You and me together ability forever

We care for the dignity...

...and we promote the rights...

of people with disability.
Introduction

It is currently estimated that 3.7% of the Afghan population (over 850,000 people) suffers from various forms of disability. Inclusive initiatives are still very limited while perceptions on disabilities are still very rooted in culture and traditions. Based on a research conducted between August and November 2004*, this document presents keys points regarding perceptions and attitudes of Afghans towards Disability and levers for positive changes.

1. Living with disability in Afghanistan … against all odds...

The main problem disabled people face is segregation from society.

- Verbal & Physical abuse,
- Lack of access to education and livelihood opportunities,
- Lack of social opportunities (marriage, family life, etc.),
- Lack of appropriate healthcare and treatment,
- Abandonment (Mariestones for intellectually disabled people)
- And discrimination

are the main forms of this segregation. This isolation is not limited to the disabled individuals; it also affects the disabled people's family's status in society.

"My daughter is very sick. She claps, jumps, laughs and runs everywhere in the streets. We are all upset about this. People call her diwana. No one wants to rent their house to us: they say ‘your daughter is mad: she will disturb and ruin the house’.

A mother of a 16 year-old mentally disabled child living in rural Kabul.

The impact of this segregation is particularly hard for:

- Poor people with disabilities who are the most vulnerable
- Disabled women who are considered to be more ‘incapable’ than disabled men and suffer from indifference, discrimination and isolation
- Mentally disabled who are the most discriminated against
- Disabled children who are isolated, deprived of access to education and not taken to public places or social gatherings.
- Mothers who have to bear ‘the burden of guilt’ since they are primarily blamed for their children's disabilities.

"I don’t like going to weddings. When I bring my two children I feel ashamed because they call me madar-e-kor (mother of blind) and ask me why I bring my two children”.

Mother of two blind children in Herat

This segregation results in a lack of self-esteem and a pervasive feeling of shame among disabled people.

* Source: 'Statistic and Disability Planning: Afghanistan Database' from the Minister of Martyr and Disabled, 2003

*Note on methodology

The contents of this document are based on a qualitative study conducted in Aug/Sept 2004 in 3 regions of Afghanistan (Kabul and neighboring districts, Jalalabad and neighboring villages, Herat - mainly urban areas).

The study involved a literary review; field research with organizations conducting projects with People with Disabilities (PwDs); 4 Case-Studies; 480 In-Depth interviews; and 48 Focus Group Discussions.

It was conducted with men and women from 7 different stakeholder groups: disabled people (people with visual impairment, people with hearing and speech impairment, people with mobility impairment, people with a physical deformity, and people with intellectual disability), families of PwDs, community members (including potential employers), opinion leaders in communities (influencers, Mullahs, WaliS / Malik, Teachers), social workers in disability projects, medical practitioners (orthopedist, physiotherapist, doctors, etc.), and traditional practitioners (hakim, bonesetter, daiyas, etc.)
Consequently disabled people tend to isolate themselves all the more so than integrating processes (like treatment, education and employment) are very weak:

- **Multiple and at times contradictory treatments**, from traditional and modern medicine, are sought by disabled people and their families.
- For children with disability, **school enrollment is low** and drop-out rates are high.
- **Traditional support systems are deteriorating**, especially at the community-level.
- **Levels of illiteracy and unemployment** are high among disabled people.

"I couldn’t communicate with them [children in school] anymore. Day by day, I became distant from the other children”. That is why many children come to the Herat Blind Association because they feel that “people understand them”, and “they can make friends with people who face the same problems”.

**A young blind man from Hirat**

"When a child gets older that is when s/he becomes a burden for the family. [...] But it all depends on the economic situation of the family, sometimes they cannot buy crutches or they need someone to go or be with his/her all the time, then this person cannot work”.

**Village Doctor, Khak I Jabar**

"Common people are not ready to get their daughters or sisters married to disabled whose family is poor. If the disabled is from a rich and literate family someone may be ready to marry them”.

**Amputee, Khak I Jabar**

"Everybody rejected me and now I have become an old single woman. The relatives and community people laugh at me that I am disabled and have become old and still single”.

**Woman of 45-50, who has a speech impairment and a leg deformity and could not get married**

2  **Ignorance... one of the main reasons of exclusion**

There is a general lack of knowledge and capacity within families and communities to interact with and care for people with disabilities, especially the intellectually disabled.

**Ignorance, taboo, and prejudice.**

People don’t know what are the causes, the preventive measures or the possible cures for disabilities:

- They lack understanding of different types of disabilities and confuse Malul (disability caused by accident) and Mayub (disability caused by birth).
- It is considered a taboo or a dishonor to discuss causes of birth-related disabilities and having disabled children is considered a shame.
- Children have a biased attitude towards disabled people.

"If I had become a martyr it would have been better for me. Becoming disabled I cannot work. I am the oldest son, but I cannot take part in tarbur and I cannot take care of my family. It is because I have a disabled life. Martyrdom is more respected than mayub”.

**Chakari, leg amputee, rural Kabul**

"He [an old man] told me:’Day by day you will loose your respect, now that you have lost your leg’. He was a very experienced person and I became sad about what he said. But then I started noticing myself that I was losing respect in my family. Before the accident I supported my family both financially and physically. I helped my brother and father. But now that I had one leg I could not do that. I was loosing respect in my family. In the community you know they loose respect for you because they can see you cannot help your family”.

**Mohmad Aslam, 50 y.o, amputee, Kabul**

"For disabled children it is still okay but as soon as they grow older they lose respect, and people start laughing at them”.

**Grandmother of three mayub children, Khak I Jabar**

5  **Steps of marginalisation**

- Loss of respect within the family
- Loss of respect within the community
- Impossibility to get employed
- Impossibility to get married
- Impossibility to have offspring
Ignorance about ‘Ability’
- “Taking care of others” is essential to be considered ‘able’. However disabled people are considered to be incapable of taking care of themselves.
- Disabled women are believed to be reproductively challenged or incapable to bear children.
- A common belief is that children with disabilities cannot learn and their parents have low expectations for them. The lack of special education facilities for these children reinforces this exclusion.

Integration of People with disability in the society can be achieved by:
- Increasing people’s understanding of the causes of disabilities and the abilities of the disabled
- Changing people’s attitudes, especially reversing negative attitudes
- Changing children’s attitude
- Improving health-workers approach towards disabled people
- Improving the self-esteem and confidence of disabled people
- Showing disabled people can take care of others, not just themselves
- Increasing opportunities for physical, economic and social integration of disabled people in daily activities

3. You and me together, ability for ever ... how to reinforce inclusive attitudes to favor ability among disabled people

“One of my teachers taught me how to make tarwiz narwiz and with this profession I got married and so far we have been making a living”.
Blind mullah, married to a blind woman, Kabul

“When a person with disability works, he feels that he is part of society and forgets his/her own disability”.
26 year-old female tailor from Kabul.

“I work as a program officer now. There is no more difference between me and the others. In school, the teacher would say that I wasn’t capable of walking up to the black board, even though I was the first of my class, and she didn’t let me play with other children. This job helped to gain confidence and now I know I am very capable. I don’t care what people say anymore”
22 year-old woman with polio-related physical disability from Herat.

Better knowledge of the causes and nature of disability
Better knowledge of how to take care of disabled people
Better awareness of abilities and capacities of disabled people
Change negative perceptions and attitudes about disabled people
Ameliorate status and position of disabled people within their family and community
10 actions to implement these changes:

1. Public information campaigns, especially presenting the abilities of persons with disabilities
2. Train and sensitize health workers, particularly female health workers
3. Provide facilities and services to families to take-care of their disabled family-members
4. Improve people’s knowledge about causes, and treatment of disabilities through mass media, religious leaders, and modern and traditional health practitioners
5. Sensitize children about disabilities in schools
6. Communicate to parents about the abilities of their disabled children. Help regular schools integrate disabled children and promote inclusive education
7. Improve health services and facilities for disabled people (e.g. at Maristoons)
8. Create network/peer groups for disabled people
9. Improve physical accessibility to public places, like mosques, govt. offices, schools
10. Create incentives for employers to hire disabled people