Understanding disability poses a number of challenges that need to be overcome, ranging from a paucity of resources, a lack of reliable data and knowledge, to stigmatization and lack of visibility of persons with disability and policies that have proven to be inefficient when based on setting up separate structures for the persons concerned. Furthermore, existing data on disability is scarce and often lacks comparability between different countries. Surveys and censuses that address this subject, either as the main theme or as a section included in a larger study, use a variety of methods and phrasing of questions that make comparability even more of a challenge. In a developing or transition country, like Afghanistan, where the literacy rates and life expectancy are low and public services inadequate, carrying out a survey on disability becomes even more difficult for various reasons: paucity of trained and qualified surveyors, total lack of awareness regarding disability, existing programs that have been set-up with lack of proper knowledge, expectations of the various actors of what the results of a disability survey should be.

In this article we will present the number of challenges that are unavoidable when carrying out a national survey on disability (1). We will also argue that using the Capability Approach to look at the issues related to disability is one way to respond to the various challenges, be it for the assessment of disability or for the defining of national policies (2). The authors of this article carried out a national survey on disability in Afghanistan: this study will illustrate the points put forward in this paper1. The opportunity to mainstream people with disability is evident and the choice to take or not to take an inclusive approach will have a huge impact on the living conditions of disabled persons in the country.

1. Capability Approach to Disability: a tool for the operationalization of a definition

1 In this context donors and international agencies have expressed a need to make evidence based decisions in order to ensure that relevant and efficient programs are set up and assessed for long term, sustainable effects and outcomes. The current period is particularly relevant. Afghanistan is in a phase of reconstruction, building health and education systems, employment policies and democratic institutions.
1.1 Lack of consensus regarding the definition of disability

The lack of cross-country comparability is an issue that systematically comes up at international conferences or meetings on the subject of disability. This issue is, of course, closely related to what we choose to call disability, how we chose to define it and, as a result, what limitations in functioning we include or exclude in the definition. There are a number of theoretical definitions that have obtained a consensus over the past decades. In general experts use three main frameworks.

For long, the medical and the societal models for defining disability have been presented as having opposite views. The medical view, based on the individual and his/her impairment considers the physical or mental ‘problem’ that a person has. This view, which looks at disability by focusing on the individual, has been considered to be biased by disability activists and organizations. The latter puts forward the argument that persons are ‘disabled’ because of the structure of the society in which they live, which does not accommodate their impairment. Thus it is the environment, physical and social, that makes a person with impairment, a person with disability. This view, which has been put forward by a number of disabled persons’ organizations, looks 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. Mainstreaming disability concerns is a progressive and sustainable way of re-designing society in order to include persons with disability.

Combining the two previous models, the World Health Organization (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 lives. “In 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.” (World Health Organization (2001)).

This definition and listing of disabilities present certain limitations. First of all it focuses on the body, individual limitations and participation and does not stress the interaction between individual and society in the definition of disability, thus does not offer a broader perspective for defining policies. Even though the ICF is now widely accepted, there persists an idea of defining a list within which persons with certain limitations are included.
or excluded. There is a need however to view the entire scale, the degrees of functioning, which are more gradual, in relation to the cultural context that is in focus. It is the social parameters that determine when and if a given limitation in functioning becomes a disability. This is very clear when we take cases of limitations of functioning such as dyslexia or diabetes. It is the social structure as well as the access to education and to health care that will determine whether this will constitute a disability. In a developed country, it is clear that these will have a high probability of being considered as milder forms of disability whereas in a developing country, in remote rural areas where the state services are close to non-existent, these problems will hardly be noticed. In the same way, the question of including chronic illness within the definition of disability arises only in a social setting where there is health care and the possibility of making a diagnosis, and, as a consequence, where there are solutions that are available.

All this clearly shows that whether a given impairment will lead to a disability and under what circumstances, is very closely related to the social and political context. Any attempt to standardize and propose a given ‘list’ of disabilities is bound to be limited and not sensitive to social and cultural variations.

1.2. Lack of standardization of methods and the over-focalization on the prevalence rate of disability

The focus on the rate of prevalence is directly linked to the concern of certain stakeholders to give exaggerated importance to one figure over analysis and in depth research. This is also linked to the belief that there is a given set of criteria for determining whether a person is disabled or not, and that this list is relatively stable over time and across countries. As a result there are comparisons of rates of prevalence across countries and cultures. This is further motivated by the belief that high numbers will provide more justification for the attribution of resources and funds and more means towards tackling the problems. Yet, donors cannot establish a disability strategy and define the scope of the measures for a given developing country based solely on a fluctuating prevalence rate. Furthermore, public actors need in depth analysis about livelihood, health and education situation, employment and social status among other concerns to define public policies. The
success of public action depends on the accuracy of the knowledge available and of the analysis of the situation.

The paradox of the prevalence rate is that the more a given country is sensitized to the issues linked with disability, equipped to take action and willing to improve the lives of persons with disability, the better the health and other state services, the higher the rate of prevalence because of longer life expectancy for persons with disability, early detection, better detection of problems that are less visible and more difficult to take into account.

Prevalence rates are also a reflection of the sensitivity of a given country to disability. Developed countries often show high prevalence rates for disability. This is partly explained, as we have stated, by the inclusion of various forms of disability in surveys and studies, 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 function 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. The prevalence rate is influenced by what we chose to call disability but also by a number of other factors.

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 internationally there have been attempts to set a standard for prevalence rates, which have so far been unsuccessful. In 1981 UN/WHO studies estimated that on an average 10% of national populations are disabled. However in 1992, this estimate was modified to 4% for developing countries and 7% for industrialized countries. 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%. If anything, this shows a variety of approaches and definitions of disability, as well as a wide range of survey techniques and tools, which make comparability a serious challenge.

The differences in rates of prevalence can also be influenced by the manner in which questions are asked. Mitra (2003) states 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” (p. 8). The author goes on to illustrate this point with the case of Turkey where two surveys carried out by the State Institute of Statistics the same year, in 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 (2001) the way in which questions are formulated will affect the results according to the fact whether (i) the questions were generic or specific in trying to clarify a given disability; (ii) absence of ambiguity in the questions; (iii) and finally inclusion of too many items in a single question. Furthermore, the choice of words is crucial in order to avoid activating negative stereotypes that are at the root of discrimination.

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 the 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 is linked to a lack of visibility of these within a given 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; in traditional cultures. Mental disability is thus sometimes viewed as a punishment that a person has to endure for his/her acts.
- The language often uses negative, stereotyped terms to refer to these forms of disability (often the equivalent of ‘mad’ or ‘crazy”).
- 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 the other siblings; for instance, the entire family carries social stigma in such cases.

2. From the identification of target-groups to the elaboration of public policies: the benefit of the Capability Approach
In view of all these challenges, we are compelled to ask: how do we approach and view disability, both in terms of definition and with the aim of determining public policies?

2.1. **Taking a capabilities perspective to view disability**

The Capability Approach 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 Capability Approach looks 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 capability set. This perspective to look at disability helps tackle some of the issues that we have stated in the previous section of the paper. By taking the view of the individual we look at the interaction between the person, with his/her limitations in functioning (which may or may not be permanent) and the context, which consists of a number of resources as well as expectations, stereotypes and often prejudice and discrimination. As a result, the policies that would be set up would aim at establishing an equality of activity and participation. “Thus, rethinking impairment and disability within the capability approach would entail asking in the space of capability what is the full set of capability one person can choose from and assessing the value an impairment has on this set of freedoms.” (Terzi, 2003).

The Capability Approach thus examines the abilities of the person but also the potentialities, the ability to do things consistently over time. Focusing on developing potentialities means to look at the adaptability of the individual to an ever-changing social context, the ability to tackle and even change the elements of the context that make a situation disabling for a given person. This approach stresses the interplay between characteristics of the individual and the social groups that he/she belongs to, as well as the institutional factors that may influence or even hinder his/her choices. Outcomes are thus measured in terms of the expanding of people’s choices and freedoms.

But here we must ask to what extent do the social and cultural dynamics of the context contribute to expanding or impeding the spectrum of choices of the person? A series of variables at a given time make a person ‘disabled’ as well as a number of resources that can prevent a person with limitations in functioning from ‘falling into’ disability. These may include the resources and services provided by the state but also the community support systems as well as the consideration within the family.
The central place that the Capability Approach gives to human diversity and the interactions between disability, gender and ethnic dynamics and religious implications are also particularly important when carrying out research on disability in developing and transition countries. This also brings us to another consideration: a disabling situation can result from a series of causes, from the interaction between impairment and other conditions related to the individual. For example the fact of being a woman may have just as much of an influence on the ‘mobility’ outside the house in certain traditional cultures. Gender, in this case, may have more of an affect than impairment such as being an amputee. Looking at the capabilities and thus taking a more comprehensive view of the living conditions of the person can be a means for accounting for all the various factors that come into play when considering human lives where elements are often intertwined in complex dynamics.

The Capability Approach also constitutes a framework to take ‘agency’ into account. 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. It is the “ability to form goals, commitments, values etc.” It is recognizing 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, p. 19). The Afghan context illustrates the importance of this aspect to view disability. Indeed, the war-disabled are extremely valorized and visible within Afghan society, they constitute a strong pressure group and influence political decisions. Other forms of disability remain hidden, shunned and discriminated against.

2.2. Definition of Disability: Example of the National Disability Survey in Afghanistan (NDSA)

Based on the Capability Approach, the main objectives of this survey, carried out by Handicap International for the Government of Afghanistan were:
- To measure prevalence of disability by type of disability
- To provide insight into the needs and opportunities of persons with disabilities in Afghanistan.
- To identify barriers, difficulties and stigmatization that persons with disabilities face in everyday life.
To provide strategic guidelines to overcome main difficulties faced by persons with disabilities

For the NDSA the main aim was to provide a comprehensive picture of disability in the country, prevalence rates and information regarding all the major issues in developing countries. However, the objectives are also dependant on the expectations and demands of the funding agencies as well as the political partners. Although the overall goal of the survey seemed clear, their political implications and consequences were less obvious. The results of the survey would impact the disability scene in the country by putting forward findings that would not always be in line with the beliefs that programs and policies had been based on to date. The political side of the survey is always more tricky to handle. The study was aimed at providing insights and recommendations for the Government of Afghanistan even though other NGOs and organizations would also benefit from it.

The Capability Approach was considered the most suited in order to devise a definition that was adapted to the needs of the Afghans and that would provide a more comprehensive view of the given situation. Based on the abundance of literature that exists on the concept of disability, the NDSA had adopted a functional definition keeping in mind its two main aims: firstly, the need to be functional in order to be able to design a questionnaire that takes into account individual, institutional and societal factors, and secondly, the view on disability needs to be relevant to the Afghan context and take into account gender, ethnic and social factors that come into play in the defining of the lives of the persons with disability.

The NDSA was based on the following definition of Disability that brings together the considerations that have been stated above. ‘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.’

2.3. Taking a Capability Approach to define policies: the case of Afghanistan

As a consequence, the tools and the methodology that are devised based on such a definition will also need to take all the factors stated into account. Needless to say, policy recommendations based on this approach will focus more on how to address the vulnerability of persons with disability and less on the numbers or prevalence rates that are
found. In other words, whether the rate is 2% or 8%, the disability strategy needs to be based on the inclusion of persons with disability in mainstream programs. Moreover, viewing disability in isolation from the fields of implementation (education, health and employment for instance) has shown its limitations. The need to push forward for the inclusion of disability within other state structures in order to improve their living conditions is even more evident in a context where resources are scarce or even non-existent.

Taking a capabilities perspective also leads decision makers to taking a comprehensive approach to disability by: 1) looking at the various factors that influence quality of life as a whole, 2) proposing policies that take into account sustainability of change and development, 3) working on individual ability as well as on the resources that exist within society.

Such an inclusive approach also implies that there be state structures and political commitment to take forward this impetus. The Afghan context is one example of the co-existence of various approaches to disability within the government structures.

In Afghanistan the disability mandate has been officially entrusted with a specific government body: the Ministry of the Martyrs and the Disabled (MMD). Within this ministry, the main program is to provide pensions for persons with disability and the family of martyrs. In order to receive this pension, the individual has to be registered with the authorities. Effectively, the registration process also reflects the strong beliefs that are persistent within Afghan society and the war-disabled lobby, which constitutes a very visible political group in view of the history of the country, largely dominates in the ministry. There is stigma and discrimination against other forms of disability, mental and those resulting from congenital causes for example that lead to their under-representation in the registration process. Therefore, although the official mandate of the MMD is to address the needs of all the disabled persons in the country, in reality efforts primarily have benefited the ‘heroes’ of war and the martyrs up to now, those who are believed to have made a sacrifice for their land. As a result, the impact of such a structure maintains beliefs and stereotypes, rather than expand the rights and choices of all persons with disability. Lastly, the existence of a specific structure with a clear mandate to address needs of the disabled also leads to other government bodies not taking responsibility for systematically including disability concerns within mainstream programs, which in the long term, would be a more sustainable and cost effective solution.
The other main government structure that was a main partner of the NDSA is the Ministry of Public Health (MoPH). But, contrarily to the MMD, the MoPH had already set up and is in the process of implementing the Basic Package of Health Services (BPHS). The aim then was to use the results of the survey to include disability services within the existing health services through an inclusive approach. This can be done at different levels. The Basic Package of Health Services established in 2003 in Afghanistan has two purposes: (1) to provide a standardized package of basic services which forms the core of service delivery in all primary health care facilities, namely, the health post, basic health center, comprehensive health center, and district hospital, and (2) to promote a redistribution of health services by providing equitable access, especially in underserved areas. The BPHS for Afghanistan consists of seven components. Mental health and disability are the sixth and seventh components. The former is composed of community management of mental problems and health facility based treatment of outpatients and inpatients. The latter is composed of physiotherapy integrated into primary health care services and orthopedic services expanded to hospital level. The integration of disability and mental health services aims at mainstreaming people with disabled who are often pushed into the background and thus avoid further stigmatization. As a result, the perspective of the MoPH is to integrate disability concerns with regards to health within a wider perspective.

In order to have better coordination of public actors in the field of disability and make sure people with disability were mainstreamed in public action, a National Disability Commission was proposed to the Government of Afghanistan in 2004-2005. The main advantage of such a structure would be to ensure that disability concerns are systematically taken into account in all policies and programs, whatever the number of the persons with disability may be. It also has the advantage of being cost efficient in a context where so much remains to be done and resources are limited. Such a structure has been implemented in the Kingdom of Cambodia. ‘In response to this situation a Ministry of Social Affairs, Labour and Veterans Affairs (MSALVA) task force recommended the establishment of the Disability Action Council

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The first one, maternal and newborn health, is composed of antenatal care, delivery care, postpartum care, family planning, care of the newborn. The second component, child health and immunization is composed of epi-services (routine and outreach) and integrated management of childhood illness. The third component, public nutrition consists of micronutrient supplementation and treatment of clinical malnutrition. The fourth component is communicable diseases composed of control of tuberculosis and control of malaria. Supply of essential drugs in the health services is a fifth component.
The Disability Action Council is a semi-autonomous national coordinating body, with representatives from government, non-government organizations, international agencies and individual members who are committed to the work of the Council in promoting the development of persons with disability in Cambodia. This council has the mandate and the neutrality to undertake this vitally important coordinating role, and to promote the collaboration and cooperation of all key participants working in the field of disability and rehabilitation. (Trani, 2004).

In a similar way, the NDC would take up the task of programming, managing and coordinating the disability policy in a field where actions are currently planned by different ministries and carried out in isolation by various local governmental bodies or implementing agencies, especially International NGOs. In fact, the existing capacity of implementation needs to be rationalized by linking existing programs to national a leadership and priorities. For this reason, line ministries, at both central and local levels are to be involved in the whole process of definition and implementation of the disability strategy.

Conclusion

In this paper we have argued that the Capability Approach is one way to come to a consensus and look at disability in relation to a given social, cultural and religious context and with a specific aim, be it increasing knowledge (measuring prevalence rate, and understanding coping strategies) or defining public action. Taking this approach can also help to improve comparability of data and information on disability worldwide. It looks at the individual as a whole and helps bring into light the various elements that are in interaction and that have an impact on his/her living conditions. This in turns allows a better understanding of the underlying factors that contribute to poverty and vulnerability or the inability of persons to improve their lives in the long term.

But even more than that, taking a Capability Approach when looking at policy design and program defining also makes us move beyond looking at the prevalence rates and numbers and focusing on the vulnerability of persons in a more comprehensive manner. Disability is still too often seen as a problem in isolation or as the cause that explains the problems that persons face: it is because (s) he is disabled. But viewing disability as a situation that is a consequence of a paucity of relevant programs and structures, sometimes more so than that of a mere impairment, shifts the focus from only the individual, to the person within a society. Taking a Capability Approach highlights the importance of
institutional structures and the necessity to find a common space within which to view the concerns and to define policies that are meaningful to the lives of persons with disabilities, taking into consideration specificities linked to cultures and countries.
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