying persons with disability through adequate queries based on abilities and difficulties of the individuals living in the households selected. Non-disabled persons were also included in the sample as match and control for respondents reporting a disability. This ensured that all members of the population of interest were effectively included in the sample. Proceeding in this manner ensured limiting the two symmetrical errors: “error of coverage” and “error of targeting”.

Data collection in Afghanistan is not easy due to several factors: difficulties to explain the scope of the survey, security constraints, and accessibility to the clusters... To limit the impact of such issues on the quality of the data, long training sessions were organised and multiple levels of checks were carried out in the field during data collection, as well as during data entry and cleaning. A one and a half-month training (theoretical and practical) of the team of monitors, master trainers and supervisors was conducted. A three-week training of surveyors covering the same topics including disability issues, cluster household survey principles, the questionnaire, the sampling, the interview process both in Dari and Pashto also took place in the five major cities of the country. A pre-test of all the tools, especially the questionnaire (elaborated by specialists and reviewed by experts, Afghan organisations of persons with disability), in both rural and urban areas, was carried out. A very close control of the field process was organised (review of questionnaires, presence of researcher in the field in half of the clusters, sending of a control after field work in 20% of the other half of the clusters).

Concerning the sample distribution, results for main indicators such as prevalence rate are very similar when we compare the results obtain with the sample to the results obtain after stratification ex post by province. A high level of similarity between the NDSA sample distribution and the total

population distribution given by the pre-census of 2004 for 30 provinces is observed. Nevertheless, a few limitations need to be addressed.

Firstly, four clusters out of 175 randomly selected clusters could not be surveyed due to security reasons. Since other clusters were surveyed in the corresponding provinces and districts, this issue was addressed by modifying the global weight of the sample without significant impact on the prevalence rate. Secondly, no persons with disability were found in the only cluster selected and surveyed in one of the provinces. This could be explained by the random selection of the sample. However, a national prevalence rate is calculated assuming that the given province has similar prevalence of persons with disability as other provinces, the national disability prevalence rate of 2.7% increases by 0.03% only. Therefore, this issue can also be addressed by modifying the global weight of the sample.

Secondly, three sub-samples exist within the main sample. A first group is composed of all the persons with disability that are interviewed in the sample. The systematic sampling of households led to a strict equal chance for all persons with disability in Afghanistan to be interviewed. The second group is composed of the matches for the persons with disability. It is a two stage random selection as these people have to be matched by age and sex with the persons with disability. If there is no match in age and sex or more than one non-disabled person matching for age and sex, then the match is randomly selected among non-disabled in the household or among non disabled with the same age and sex. The fact that the population of persons with disability, as discussed below, consists of more males and old people introduces a possible bias among matches. This bias, even limited, can be partially rectified by weighting the population of matches by the number of non-disabled in the household². The third group is composed of “controls”,

² For the NDSA, the household is a group of people who may or may not be related by blood or marriage, who live under the same roof or within a same compound, who take their meals together or in small groups (one kitchen in the house), who put together part or all of their income for the needs of the group and who are dependant on the authority of the head of the household for all the expenses entailed. The surveyor may come across 'uni-personal' households that consist only of one person: for our survey this concerns the situation where the interviewee lives alone. The definition adopted is similar to the one adopted by the CSO for the pre-census of 2004 and other recent surveys in the country (National Risk Vulnerable Assessment in 2003 and 2005).

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individuals living in a household without persons with disability. For this group, the selection is done according to a three-stage random method: at the cluster level, at the household level (one every five household without disabled persons) and finally at the individual level. For a non bias estimate of this third group of individuals, the selected individual has to be weighted with the number of people living in all the households without persons with disability.

Thirdly, another possible source of bias is due to the choice of a household cluster survey itself which excludes 3 groups from the sampling. First of all the Kuchis³ who are still nomadic, and are not settled within the boundaries of one cluster are not very numerous. The nomadic part of this group of people probably represents a few hundred thousands of people in Afghanistan today. These persons were however included in the sample when they were temporarily settled within the boundaries of a cluster, mainly during winter. Complete nomadic people need to be surveyed with a specific methodology and do not fit within the frame of a household cluster survey. The second group is composed of persons with disability living in hospitals or other socio-medical institutions. Except the Marastoons⁴ which welcome a few dozens of persons with disability in major towns in Afghanistan, there are no specific institutions welcoming a high proportion of persons with disability on a permanent basis. The last group is composed of non responses, refusal to answer, but this was very limited, under 0.3% of the total sample.

Finally, the hypothesis put forth is that persons with disability have a higher rate of mortality, especially in the early years, since they are more vulnerable and need more resources in order to survive dramatic events. Considering the

³ Kuchi in Persian means “those who move”. Afghan nomads comprise two large groupings. The Western group comes from the desert in the South West region of the country. They are largely from the Durrani tribes. The Eastern group drawn from various Ghilzai tribes associated with better watered, lush grazing grounds of the East region of the country. In Richard Tapper “Nomadism in Modern Afghanistan: Asset or Anachronism?” in Louis Dupree and Linette Albert (Eds.), *Afghanistan in the 1970s*, New York, Praeger Publishers, 1974: 128-9.

⁴ Marastoon means “place of assistance” in Pashto. They were set up by the Government as public institutions in 1930. They are social centers and temporary refuges for poor isolated families run by the Afghan Red Crescent Society since 1964, in five major towns (Kabul, Kandahar, Mazar-I-Sharif, Herat, Jalalabad).

poor health statistics of Afghanistan and the limited health care available in the previous decades of war and instability, it is possible that higher mortality rates contribute to the lower prevalence rate that is found for severe disability.

2.2 The Screening Tool: Assessing the Rate

The NDSA utilised a screening tool to assess a disabling situation. Once this assessment was made, in depth interviews were carried out with a sample of individuals identified with the screening tool as being disabled as well as with the matches and the controls. The screening tool aims to identify the different types of disability that might exist within a given household.

The NDSA adopted a definition of disability based on activities and participation, concentrating on the functionings of the individual. This definition was translated into a screening tool of 27 questions identifying all kinds of disabilities. This screening tool consisted of various sections relating to specific aspects of physical and mental disabilities. These questions were asked to the head of each household surveyed or to the person present who knew most about the household.

According to this procedure, a person was considered to be disabled if the respondent had at least one positive answer to the physical disability section (Section A) and/or at least two affirmative answers to each of the other sections: learning (Section B), psychological (Section C), social and behavioural (Section D), and lastly epilepsy and seizures (Section E). Each question referred to a specific type of difficulty related to activities carried out in everyday life. Therefore, to be considered as being disabled, the person(s) in the household had to answer “yes” to the physical disability section and/or to the other sections according to the criteria stated above. Each person identified as disabled was then interviewed in depth with the adult or child questionnaire regarding health, education, employment, livelihoods and social status. The answers in the screening questionnaires were cross-checked with the 13 possible categories identified by the surveyor him/herself in the checklist. An updated version of this screening tool is provided in appendix.

Lastly, all the questions of the screening process referred to the term ‘difficulty’, avoiding stigma and negative stereotypes. The NDSA made the

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choice, as a number of other surveys have previously made, to use the term “difficulty” or “mushkel” in Dari and Pashto. This term was considered to be less threatening and constituted less of a ‘label’ for the persons concerned, making the reference to disability easier.

In order to better comprehend the various aspects of the survey, the NDSA training of master trainers/monitors as well as the surveyors for Kabul was more than a month long and carried out by a number of persons working on the field in Afghanistan.

2.3 The Health Module: Looking at the Continuum of Abilities

If disability is seen as a continuum of difficulties in functioning, ranging from very severe to mild, then the prevalence rate mainly depends upon where researchers or policy makers choose to place the “cut off” or the threshold. As a result, persons falling within this limit will be considered as being disabled.

The health module of the questionnaire allows a more in-depth assessment of the interrelation between the individual and her/his environment. It looks at the functioning of a given individual in different contexts. For the NDSA analysis and in order to present a comprehensive and different picture, nine main dimensions of well-being were determined. Each of these dimensions consists of a set of items that help establish a score on the given dimension:

1. The ability to take care of oneself on a day-to-day basis.
2. The ability to contribute to tasks within the household.
3. The ability to move around and contribute to tasks outside the house.
4. The ability to communicate with other members of the family and the community.
5. The ability to interact and have social relations with people.
6. Intellectual and memorization abilities.
7. The ability to have coherent individual behaviour.
8. The absence of depressive symptoms and signs of trauma and other psychological problems.

9. The absence of fits, seizures and signs of epilepsy.

The answers to these forty-six questions organised in nine dimensions were analysed as a continuum of level of ability to function. The scores for the first three dimensions were calculated on the three possible answers: ability (answer "Yes"); absence of ability (answer "No") and ability, but with some difficulty (answer "Yes, but with difficulty"). The sets of questions for these three dimensions look specifically at the health situation in terms of ability and difficulty to function in everyday life. Various aspects of everyday life, both within the house, with the family and in the community are analysed.

Concerning abilities related to self-care and autonomy, questions asked concerned the ability to perform a series of simple everyday life acts, such as bathing or getting dressed, drinking or eating, or moving around. This is a first set of questions. The questions also relate to abilities in terms of everyday contributions to household running: this second set of questions asked only of children over 8 years old and women concern the capacity to perform household tasks such as preparing a meal for the family, sweeping, and taking care of children or elders. Because in the Afghan culture adult men barely participate to household chores, these questions were not ask to them to avoid underreport due not to limitations in functionings but to confusion between effective difficulty and the fact that they do not take part.

The scores on the other dimensions were calculated on two possible answers, ability or absence of ability. Dimension four is related to simple communication within family and the community: the ability of delivering and receiving messages and information, of understanding others and making oneself understood. Dimension five is different and more complex than the previous one. It deals with the ability to be with other people, therefore closely linked to social acceptability and social integration of the individual. The sixth dimension is related to concentration, remembering things and learning new things. It compiles intellectual abilities that are necessary in order to function on a daily basis and within a family and a community. Dimension seven consists of individual behaviour. It refers to the ability that the person has to have a calm and coherent attitude towards oneself. This dimension includes violence that can be conducted towards oneself, as well as loss of

consciousness... All these indicators linked to individual behaviour invariably have an impact on the ability to be with other people and influence the degree of isolation, whether the person is kept at home, hidden away because believed incapable to “behave” in a manner considered adequate and coherent by others. Dimension height is probably the component of mental health that has been addressed most extensively within the Afghan context (Lopes Cardozo et al., 2004; Ventevogel et al., 2006; Ventevogel, 2005). The main belief is that a very large number of persons in the country, in view of the history and the recent conflicts, are subject to various forms of depression, anxiety and Post Traumatic Stress Disorder (PTSD). The NDSA tried to address this dimension through 10 different items that include various signs of depression and related problems. The NDSA findings do not propose a “diagnosis” but try to bring into light the extent of this problem for persons with disability in the country. The ninth and final dimension is specific, as it consists of only one item and it relates to one of the categories of disability that was included in the screening of the NDSA. Epilepsy and other forms of seizures represent 1% of the population of Afghanistan, and are a lot more prevalent in rural setting and it is mostly women who show signs of epilepsy, or some other form of seizures.

For comparability reasons with other surveys based on the ICF, the use of qualifiers which record the presence and severity of the functioning problem on a five-point scale (e.g., no impairment, mild, moderate, severe, and complete) was modified in the case of the NDSA. Test of the questionnaire and discussion about such a choice with disability experts and persons with disability in Afghanistan, led the research team to simplify the scale into three answers offering clear choices, and therefore reducing the risk of misinterpretation and misunderstanding.

The ICF codes require the use of qualifiers, which record the presence and severity of the functioning problem on a five-point scale. But when the NDSA questionnaire was tested, respondents had trouble to choose between the five levels, i.e. 1: “yes, able without problem”; 2: “yes, able with mild difficulty”; 3: “yes, able with moderate difficulty”; 4: “yes, able with severe difficulty”; 5: “unable” to do the task. A simplification of the scale to three points seemed to

be more adapted. To compensate for this diminution of precision in the evaluation of the difficulties in functioning, the use of a larger set of questions was designed.

The higher the score on each dimension, the higher the level of difficulties the persons face on the given dimension.

It is a fact that the authors found that in Afghanistan the assumption according to which the questionnaire using the five-point scale consistently measures the same degrees of well-being for all individuals, is erroneous. Tests of tools in the field showed that there was no reliable internal consistency of the five-point scale: items using such a scale did not measure reliably the same underlying concept of well-being according to individuals. Different individuals, due to ethnic, socio-economic or demographic background have not the same end-points, low and high, on an underlying scale of well-being states, and the same cut-points between meaningful levels along that scale in Afghanistan. Other studies have shown that response category cut-points are different across socio-economic groups within a country (Murray et al., 2001) and between countries (Sadana et al., 2000). In the Afghan culture, median score is often considered as the right choice. The second intricacy deals with the distance between two positions. In Afghanistan, it cannot be assumed that respondents perceive the difference between adjacent levels as equidistant: the difference between mild and moderate difficulty is considered closer than between moderate and severe or severe and complete. The last limit is that if there is one position in the scale which is more in line with social norms and expectations, there is a tendency to choose it over the others. This was not clearly identified during the test. In Afghanistan, due to security constraints, low level of education, lack of general awareness on disability, it was not possible to have a multi-position scale with valid interpretation. In order to present coherent results, a simpler scale was chosen in order to present a clear and dependable analysis.

3. Findings of the NDSA: Prevalence Variability

Disability is not a permanent and immutable state but should be understood as a spectrum of limitations in abilities and capabilities. It can be considered

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more comprehensively as a general situation of anyone having a certain level of limitations in one or more of the following domains:

- Functioning of the body;
- Ability to carry out certain actions;
- Ability to participate to society and community;
- Finally limitations due to environmental factors.

Considering this approach, one can re-define the level of prevalence of disability in Afghanistan. The rate of prevalence varies according to where the threshold is set.

Setting the threshold can leave no space for uncertainty in certain cases of severe impairment: a total lack of functioning or complete incapacities in one or several given dimension, or for some domains of body functions (vision, hearing, and paralysis), body structures, activities limitations and social participation. But most often there is no standardised threshold. The policy makers or the disability programme managers can decide where the threshold should be set for each domain of functioning, according to their own objectives. With this perspective, there is no determined rate of prevalence but different levels of prevalence of disability depending on what the priorities are and the goals identified for action.

In the NDSA questionnaire based on the ICF and Sen`s capabilities approach, two sets of questions can be considered in order to define what the prevalence rates are:

- The 27 queries of the screening questionnaire;
- The 46 queries of the health questionnaire.

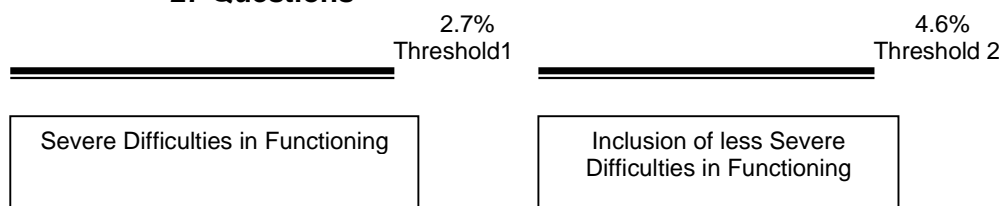
3.1 Prevalence Rates according to the Screening Tool...

The prevalence of persons with disability identified by the National Disability Survey in Afghanistan stands at 2.7% (95% confidence interval (CI): 2.5% and 2.9%). This rate is based on an identification of intellectual disability, mental illness and psychological distress considering two affirmative answers to learning (Section B), psychological (Section C), social and behavioural

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(Section D), and epilepsy or other forms of seizure (Section E) of the screening tool which refer to the more “hidden” forms of disability. Considering the priorities defined, the proportion of the Afghan population that urgently needs to be targeted by public policies and programmes is 2.7%. This prevalence rate will invariably increase according to the inclusion of persons having less severe difficulties.

Figure 1 **Prevalence Threshold with Regard to the Screening Questionnaire: 27 Questions**



It is believed that a large number of all Afghans indicate having high levels of mental distress, which could mean anxiety, depression, trauma, stress... A few studies have looked at this issue in particular for the overall population (Lopez Cardozo and al. 2004; Rasekh et al. 1998; Scholte et al. 2004; Ventevogel et al. 2002). A wider approach of disability takes into consideration only one affirmative answer in the physical disability section (A) and/or one affirmative answer to section (B) to (E) of the screening tool. This wider approach brings the prevalence rate up to 4.6% (95% CI: 4.4% to 4.8%). This translates to 1.09 million Afghans who report having a physical disability and/or some form of mental distress. These trends do seem to confirm what Ventevogel (2005) writes regarding the high rate of psychiatric morbidity among the Afghan population. The “history of violence and social disintegration” of Afghanistan, might have “had an effect on the mental health status of its inhabitants”, which will need public attention in the very near future.

3.2 ...Prevalence Seen as a Continuum: Setting Different Thresholds

For results pertaining to the health questionnaire, according to the nine dimensions defined above, the threshold can be put at various levels of severity of limitations. Comparing the well-being profiles of different groups can yield interesting information regarding how they experience everyday life. The dimensions can be easily divided into three different groups in view of the

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level of functionings. The first three dimensions relate directly to physical abilities to function in everyday life, within the household and outside. The dimensions 4 to 7 deal with various aspects of life in society, interacting with others and inclusion, acceptance and participation in various groups. The dimension height is specific as it looks at signs of depression and trauma. The overall view can be assessed by looking at a combined score for all dimensions. This score is calculated using the same method as for each of the dimensions. A high score reflects a high level of difficulty and, as a consequence, lower feelings of well-being.

- “No Difficulty” is defined by a score 1 corresponds to the absence of difficulty on any of the items stated;
- “Mild Difficulty” is scored at 2;
- “Severe Difficulty” is scored at 3;
- “Very Severe Difficulty” is scored at 4, the maximum score.

Dimension 9 is linked to epilepsy and other seizures experienced and is only scored in two scores “Difficulty” or “No Difficulty” whether the phenomenon is reported or not by the respondent.

Table 1. Rate of Prevalence According to Different Thresholds on 45 Questions of the Well-Being Profile

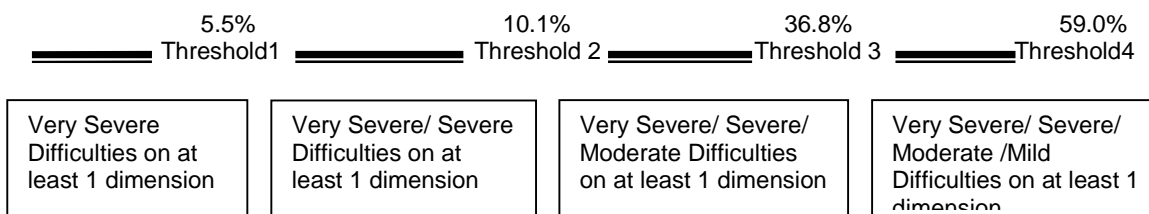
Threshold (from Various levels of Limitations)	Prevalence Rate (%)
‘Very severe difficulty or inability’ on any one of the 8 dimensions of ability and “yes” to dimension 9	5.5
‘Severe, Very severe difficulty or inability’ on any one of the 8 dimensions of ability	10.1
‘Moderate, Severe or Very severe difficulty or inability’ on any one of the 8 dimensions of ability	36.8
‘Mild, Moderate, Severe or Very severe difficulty or inability’ on any one of the 8 dimensions of ability	59.0

Source: NDSA, 2005.

One option is to take into consideration the answers ‘*very severe difficulty or inability*’ to any one of the dimensions. In this configuration, the rate of prevalence is 5.5%. Adding people with the score of ‘*severe difficulty*’ to any of the dimensions, takes the rate of prevalence to 10.1%. Then, including level of ‘*moderate difficulty*’, further increases the rate to 36.8%. Finally, if we

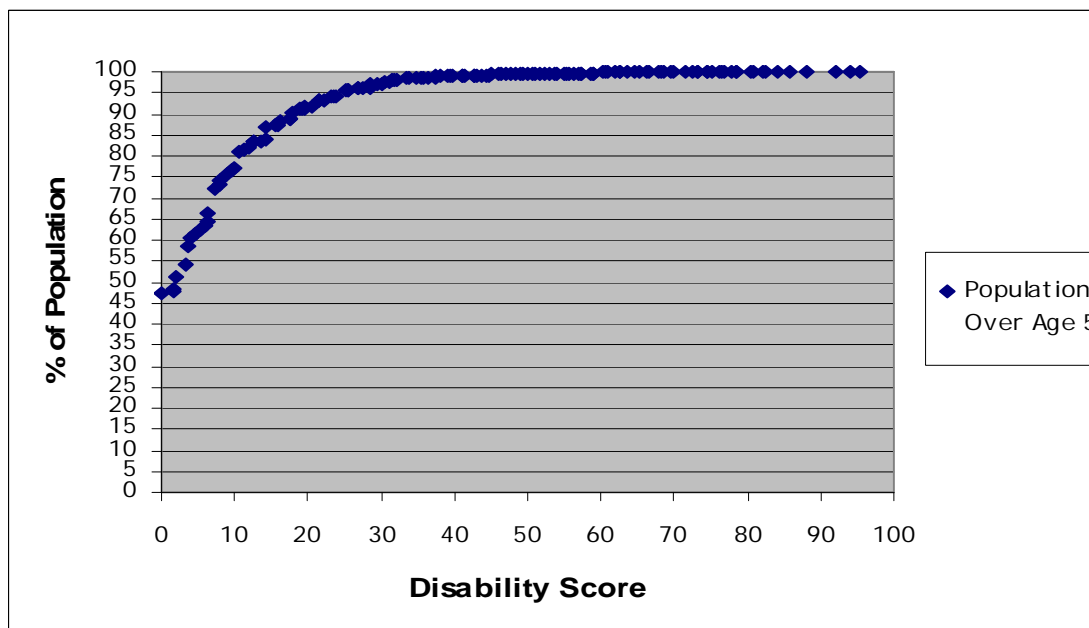
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add people with the score of 'mild difficulty' to any of the dimensions, the prevalence rate becomes 59.0%.



Another method that can help get an overall perspective and allow international comparisons with other countries in the region is to calculate an overall disability score for the nine dimensions for the entire population by considering the scores on a scale going from “no difficulty” to a maximum level of difficulty (95.2%). Thus, it does not provide a predetermined prevalence rate, but rather shows the proportion of the population facing various levels of difficulties in everyday life.

Figure 2 Disability Score for Afghan Population Above Age 4



Source: NDSA, 2005.

Prevalence depends on threshold decisions concerning where – on a continuum of difficulty – to draw the line that separates persons with disability from non-disabled. The figure shows that more than 40% of the Afghan population reported that they have absolutely no difficulty in functioning when

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asked all the 46 questions. For the remaining of the population, there is a certain level of difficulty. The determination of the level of difficulty at which the threshold is set, defining the percentage of the population that 'qualifies' as being disabled is a political decision that relies on aspects such as the health system, the social situation, the economic resources, the overall capacity to address the specific needs of persons with disability. The decision to set the threshold at a given point should be widely discussed with the various stakeholders in order to ensure that the decision is relevant to the goals and objectives as well as to the context.

3.3 Links Between Prevalence Approach and Typology

There are different ways in which to consider the distribution of persons with disability according to various thresholds for the prevalence rate (Bakhshi and al., 2006b). Table 2 below shows a first possible breakdown by types of disability based on results of the screening process of the survey and on the 2.7% prevalence rate reported earlier. Multiple physical impairments are included in overall "physical disability" category when the two impairments are physical. The same was done for multiple sensorial disabilities, which were included in the overall sensorial disability category. Associated disabilities category includes more than one type of disability such as sensorial, physical, mental, and epilepsy.

Results clearly indicate that the majority of Afghans with disability have physical impairments (36.5%). Sensorial impairment also affects a considerable section of persons with disability in Afghanistan(25.5%). Other forms of disability, including seizures and epilepsy explain 28.5% of all persons with disability. Associated disabilities, physical and/or sensorial and mental together represent 9.4% of the sample.

Table 2. Prevalence rates by Types of Disability

Type of Disabilities	Number	Prevalence Rate	%
Physical Disability	379	0.99% (0.89-1.09)	36.5
Sensorial Disability	265	0.69% (0.61-0.77)	25.5
Mental Disability	101	0.26% (0.21-0.31)	9.8
Associated Disabilities	98	0.26% (0.21-0.31)	9.4
Epilepsy /Other Forms of Seizure	195	0.51% (0.44-0.58)	18.8
Total Disabled	1038	2.71% (2.55-2.87)	100.0

Non-Disabled	37282	97.29% (97.28-97.30)
Total	38320	100%

Source: NDSA, 2005.

The typology resulting from the screening tool is quite similar to the identification of disability carried out by the surveyors. Mental disability compounds all forms of intellectual and psychological difficulties as well as epilepsy and other forms of seizure, wherever the surveyors felt that it was a problem. A direct observation of disability did not allow surveyors to identify different types of mental illness and intellectual disability in a very limited time frame.

However, the identification of physical disability by surveyors is more accurate. This is due to two major factors. The first one is that the often high visibility of physical impairment making it easier for the surveyor to notice it compared to, say a mental illness. Secondly, the screening questionnaire aims at identifying impairments with sensitivity, but it was not designed to detail all types of signs and symptoms linked to a physical disability; this would have increased the duration of the interview considerably. Consistency was therefore verified by comparing the assessment made by the surveyors with the findings of the screening tool; this was particularly reliable for physical and sensorial disability.

**Table 3. Prevalence Rates by Types of Disability according to the
Observation of Surveyors**

Type of Disabilities	Number	Prevalence Rate	%
Physical Disability	325	0.85% (0.81-0.89)	31.3
Multiple Physical Disabilities	58	0.15%(0.11-0.19)	5.6
Sensorial Disability	180	0.47%(0.43-0.51)	17.3
Multiple Sensorial Disabilities	49	0.13%(0.09-0.17)	4.7
Sensorial and Physical Disabilities	46	0.12%(0.08-0.16)	4.4
Mental Disability	293	0.76%(0.73-0.80)	28.2
Physical and Mental Disabilities	48	0.13%(0.09-0.16)	4.6
Sensorial and Mental Disabilities	39	0.10%(0.06-0.14)	3.8
Non-Disabled	37282	97.29 (97.28-97.30)	
Total	38320	100	

Source: NDSA, 2005.

Physical disability still constitutes the main type of disability. However, multiple disability accounts for 15.1% of all persons with physical disability, without including associated disabilities in the counting, and 12.2% if these are included. Mental disability, including epilepsy and other forms of seizures is the second type of disability; this category encompasses a variety of difficulties. The high level of multiple sensorial disabilities (21.4% without including associated disabilities or 15.6% if included) is also striking. It is mainly due to a combination of speech and hearing impairments. Associated disabilities are slightly under-represented: there is 1% less between the two sources of assessment (the screening tool and the surveyors). One explanation of this gap lies in the limitation to two possible answers for the surveyor, thus excluding the detection of triple associated disabilities.

Focusing on the 4.6% prevalence rate using a single criterion in sections B to E of the screening questionnaire of the survey, increases not just the rate of prevalence, but also the risk of error of targeting, by including people considered as non-disabled in the sample. The persons identified as having mental distress but not severe difficulty of functioning in the Afghan society, do not constitute a priority for implementation of public policies such as education, health or employment support for the time being. Nevertheless, such a choice would lead to a different typology of disability in Afghanistan (See Table 4 below). In doing so, the most salient result is that physical disability is no longer the main type of disability; the majority of difficulties are then linked to mental issues. In any case, the probability of having high levels

of mental distress has been underlined by previous studies (Scholte W.F. et al., 2004).

Table 4. Prevalence Rates by Types of Disability Including Mental Distress Identified in the Screening Tool

Type of Disabilities	Number	Prevalence Rate	%
Physical Disability	379	0.99% (0.89-1.09)	21.6%
Sensorial Disability	265	0.69% (0.61-0.77)	15.0%
Mental Disability	101	0.26% (0.21-0.31)	5.8%
Mental Distress	719	1.88% (1.74-2.01)	40.9%
Associated Disabilities	98	0.26% (0.21-0.31)	5.6%
Epilepsy /Other Forms of Seizure	195	0.51% (0.44-0.58)	11.1%
Total Disabled	1757	4.59% (4.38-4.79)	100.0%
Non-Disabled	36563	95.41% (95.20-95.63)	
Total	38320	100%	

Source: NDSA, 2005.

Based on the 4.6% prevalence rate, Table 4 shows that there is a certain number of Afghans (1.9%) possibly reporting some form of mental distress. The CDC survey concluded that a large majority of Afghans (57.7%) suffer from some form of neurological, psychological/mental or intellectual condition (Cardozo et al., 2004). This shows that currently there are a significant number of Afghans who suffer from some form or other of mental distress and need to be better identified and their needs addressed. However the implications of these types of difficulty in terms of policies and programmes are very different. Moreover, the needs with regards to education, health and employment are not the same for persons with disability and those who suffer from mental distress. For example, the requirements for education are not in terms of access or adaptation of teaching tools but more in terms of sensitisation of teachers and families. Furthermore, during the fieldwork, the NDSA found that mental distress was something familiar and frequent for families and that they learned during decades of conflict to cope with these difficulties. Ever if this strongly influences well-being, persons more often than not function on a daily basis.

Different thresholds of prevalence rates can be observed when considering the nine dimensions of well-being taking the capabilities perspective to consider the disability process (Table 5). The profile of well-being determined provides the degrees of difficulties faced on each of the dimensions. The

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overall view can be assessed by looking at a combined score for all dimensions. This score is calculated using the same method as for each of the dimensions. A high score reflects a high level of difficulty and, as a consequence, lower feelings of well-being.

Table 5. Prevalence Thresholds Considering 8 Dimensions of Well-being

Thresholds		Dimension1 Daily Autonomy	Dimension2 Contribution to Household Work	Dimension3 Contribution to Work outside House	Dimension4 Communicating with Family/ Community	Dimension5 Interacting, Having Social Relations	Dimension6 Rememberin g, Memorising	Dimension7 Positive Individual Behaviour	Dimension8 Signs of Depression/ Anxiety	Dimension9 Epilepsy/ Seizures
No Difficulty	Number	21017556	10888052	14342759	23975227	24036805	10401925	24368725	9206232	25656788
	% in category	90.7	66.5	62.3	92.5	92.7	89	94.1	79	99
Mild Difficulty	Number	1926961	2578722	3849376	1463570	1614268	612267	1466947	1498256	NA
	% in category	8.3	15.8	16.7	5.6	6.2	5.2	5.7	12.8	NA
Severe Difficulty	Number	187591	2154434	4556219	291389	240076	350759	40921	800898	NA
	% in category	0.8	13.2	19.8	1.1	0.9	3	0.2	6.9	NA
Very Severe Difficulty	Number	47418	743088	277228	194737	28581	325035	20786	154852	265536
	% in category	0.2	4.5	1.2	0.8	0.1	2.8	0.1	1.3	1
Total population		23179526	16364296	23025582	25924923	25919730	11689986	25897379	11660238	25922324

Source: NDSA, 2005.

Table 5 shows that level of well-being for the entire population of Afghanistan varies according to the dimension examined and intensity or level of difficulty. On each dimension, some difficulty is observed. The most severe difficulties being in the domain of contributing to household chores (dimension 2) and to work in general (dimension 3). They also face very severe problems related to memory (dimension 6) and depression/anxiety (dimension 8). Globally, the results on dimensions link to mental distress, anxiety, depression and trauma corroborate other studies done in Afghanistan (Bhutta Z. A., 2002; Rasekh Z. et al., 1998; Scholte W.F. et al., 2004).

4. Discussion

The present article examines the challenges of prevalence rate measurement using a population based survey. Prevalence measurement has to be considered with caution for several reasons. The rate largely depends on the model adopted to define disability and the objectives pursued on one hand, on the tools, method used to survey and the conditions of interview on the other hand. All these factors influence the results of analysis and must be kept in mind when interpreting the outcomes. Finally, prevalence measurement only offers a small interest when considering disability policies to improve inclusion, participation and well-being of persons with disability.

4.1 Limitations of Survey Methodology: Difficulty to Overcome Bias in Prevalence Measurement and Comparison

Beyond conceptual choices and field constrains, methodological limitations are also to be considered when measuring and comparing prevalence rates. For international comparison, a possible way to overcome the difficulty is to shift the focus from prevalence rates to threshold settings as proposed in the present article. Of course, this solution does not overcome all difficulties if conceptual framework, aims of the survey and instruments of measures are completely distinct. But, using an equivalent approach in different countries for population based surveys, setting thresholds on a continuum of human experience based on similar calculations should allow for quite reliable international comparisons.

Other solutions put forward by several authors did not produce the expected outcome. For instance, Sadana et al., based on analyses of data from more than 50 household surveys conclude that survey self reports of non-fatal health status are biased from population to population, even when survey questions and survey methods are standardised (Sadana et al., 2000). As long as surveys are based on self-reporting, the health status reported will be different from the effective health state and even probably from the health status perceived. Yet, in countries like Afghanistan, health examination surveys cannot be carried out due to the absence of a performing health system.

A solution put forward by some authors (Murray et al. 2001) to overcome difficulties when using a scale of references is the employment of case vignettes to control for response category cut-point shifts. A vignette is a depiction of a tangible level of ability on a given domain that individuals are then asked to assess. To judge the response category cut-points, each respondent is also asked to assess ability to move around for a hypothetical cases described with a vignette. The vignette fixes a given level of mobility so that variation in the response categories is attributable to variation in the response category cut-points. Then, a specific model allows estimating the cut-points. This method seems very attractive because vignettes can easily be included in survey tools. Yet, in a population based survey such as the NDSA, the vignette might be not so easily exploited. First of all, prevalence measurement is only one aspect of the survey that several objectives, therefore several modules of questions are required for other topics. Secondly, the vignette requires time and explanation in order for the respondent to catch the idea. Already, the screening and the ability questions sets are limited not to be too challenging to ask...

4.2 Ways of Assessing Prevalence Depend Closely Upon the Approach and the Objectives of the Study

For the NDSA, we considered that the Capabilities Approach offered the best method to meet the goals fixed by the users of the survey: identifying the level of disability, evaluate access to public services, gather information regarding livelihoods and well-being, and identify barriers to mainstreaming and

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participation to community. The Capabilities Approach covers the full range of the disability experience, away from limited approaches in terms of types of impairments only.

Public action needs to focus on fighting vulnerability and enhancing capabilities, viewed as composed of ability and potentiality. While the former looks at what a person can do and be in a given context, the latter refers to the ability to cope over time, in a sustainable manner. The multidimensional view of well-being can allow decision makers to assess the vulnerabilities where the health of Afghans with disability is concerned.

The agency of the individual looks at to what extent the person considers him/herself as the main actor and decision maker in his/her own life. Needless to say, this is very closely related to the degree of acceptance that he/she experiences as well as the support and services that are available. It is recognising a person as “someone who acts and brings about change, and whose achievements can be judged in terms of her/his own values and objectives, whether or not we assess them in terms of some external criteria as well” (Sen A., 1999: 19).

The well-being profiles can be used in to define relevant policy measures and to assess the impact of policy decisions.

Looking at a set of abilities or capabilities constitutes “a space within which comparisons of quality of life across nations can most revealingly be made” (Nussbaum M., 2000: 116). The author also affirms that “the threshold level of each of the central capabilities will need more precise determination, as citizens work toward a consensus for political purposes. This can be envisaged as taking place within each constitutional tradition, as it evolves through interpretation and deliberation” (Nussbaum M., 2000: 77). This list of dimensions can be seen as a set of “principles” that need to be taken into account, what exactly each of them refer to will depend on the cultural and social context and will evolve over time. However, well-being is defined by all of these and one cannot be ignored or underestimated to the detriment of the other.

Last, this comprehensive view can be useful when it comes to assessing the general living conditions and well-being of individuals, as well as evaluation of the progress made. In present day Afghanistan, it can be seen as a scale to evaluate improvements or degradations of everyday life and make relevant comparisons between individuals and groups, and ensure that vulnerable sections of society are consistently taken into account.

4.3 Beyond Prevalence, Grasping the Various Facets of Disability which is a political issue...

The present article highlights some of the currently unresolved barriers towards obtaining accurate measurements for disability prevalence, and introduces an innovative way to identify disability based on level of well-being in a continuum of human experience, going a step further than the tools based on the ICF. But a survey like the NDSA does not aim at “pursuing the elusive single measure for disability” (Altman, 2001: 96). It does not limit either its scope at providing prevalence rates which are only thresholds which have to be determined politically with transparency on the continuum of human experience. It more largely aims at providing evidence based knowledge for adapted and well-focused public action. The costs of disabilities are borne not only by the individuals but also by the society as a whole. The lack of preventive measures and adapted responses including low cost interventions within Afghanistan allow for the continued increase in the prevalence of disabilities as well as the increased pressure on the public infrastructures and the raising cost of public policy to cope: health system, education system, employment support and livelihood policies, etc. Families continue to bear the brunt of the financial burden including additional costs resulting from the disability, reduction of living standards and often, social exclusion and stigmatization from the community. The need for an integrated policy approach towards PwDs that encompass prevention, detection, rehabilitation and inclusive based programs will be necessary to reduce and better serve the needs of the disabled.

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Appendix : Disability screening tool

1. Do(es) (name)/you lack part of one or more limb?

- 1 = YES, part of one limb
- 2 = YES, one limb
- 3 = YES, two or more limbs
- 4 = NO

2. Is/are (name)/you partially or totally paralysed?

- 1 = YES, totally paralysed
- 2 = YES, partially paralysed
- 3 = NOT paralysed

3. Is/are (name)/you unable to move part or entire body?

- 1 = YES, unable

2 = YES, a lot of difficulty

3 = YES, some difficulty: move at a slow pace

4 = NO difficulty to move the body at all

4. Do(es) (name)/you any difficulties walking/moving around or climbing steps?

1 = YES, unable

1 = YES, a lot of difficulty

3 = YES, some difficulty: move at a slow pace

4 = NO difficulty to move around or climbing steps

5. Do(es) (name)/you have a part of the body that looks different from the other persons of the family?

1 = YES

2 = NO

6. Does (name)/you have any difficulties seeing even if wearing glasses?

1 = YES, cannot see at all

2 = YES, a lot of difficulty to see, needs glasses

3 = YES, some difficulty to see, needs glasses

4 = NO difficulty to see at all

7. Does (name)/you have any difficulties hearing, even if using a hearing aid?

1 = YES, cannot hear at all

2 = YES, a lot of difficulty to hear, needs a hearing aid

3 = YES, some difficulty to hear, needs a hearing aid

4 = NO difficulty to hear at all

8. Does (name)/you unable to talk, or has difficulties pronouncing words?

1 = YES, cannot talk at all

2 = YES, a lot of difficulty to talk, pronounce words

3 = YES, some difficulty to talk, pronounce words

4 = NO difficulty to talk at all

9. Was (name)/you later than the others beginning to walk?

1 = YES, several years

2 = YES, more than a year

3 = YES, but less than a year

4 = NO

10. Was (name)/you later than the others beginning to talk?

1 = YES, a lot late, more than 5 years

2 = Yes, rather late between 2 and 5 years

3 = Yes, slightly late about 1 year

4 = NOT late at all

11. Does (name) have more difficulty or is slower than others in learning things and needs to be constantly encouraged to do things?

- 1 = YES, cannot learn or with very high difficulty
- 2 = YES, have some difficulty to learn and to do things
- 3 = Little difficulty to learn and to do things
- 4 = NO difficulty to learn and do things at all

12. Do(es) (name)/you have difficulty acting/behaving his/her age or behave much younger than his/her/your age?

- 1 = YES, constantly/ always
- 2 = YES, often/ many times
- 3 = YES, sometimes/few times
- 4 = NO, never

13. Do(es) (name)/you have difficulty in generally understanding what people are telling his/her/you?

- 1 = YES, constantly /always
- 2 = YES, often
- 3 = YES, sometimes
- 4 = NO, never

14. Do(es) (name)/you have difficulty in generally to make himself/herself understood by others?

- 1 = YES, constantly /always
- 2 = YES, often
- 3 = YES, sometimes
- 4 = NO, never

15. Do(es) (name)/you have difficulty concentrating or remembering things?

- 1 = YES, constantly /always
- 2 = YES, often
- 3 = YES, sometimes
- 4 = NO, never

16. Do(es) (name)/you behave in a strange manner?

- 1 = YES, constantly /always
- 2 = YES, often
- 3 = YES, sometimes
- 4 = NO, never

17. Do(es) (name)/you constantly make up (imaginary) stories which are not true?

- 1 = YES, constantly /always
- 2 = YES, often
- 3 = YES, sometimes
- 4 = NO, never

18. Do(es) (name)/you see or hear things that are not there?

- 1 = YES, constantly /always
- 2 = YES, often
- 3 = YES, sometimes
- 4 = NO, never

19. Do(es) (name)/you talk to him/herself/yourself constantly or often ?

- 1 = YES, constantly /always
- 2 = YES, often
- 3 = YES, sometimes
- 4 = NO, never

20. Do(es) (name)/you have difficulty or need assistance taking care of themselves, such as bathing, getting dressed, or going to the toilet?

- 1 = YES, constantly /always
- 2 = YES, often
- 3 = YES, sometimes
- 4 = NO, never

21. Do(es) (name)/you refuse to be with family or other people and prefers to stay alone?

- 1 = YES, constantly /always
- 2 = YES, often
- 3 = YES, sometimes
- 4 = NO, never

22. Do(es) (name)/you become angry and aggressive without reason or fight a lot?

- 1 = YES, constantly /always
- 2 = YES, often
- 3 = YES, sometimes
- 4 = NO, never

23. Do(es) (name)/you have a tendency to physically hurt her/himself/yourself? (like hitting her/ his/your head against the wall, pulling her/his/your hair)

- 1 = YES, constantly /always
- 2 = YES, often
- 3 = YES, sometimes

4 = NO, never

24. Do(es) (name)/you have rapid changes of mood, for instance feel depressed, then happy and then angry?

1 = YES, constantly /always

2 = YES, often

3 = YES, sometimes

4 = NO, never

25. Do(es) (name)/you make the same gestures over and over again such as rocking, biting their arm, swinging their head?

1 = YES, constantly /always

2 = YES, often

3 = YES, sometimes

4 = NO, never

26. Is (name) extremely active and cannot keep still or sit in one place for long?

1 = YES, constantly /always

2 = YES, often

3 = YES, sometimes

4 = NO, never

27. Do(es) (name)/you seem to not care about others or be aware of the feelings of others?

1 = YES, constantly /always

2 = YES, often

3 = YES, sometimes

4 = NO, never

28. Do(es) (name)/you not notice when someone is speaking to them, or not be aware of the presence of others?

1 = YES, constantly /always

2 = YES, often

3 = YES, sometimes

4 = NO, never

29. Do(es) (name)/you scream loudly when they are touched or hear a noise that they/you do not like?

1 = YES, constantly /always

2 = YES, often

3 = YES, sometimes

4 = NO, never

30. Do(es) (name)/you feel afraid for no reason or feel easily scared?

- 1 = YES, constantly /always
- 2 = YES, often
- 3 = YES, sometimes
- 4 = NO, never

31. Do(es) (name)/you have trouble adjusting to change and always want to do things in the same way?

- 1 = YES, constantly /always
- 2 = YES, often
- 3 = YES, sometimes
- 4 = NO, never

32. Do(es) (name)/you have trouble getting along with other people/ children the same age?

- 1 = YES, constantly /always
- 2 = YES, often
- 3 = YES, sometimes
- 4 = NO, never

33. Has (name) fainting in the past 3 months?

- 1 = YES, more than 10 times
- 2 = YES, often, more than 5 times
- 3 = YES, sometimes, 1 to 3 times
- 4 = NO, never

34. Do(es) (name)/you experience sudden jerking of the (parts of) body with loss of consciousness during the last 3 months?

- 1 = YES, more than 10 times
- 2 = YES, often, more than 5 times
- 3 = YES, sometimes, 1 to 3 times
- 4 = NO, never

35. Do(es) (name)/you bite his/her/your tongue or froth at the mouth on occasions in last 3 months?

- 1 = YES, more than 10 times
- 2 = YES, often, more than 5 times
- 3 = YES, sometimes, 1 to 3 times
- 4 = NO, never