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Lack of a will or of a way?

Taking a Capability Approach for Analysing Disability Policy Shortcomings and Ensuring Programme Impact in Afghanistan

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Abstract

The present paper attempts to analyse some of the shortcomings that have impeded efforts in the field of disability in Afghanistan. After an overview of recent disability initiatives, this article presents elements that have contributed to the limited impact. The context of a Conflict Affected Fragile State (CAFS) makes particularly intricate the development of state-capacity as well as the delivery of basic services for the population. To overcome identified gaps, it is argued that Amartya Sen's Capability Approach (CA) constitutes a relevant framework for designing disability policy and implementation. While the definition of human development has evolved considerably over the past decade, the translation of this change often remains at the theoretical level, without any visible impact on the policy-making process and in terms of well-being. We argue that one reason for this gap is the paucity of knowledge, and the insufficient focus placed on enhancing the agency of vulnerable groups. Through the example of the National Disability Survey in Afghanistan (NDSA) the paper discusses the need for scientific based knowledge and the challenges of a research initiative based on the Capability Approach to inform policy design and implementation: design of research tools and methodology for analysing disability issues.

Key Words: Afghanistan, Capability Approach, Disability, Policy development, Research, Vulnerability.

Introduction

Disability is too often a low priority on state welfare agendas worldwide. However, over the past decade, there has been growing acknowledgment that disability is essentially a global human rights issue, inextricably linked to broader development concerns. These include mutually reinforcing links between multidimensional poverty and disability; the first considered a determinant of higher prevalence of the latter ((Beresford, 1996; DFID, 2000; Elwan, 1999; Yeo and Moore, 2003; Filmer, 2008). Conversely, disability is considered a major factor pushing individuals and their families into poverty (DFID, 2000; Lwanga-Ntale and Mc Clean, 2004). Disabled children may need extra care and this responsibility falls disproportionately on women and siblings who take time from work and school to provide care (Miles, 1999). Disability is also intrinsically connected with other development challenges such as fighting systematic discrimination and social exclusion of marginalised groups (Lenoir, 1974; Rodgers et al., 1995; Sen, 2000), empowerment and effective participatory approaches to development ((Freire, 1970; Fay, 1987; Kabeer, 1994, 1999) research (Campbell, 2002), and identifying human rights violations (Quinn et al., 2002). Consequently, development policy-makers and practitioners view mainstreaming disability concerns within their activities as a means of fighting poverty and reducing vulnerability in a sustainable manner.

The Government of Afghanistan, through the Ministry of Martyrs and Disabled (MMD), decided to invest in a National Disability Strategy. This pledge was in line with international frameworks and now with the International Convention on the

Rights of Persons with Disabilities adopted by the General assembly of the United Nations on the 13th December 2006, which entered into force on the 3rd of May 2008.

Yet, in Afghanistan, as in many other countries, a void exists between overarching objectives defined at the national level, and the lack of adequate policies and programmes designed to achieve these. In the case of the disability policy, the proclaimed goals of the national disability strategy in Afghanistan aimed to improve livelihoods and social protection of persons with disabilities, eradicate poverty and fight for the recognition of their rights (Italian Cooperation, 2003; Trani, 2004; UNDP, 2004). On the other hand, field programmes continued to over-focus on certain types of impairments and interventions, overlooking others that were less visible. This disconnect can partly be explained by the absence of a unifying basis on which a comprehensive view of disability issues can be conceived, relevant knowledge be provided and field programmes operationalised. This has also led to a total lack of an adequate understanding of needs, aspirations and living conditions of vulnerable groups in general, persons with disabilities in particular. As a result practically no sustainable structures exist in rural areas, those in urban areas remain specialised, limited and extremely costly. There are few employment and income generation activities, and education and health facilities remain inaccessible for the most vulnerable. The ongoing violence and the broadened capacity of armed grouped opponents to strike government and international structures out of their strongholds in the Southern part of the country have dramatically worsen the situation.

Through the example of a National Disability Survey in Afghanistan (NDSA), this paper discusses the utility of taking a capabilities framework as a basis for conducting action research and designing policy. It highlights the difficulties that often impede academic research concepts from being translated into effective policy and practice by raising some crucial questions. What major challenges do researchers face when moving from theoretical and philosophical considerations to a methodology that will serve as the basis for collecting data? How can these findings be translated into effective policy and trigger social change in a visible and sustainable manner?

By focusing on human freedoms as primary ends as well as principal means of development, the Capability Approach (CA) (Sen, 1999: 11) provides an innovative basis for assessing disabling situations by integrating and moving beyond existing models.

The first section of the paper presents an overview of the various disability initiatives in Afghanistan as well as the failure to achieve meaningful results. Based on findings of the NDSA, the second section analyses and discusses the factors that explain this limited impact. The third and final section focuses on the contribution of the Capabilities framework to operationalising definitions and methods used for the NDSA. Through the examples of the process of building a disability strategy based on the research results, we argue that the CA could provide a strong foundation for defining public policy, developing sustainable operational modalities for service provision and ensuring that the most vulnerable do not fall through the cracks.

A Critical Overview of Disability Initiatives in Afghanistan

As a result of several decades of conflict in Afghanistan, there was a significant increase in the number of existing persons with disabilities, which was already high due to diseases, accidents and social conflicts. Aware of this situation, and under political pressure from former Mudjahidin victims of war who are structured in powerful organisations, the Government of Afghanistan, since 2002, has sought to design sustainable solutions able to re-integrate persons with disabilities within mainstream economic and social life, thus promoting an inclusive society. Specialised non-governmental organisations (NGOs), the United Nations organisations, bilateral and multilateral donors have supported several of these initiatives on this field. However, from the very onset, policy and programmes have mainly targeted the socially visible and accepted groups. The following section presents an overview of the manner in which the various national and international partners comprehend and address issues related to disability.

Specific Mandates Impede Attempts to Mainstream Disability Concerns

The former Ministry of Martyrs and Disabled (MMD) now the Ministry of Labour, Social Affairs, Martyred, and Disabled (MLSAMD) was established at the beginning of the Soviet era. Initially, its main role was to provide pensions for persons with disabilities and the families of martyrs. In order to receive this pension, the individual had to be registered with the authorities. A huge effort was been made to register the war-disabled: the recipient base was expanded in 2003 to include those having lost more than 30 per cent of mobility, sight or hearing. Mental illness and

intellectual disabilities are still not included in state records as there is no expertise to assess these. Approximately \$8 (400 afghani) per month is paid to approximately 300,000 people, which totalled \$24 million in 2007 (MLSAMD, 2007). As recipients are expected to appear in person to collect their payments, and the main payment centres are in the major cities, the rest of the country is de facto left out of the scheme. Strategies have been developed to distribute welfare pensions outside of Kabul, which in 2003 was the sole centre throughout the country. The pension system is not adapted for persons with disabilities living in rural areas, the cost of transportation often being more expensive than the sum of the pension itself. Resuming pervasive fighting since spring 2005 made unfeasible any further attempt to extend the programme.

The MLSAMD has since also been given the overall responsibility of responding to the different needs of all persons with disabilities, moving beyond the socially accepted categories. Created originally to cater for the needs of Martyrs and war disabled, the ministry is currently the principal government agency responsible for disability coordination, advocacy and information dissemination in Afghanistan. The MLSAMD is theoretically structured to develop and deliver a comprehensive package of services to the disabled community in order to enable effective participation in economic life. Currently, MLSAMD is heavily involved in the development of a national disability policy and strategy so that the needs of disabled people are better served and their rights are ensured (MLSAMD, 2007).

A few initiatives have been launched by the MLSAMD to better organise responses to disability-related needs. In particular, coordination of implementing agencies and

local government actions has been attempted through regular meetings where all stakeholders were invited to present their activities. In reality, the focus still remains limited to the welfare pension activity that the ministry regards as its main mandate. At least 1000 of the 1600 civil servants of the MLSAMD work full-time for the welfare pension system. Most of the other functions: delivering services, representing persons with disabilities and defining a strategy were delegated and carried out by the UNDP National Policy for Action on Disability (NPAD) until April 2008.

Since the Ministries of Work and Social Affairs were merged with the MMD in 2007, employment of persons with disabilities falls officially under the responsibility of the new MLSAMD (2007). In theory, persons with disabilities are now eligible for the National Emergency Employment programs (NEEP), and can access the employment service centres established in 10 provinces of the country, be trained in one of the 18 skill development and vocational training centres established by the ministry and benefit from microfinance and trade development projects.

Other main government structures provide some additional services to persons with disabilities but few ministerial programmes focus on their welfare in the country. The ministry of Education (MoE) has committed itself to supporting inclusive education and access to schools for children with disabilities since 2004. A positive step in this direction was taken in June 2004 with the decision taken to create an inclusive education unit within the Ministry. The MoE is responsible for the only governmental special education facility in the entire country, a non-residential school

for children with visual impairments in Kabul (90 children attend, both boys and girls). Recently, the MoE requested the donor community to respect accessibility rules when building new schools (MoE, 2007).

These various recent attempts to mainstream issues regarding persons with disabilities and families of martyrs within other ministries lack a coherent vision. This is largely due to an inability to expand the understanding of disability, as well as continuing over-focalisation on the needs of the war-disabled. This compounded with resuming conflict, insufficient geographical coverage, financial resources and the absence of any evidence for the establishment of successive policies has led to incoherence and inefficiency, as we will argue below.

Investing in Research to Effectively Include Disability in the Basic Package of Health Services

Despite recent efforts, Afghanistan remains one of the poorest and least developed countries in the world with some of the worst health statistics. In 2001, maternal mortality rate was reported to be 1600 per 100,000 live births; the under-five mortality rate was estimated as 257 per 1000 births and infant mortality as 165 per 1000 births (Ministry of Public Health, 2004). These numbers were a glaring reflection of many years of conflict and a disjointed and dysfunctional health care system and ministries of health without coherent vision and policies. After over twenty years of conflict and instability, the dismal health statistics were a reflection of the lack of health infrastructure, which has impeded individuals from expanding choices. Yet, infant mortality rates declined from 165 per 1,000 live births in 2001 to about 135 per 1,000 in 2006, according to preliminary findings of Johns Hopkins University household survey (JHU, 2007) mainly due to improvement of health

facilities coverage and nationwide vaccination campaign against diseases such as measles, poliomyelitis and tetanus.

One of the specificities of the MoH and the subsequent Ministry of Public Health (MoPH), established after the presidential elections of 2004, was the endorsement of a strategy focusing on the development of the foundations for the delivery of equitable health services to all Afghans. This strategy specifically took into account the limitation of resources available by using scientific evidence to define policies. As a result, health sector research has become a priority. This political will to establish baseline data and monitor mechanisms was concretely reflected in the creation of the MoPH's Health Monitoring and Information Systems Unit. Within this perspective a series of surveys have been commissioned and analysed for policy design. The MoPH, with the help of UNICEF, carried out the Multiple Indicator Cluster Survey (MICS), providing a first multidimensional mapping of the national situation in 2003. With the assistance of Management Sciences Health, the MoPH also carried out the National Health Resources Assessment (NHRA) that same year. This assessment of services has been an ongoing process ever since. More recently the MoPH was a partner in the National Risk and Vulnerability Assessment (NRVA 2003 and 2005), and a major collaborator of the NDSA.

The establishment of a sound evidence base and monitoring mechanisms have ensured continuity and coherence of health policies despite degradation of political and security conditions. In 2002, with the supported of donors, WHO, UNICEF, and other development partners, the MoPH developed the Basic Package of Health Services (BPHS), which addressed the most urgent health needs of the population.

The focus was placed on the provision of cost-effective services that could have the greatest impact on the major health problems in both rural and urban settings. Promoting equity in health also meant combating discrimination in the delivery of care: as a result, emphasis was set on giving priority access to the groups in greatest need, such as women, children, persons with disabilities and those living in poverty (MoPH, 2003; 2005a) by expanding opportunities to ‘achieve good health, free from escapable illness, avoidable afflictions and premature mortality’ (Sen, 2002: 660). The BPHS covers seven health categories which are considered to be priorities in Afghanistan: maternal and newborn health, child health and immunization, public nutrition, communicable diseases with concentration on tuberculosis and malaria, mental health, disability, and the supply of essential drugs. Disability and mental health were second tiers priorities until the review of the BPHS in 2004 (MoPH, 2005b) largely because of the incapacity of health staff to implement required interventions. The entire process of building the health system based on comprehensive geographical coverage with a wide range of service provision has been developed through a continuous consultation with stakeholders. The relative success of the BPHS is a consequence of the general consensus obtained during the process of definition of means (funding, human resources, drugs provision etc.), implementation and intervention.

In 2005, during the revision of the BPHS, the lack of data available in the fields of disability and mental health became evident. This void has contributed to the inability of the MoPH to develop a cohesive strategy on providing health services to persons with disabilities and tackling mental health concerns. In the field of mental

health, the only two services covered were community-based mental health management and health facility based mental health treatment of outpatients and inpatients with limited anti-psychotic and antidepressants medication. Regarding disability, the services covered under the BPHS were limited to physiotherapy which was integrated into Primary Health Care (PHC) services and orthopaedic services expanded to the hospital level. Limited experience on how to translate knowledge of a situation into public action has led to insufficient action at the policy level. Aware of this gap, the MoPH was a major partner of the NDSA.

Following the NDSA report at the end of 2006, two international advisors of the NPAD joined the Ministry with the task of integrating disability and mental health issues into policies and programmes. Convincing the donors, implementing partners and the administration of the MoPH to expand the BPHS from its focus on women and children to integrate persons with disabilities as a national priority remains a daunting task, even now that the data is available. This is compounded by the fear of budgetary implications on the health sector of such an expansion of services. Yet, basing their decisions on evidence and not assumptions has enabled the MoPH to follow a comprehensive approach to health equity by looking widely at social and economic factors as well as other parameters such as disability to ensure process fairness (Sen, 2002).

International and National Associations: Delivering Specialised Services, Ignoring Complementarities

Years of on-going conflict and the importance of disability issues in Afghanistan as well as the high social and political visibility of the war-disabled have also largely contributed to the establishment of a myriad of programmes on the field. Despite the

conflict, several agencies and international NGOs have taken the initiative to advance the cause of persons with disabilities, the International Committee of the Red Cross (ICRC), the International Assistance Mission (IAM), Sandy Gall's Afghanistan Appeal (SGAA), Handicap International (HI), Serving Emergency Relief and Vocational Enterprises (SERVE) and Swedish Committee for Afghanistan (SCA). A few Afghan NGOs and disabled people organisations (DPOs) also provide services for Afghans with disabilities. Among them are the Afghan Amputees Bicycle for Rehabilitation and Recreation (AABRAR), the Hearing Impaired Foundation for Afghanistan (HIFA), the Afghan National Association of Deaf (ANAD), Afghan National Association of Blind (ANAB) and the National Association of Disabled Afghans (NADA).

Some international NGOs such as SGAA and SCA have been operating in the country since the early 1990s. After merging with SGAA in 2006, the Rehabilitation of Afghans with Disabilities (RAD) community based rehabilitation programme of SCA covers 16 provinces of north, east and north-east Afghanistan and provides a large array of services: physiotherapy and orthopaedic services, sensitisation and awareness, employment support and vocational training, special and inclusive education. ICRC has been operating since 1979, providing services for Afghan refugees in Pakistan who had been wounded in the fighting. After 1987, ICRC opened a hospital for war victims in Kabul and, in compliance with its mandate, the principal mandate of the ICRC being the treatment of war victims, the physical rehabilitation centre only provided treatment to those disabled by war. Progressively, physical rehabilitation centres were opened in other major cities and six exist today.

In 1996 a home-care program was implemented in Kabul area providing help for those with spinal injury, paraplegics and quadriplegics, and their families. In 1997, ICRC developed micro-credit, employment support and education programmes for persons with disabilities in Kabul area.

The majority of non-governmental organisations and national associations remain highly specialised in a certain field. They were set-up during the conflict or in the post Taliban era and responded to urgent needs of the population. As a result, they remain specialised on certain forms of disabilities that constitute their expertise, and are well established in certain areas where they first started. There still is no mechanism for analysing the complementarities between initiatives to reduce multiplication of efforts, and no national referral system to improve geographical coverage of services. Lastly, organisations tackling mental disability issues remain extremely few.

The UN Programme for Disability: Staving Participation, Hindering National Ownership

The role of the successive United Nations programmes specifically addressing the issues related to disability reflects a different problem: the ability to adapt to an ever-changing political, economic and social reality. The following section explains the various UN initiatives as well as their implications for policy designing.

Bengt Kristiansson, paediatrician, after having carried out several local field surveys of resources in the capital Kabul and the provinces of Takhar and Wardak, set up the first disability programme with Swedish International Development Agency (SIDA) funding in 1991, co-funded by ILO and UNDP. Service delivery was limited to community awareness raising, special education for those with visual impairments,

and employment services led by ILO. Programme activities were defined by the management in Kabul and regional staffs were in charge of recruiting field workers and volunteers for the new Community Based Rehabilitation (CBR) programme which was launched in 1995. Between 1995 and 1999 there was no effective government in the country, and the CDAP created by the UNDP, was run by United Nations Operational Programmes Services (UNOPS), with the introduction of CBR programmes in Herat province, extended in 1997, to Kandahar province (CDAP, 1995; Gutron and Jarrar, 1996). These regions were believed to consist of a number of landmine/UXO survivors (Coleridge, 2001). The CBR programme operated with field workers and volunteers recruited from the communities was primarily a service delivery programme. According to Coleridge “there is a strong sense of community ownership of the programme” (Coleridge, 2002: 1). CDAP managed the coordination of disability related activities amongst the relevant agencies and NGOs.

In 2000, the CDAP took over direct implementation in Herat and Kandahar following recommendations made by external experts report in charge of evaluating the programme (Krefting and Krefting, 1999). It started acting essentially as a direct service provision component of the MMD. But, the deterioration of the political situation led to the limitation of program activities and to the move of the management to Islamabad, from where it conducted remote control of teams still operating in the country. After the end of the Taliban regime and exile in Pakistan, CDAP management moved back to Afghanistan, but it was only in August/September 2002, that it resumed direct implementation of service delivery. According to Coleridge, the programme employed 400 people and used about 2000

volunteers by the end of 2001 (Coleridge, 2002). After an external evaluation that concluded that there was a “management vacuum”, which has seriously dilapidated the managerial, technical and implementation capacity of the Programme” (Rathnam et al., 2003: 10), the CDAP was replaced by a new program in September 2004. In view of the changing context as well as the conclusions of the assessments of programmes and recommendations made by various experts, one major goal assigned to CDAP by Rathnam et al. was to provide technical support for coordinating actors, mainly NGOs, INGOs and DPOs in charge of implementing services for persons with disabilities based on an inclusive and participatory approach. Actors in the disability field were to be organised in a consortium under the impetus of a National Disability Commission (NDC) (Trani, 2004). Coordination would improve quality and quantity of services provided as well as extend geographical coverage (Rathnam et al., 2003: 37). The role of UN would be to provide capacity building and technical support to the NDC, the MMD and the implementation agencies, coordinate donor assistance, and to mobilise resources. The CDAP management decided not to follow-up with the NDC project and to launch a new programme.

The National Program for Action on Disability (NPAD) replaced the CDAP in early 2005 based on a limited interpretation of the recommendations of the June 2003 external evaluation. The NPAD focused on developing a strategy, which, in the first phase, would still be carried-out by international experts and UN staff. The underlying implication was that, after a given period of time, the responsibility would be transferred to Afghan officials. Hence, the NPAD was designed to be the

central coordination body, which would provide support to selected Ministries in order to push for the inclusion of persons with disabilities into the national dialogue and policies. UN staffs were placed as advisors within key ministries: health, education, and the new MMDSA, providing technical support. Advisors within these key ministries reported not to the minister but to the NPAD management, which became *de facto* the coordinator body of disability programmes: headed by an international UN staff. This led to a parallel functioning of two mechanisms: the ministries holding a symbolic role for defining policy and the UN structure which held the financial resources. No further concrete steps were defined in order to ensure that in the medium-term, ownership of initiatives would increasingly be national and under the responsibility of the Government. At the same time, direct service provision was stopped, emphasis was placed on NGO sub-contracting and the programme was limited to focus much more strongly on policy definition, development, institutional reform and coordination of the disability sector (UNDP, 2004: 6). This approach held back all possibility for long-term planned actions.

All these conditions contributed towards staving off any participatory approach for coherently building capacity of national officials and progressively holding them accountable for the efficiency and impact of policies. In April 2008, the NPAD was shut down by UNDP because of reluctance of donors to further fund a programme that did not provide any of the expected results.

Unsuccessful Attempt to Promote National Ownership and Empowerment of Persons with Disabilities

One of the more ambitious attempts to work on empowerment and agency of Afghans with disability was the idea of creating the NDC. A first NDC was created

in 2002 within the MMD but never managed to meet its mandate of coordinating stakeholders. A second project was mapped out through a consultative process under the responsibility of the MMD. This new body was designed to consist of various organisations, most importantly the Afghan DPOs represented in the executive board (see Figure 1 below), and would be placed directly under the Presidential office and no longer within a ministry (Rathnam et al., 2003: 4-6; Trani, 2004: 24-33). Technical committees composed of stakeholders including DPOs would support the action of a secretariat, in charge of implementing the disability strategy, by providing policy documents on major issues (physical rehabilitation, mental health, disability law and rights, education, health...) on a permanent or temporary basis and with the mandate to address quite diverse considerations. The NDC was an attempt to coordinate actors by giving the political leadership to the Government, with strong support from UNDP staff and other experts in the initial stages (Italian Cooperation 2003). Yet, this project was dropped, essentially because of resistance both within the Ministry as well as the CDAP, thus reflecting irreconcilable differences in views.

Figure 1: NDC descriptive framework (see Figure.doc)

The restructuring that took place in 2005 led the way to the development of the NPAD. The program has suffered the same limitations: overall lack of participation and of a comprehensive view of what disability entails for the lay population. Decisions have been taken by the programme manager with little consultations of stakeholders. Although NPAD management placed staff in several ministries, there

was limited sharing of decisions and very little capacity building. Since 2001, only one training has been organised for civil servants of the MMD on disability awareness, and none for the other ministries, if we exclude the training of the staff associated to the NDSA research process.

The failure of the NDC can be explained by a combination of a series of factors that are inherent to the way disability is viewed and addressed in the development programmes: the proliferation of mandates, the lack of clear responsibility and accountability, the absence of a coherent framework that could improve coordination reflecting similar weaknesses in the overall functioning of the international community in Afghanistan. The following section discusses these gaps through the findings of the NDSA.

An Analysis of the Gaps in Current Policy and Implementation

A number of shortcomings, namely unplanned delivery of services, lack of knowledge regarding the needs of persons with disabilities as well as available resources for action, deficiency in the participation and coordination of all stakeholders, and poor understanding of cultural specificities need to be overcome. Implementation of public policies tackling disability issues remains limited to efforts to provision of a few services, ignoring the needs to strengthen potentialities, enhance capabilities of individuals by taking into account their diversity and working towards equality of opportunities, empowerment and participation (Sen, 1995, 1999), thus decreasing their vulnerability (Bakhshi et al., 2004). The urgent need to understand the complexity and diversity of the situation of persons with disabilities

became obvious in view of the inability of existing programmes to have any visible impact on a large scale. The remedy lies within policies that take into account sustainability of change and development, based on individual ability as well as on the resources that exist within society.

Using Evidence to Analyse Gaps between Needs, Capacity and Impact

The needs of persons with disabilities in Afghanistan are many and diverse. The limited impact of efforts can be explained by a number of factors:

- Political factors: the lack of a long-term strategic plan for the disability and rehabilitation sector; the absence of legislative instruments to protect their rights.
- Social factors: the existence of discrimination, especially for women with disabilities who face additional constraints due to cultural beliefs and practices.
- Geographical factors such as lack of services and programmes in remote and rural areas, which have a high rate of person with disabilities, including those having sustained landmine injuries.
- Research and monitoring needs: a lack of quantitative data on the numbers of persons with disabilities as well as qualitative information on their situation within the Afghan society.
- Finally, an overall lack of technical and financial resources needed to provide adequate services.

These gaps were not taken into account by the CDAP and the following NPAD or addressed simultaneously in a comprehensive manner. They were however identified by the evaluation mission in 2003 and similar to earlier critics formulated by the mid-term evaluation in 1996. This is indicative of the incapacity of CDAP to amend

its approach as the same weaknesses and problems identified in 1996 remained (Rathnam et al., 2003: 24) and discussed in this section.

Lack of Participatory Mechanisms that leads to a Lack of Continuity of Programmes

One of the main barriers that persist on the field is a complete absence of local synergies that would have ensured that efforts are sustained despite political and security conditions. Most of the services have been provided directly without transferring skills and knowledge to communities to increase coverage. Over a period of 12 years (1991 to 2003), consistent effort for building expertise through appropriate training would have allowed better empowerment of local partners. Continuity of programmes as well as their relevance to field realities would have been ensured by setting-up participation in the decision-making process and progressive transfer of ownership of the programme to the ‘beneficiaries’ themselves as emphasised by several authors. They stressed the need to transfer appropriate knowledge and skills to health staff, to raise awareness of key members of the community at an early stage, using existing materials available in *Dari* and *Pashto*, together with mass media (Miles, 1992; Kristiansson, 1990). But these were never considered a priority within a traditional service-delivery process.

Lack of Evidence-based Programming that leads to Persisting Incoherence of Actions and Inadequate Geographical Coverage

The ineffectiveness of the disability initiatives was first visible in the limited section of the population with disabilities that has actually benefited from services, especially in rural areas where 71.6 per cent of Afghan population live (Trani et al., 2006). There is an evident geographical difference between the areas where services are available, mainly urban centres, and areas with high proportion of the disabled

population. For instance, figure 2 shows a geographic distribution of physiotherapy services in Afghanistan. The service coverage of northern, central and eastern areas of Afghanistan is high while the western and southern areas benefited from fewer services except around major cities such as Kandahar and Herat.

Figure 2: Community Based Rehabilitation and Physiotherapy Services in 2005 and Population Density in 2002 (see Figure.doc)

Yet, figure 3 shows a higher prevalence of severe disability in provinces with fewer services. If the national prevalence rate of severe disability was of 2.7 per cent (Table 1), it varied from one geographical area to another. Three groups of provinces were above national average prevalence: the western area (3.7 per cent), the southern area (3.1 per cent) and central area (3.0 per cent). On the other hand, three areas are below national average: the north western area (2.6 per cent), eastern area (1.9 per cent) and the north eastern (2.1 per cent). The highest prevalence rates are observed in Samangan (4.4 per cent), Herat (4.1 per cent), Kabul and Ghor (both 3.9 per cent). In 2005, concentration of services was observed in central, north western and north eastern regional, areas where prevalence is relatively lower with the exception of Kabul area. This difference between programme implementation and presence of persons with disabilities is often justified by security constraints and inaccessibility of the terrain. Even if these factors have hindered development work in some regions, they cannot account for the total absence of measures that have been taken to plan services, transfer skills and scale-up initiatives. This difference is an

additional reflection of the fact that development is done through direct presence of international organisations and not through local empowerment of partners.

Table 1. Rate of Prevalence by Regional area (see Tables.doc)

Moreover, the trends in figure 3 indicate that, for Kabul and Herat cities, the relatively higher concentration of services corresponds to the presence of a large proportion of persons with disabilities. In the rest of the country, there is often a distortion between the density of services and that of population with disabilities.

Figure 3: Density of Disability by Province (Trends). (See Figure.doc)

Considerable investment; limited impact

A small percentage of Afghans with severe disabilities were actually able to access services. For instance, UNDP CDAP programme operated in 13 provinces and 45 of Afghanistan's 350 districts, employed 400 paid staff and 700 to 6000 volunteers and the accumulated total of disabled beneficiaries amounted each year to between 27,000 and 30,000 according to estimates (Coleridge, 1999: 153, Miles, 2002a: 953). ICRC and SCA also have deployed an extended programme. For instance, in 2007, 14,787 (of which 4,780 are women) persons with disabilities but 35,212 (10,937 women) persons without disabilities having temporary ailments (especially farmers having chronic back pain due to heavy loads and harmful postures while in the field) received physiotherapy services in the 42 clinics of the Rehabilitation of Afghans with Disabilities (RAD) programme of SCA (SCA, 2007). Between 1988 and 2007,

ICRC made 64772 prosthesis, 81212 orthoses, 121538 crutches and 11966 wheelchairs. Between 1998 and 2007, ICRC did 1077 job placements and provided 5965 loans (ICRC, 2007). Yet, this must be compared to an estimated population of 655,930 persons with severe disabilities, needing improved access to school, rehabilitation and other health services, employment and income. One of the reasons for the limited scaling-up of initiatives is that these have continued to focus on a certain segment of the disabled population. Programmes seem to be unable to move beyond the socially accepted forms of disability (war-related) to include more complex impairments which, invariably call for more complex interventions.

Access to Health Services: a Series of Hurdles

Similarly, limited coverage is observed for public services. This fact can be illustrated by looking at access to various health facilities. According to table 2, only half of the population declared having access to a Basic Package of Health Services (BPHS) facility in 2005. A higher percentage, 68.3 per cent and 67.1 per cent respectively of persons with and without disability, declared having access to a private clinic or a private doctor. When respondents were asked to state the types of health providers/facilities they visited in the past year, 52.1 per cent of persons with disabilities reported having gone to a private clinic or doctor, which was followed by hospitals (17.9 per cent), and health centres (17.5 per cent). These results confirm that persons with disabilities do not have access to adapted health services.

Table2: Types of Health Services Available according to People with and without Disability (See Tables.doc)

When asked about difficulties people face when effectively accessing health services (table 3), persons with disabilities stated problems mainly pertaining to money for fees, medication and transportation then came the absence of transportation and the absence of medication.

Table 3. Types of Difficulties Encountered during the Visits to Health Services (see Tables.doc)

In fact, specialised services are not available in rural areas. For example, a majority of the physiotherapists and physiotherapy assistants work in cities, and out of the 230 physiotherapists working for NGOs (out of a total of 300 in the country), 149 work in the four provinces with the largest cities (Kabul, Mazar-e-Sharif, Herat and Jalalabad (Amin, 2008). Results of the NDSA suggest that the barriers to accessing public health services appear in succession: once the health centre exists, there are transport problems; once the person with disabilities reaches the centre, there is a lack of adequate cure or available medication; finally, the attitudes of staff can be an additional hurdle to overcome for stigmatised forms of disabilities.

Access to Education: Increasing Discrimination

The example of access to education, despite the huge effort made since 2002 to generalise primary education, is also a striking example that shows the failure of mainstreaming disability within public policies (see Table 4). Access to education is higher for the new generation of children of school age, but is, as it was previously for former cohorts, remarkably and significantly different for children with disabilities and the non-disabled. The proportion of non-disabled children aged 7 to

14 accessing public school today was almost twice as high (65.4 per cent), compared to the proportion of children with disabilities disabled before school going age (36.1 per cent) regardless of where they live and their gender. The same gap in attendance between disabled and non-disabled children was lower for the 15-18 years old: war was still on-going when these children were of school age and many of them, regardless of disability, did not have access to school. Table 4 also shows the large difference in access between girls and boys. For the new generation, disability combined with the fact of being a girl exponentially decreases chances of accessing school.

Table 4: School Attendance in Afghanistan for 7-18 years old children (See Tables.doc)

Disability Initiatives fail to give Specific Focus to the Most Vulnerable

Social exclusion and inequalities have been perpetuated through unequal access to development programs particularly for women with disabilities and persons with mental disabilities. Gender inequalities, severe disabilities have not been addressed: employment support activities have only reached a small number of beneficiaries and level of activity remains higher among men, especially non-disabled men or men disabled at war. Women, women with all types of disabilities and men with mental or associated disabilities had no means of securing livelihoods (see Table 5).

Table 5: Level of Activity of Afghans Aged 15-64 by Disability Type and Gender (see Tables.doc)

The pre-dominance of certain categories within the services as well as the priorities of the DPO set-up were additional signs of the perpetuation of traditional social structures. Men, (physically) disabled by war continued to overshadow the other forms of disabilities that are more stigmatising such as disabilities resulting from congenital problems as well as mental illness and intellectual disabilities. The former Mujahidin uphold a strong political voice and are well organised to negotiate with the MMD and the CDAP/NPAD. One example of this was the fact that they obtained a privileged access to the Community Centre for Disabled (CCD) in Kabul when it was created in 2004 by Handicap International, and they continue to be the main beneficiaries of the welfare pension system. Yet, few women with disabilities benefit from employment support programmes. Responses for reducing inequality and social exclusion cannot be conceived without taking into account aspects that are crucial to any development process in the long term.

Urgent Needs in Order to Forward Disability Policy

In the field of development, especially in a post-conflict country such as Afghanistan, viewing individuals and communities as actors and partners to consult and not as receivers, remains to be achieved (Miles 2002a: 955). Programmes often follow a top-down delivery mechanism that allows little scope for real participation of local partners.

Policy Defining and Field Implementation: Repairing the 'Disconnect'

The NDSA was commissioned in view of the weaknesses of programmes that resulted from the absence of mechanisms for taking into account the expressed needs of persons with disabilities. If the number of DPOs effectively increased between

2001 and 2003 (14 to 15 women's DPOs and 77 to 143 men's DPOs, Rathnam et al., 2003), their participation in the process of selection of priorities, in the implementation of activities and in the evaluation of actions, largely remained non-existent.

This incoherence was also reflected in the difficulty of implementing a paradigm shift in disability policy and practice, from delivering services to expanding freedoms and participation. The role of the research was to define ways in which this paradigm shift could be made so that policy decisions were not only based on funding capacity. Another constraint was the belief that local structures have to be 'brought up to mark' before they are considered capable of taking over responsibility of initiatives. Participation was viewed solely as sharing information and capacity building as training of staff. The NDSA, by giving voice to the needs of persons with disabilities, assessed impact not in terms of number of services provided but in terms of whether people had felt any tangible impact in their everyday functioning. By giving value to people's voices, or agency, research shifted the focus from a welfare perspective to a well-being framework.

Improve Understanding of the Multidimensionality of Disability

The focus of disability initiatives in Afghanistan has been put on 'categories' of disability. Actions have not been designed to take into account the other factors, which also contribute to making a person vulnerable, resulting in programmes not reaching those most in need, and in a lack of an inclusive outlook. A gender focus of policies and programmes undertaken entails looking at deep-rooted beliefs and cultural practices that cannot be changed overnight. For instance, the challenges of education and access to health services for girls and women will require thought and

discussion among different actors involved, including Ministry of Women Affairs. At school, sensitisation of girls and women's rights should start within the boys' classes. Training of women as health workers, nurses, midwives and doctors should be increased and delocalised to ensure that all health facilities have women staff. All of the above clearly demonstrates that beyond making school and health accessible in terms of distance, facilities and teachers or health staff, a huge effort needs to be made regarding gender stereotypes and gender specific attitudes. For education, this should be done at every level including teacher training, curricula and material development, and teaching methodologies in order to encourage girls with disabilities to access education at par with other children. We can further argue with Miles that because women have a major participation due to their socialisation to providing informal care and assistance, they 'should be primary targets and participants for developing appropriate, conceptually adapted, confidence building information about disability care and management in the home and neighbourhood (Miles, 2002a: 954).

Moving from Welfare to Well-being

We also argue that, now that there is scientific evidence of needs, disability policy should move from a narrow service provision conception to a broader general well-being of persons with disabilities approach. Sen's CA looks at well-being in general defined as achievement of beings and doings that an individual values and has reason to value (Sen, 1999). Without a comprehensive view of livelihoods and other needs of persons with disabilities, stakeholders involved in the field have so far been unable to develop policies for achieving basic functionings and the corresponding capabilities of persons with disabilities also considered by Sen (1995) as basic

freedoms. This allows shifting the focus from the specificities of the disabling situation, to how to look at establishing equality in terms of possibilities and choices. Taking this approach also means moving away from a sequential approach to programming, thinking that certain concerns can be addressed at a later stage, once basic services are in place. Experience shows that this just marginalises already fragile groups by not mainstreaming them into the process. The main issue in Afghanistan is still the lack of an independent and single governmental structure officially invested with the decision making power for rights of all persons with disabilities. The NDSA was commissioned in view of the increasing awareness of the government of Afghanistan and other stakeholders of the shortcomings of existing policies and programmes. The following section discusses the ways in which the gaps identified can be bridged through a comprehensive framework.

Using the Capability Approach to comprehend Disability Issues

One of the main challenges that various programmes have failed to overcome is the need to give coherence and continuity to initiatives. This is also the main reason why activities remain dependent on political and security unrests. As a result, programmes have been implemented in a sporadic manner with little accountability in terms of efficiency and impact, similarly to other international community initiatives in the country (Donini, 2007).

The research methodology of the NDSA attempted to operationalise the capabilities approach to collect information in the field of disability. The project aims at bridging the gap between research and development policy at a time when more attention was

being paid to the needs of the most vulnerable groups in the country, and when all stakeholders agreed that a coherent strategy based on evidence was required. It was a means to overcome shortcomings described earlier and view disability through a human rights perspective.

A Framework for Coherence and Continuity between Evaluation and Public Action

Until recently, the need to provide a comprehensive assessment of disability was not perceived as a priority in Afghanistan, even though some stakeholders had pushed for a ‘comprehensive assessment of the social, economic, educational and medical needs of all impairment groups’ (Rathnam et al., 2003: 32). To date, all the quantitative data regarding disability remains limited to the estimation of prevalence rates varying between 3 per cent (UNDP/UNOPS, 1999) and 4 per cent (CVG, 2003). A 2002 survey estimated that about 67.7 per cent of Afghans show signs of mental disorders or psychosocial stress such as depression, anxiety and psychosomatic problems (Lopes Cardozo et al 2004). The MMD indicated that the estimated number of persons with disabilities ranged from 800,000 to 2 million Afghans (MMD/UNDP, 2005). Such disparities in the estimates of prevalence rates inevitably resulted in policy planning and service delivery being extremely difficult. More importantly, no data regarding living conditions was available.

The first challenge of the NDSA was to define a coherent participatory and continuous process from assessment to policy. The survey attempted to assess to what extent individuals with disabilities were actually able to do and be what they valued in the different areas of human activity and to identify obstacles to making relevant choices in the Afghan context to live a life with human dignity (Nussbaum,

2007: 168). The Capability framework lays emphasis on individuals' freedom of choice and focuses on the processes that allow effective freedoms, as well as actual opportunities that people have, given personal and social circumstances (Sen, 1999: 17). Participation in decision, quality of life, access to services, and social status of persons with disabilities are dimensions that relate to the Capability framework.

Understanding the Multidimensionality and Dynamics of Disability: Ensuring Socio-Cultural Relevance

Disability is defined according to social and cultural norms. What may be considered to lead to 'disability' in one given context is not necessarily the same in another (Lang, 2001). Beliefs and attitudes pertaining to persons with disabilities vary depending on whether they are perceived as a homogenous group or considered as several distinct sub-groups. These lead to social valorisation or discrimination and make persons more or less vulnerable in everyday life. Vulnerability itself has been defined as 'the probability of having his/her own situation worsen when facing a dramatic event' (Dubois & Rousseau, 2001: 1). Poverty reduction strategies require setting-up measures that not only reduce 'monetary' and resource poverty but also reduce vulnerability, or that mitigate the probability of falling back into poverty. Within this framework, policies need to aim at reducing vulnerability by enhancing capability, viewed as being composed of ability and potentiality. While the former examines 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.

Afghanistan differs from other cultural contexts where prejudice against persons with disabilities is generalised (Douglas, 1966; Murphy, 1987; Shakespeare, 1994). In the Afghan culture, disability is perceived differently according to gender differences,

traditional or ethnic attitudes, religious beliefs, and economic status. Afghans with disabilities do not constitute a homogeneous group, but various sub-groups confronted with different realities that have diverse needs and opportunities. Understanding the notion of ‘disability’ within this context requires a framework that allows in-depth multidimensional and dynamic analyses of the religious, cultural, economic and social realities in order to grasp all the factors that come into play. Disability combines with other factors (gender, age, etc) to make the individual more or less vulnerable to chronic poverty.

A study carried out on the perceptions of disability in Afghanistan (Thakkar et al., 2004) presented a multifaceted analysis of the beliefs, knowledge and attitudes related to different types of disabilities and the level and type of discrimination these encounter. A very intricate set of social representations are linked to the term itself, and persons with disabilities are valorised or shunned, admired or hidden according to the identified cause. Disability has been closely associated with the issue of martyrdom (Italian Cooperation, 2003). There is a common belief that men disabled by war are heroes, having made a sacrifice for their country. The landmine/unexploded ordnance (UXO) survivors also benefit from a particular image within society, as they are viewed as being the first victims of the situation and receive sympathy (and often pity) from the community. These beliefs have led to, and been strengthened by, a myriad of field initiatives specifically targeted at improving lives of these groups, and have received widespread international attention. As a result, the war-disabled men and the landmine/UXO survivors are very respected and visible in the Afghan society and they efficiently lobby the

Government through strong DPOs they lead, whereas persons with other types of disabilities endure more entrenched forms of discrimination. It can be argued that within Afghanistan, a "social hierarchy of impairment" exists, which is reflected in the arena of political legitimacy and privileged access to disability services.

Table 6: Level of Activity of Afghans Aged 15-64, Gender and Cause of Disability (see Tables.doc)

Men whose impairments can be directly attributed to the war have the better access to the labour market (see Table 6), which further reinforces their positive social status. Employment provides an income, the ability to take care of oneself and the family, and is an essential element in a context of scarce financial resources (Coleridge, 1998; Thakkar et al., 2004; Trani et al., 2006). Persons with disabilities who are considered to constitute a financial burden on the family often endure exclusion. The situation is even more complex for women, in a society where their movements outside the compound are highly restricted. In Afghanistan, as is the case in other South Asian countries, disabled women have extremely limited access to the labour market (see Table 6 and Erb and Harriss-White, 2004; Trani and Bakhshi, 2007).

Going beyond Categories and Labels: Expanding the concept of Disability

Strong cultural and religious beliefs lead to certain causes of impairment being commonly considered as shameful. This is the case for inexplicable forms of

disabilities, such as mental illness and intellectual disability which are perceived as a curse in Afghanistan: *diwana* is the colloquial term which refers to any impairment related to *asab* (mind). The *diwana* are the most stigmatized group and face great difficulties integrating within society (Thakkar et al., 2004). The stigma and the related discrimination are shared by the other members of the family in crucial decision such as ability to marry and have children. Disability not clearly resulting from an identifiable cause is often considered as a divine punishment or a person's bad luck. In the case of severe epilepsy for instance, Miles (2002b) states that Afghans believe that people with epilepsy are possessed by a *djinn* or spirit. As a consequence persons with mental illness and intellectual disability are not believed to be beneficiaries of the rights at par with other Afghan citizens (Table 7).

Table 7: Rights, Mental Illness and Intellectual Disability (see Tables.doc)

The challenge for the NDSA in this setting was to have a framework, which would encompass all these differences and go beyond stigmatising beliefs that marginalise the most vulnerable. By attempting to assess the vulnerability of persons who estimate having problems in functioning and choices, the NDSA was able to include the more stigmatised and thus hidden forms of disabilities. Focusing on the activities and participation of an individual allows for a more comprehensive view of the various aspects of what constitutes a disabling situation.

Conceptualising Disability for Applied Research

Disability being the complex phenomenon described above, it can be conceptualised using several paradigms, each of them focusing on different and often complementing ideologies, which respond to research, policy implementation or advocacy demands. However, the manner in which disability is conceived is not just of semantic interest, as definitions determine who has legitimacy and access to resources within a given political context.

The NDSA drew upon various theories to elaborate tools and methods. However, to design the research to provide recommendations for action, the CA provided the required continuity by placing disability within the wider spectrum of human development. This comprehensive approach includes elements of both the medical and social models (Burchardt, 2004; Mitra, 2003) and what can be referred to as the ‘bio-psychosocial’ model based on the International Classification of Functioning, Disability and Health (WHO, 2001). By allowing for the expression of human diversity, freedoms and choices, the Capability framework complements existing models because it allows an analysis that goes beyond categorising.

Limitations of Existing Models

The medical and social models of disability are often presented as opposite ends of a spectrum. Whereas the former has been useful in designing aids and equipment to improve functioning, the latter has been used by disabled persons’ organisations and lobbies to formulate policies and services based on the principles of equal access, equality of opportunity and human rights.

The medical view, based on the individual and his/her impairment, considers the physical or mental ‘problem’ that a person has (Amundson, 2000; Marks, 1999;

Pfeiffer, 2001). Impairment, in the traditional medical approach, relates to individual-based biophysical conditions. Thus, disability is first a 'deficit' in the body, the goal of disability services being to ameliorate, if not cure the physical and/or psychological manifestations of impairment. In other words, disability is the situation defined by any restriction or lack, resulting from impairment, of ability to perform an activity in a manner or within the range considered 'normal' for human beings (WHO, 1980). As a result, quantitative research, based exclusively on this model needs to establish a medical diagnosis of the health situation of the person. Not only is this unfeasible in a country like Afghanistan where medical capacity is limited (Ventevogel et al., 2006) but more importantly, this view of deviation from a 'normal' condition, is of little utility when the aim is to provide knowledge for designing equitable and rights-based public policies at national level.

Moreover, this medical focus on the individual's 'insufficiencies' is considered biased by disability activists and organisations, especially in the British approach (Barnes, 1991, 1997; Finkelstein, 1981; Hunt, 1966; Oliver, 1996). In juxtaposition to the medical model, the social model perceives disability as a consequence of the exclusion of persons with impairments from mainstream society. The social model argues that persons are 'disabled' because of the structure of society, which does not accommodate their impairment: it is the physical and social environment, which makes an individual with impairment a person with disabilities (Shakespeare, 2001). This approach looks at the barriers that exist within the social context and that prevent a person from achieving the same level of functioning as a non-disabled person. From this perspective, it is society that needs to be redesigned in order to

take into account the disabled person's needs (Olivier, 1996). However, the individualistic rights-based approach to empowerment at the basis of the social model raises many questions, as it fails to sufficiently take into account certain factors prevalent in traditional societies, such as the influence of the family and local communities in the decision-making process (Lang, 2001).

Going a step further, the WHO established the International Classification of Functioning, Disability and Health (ICF), which defines guidelines for collecting relevant data (WHO, 2001). The ICF conceives disability as a combination of individual (body limitations), institutional and societal factors of the environment within which a person with impairment lives (VanLeit, 2008). This definition is centred on two main concepts:

1. Body functions and structures take into account attributes specific to an individual;
2. Activities and participation refer to the environmental factors, including the physical environment, the social environment and the impact of attitudes.

The ICF definition is compatible with the CA (Seddon et al. 2001), but it presents certain limitations. First of all it focuses on the body, individual limitations and participation but does not sufficiently stress the interaction between individual and society, thus it does not offer a broader perspective for defining policies (Terzi, 2004). Moreover, the ICF does not allow enough space for the diversity of individuals' situations and the socio-cultural factors inherent to the context within which the phenomenon of disability is considered. A disabling situation in Afghanistan (i.e. a farmer with a missing leg not having access to an artificial device) can be completely overcome in Australia since the difficulty will be directly

addressed: the farmer will be equipped with an artificial leg and will use a tractor to do the farm work. The manner of defining a disabling situation can lead to segregation between persons with disabilities and non-disabled persons, which further reinforces stigma and marginalisation rather than encouraging mainstreaming and participation. Finally, by giving importance to specific aspects of the disabling situation, these models fail to place central focus on reducing the vulnerability of the person with disabilities in the long term. They also fail to take into consideration the impact of disability on families and communities.

The Capability Approach to Disability

With the CA, the focus is no longer solely on the disabling situation (individual or social) but on equality of choices, available to an individual. It provides new insights into the issues by highlighting not what a person actually is or does, his/her 'functionings', but the range of possibilities that he/she chooses that specific functioning from – the capability set (Sen, 1999). Furthermore, it can be argued that the person's relationship with his/her environment has to be included in this view; most choices are made with (and often by) the family and the community, as well as the social opportunities that society arranges for (Sen, 1999: 39). Focusing on this range of choices ensures that the action taken is sustainable rather than contextual. The CA applied to disability complements the medical model by considering the individual as a person connected to his/her environment, which strongly influences the vulnerability of a person, especially in traditional social settings like Afghanistan. While the social and bio-psychosocial models do this to a certain extent, they often put too much emphasis on the shortcomings and insufficiencies of the social environment. The CA adds to these views by stressing certain neglected dimensions.

Looking at the capabilities of persons with disabilities from a policy point of view entails considering ways of reducing vulnerability. This means comprehending and building on the social connections and coping strategies that are in place within the family and the community. The Capability perspective looks at the interaction between individual characteristics and social restrictions and measures outcomes in terms of expanding choices and freedoms. Limiting the definition to a merely quantitative one, or gathering information on income and institutional access, and trying to categorize different types of disabilities into broad groups, would mean underplaying the dynamics that exist between the individual and the community. The CA takes into consideration the individual within the social groups that he/she belongs to, as well as the institutional factors, which may influence his/her choices. It forces the analysis to focus on the extent to which social and cultural dynamics of the context contribute to expanding or impeding the spectrum of choices of the individual, notwithstanding the fact that such choices may be extremely limited.

Secondly, the value placed on human diversity and the interactions between disability, gender, cultural and ethnic dynamics and religious implications is also particularly important in view of the research carried out in a context such as Afghanistan. 'The difference entailed by these variations has to be accounted for, when addressing the demands of equality' (Terzi, 2005: 209). The burden of physical disability on men injured during the war is considerably less than that of the same disability on a young unmarried woman disabled at birth. Comprehending the dynamics of a disabling situation in all its complexity is the first stepping-stone to

defining policies that will be accepted and consequently achieve long-term sustainability.

Finally, the agency of the individual in the capability perspective looks at whether and to what extent, the person considers him/herself as the main actor and decision maker in his/her own life. This aspect is linked with viewing oneself as the main actor in defining a positive outcome for the future, and is closely linked to the concept of 'power', 'agency' developed by Sen as a person's '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: 19). In Afghanistan, the agency of the individual needs to be considered alongside the power structures of the family and of the community.

Defining Disability for Data Collection

The main aim of the NDSA was to provide a comprehensive analysis of disability in Afghanistan, prevalence rates and information regarding all major issues concerning access to public services, livelihoods and social participation of persons with disabilities. These objectives were defined to fit with the demands of the funding agencies as well as the political partners. Although the overall goal of the survey seemed clear, its political implications and consequences were less obvious. The results of the survey would impact disability policy and practice in Afghanistan by explicitly challenging the premises upon which the then existing policies and practices were based. The study was also aimed at providing insights and recommendations for a national disability strategy, even though other organisations would also benefit from it.

The NDSA, a national cross sectional random sample survey, was conducted from 21st of December 2004 until 20th of August 2005. A sample size of 5250 households was calculated: this estimates a disability prevalence rate of 8 per cent or greater with 95 per cent confidence and 10 per cent precision when considering a design effect of 2. Face-to-face interviews were conducted with all disabled persons over 4 years old, or with a caretaker as a proxy respondent, as well as with a control group of non-disabled people. 5,130 heads of household as proxy respondents for 38,320 people, 957 persons with disabilities and 1,739 non-disabled persons participated in the study (for more details see Bakhshi et al., 2006; Trani and Bakhshi, 2008).

Based on the abundance of literature on the concept of disability, the NDSA adopted a functional definition keeping in mind certain pre-requisites. Firstly, the definition needed to be functional and serve as a basis for the design of a questionnaire that took into account individual, institutional and societal factors and their interrelations. Secondly, the conception of disability needed to be relevant to the Afghan context and take into account gender, ethnic and social factors that contribute to vulnerability. Finally, the definition needed to reflect that dynamic interrelations between the individual and the family/community.

Conclusion

We have argued that this research, built on the CA, provided the necessary information about needs, well-being as well as values and goals or agency of persons with disabilities (Sen, 1985a, 1985b, 1995, 1999) to develop a disability strategy in a somewhat different perspective from the one that has been to date unsuccessfully implemented. As several studies and observers have been increasingly emphasizing

the relative failure of the international intervention as well as the raising frustration of the Afghan population in this regard, the need for a shift in the conception and implementation of the development process seems critical (Donini, 2007; Montgomery and Rondinelli, 2004; Tadjbakhsh and Schoiswohl, 2008). The lack of effectiveness is increasingly a consequence of the international community mistakes and passivity as well as general political reluctance of policy makers to hand over ownership of the implementation process and enhance the agency of vulnerable groups in a coherent manner. Yet, some of the principles for improving humanitarian and development aid impact have been suggested at the very beginning of the current situation (Allan, 2003; Goodhand, 2002; Stockton, 2002): political will to deal with regional conflict issues, significant resources for a significant impact, right timing, having an historical perspective to avoid perpetuating inequalities between the few benefactors and the huge mass of excluded from the aid effort, bottom up strategies, Afghan leadership and capacity building. Our study shows that disability initiatives should be based on the same principles. We further argued that by providing relevant knowledge gathered using the CA, we provided elements of understanding for lobbying decision makers, improving the coordination of stakeholders, strengthening relevance and legitimacy of policies and programmes. These have to be adapted to the needs of the community.

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