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## **Challenges for assessing disability prevalence: the case of Afghanistan**

### **Les défis de la mesure de la prévalence du handicap : le cas de l'Afghanistan**

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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 International Classification of Functioning, Disability and Health of the WHO and the Capability framework, developed by Amartya Sen and others. After a rapid overview of the Afghan context and the process leading to the research programme, it presents the example of the methodology used in the NDSA and the survey protocol. The authors argue that prevalence rates can be measured using different instruments in terms of impairments, activity limitations or in terms of well-being. Thus, the disability experience is measured through a multidimensional approach. The article concludes that whatever the conceptual framework adopted, understanding the situation of persons with disability requires to go beyond measurement of disability prevalence. It implies to look at the links between disability prevalence and the persons' valuable functionings and social agency, in a given environment, using other variables made available by the survey.

Disability, prevalence, capability approach.

Le présent article explore les difficultés méthodologiques de la mesure du taux de prévalence du handicap basée sur une enquête auprès des ménages en utilisant le cadre théorique des « capacités », développé par Amartya Sen et d'autres auteurs à sa suite. Après un examen rapide des différents cadres conceptuels et du contexte dans lequel la recherche a été lancée, cet article présente l'exemple de la méthodologie retenue dans l'enquête nationale sur le handicap en Afghanistan. Les auteurs montrent que la prévalence peut être mesurée au travers de différents instruments sur la base des invalidités, des limitations subies dans les activités et comme mesure du bien-être. Dans ce cas, la mesure de la prévalence du handicap est une approche

multidimensionnelle. L'article conclut que, quel que soit le cadre conceptuel utilisé, la compréhension de la situation des personnes handicapées requiert d'aller au-delà de la simple mesure de la prévalence. Elle implique de tenir compte des liens existant entre l'incidence du handicap, les fonctionnements que valorisent les individus ainsi que leur capacité d'acteur social (agencité), dans un environnement donné et en utilisant pour cela d'autres informations disponibles dans l'enquête.

Handicap, prevalence, approche par les capacités.

## **1. Introduction**

Researchers, policy makers and persons with disability 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 are referred to in this article and used in the National Disability Survey in Afghanistan (NDSA) are the International Classification of Functioning, Disability and Health (ICF) defined by the World Health Organization, and the Capability 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 capability 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. In this paper we consider exclusively calculation of prevalence of disability using ICF and the capability approach. In further papers, we

will demonstrate how empirical variables used in the survey can show possible relationships between disability types or prevalence rates and socio-economic variables<sup>1</sup>.

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 disability as a dynamic phenomenon. 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.

## **2. Disability and the Afghan context**

Since 2001, Afghanistan has been in the process of reconstruction which has been partly jeopardized by the persistence of a conflictual situation, lack of skilled human resources and financial capacity as well as poor infrastructure. As a result, neither political stabilization nor improvement in livelihoods of the population has been achieved. Furthermore, the security situation, already hazardous in 2005 when the

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<sup>1</sup> See also reports on <http://www.handicap-international.fr/dans-le-monde/nos-pays-d'intervention/programmes/afghanistan/afghanistan-understanding-th/index.html>.

NDSA fieldwork was carried out, is now of concern for all implementing agencies countrywide.

The NDSA was the first survey carried out in 2005 in Afghanistan which focused specifically and solely on all characteristics of disability. The decision to undertake a survey was the outcome of an agreement regarding the requirement for reliable data among different stakeholders — line Ministries such as Ministry of Martyrs and Disabled, Ministry of Public Health, Ministry of Labour and Social Affairs, United Nations agencies such as UNOPS, UNDP, UNICEF, Disabled persons organizations (DPOs) and non governmental organizations (NGOs). Actors working in the disability field considered that a gap existed between programmes and public policies on one hand and needs of persons with disability on the other hand (Bakhshi, Dubois and Trani 2004). No relevant, accurate and reliable national data was available regarding the situation of persons with disability in Afghanistan. To date all of the quantitative knowledge was limited to estimation data of prevalence. For instance in 1999 UNDP/UNOPS estimated they were 700,000 Afghans with disability, or 3% of the population (UNDP/UNOPS 1999). In 2003, The Italian Cooperation estimated that 4% of the population, 800,000 people were disabled in Afghanistan (Italian Cooperation 2003). A 2002 survey by the Center for Disease Control and Prevention, the United Nations Children's Emergency Fund, and Vietnam Veterans of America Foundation, in collaboration with the Ministry of Health and the Ministry of Martyrs and Disabled of Afghanistan, and Healthnet International estimated that about 67.7% of Afghans had been affected by mental disorders or psychosocial stress such as depression, anxiety and psychosomatic problems (Cardozo et al 2004). This last survey targeted Afghans above the age of 15 and was limited to 50 clusters. However, the sample was limited to district level population. At the end of 2005, the UNDP

National Policy for Action on Disability (NPAD) and the Ministry of Martyrs and Disabled still indicated that the estimated number of persons with disability range from 80,000 to 2 million of the total estimated 25 million Afghans (MMD/UNDP 2005). This was the latest of many other estimates.

Thus, the limited body of work that did exist consisted mostly of qualitative experiences (Turmusani 2004; Miles 1990); very small scale studies limited to a region and children in school (Civic Voluntary Group 2003); limited to a certain subject, the social perception of disability (Thakkar, Cerveau, and Davin 2004); or limited on both aspects, geographic coverage and subject for the survey on mental distress in Afghanistan (Scholte et al. 2004). Whenever disability was included in a quantitative national household survey, it was not the main focus. As a result questions relating to disability consisted in one or two queries aimed mostly at defining categories of persons with disability within more general surveys (Vulnerability Analysis and Mapping Unit of the World Food Programme et al. 2004; UNICEF et al. 2003). The surveys and research that addressed the situation of persons with disabilities in Afghanistan provide few figures. Among youth, the 2003 Italian Cooperation survey in 65 schools showed that congenital disability accounted for over 30% of overall causes of disability (GVC 2003). The National Risk and Vulnerability Assessment estimated the rate of persons with disability in Afghanistan at 2% for physical disability and 1% for mental disability, and 17% of the sample stated that they shared their home with at least one person who was physically or mentally disabled (Vulnerability Analysis and Mapping Unit of the World Food Programme et al. 2004).

Comparison of prevalence rates among various countries show a high level of variability (see Table 1 below). These variations are due to different approaches of



surveying the disabled population. A number of surveys, as well as disability data included in some census and surveys around the world, have shown a wide range of prevalence rates that vary from 20% (1996 Survey Statistics, New Zealand, Disability Counts, 1998) to 0.6% in Lao PDR (1996) or 1.6% for Cambodia in a 1999 survey. More recently the last Indian Census carried out in 2001, established the national prevalence rate at 2%. The rate of severe disability measured in Afghanistan is of 2.7%. The literature explains these differences in prevalence rates by many factors:

- objectives of the data collection (UN 1990, 2001) and definition of disability and choice of the conceptual framework (Mont 2007; Altman 2001; Me and Bogoni 2006);
- instrument of measurement used and types of questions: impairment based questions or activity based questions (Mbogoni 2003);
- technics of measurement: wording of questions (UN 2001), administration mode of questions, use of self or proxy respondent (Moore 1988; Hess et al. 2001; Hendershot 2004), etc.
- and quality of the survey process such as the training of data collectors (Black 2004) determining largely the way questions are asked (Mathiowetz 2001), supervision of the fieldwork, etc.

**Table 1:** Rate of Prevalence for countries in Asia Pacific Region

<b>Countries</b>	<b>Source</b>	<b>Rate of Prevalence</b>
Afghanistan	2005 NDSA	2.7%
Bangladesh	1987 Demographic Sample Survey	1.0%
Cambodia	1999 Survey <sup>2</sup>	1.6%

<sup>2</sup> Wei Liu, Statistics Division UNESCAP. *Improving National Statistical Systems for Disability information in the Asia-Pacific Area*. Presentation at Regional Workshop on Comprehensive National Plan of Action on Disability, Bangkok, Thailand, October 19 – 21, 2005.

Lao PDR	1996 Survey <sup>3</sup>	0.6%
India	2001 Census <sup>4</sup>	2.0%
Iran	Welfare Organization <sup>5</sup>	2.3%
Nepal	1999-2000 Survey <sup>6</sup>	1.6%
Pakistan	1998 Census <sup>7</sup>	2.5%
Australia	1998 Survey	19.3%
New-Zeland	2001 Survey	19.5%

The NDSA was undertaken by Handicap International on behalf of the Government of Afghanistan and supported by a number of donors interested in obtaining reliable information that could help the government and relevant stakeholders to commit limited resources adequately by specifically addressing the needs of persons with disability throughout the country.

The NDSA, whilst looking at the interaction between impairment and social context, looked at the disabling factors from the individual perspective, providing insights on the living conditions of persons with difficulties and making recommendations that are rights and entitlement based. Furthermore, following the capability approach, this survey aimed to identify assets that are perceived as available and useful as well as the needs of persons with disability in order to reorient existing resources to be more effective and make recommendations for further development. Finally, the NDSA looked at the individual within the community, according to an inclusive approach, believing that wherever this is plausible, and keeping in mind the paucity of public infrastructures and services, the best option remains to propose solutions that maintain the links with the family, community and society at large. The main objectives of the NDSA were:

<sup>3</sup> Ibid.

<sup>4</sup> <http://disabilityindia.org/mod1.cfm> Accessed January 2004.

<sup>5</sup> Welfare Organization Office for Preventing Disabilities "Iran Daily" Newspaper, October 16<sup>th</sup> 2005. <http://www.iran/daily.com/1384/2402/html/panorama.htm> Accessed: 6 December 2005.

<sup>6</sup> UNICEF National Planning Commission and New Era Report. *A Situation Analysis of Disability in Nepal*. February 2001.

<sup>7</sup> Statistics Division, Ministry of Economics and Statistics, Pakistan.

[http://www.statpak.gov.pk/depts/pco/statistics/demographic\\_indicators98/demographic\\_indicators.html](http://www.statpak.gov.pk/depts/pco/statistics/demographic_indicators98/demographic_indicators.html). Accessed December 6, 2005

- To measure prevalence of disability by type of disability.
- To provide insight into the needs and opportunities of persons with disabilities in Afghanistan. These include rehabilitation needs, education needs, employment needs, vocational training, social integration and political participation.
- To identify barriers, difficulties and stigmatization that persons with disabilities face in everyday life, structural environmental constraints that are considered using Sen' capability approach (Sen 1999).
- To provide strategic guidelines to overcome main difficulties faced by person with disability and foster a national disability strategy based on mainstreaming, inclusion, participation principles.

Gathering the data on the field to provide useful information necessitated tools and methods based on a clear understanding of the socio-cultural construction of disability in the Afghan context.

### **3. The NDSA methodology**

The NDSA was commissioned in view of the void that exists between the overall aims that had been defined by the government of Afghanistan and the lack of policies and programmes to achieve these. This void could, for a great part, be explained by the absence of relevant knowledge regarding the field realities as they stood, with regard to the needs, aspirations and the living conditions of vulnerable groups in general, persons with disabilities in particular.

In this article we look at the difficulties that often separate academic and somewhat 'idealistic' definitions and the operationalization of these definitions (Me and

Mbogoni 2006; Mbogoni 2003; Altman 2001). How to move from a theoretical and philosophical consideration to a methodology that will serve as the basis for collecting data? How do we look at the disability picture in Afghanistan through a capability lens according to the theory of Sen?

### ***3.1 Definition, identification of disability and assessment of the level of ability/inability***

The definition of disability used in the screening tool<sup>8</sup> (as well in the other modules) to identify disabling situations in the NDSA encompasses several conceptual frameworks. Developed countries often show higher prevalence rates for disability than developing countries, and the data from the NDSA does not contradict this fact. This “low” prevalence can be explained by several factors. First of all, the goals determined by stakeholders were to identify persons with ‘severe disability’, in order to prioritise them in provision of adequate services and to ensure inclusion within public policy, currently in the process of being defined. These goals are inevitably different in developed countries, where the response capacity of services and public policies is far less limited with regards to resources, funding etc. The decision to include (and thus to exclude) certain forms of disability is closely linked to diverse aspects of policies that are being implemented. This impacts on non-physical types of problems such as dyslexia or hemophilia, which are considered as disabilities in “developed” countries. It is also partly justified 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 culture but also depending on the level of awareness and visibility of different types of disability (Me and Mbogoni 2006). As a result, some surveys find

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<sup>8</sup> The measurement instrument used in the NDSA which is presented extensively below.

very high prevalence rates since they include various forms of chronic illness in the definition of disability. In Afghanistan, some of these disorders, considered as part of the disability experience in some countries, do not prevent the person from functioning in his/her environment. The main example is the situation of persons with mental distress, anxiety and depression due to the war situation which results in mild mental impairment but which does not represent major impediment to functioning in Afghan environment.

The frameworks used in the NDSA screening tool, a combination of the WHO International Classification of Functioning, Disability and Health (WHO 2001) and the capability approach include impairments, but also limitation in activities and participation of individuals in order to understand the disabling experience. This does however narrow the definition used in this context.

The capabilities framework offers a general theoretical framework for disability studies that encompasses the social model of disability (Bakhshi and Trani 2006c; Burchardt 2004; Mitra 2003). This approach places the definition of disabilities within the wider spectrum of human development and enhancing freedoms. The view held in the screening tool is based on functionings, which are states of being or activities (Burchardt 2004:738). The screening tool is a measure of the limitations of the basic capability set, resulting from an impairment. It looks at the whole set of combinations of key functionings and measures what a given individual is able to achieve: “A functioning is an achievement of a person: what she or he manages to do or be. It reflects, as it were, a part of the ‘state’ of that person” (Sen 1985:10). Amartya Sen’s capability 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). Achieving a functioning depends on a range of personal (gender, age, health state) and social factors (for instance access to medical services or to the education system, prejudice in the society...). Both are examined and questioned in the Afghan context using the other modules of the questionnaire (see section 3.2 below) as their combination leads to the disabling situation. Thus, the NDSA assesses the opportunities a person, with or without disability, has to be or to do a range of things. If we consider that these beings and doings are the ones, as Sen says that an individual values and has reason to value (1999) to reach a state of well-being, then we shift the focus from the specificities of the disabling situation, to how to look at establishing equality in terms of possibilities and choices.

A similar approach can be found in the disability creation process framework constructed on accomplishment of life habits that are valorised by a given individual in her/his environment (Fougeyrollas, Cloutier, Bergeron, Côté, St Michel 1998). The fact, for instance, that each individual is asked in the health questionnaire to assess the level of difficulties faced on each dimension helps assess the situation in a comprehensive manner and confirm the validity of the screening instrument. 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, Trani, Rolland 2006a). In our survey, the conditions that prevent an individual from taking part in all spheres of life were taken into account in all the

modules of the questionnaire by asking questions about existing resources, for instance: “What kind of health services are available for you?”, as well as questions based on choices made, for instance “What kind of health services are more useful for you?”.

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, which includes concerns about structural constraints by the socio-economic environment (lack of resources, absence of public services, but also social exclusion...);
- 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 keeps in mind the aims of the survey draws on the capability framework and relates to 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". The disability experience is thus defined in terms of limitation in capabilities.

### **3.2 Survey protocol**

The NDSA is a national household survey carried out from December 2004 to July 2005. It is a probability proportional to size (PPS), three stage random sample survey according to the administrative organization of Afghanistan in 34 provinces, 397 districts and 32,000 villages in 2004. The first stage of sampling was the district. Two sources of population data were used to define the district population frame. For the 30 provinces where the 2003-2004 population pre-census figures were available, districts were ordered and the number randomly selected according to the population size. For the remaining four provinces, which were not covered by the pre-census due to security issues, the Central Statistics Office projections for 2003-2004 of the 1979 census were used. The districts were selected following the same method as for the others. As a result we had 175 districts throughout the country, in all 34 provinces.

The sample size of 5250 households allows for estimation of a disability rate that is 8% or greater with 95% confidence and 15% precision when considering a design effect of 2. In the case that the disability rate is lower than expected, the planned sample size will allow for estimation with 20% precision and 95% confidence.

The second stage of sampling located the village or section of town. All sections of towns and villages in a district were listed and then one (or more if there were multiple clusters within the district) was randomly selected.

At the third stage of sampling, a constant number of 30 households per cluster were randomly selected for a total of 5250. In order to do this appropriately we proceeded in the following manner:



- The survey team proceeds to the center of the cluster indicated by the Mullah or another authority in the cluster.
- The team chooses a direction by spinning the pointer.
- They number the houses from 1-30 in that direction in chalk. One household between 1 and 30 is randomly selected: this is the first household where the interview is carried out.
- That first household, and the nearest 29 are selected for interview.
- The next 29 households of the cluster are chosen using the “nearest front door” method. When no one is home, the next closest house is chosen.
- All the persons with disability older than 4 years old are interviewed with modules 3 to 20 for adults or modules 3 to 7<sup>9</sup> for children under 15.

The detection of persons with disability was done through a screening questionnaire that comprised of 27 questions and different sections relating to physical and mental disabilities. The head of household answers the screening questions (module 2) regarding all the members of his household and the family questionnaire (module 1). The screening tool could not be person-based because of the time constraint for the overall interview, even if it is supposedly better for identification of persons with disability (Me and Mbogoni, 2007; Hess, Rothgeb, Moore, Pascale and Keeley, 2001). Security conditions and availability of respondents do not allow for two long interviews. Moreover, the average size of households of 8 persons made it difficult to

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<sup>9</sup> The modules for persons above 14 are the following: health conditions and accessibility to existing services (module 3); education (module 4); activity and inactivity (module 5); main employment (module 6); secondary employment (module 7); duration of activity (module 8); employment seeking and unemployment (module 9); income (module 10); livelihoods (module 11); self perception (module 12 and 16); awareness measurement (module 13 and 17); marriage (module 14 and 18); social participation (module 15 and 19); final question about self perception as being disabled, causes of impairment, nutrition (module 20). Modules 12 to 19 are different for men and women. Modules for children are livelihood (module 3); health (module 4); education (module 5); activity and inactivity (module 6); future prospects (module 7); social participation (module 8); final questions (module 9). The complete questionnaire is available in Bakhshi et al., 2006a.

screen individually. All interviews were carried out in Dari or Pashtu with translated questionnaires (Bakhshi et al. 2006a).

Each question refers to the term ‘difficulty’ or ‘ability to do’, avoiding stigma and negative stereotypes. We made the choice, as a number of other surveys that have been carried out, to use the term “difficulty” or *mushkel* in Dari. This term is less threatening and constitutes less of a ‘label’ for the persons concerned, thus making the reference to disability easier.

The training of master trainers and monitors as well as the surveyors was more than a month long and carried out by a number of persons working in the field in Afghanistan. The surveyors were trained to explain the aims and objectives of the survey to the village leaders as well as in the household. Special emphasis was given to the fact that the survey team needed the help of the people to gather information.

In order to understand the living conditions and coping strategies of persons with disability, a control group was interviewed. This allowed comparison between the capabilities of persons with disability and those who were considered less vulnerable. Thus, we determine whether a given problem was specifically linked to disability, or whether the family or the community as a whole shared this problem. Two sub-groups of persons without disability were interviewed for comparison of living conditions. The first one comprised of persons without disability within the household of a person with disability matching her/him in terms of sex and age. A number of rules were elaborated in order to find the most appropriate “match” within the household, the sex variable being the most essential since gender differences are the most salient in a context like Afghanistan. Interviewing the in-household match permitted to compare the situation of a person with disability and one without disability within the same household.

The second sub-group comprised of persons without disability living in households where no person with disability lives. Therefore, one can compare the situation of a person with disability with one without disability and from a “non-disabled” family. This control person was randomly selected among persons aged more than age 4 within every fifth household where there is no person with disability. This allowed a comparison at the individual level but also at the household level to see how disability impacts the family as a functioning entity. The total sample of respondents to module 3 (health) onwards is 2696.

### **3.3 Measuring impairment and disability**

With the capability perspective, the NDSA measurement instrument was designed to screen for activity limitations presumably linked to some kind of impairment and to focus on functionings, the doings and beings that persons achieve. The rest of the questionnaire looked at disability considered as the capability set, the real opportunities a person has to do or be (Sen 1985, 1992, 1999; Burchardt 2004; Mitra 2003), and it was a tool for seizing constraints which persons with disability face in their environment that non-disabled do not face, thus measuring inequality in terms of lack of capabilities and of well-being. Once this was assessed, public policy could then aim at increasing the capabilities of persons with disabilities by removing the identified constraints, modifying the environment and thus expanding choices and freedoms of the most vulnerable (Bakhshi and Trani 2006c).

#### **The Screening Tool: Identifying limitations in functionings**

The NDSA utilised a screening tool to assess impairments and functioning limitations. Once this assessment was made, in depth interviews were carried out with

a sample of individuals identified with the screening tool as being impaired or having functioning limitations as well as with the matches and the controls, for comparisons.

As explained above, the NDSA survey was based on a definition of disability that focused on activities and participation, concentrating on the functionings of the individual. This definition was translated into a screening tool of 27 questions identifying different types of functioning limitations as well as conditions that impeded participation in the family and community life. This screening tool consisted of five sections relating to specific aspects of physical, sensory, psychological and mental impairments. The questions were directed to the head of each household surveyed or to the person present who knew most about the household (see Table 2). According to this procedure, a person was considered to be disabled if the respondent had at least one positive answer to the physical and sensory 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 conditions of epilepsy and seizures (Section E<sup>10</sup>). 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/sensory 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 which looked at their situation in terms of health, education, employment, livelihoods and social status participation. The answers in the screening questionnaires were however cross-checked wherever possible with the 13 possible categories identified by the surveyor him/herself in the checklist.

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<sup>10</sup> The specificity of epilepsy and other forms of seizure is common to other countries in the region. See Ventevogel (2005) and Aziz, H., Ali S.M. , Frances P. , Khan, M.I., & Hasan, K.Z. (1994).

**Table 2:** Set of questions in the screening tool of the NDSA

<p><b>Section A: Physical and Sensory Difficulties</b> Does any member of your family lack part of one or more limbs? Is any member of your family partially or totally paralysed/ unable to move part or entire body or have problems moving around? Does any member of your family have a part of the body that looks different from the other persons of the family? Is any member of your family blind, or has difficulties seeing? Is any member of your family deaf, or has difficulties hearing? Is any member of your family unable to, or has difficulties pronouncing words?</p> <p><b>Section B: Intellectual and Learning Difficulties</b> Did any member of your family begin to walk later than the others ? Did any member of your family begin to talk later than the others ? Is any member of your family considerably slower than the others in learning things and needs to be constantly encouraged to do them? Does any member of your family behave differently to others or behave much younger than his/her age?</p> <p><b>Section C: Behavioural and Psychological Difficulties</b> Is anyone in the family “asabi”? Does any member of your family constantly make up imaginary stories, which are not true? Does any member of your family see or hear things that are not there? Does any member of your family talk to him/herself constantly? Does any member of your family have difficulty taking care of him/herself? Does any member of your family refuse to be with family or people and remains Does any member of your family become angry and aggressive without any adequate reason? Does any member of your family have a tendency to physically hurt him/herself?</p> <p><b>Section D: Communication and Social Functioning Difficulties</b> Does any member of your family make the same gesture over and over again (rocking, biting their arm, hitting their head)? Is any member of your family extremely active and cannot sit in one place ? Does any member of your family seem to not care at all, not be aware of the feelings of others? Does any member of your family not notice when someone is speaking to him/her, not be aware of the presence of others? Does any member of your family scream loudly when they are touched or hear a noise that they do not like? Does any member of your family have trouble adjusting to change and always want to do things in the same way?</p> <p><b>Section E: Fits and Seizures</b> Does any member of the family have “Mirgi” ? Does any member of your family have sudden jerking of the parts of the body with loss of consciousness? Does any member of your family bite his/her tongue often, froth at the mouth?</p>
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Source: NDSA

Lastly, all the questions of the screening process referred to the term ‘difficulty’, avoiding stigma and negative stereotypes. The NDSA made the 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. Finally, using this term allowed easier comparison between those who had a “difficulty” and those who did not. While the screening tool identifies functioning limitations, the health module assesses these limitations in more detail and allows for a multidimensional approach for evaluating living conditions alongside the other modules of questionnaire.

### **The Health Module: A multidimensional approach**

The health module of the survey comprised of a set of 46 questions in nine dimensions of functionings (see Table 3 below). It allowed a more in-depth assessment of the interrelation between the individual and her/his environment. It focussed on the functioning of a given individual in a variety of 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 consisted of a set of items that helped establish a score on the given dimension. Some of these items were similar to those suggested by the Washington Group on Disability Statistics (WG)<sup>11</sup>.

**Table 3:** Set of questions in the health module according to the 9 dimensions

1. The ability to take care of oneself on a day-to-day basis. Are you able to do the following for yourself without assistance or equipment?
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<sup>11</sup> For more details about the set of questions developed by the WG, the reader is referred to [www.cdc.gov/nchs/citygroup.htm](http://www.cdc.gov/nchs/citygroup.htm).

bathing/ablutions  
getting dressed  
preparing meals for yourself  
going to the toilet  
eating/drinking  
moving around

2. The ability to contribute to tasks within the household.

Are you able to do the following inside the house/compound without assistance or equipment?

sweeping, cleaning the house  
cooking meals for everyone  
washing dishes  
looking after younger children  
looking after elder members  
doing the laundry

3. The ability to move around and contribute to tasks outside the house.

Are you able to do the following outside the house/compound ?

climb stairs  
go to the bazar/shop on your own  
carry heavy things (e. g. fetching water...)  
work in the field  
ride a bicycle/or animal

4. The ability to communicate with other members of the family and the community. (Do you have any difficulty in?)

Finding the way to express what you need  
talking easily to other men/other women  
understanding what people say  
making yourself understood  
hearing clearly someone calling you in the house  
seeing clearly someone in front of you

5. The ability to interact and have social relations with people. (Do you have any difficulty in?)

Feeling comfortable with people  
Feeling scared when going out of the house;  
Feeling comfortable when going out of the house because people stare at you;  
Showing verbally violent behaviour towards others;  
Showing physically violent behaviour towards others.

6. Intellectual and memorization abilities. (Do you have any difficulty in?)

Concentrating on more than one thing at a time;  
Learning new things easily;  
Remembering things.

7. The ability to have socially acceptable individual behaviour. (Do you have any difficulty in?)

Keeping calm and staying still in one place;  
Having repetitive, stereotyped movements;  
Showing violent behaviour towards oneself;  
Fainting or passing outkeeping calm, staying in one place

8. The absence of depressive symptoms and signs of trauma, anxiety and other psychological problems. (Do you have any difficulty in?)

Wanting to stay locked up inside the house;  
Feeling sad/crying without any particular reason;  
Not feeling hungry for long periods of time;  
Feeling afraid for no reason;  
Sitting and thinking for long periods of time;  
Wanting to live somewhere else, away from the family;  
Having rapid changes of mood;  
Feeling oppressed for no particular reason;  
Feeling suffocated for no particular reason;  
Feeling angry and resentful for no particular reason.

9. The absence of fits, seizures and signs of epilepsy. (In the past 6 months have you experienced the following?)

fits/epilepsy  
fainting or passing out

Source: NDSA

The first three dimensions (autonomy for daily functioning, contribution to housework, contribution to work outside the house) were assessed through three possible answers for each item:

- 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 focused specifically on the health situation in terms of ability and difficulty to function in everyday life. Various aspects of everyday life, both within the house, within the family and in the community were



analysed. The first set of questions concerned abilities related to self-care and autonomy, the ability to perform a series of simple everyday life acts, such as bathing or getting dressed, drinking or eating, or moving around. A second set of questions were related to abilities in terms of everyday contributions to household running; these questions were asked only to children over 8 years of age. Questions regarding the capacity to perform household tasks such as preparing a meal for the family, sweeping, and taking care of children or elders were only asked to women<sup>12</sup>. The third set of questions pertained to the tasks carried out outside the compound. These are a major benchmark for identification of a high or low capability to function in the community and to further contribute to the running of the family. These tasks included the ability to move outside the household and the compound, climb stairs, go to the bazaar, carry heavy things, work in the field, and ride a bicycle or an animal. The items related to tasks within the house were primarily within the domain of women; work outside was predominantly carried out by boys and men. The gender factor contributes greatly to the understanding of the results presented in this paper.

The remaining dimensions were calculated according to items that allowed two possible answers, ability or absence of ability. The pilot survey showed that three discrete response categories created considerable trouble in comprehension for a majority of respondents. Dimension four was related to communication ability within family and the community: the ability of delivering and receiving messages and information, of understanding others and making oneself understood. Dimension five was different and more complex than the previous one. It dealt with the ability to socialize with other people, therefore closely linked to social acceptability and social integration of the individual. The sixth dimension was related to concentration,

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<sup>12</sup> The pilot survey showed that, in the Afghan culture, adult men barely participate to household chores. The second set of questions was not ask to them to avoid underreport due not to limitations in functionalities but to confusion between effective difficulty and the fact that they do not take part.

remembering things and learning new things. It compiled intellectual abilities that were necessary in order to function on a daily basis and within a family and a community. Dimension seven consisted of individual behaviour. It referred to the ability that the person has to have a calm and coherent attitude towards oneself. This dimension included items assessing violence that could 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, and seclusion within the home because the person is believed incapable to “behave” in a manner considered adequate and coherent by others. Dimension eight (depression, trauma, anxiety) is probably the component of mental health that has been addressed most extensively within the Afghan context (Cardozo et al. 2004; Ventevogel, Nassery, Azimi, Faiz 2006; Ventevogel 2005). In view of the history and the recent conflicts, it is believed that a very large number of persons in the country are affected by various forms of depression, anxiety and Post Traumatic Stress Disorder (PTSD). The NDSA tried to address this dimension through ten different items that included various signs of depression and related problems. Our findings do not propose a “diagnosis” but try to bring into light the extent of the 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: epilepsy signs and seizures.

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 or even two points seemed to be more adapted. For comparability 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 or two possible responses offering clear choices, and therefore reducing the risk of misinterpretation and misunderstanding. 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 person faces on the given dimension.

It is essential to state 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 reliably measure the same underlying concept of well-being according to various individuals. Different individuals, due to ethnic, socio-economic or demographic background did not have the same end-points, low and high, on an underlying scale of degrees of well-being, nor did they have similar cut-points between meaningful levels along that scale in the Afghan context. Other studies have shown that response category cut-points are different across socio-economic groups within a country (Murray, Tandon, Salomon and Mathers 2001) and between countries (Sadana, Mathers, Lopez, Murray, Iburg 2000). In the Afghan culture, median score is often considered as the right choice. A second intricacy deals

with the distance between two positions. In the context of our survey, it cannot be assumed that respondents perceived the difference between adjacent levels as equidistant. On a five point scale, the difference between mild and moderate difficulty was considered closer than between moderate and severe or severe and complete. Lastly, it was believed that if one position in the scale was perceived as being more in line with social norms and expectations, there was a tendency to choose it over the others. This was however 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 for a clear and dependable analysis.

#### **4. Results of the NDSA: Prevalence Variability**

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

Following this approach, one can re-define the level of prevalence of disability in Afghanistan. The results presented in this paper look at prevalence of disability according to two instruments stated in the previous sections: the 27 screening tool questions and the health module consisting of 46 questions.

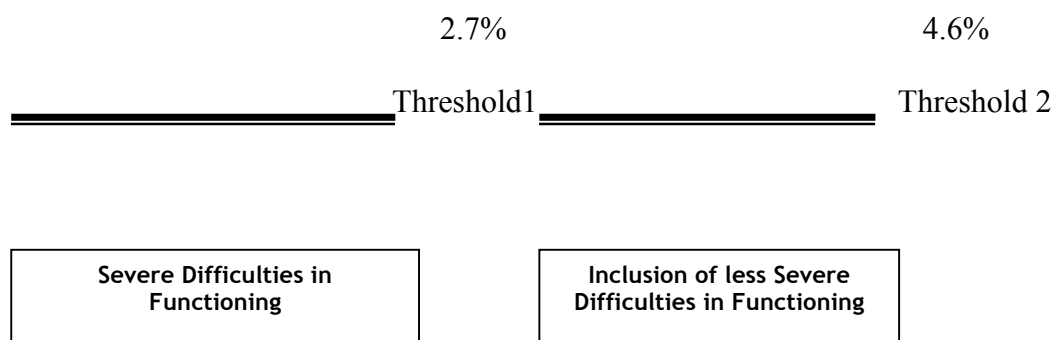
The screening tool focuses on the first two domains mentioned above and focuses on high level of functionings limitations: lack of functionings or complete inability in body functions (vision, hearing, and paralysis), body structures, and basic activities.

The health questionnaire looks more broadly at all four domains thus including a larger proportion of the Afghan population. It is a multidimensional approach that comprehensively analyses the disability experience in Afghanistan. This second instrument also validates the findings of the screening tool. All individuals identified with severe functionings limitations through the screening questions have at least some level of difficulty in the corresponding dimension of the health set of questions.

#### 4.1 Measurement of prevalence rates

The prevalence of persons with severe disability identified by the NDSA using the screening tool stands at 2.7% (95% confidence interval (CI): 2.5% and 2.9%). This rate is based on an identification of functioning limitations due to physical, sensory, intellectual disability, mental illness and psychological distress. Considering the priorities defined by stakeholders, 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 as and when more persons with less severe difficulties are targeted through broader inclusion.

**Figure 1.** Prevalence threshold with regard to the screening questionnaire



It is believed that a large number of Afghans indicate having high levels of mental distress (for example anxiety, depression, trauma, stress). A few studies have looked at this issue in particular for the overall population (Rasekh, Bauer, Manos, Iacopino 1998; Cardozo and al. 2004; Scholte et al. 2004; Ventevogel et al. 2002). A wider approach to 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%), which 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 Ventevogel (2005) with regard to 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.

Table 4 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% and 4.6% prevalence rate reported above, including or not including mental distress. Multiple physical impairments are included in the broad “physical disability” category when the two impairments are both physical. The same was done for multiple sensory disabilities, which were included in the overall sensory disability category. Associated disabilities category includes more than one type of disability such as sensory, physical, mental, and epilepsy. A striking result is the finding that 0.56% of the population reports some form of epilepsy. This figure does confirm other studies in the region, such as in rural Pakistan where high prevalence figures for epilepsy (1%) were found (Aziz et al. 1994). Women are over-represented in this category, and one plausible explanation is

that signs are more easily detected in women due to cultural acceptance and identification.

The distribution of disability (without taking into account mental distress), indicates that the majority of Afghans with disability have physical impairments (36.5%). There is a significant over-representation of men (58.9%) among persons with disability in Afghanistan, especially among the physical and sensory categories. This can partially be explained by the higher number of war-survivors among men who were wounded during the conflicts. Sensory impairment also affects a considerable section of persons with disability in Afghanistan (25.5%). Other forms of disability affect 28.5% of all persons with disability. Associated disabilities, physical and/or sensory and mental together represent 9.4% of the sample.

The major danger, focusing on the 4.6% prevalence is that this increases 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 Afghan society, do not constitute a priority for implementation of public policies such as education, health or employment support for the time being. Nevertheless, the choice to include mental distress would lead to a different typology of disability in Afghanistan. By 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 health issues. However, the probability of having high levels of mental distress has been underlined by previous studies and cannot be undermined, even if they require very specific responses in terms of policy (Scholte W.F. et al. 2004).

**Table 4:** Prevalence rates (in %) and distribution of the population by types of disability including (or not) mental distress identified in the screening tool (N=38320)

Types of Disabilities	Prevalence Rate	Distribution		Gender Distribution	
		without mental distress	with mental distress	Male	Female
Physical Disability	0.99% [0.89-1.09]	36.5	21.6	72.6	27.4
Sensory Disability	0.69% [0.61-0.77]	25.5	15.0	63.3 <sup>**</sup> (1)	36.7 <sup>**</sup> (1)
Mental Disability	0.26% [0.21-0.31]	9.8	5.8	58.8	41.2
Associated Disabilities	0.26% [0.21-0.31]	9.4	5.6	55.1	44.9
Epilepsy /Other Forms of Seizure	0.51% [0.44-0.58]	18.8	11.1	28.2 <sup>**</sup> (1)	71.8 <sup>**</sup> (1)
Mental Distress	1.88% [1.74-2.01]	NA	40.9	58.9	41.1
Non-Disabled	95.41% [95.20-95.63]			50.7	49.3

Source: NDSA. (1) <sup>\*\*</sup> Test of comparison of proportion between males and females.

Significant at  $p < 0.01$ .

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 are affected by 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. The requirements are different and cannot be



understood in terms of access or adaptation of teaching tools but more in terms of sensitisation of teachers and families. Furthermore, we found that mental distress was something familiar and frequent for families and that they had learned to cope with these difficulties during decades of conflict. Ever if this strongly influences well-being, persons more often than not manage to function on a daily basis.

The Afghan population is young, 50.2% is under age 15. Table 5 shows that the majority of persons with disability are also in the 0 to 14 years age group. But, compared to the total age class, the proportion of persons with disability under 15 or even under 20 is lower than the same proportion in the age class above 45. The risk of becoming disabled increases with age and is high after 45 years old, and higher after 60 years old. This was found to be a statistically significant result. A higher number of older people are more likely to become disabled especially if one compares the figures to the age proportion in general population. In the 45 years old and above category, the proportion of people with disability is 22.3% of the total people with disability, when this age category represents only 12.1% of the sample. The gap is of more than 12%. The proportion of persons with disability aged less than 25 in the total disabled population is lower than the proportion of persons under the age of 25 in the population. The gap is higher for the youngest and diminishes with higher age categories. The situation is almost at equilibrium for the 25-34 age category.

**Table 5:** Distribution of the population by types of disability including mental distress identified in the screening tool (N=38320) by age groups

Disability Types	Age in 6 categories					
	0 to 4	5 to 14	15 to 24	25 to 34	35 to 44	45 and above
Physical Disability	5.8	23.5	15.3	13.5	14.5	27.4

Sensory Disability	11.4	28.4	11.7	3.8	8.7	36.0
Mental Disability	9.8	21.6	11.8	15.7	19.6	21.6
Associated Disabilities	3.1	40.8	18.4	10.2	8.2	19.4
Epilepsy/ Seizures	8.2	21.0	14.9	22.6	13.3	20.0
Mental Distress	12.5	32.0	20.5	9.7	9.5	15.7
Total Disabled	9.7	28.3	16.8	11.4	11.4	22.3
Non Disabled	20.7	29.6	18.5	11.0	8.5	11.6
Total Population	20.2	29.6	18.5	11.1	8.6	12.1

Source: NDSA.

This can be explained by a series of reasons. First of all, many disabled children under age 5 die in the first years of life due to lack of adequate health care. Secondly, the probability of acquiring disability increases with age and time as people are more at risk of impairing diseases and poor access to health care, accidents, and social and economic shocks. Lastly, conflict related impairments are more significant in people over 35 years old who were caught up in the two and a half decades of war.

#### **4.2 Prevalence through a multidimensional approach**

As we have extensively stated above, the health questions set can be structured in nine dimensions of well-being taking the capability perspective to consider the disability process. The profile of well-being provides the degrees of difficulties faced on each of the dimensions. For each of the core dimensions, the proportion of persons with disabilities based on four cut-off determined according to the degree of difficulty is calculated (see Table 6 below). Each individual was asked to assess her/his level of difficulty for all the dimensions considered, thus allowing identification of restrictions

in functionings. Once this is done, the prevalence rates by dimension are calculated depending on the number of items. For instance on the first three dimensions:

- “No Difficulty” is defined by the absence of difficulty on any of the items stated;
- “Mild Difficulty” is defined by at least 1 ‘yes, but with difficulty’;
- “Severe Difficulty” is defined by at least 5 ‘yes, but with difficulty’;
- “Very Severe Difficulty” is defined by at least 3 ‘No, I cannot do it’.

**Table 6:** Prevalence rates (in %) considering nine dimensions of well-being (N=2696)

<b>Dimensions of Well-being</b>	<b>Level of Difficulty<sup>(1)</sup></b>			
	<b>D1</b>	<b>D2</b>	<b>D3</b>	<b>D4</b>
Dimension1 Daily Autonomy	90.7	8.3	0.8	0.2
Dimension2 Contribution to Household Work	66.5	15.8	13.2	4.5
Dimension3 Contribution to Work outside House	62.3	16.7	19.8	1.2
Dimension4 Communicating with Family/ Community	92.5	5.6	1.1	0.8
Dimension5 Interacting, Having Social Relations	92.7	6.2	0.9	0.1
Dimension6 Remembering, Memorising	89	5.2	3	2.8
Dimension7 Positive Individual Behaviour	94.1	5.7	0.2	0.1
Dimension8 Signs of Depression/ Anxiety	79	12.8	6.9	1.3
Dimension9 Seizure and epilepsy	99	NA	NA	1

Source NDSA. (1) D1=no difficulty; D2=mild difficulty; D3=severe difficulty; D4=very severe difficulty, unable.

Table 6 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 level of difficulty is consistently observed: the most severe difficulties being in the domain of contributing to household chores (dimension 2: 4.5% of very severe limitations and 13.2% of severe difficulty) and to work in general (dimension 3: 1.2% of very severe limitations and 19.8% of severe difficulty). Very severe problems related to memory (dimension 6) and depression/anxiety (dimension 8) are also observed in Afghanistan. In general, the results on dimensions link to mental distress, anxiety, depression and trauma corroborate other studies carried in Afghanistan (Rasekh et al. 1998; Scholte et al. 2004; Bhutta 2002). Some persons have associate difficulties on various dimensions.

## **Discussion**

The present article examines the challenges of prevalence rate assessment in the case of a cross-sectional population based survey in Afghanistan. Prevalence measurement has to be considered with caution for several reasons. The rate largely depends on the model chosen to define disability and the objectives pursued on one hand, and on the tools, method used to survey, the conditions of interview and the cultural environment on the other. All these factors influence the analysis and must be kept in mind when interpreting the outcomes. Finally, prevalence measurement only offers a limited interest when defining disability policies to improve inclusion, participation and well-being of persons with disability; living conditions need to be considered through a multidimensional perspective. As a result, prevalence rates need to be completed by data collection and analysis directly linked to other issues that are essential for understanding the situation of persons with disability in Afghanistan: access to education, rehabilitation and health facilities, livelihoods, income, social status and

participation. Further research will show the links between profiles of persons with disability according to dimensions of well-being and socio-economic variables.

### **6.1 Advantage of the capability approach to measure well-being**

The capability approach offered one of the most adapted frameworks to meet the goals fixed by the partners 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 participation to community. The capability approach covers the full range of the disability experience, beyond 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 1999: 19)

The well-being profiles can be used 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 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 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.

## **6.2 Beyond prevalence: Grasping the various facets of disability as a political issue**

The present article introduces an innovative way to identify disability based on level of well-being in several dimensions of the human experience, going a step further than the tools based on the ICF by associating the capability framework. But a survey like the NDSA does not aim at “pursuing the elusive single measure for disability” (Altman 2001: 96). Nor does it limit its scope to merely providing prevalence rates which are only thresholds which have to be determined according to priorities of

action. It largely aims at providing evidence-based knowledge for adapted and well-focused public action. The costs of disability 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 leads to the continued increase in impairments as well as the increased pressure on the public infrastructures (health system, education system, employment support and livelihood policies, etc.), and the raising cost of public policy to cope with this. 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 persons with disabilities that encompass prevention, detection, rehabilitation and inclusive based programs will be necessary to reduce and better serve the needs of disabled people according to the choices they themselves make.

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**Table 1:** Rate of Prevalence for countries in Asia Pacific Region

Countries	Source	Rate of Prevalence
Afghanistan	2005 NDSA	2.7%
Bangladesh	1987 Demographic Sample Survey	1.0%
Cambodia	1999 Survey <sup>13</sup>	1.6%
Lao PDR	1996 Survey <sup>14</sup>	0.6%
India	2001 Census <sup>15</sup>	2.0%
Iran	Welfare Organization <sup>16</sup>	2.3%
Nepal	1999-2000 Survey <sup>17</sup>	1.6%
Pakistan	1998 Census <sup>18</sup>	2.5%
Australia	1998 Survey	19.3%
New-Zeland	2001 Survey	19.5%

**Table 2:** Set of questions in the screening tool of the NDSA**Section A:** Physical and Sensory Difficulties

Does any member of your family lack part of one or more limbs?

Is any member of your family partially or totally paralysed/ unable to move part or entire body or have problems moving around?

Does any member of your family have a part of the body that looks different from the other persons of the family?

Is any member of your family blind, or has difficulties seeing?

Is any member of your family deaf, or has difficulties hearing?

Is any member of your family unable to, or has difficulties pronouncing words?

**Section B:** Intellectual and Learning Difficulties

Did any member of your family begin to walk later than the others ?

Did any member of your family begin to talk later than the others ?

Is any member of your family considerably slower than the others in learning things and needs to be constantly encouraged to do them?

Does any member of your family behave differently to others or behave much younger than his/her age?

**Section C:** Behavioural and Psychological Difficulties

Is anyone in the family “asabi”?

Does any member of your family constantly make up imaginary stories, which are not true?

Does any member of your family see or hear things that are not there?

Does any member of your family talk to him/herself constantly?

Does any member of your family have difficulty taking care of him/herself?

<sup>13</sup> Wei Liu, Statistics Division UNESCAP. *Improving National Statistical Systems for Disability information in the Asia-Pacific Area*. Presentation at Regional Workshop on Comprehensive National Plan of Action on Disability, Bangkok, Thailand, October 19 – 21, 2005.

<sup>14</sup> Ibid.

<sup>15</sup> <http://disabilityindia.org/mod1.cfm> Accessed January 2004.

<sup>16</sup> Welfare Organization Office for Preventing Disabilities “Iran Daily” Newspaper, October 16<sup>th</sup> 2005. <http://www.iran/daily.com/1384/2402/html/panorama.htm> Accessed: 6 December 2005.

<sup>17</sup> UNICEF National Planning Commission and New Era Report. *A Situation Analysis of Disability in Nepal*. February 2001.

<sup>18</sup> Statistics Division, Ministry of Economics and Statistics, Pakistan.

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Does any member of your family refuse to be with family or people and remains  
Does any member of your family become angry and aggressive without any adequate reason?  
Does any member of your family have a tendency to physically hurt him/herself?  
**Section D: Communication and Social Functioning Difficulties**  
Does any member of your family make the same gesture over and over again (rocking, biting their arm, hitting their head)?  
Is any member of your family extremely active and cannot sit in one place ?  
Does any member of your family seem to not care at all, not be aware of the feelings of others?  
Does any member of your family not notice when someone is speaking to him/her, not be aware of the presence of others?  
Does any member of your family scream loudly when they are touched or hear a noise that they do not like?  
Does any member of your family have trouble adjusting to change and always want to do things in the same way?  
**Section E: Fits and Seizures**  
Does any member of the family have “Mirgi” ?  
Does any member of your family have sudden jerking of the parts of the body with loss of consciousness?  
Does any member of your family bite his/her tongue often, froth at the mouth?

Source: NDSA

**Table 3:** Set of questions in the health module according to the 9 dimensions

1. The ability to take care of oneself on a day-to-day basis.

Are you able to do the following for yourself without assistance or equipment?  
bathing/ablutions  
getting dressed  
preparing meals for yourself  
going to the toilet  
eating/drinking  
moving around

2. The ability to contribute to tasks within the household.

Are you able to do the following inside the house/compound without assistance or equipment?  
sweeping, cleaning the house  
cooking meals for everyone  
washing dishes  
looking after younger children  
looking after elder members  
doing the laundry

3. The ability to move around and contribute to tasks outside the house.

Are you able to do the following outside the house/compound ?  
climb stairs

go to the bazar/shop on your own  
carry heavy things (e. g. fetching water...)  
work in the field  
ride a bicycle/or animal

4. The ability to communicate with other members of the family and the community. (Do you have any difficulty in?)

Finding the way to express what you need  
talking easily to other men/other women  
understanding what people say  
making yourself understood  
hearing clearly someone calling you in the house  
seeing clearly someone in front of you

5. The ability to interact and have social relations with people. (Do you have any difficulty in?)

Feeling comfortable with people  
Feeling scared when going out of the house;  
Feeling comfortable when going out of the house because people stare at you;  
Showing verbally violent behaviour towards others;  
Showing physically violent behaviour towards others.

6. Intellectual and memorization abilities. (Do you have any difficulty in?)

Concentrating on more than one thing at a time;  
Learning new things easily;  
Remembering things.

7. The ability to have socially acceptable individual behaviour. (Do you have any difficulty in?)

Keeping calm and staying still in one place;  
Having repetitive, stereotyped movements;  
Showing violent behaviour towards oneself;  
Fainting or passing out/keeping calm, staying in one place

8. The absence of depressive symptoms and signs of trauma, anxiety and other psychological problems. (Do you have any difficulty in?)

Wanting to stay locked up inside the house;  
Feeling sad/crying without any particular reason;  
Not feeling hungry for long periods of time;  
Feeling afraid for no reason;  
Sitting and thinking for long periods of time;  
Wanting to live somewhere else, away from the family;  
Having rapid changes of mood;  
Feeling oppressed for no particular reason;  
Feeling suffocated for no particular reason;  
Feeling angry and resentful for no particular reason.

9. The absence of fits, seizures and signs of epilepsy. (In the past 6 months have you experienced the following?)

fits/epilepsy  
fainting or passing out

Source: NDSA

**Table 4:** Prevalence rates (in %) and distribution of the population by types of disability including (or not) mental distress identified in the screening tool (N=38320)

Types of Disabilities	Prevalence Rate	Distribution			
		without mental distress	with mental distress	Male	Female
Physical Disability	0.99% [0.89-1.09]	36.5	21.6	72.6	27.4
Sensory Disability	0.69% [0.61-0.77]	25.5	15.0	63.3 <sup>**</sup> (1)	36.7 <sup>**</sup> (1)
Mental Disability	0.26% [0.21-0.31]	9.8	5.8	58.8	41.2
Associated Disabilities	0.26% [0.21-0.31]	9.4	5.6	55.1	44.9
Epilepsy /Other Forms of Seizure	0.51% [0.44-0.58]	18.8	11.1	28.2 <sup>**</sup> (1)	71.8 <sup>**</sup> (1)
Mental Distress	1.88% [1.74-2.01]	NA	40.9	58.9	41.1
Non-Disabled	95.41% [95.20-95.63]			50.7	49.3

Source: NDSA. (1) \*\* Test of comparison of proportion between males and females significant at 0.01.

**Table 5:** Distribution of the population by types of disability including mental distress identified in the screening tool (N=38320) by age groups

Disability Types	Age in 6 categories					
	0 to 4	5 to 14	15 to 24	25 to 34	35 to 44	45 and above
Physical Disability	5.8	23.5	15.3	13.5	14.5	27.4

Sensory Disability	11.4	28.4	11.7	3.8	8.7	36.0
Mental Disability	9.8	21.6	11.8	15.7	19.6	21.6
Associated Disabilities	3.1	40.8	18.4	10.2	8.2	19.4
Epilepsy/ Seizures	8.2	21.0	14.9	22.6	13.3	20.0
Mental Distress	12.5	32.0	20.5	9.7	9.5	15.7
Total Disabled	9.7	28.3	16.8	11.4	11.4	22.3
Non Disabled	20.7	29.6	18.5	11.0	8.5	11.6
Total Population	20.2	29.6	18.5	11.1	8.6	12.1

Source: NDSA.

**Table 6:** Prevalence rates (in %) considering nine dimensions of well-being (N=2696)

<b>Dimensions of Well-being</b>	<b>Level of Difficulty<sup>(1)</sup></b>			
	<b>D1</b>	<b>D2</b>	<b>D3</b>	<b>D4</b>
Dimension1 Daily Autonomy	90.7	8.3	0.8	0.2
Dimension2 Contribution to Household Work	66.5	15.8	13.2	4.5
Dimension3 Contribution to Work outside House	62.3	16.7	19.8	1.2
Dimension4 Communicating with Family/ Community	92.5	5.6	1.1	0.8
Dimension5 Interacting, Having Social Relations	92.7	6.2	0.9	0.1
Dimension6 Remembering, Memorising	89	5.2	3	2.8
Dimension7 Positive Individual Behaviour	94.1	5.7	0.2	0.1
Dimension8 Signs of Depression/ Anxiety	79	12.8	6.9	1.3
Dimension9 Seizure and epilepsy	99	NA	NA	1

Source NDSA. (1) D1=no difficulty; D2=mild difficulty; D3=severe difficulty; D4=very severe difficulty, unable.



**Figure 1.** Prevalence threshold with regard to the screening questionnaire

