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Disability Assistance in Afghanistan: Afghan Perceptions on Disability

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DISABILITY ASSISTANCE IN AFGHANISTAN

"Afghan Perceptions on Disability"

*A research project on
the perceptions and practices regarding disability in Afghanistan,
for the development of awareness raising and advocacy communication
strategies*

FORMATIVE RESEARCH - DRAFT DOCUMENT

Prepared by Altai Consulting for
UNICEF AND UNOPS/CDAP-UNDP/NPAD
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THANK YOU TO THE FOLLOWING:
ALL PARTICIPANTS
HERAT BLIND ASSOCIATION
HANDICAP INTERNATIONAL IN AFGHANISTAN
And all people who directly and indirectly
collaborated and provided support on this project

Executive Summary

More than 20 years of war in Afghanistan has left a legacy of landmines, malnutrition, poor health conditions and inadequate health care. It is currently estimated that approximately 3.7% of the Afghan population live with some form of disability. This significant number of affected people and the problems they face in daily life activities represents a significant challenge for the entire Afghan society. Discriminatory practices and prejudiced attitudes render disability more handicapping, making the persons with disabilities more vulnerable and more exposed to poverty. UNICEF and UNOPS/CDAP in collaboration with the Ministry of Martyrs and Disabled and UNMACA put together a strategy plan named “Awareness and Advocacy for the Rights and Hopes of Landmine Victims and People with Disability”. Part of this plan was to elaborate and implement a communication strategy for awareness raising activities. As a first step, a formative research study was carried out in 2004 in order to gain an understanding of the perception of disability in Afghanistan and its impact on the livelihood of the persons with disabilities.

1. Objectives of the research

The overarching objective of the research is to explore the beliefs and associations, knowledge, attitude and practice of the different stakeholders and explore the change agents related to the integration of the persons with disabilities into Afghan society. It aimed to provide better understanding of what exclusionary attitudes are based on: what are the social and cultural barriers in the community/society that keep people with disabilities from fully participating in social and economic activities.

2. Research findings

a) Social interpretation of ‘disability’ and its causes

Mayub versus malul

In Dari language there are words to describe persons who were born with impairment (*mayub*) and those who acquired the impairment through their lives (*malul*). The popular interpretation of disability often associates the *mayub* with the image of a full body that doesn’t function well, and the *malul* as a body with missing parts. *Mayub* are often related to unexplained or unclear causes. There is a tendency to feel more pity towards *malul* because they used to be ‘normal’. As for *mayub*, they are generally perceived as incurable. In those cases, the person with disabilities and his/her family will resort to religious and supernatural explanations (God, spirits, magic, fairies).

Consequences on management of symptoms

A general lack of understanding of the causes of disability has consequences on sought after treatments. This lack often leads to a combined use of modern medicine, traditional medicine (bonesetter, masseur) and spiritual healing (mullah, shrines) to treat disabilities. However, medical and traditional healing practices tend to be incompatible. Communication difficulties

between medical practitioners and their patients can also provoke confusion about the causes of disability.

b) General perception of disability

People with disabilities suffer from verbal abuse and indifference. Physical abuse is also a reality for the disabled. People with disabilities are still seen as half, not complete and sometimes unhealthy, and therefore not in total possession of their abilities. Due to these forms of social hostilities, people with disabilities not only find it difficult to socially integrate in the community at large but these hostilities also affect their self-esteem and their willingness and ability to engage in social activities.

The research also examines the variation of attitude towards different types of impairment.

- Visually impaired persons are often associated to the character of a qori, they might benefit from the positive image as being wise, religious and knowledgeable. However marriage and employment remain difficult.
- Physically impaired persons, depending if they are mayub or malul, are considered to have different capabilities. Malul are perceived as more capable and gain more respect, as they are associated with war-victims.
- Physical deformities particularly affect women, as they decrease considerably the chances of marriage.
- Speech/hearing impaired persons, though often are confused with the intellectual/learning impaired, are usually perceived as more capable than those with other types of disability in terms of ability to work and get married.
- Intellectual/learning disabled are frequently ignored and left aside. They are the most stigmatized and excluded among people with disability. The existence of maristoons is relevant to this matter.

c) Position of the person with a disabilities in the household

The role a person has in his/her own family is crucial so it changes according the expectation of his/her family members at the different phases of life. Each stage presents opportunities and barriers.

During **childhood**:

- Families tend to have a mix feeling of shame and over-protectiveness that can leave a child isolated and under stimulated. If a child is born with a disability, the guilt is often put on the mother.
- Families generally tend to be supportive of children with disabilities, though they may feel lost regarding knowledge on how to take care and communicate with the child.
- The rate of school drop out among children with disabilities is high.
- There is reluctance from families to send a disabled child to regular formal school for fear of the child will be ridiculed by of other children and because of inadequate school structures.

During **adulthood**, there are three distinguishable stages:

- i. From Child to Adult:
 - There is little confidence in a person with disability's capacity to work. The status of an individual is based on his/her productive ability and his/her participation in household livelihood.
 - Having a family member with disabilities might disrupt competition between families, as the traditional *trabgani* requires.
 - Asking for assistance or accepting traditional charity support derived from religious obligations is often perceived by the recipients as shameful.
- ii. Marriage:
 - Eligibility for marriage is very much linked to employability and on the social status of a person within the family and within the community.
 - The presence of a person with disabilities in the family can affect the eligibility of other members of the family or their marriage negotiation process.
 - Arranged marriages can help facilitate the chance of a person with disabilities to get married.
 - Marriage, for both sexes, improves a disabled person's position in the family and community and provides the opportunity to overcome marginalization.
 - It is more difficult for women with disabilities than for men. They are often perceived as reproductively challenged.
- iii. Bearing children:
 - The amount of non-disabled children, especially sons, will further normalize the position of the person with disabilities within the extended family.
 - If a child with disabilities is born there remains hope for a non-disabled child to be born to carry the family forward.

3. Recommendations

Disability is a social phenomenon. How a person with impairments is perceived will considerably affect family status, eligibility of marriage, employability, and self-esteem. Though health and social service provision are crucial to enable persons with disabilities to live a full and independent life, a sustained communication program is also needed to challenge the negative attitudes and ignorance towards persons with disabilities. This research indicates to what extent prejudicial perceptions, discriminatory attitudes and practices are based on a lack of knowledge and awareness about disability.

In this context, integration process for people with disabilities first means:

- Changes in the self-perception and empowerment of segregated individual
- Changes in the family representation and attitude towards the people with disabilities, especially focusing on his/her abilities.

And in a broader way:

- Encourage the participation and the contribution of the person with disabilities in the household livelihood and welfare

- Encourage employment or creation of income-generating activities of person with disabilities
- Encourage information and knowledge about causes, treatments and means of prevention of disability

A communication campaign should target the different levels of the society:

- a) Focus on self-perception by giving self-confidence and self-esteem of people with disabilities: through the participation of the people with disabilities themselves and organization of people with disabilities
- b) Focus on the integration in the family and stigmatization that family have for their disabled family members
- c) Focus on inclusive attitude within the communities: schools, mosques, medical/traditional practitioners and society as a whole

A communication campaign should also target the different stages of person with disability's life:

- During childhood
 - Improve education ability
 - Improve the knowledge of parents and relatives on how to communicate with the child and child development
 - Improve community awareness; including behavior of other children
- During adulthood
 - Improve employability
 - Improve awareness on causes of disability
 - Improve awareness on prevention; especially break the taboo on genetically and consanguinity caused disability
 - Remove prejudices on inability of disability in order to improve eligibility to marriage

Special attention should be given to each type of disability as they suffer from different stigmas and discriminative attitudes. The research confirms that disability is a cross-cutting issue. Therefore changing the perceptions of disability should be accompanied by macro level programmes, by the development of indigenous economic and support systems, and should be incorporated in all development programmes and projects, including existing health and education sector programmes.

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1. Introduction

More than 20 years of war in Afghanistan has left a legacy of landmines, malnutrition, poor health conditions and inadequate health care. It is currently estimated that approximately 3.7% of the Afghan population (some 850,000 people)¹ live with some form of disability. Persons with disability and their families are often marginalized. This significant number of affected people and the problems they face in daily life activities represents a significant challenge for the entire Afghan society.

Different Afghan and international organizations have developed projects in recent years to raise public awareness and improve the general perception of persons with disabilities, to create support structures, and to advocate on behalf of people with disabilities to potential employers and for public services. UNICEF and UNMACA in collaboration with the Ministry of Martyrs and Disabled and CDAP/UNOPS put together December 2003 a plan named “Awareness and Advocacy for the Rights and Hopes of Landmine Victims and People with Disability”. Part of this plan is to elaborate and implement a communication strategy for Disability Awareness and Advocacy assistance.

This communication strategy aims to raise the level of awareness within Afghan society towards disability, changing behaviors, and creating opportunities for social integration and advocacy for people with disabilities. It will target not only the people with disabilities and their family members, but also the communities, influencers and stakeholders involved in health and social care.

As a first step of the elaboration of a communication strategy, a "formative research" study was undertaken. This was a necessary phase to gather up-to-date, comprehensive data and insights on disability issues for which a communication strategy can be developed.

1.1 Research Objectives

The overarching objective of the research is to explore the beliefs and associations, knowledge, attitudes and practices of different stakeholders, and explore change agents related to the integration of people with disabilities into afghan society:

- The perceptions and self-attitude of the people with disabilities;
- The perceptions and attitudes of the family about their disabled family member;
- The perceptions and attitudes of the community about people with disabilities;
- The perceptions and attitudes of potential employers and institutional service providers;
- The advocacy practices and possibilities around disability;

This research will be the basis for the design of the communication strategy for disability awareness and advocacy assistance in Afghanistan. It will also bring together the different organizations involved in the field of disability assistance and provide them with a common base

¹ Source: ‘Statistic and Disability Planning: Afghanistan Database’ from the Ministry of Martyr and Disabled, 2003

of information about awareness, practices and communication opportunities throughout the country.

These outcomes translate into the following objectives for the study:

- Identify beliefs and associations, drivers and barriers related to disability; this will include an understanding of the perceptions each audience has of the different types of disability, some being more acceptable than others.
- Understand the **k**nowledge, **a**ttitude and **p**ractices (KAP) related to disability, in the different circles of life/audiences identified above.
- Identify influencers and forces for change/change agents.
- Gather input from the various stakeholders on sustainable ways to increase the level of awareness of the different audiences.
- Explore communication opportunities through media, influencers and decision makers and informal sources of communication.

2. Research Methodology

2.1 Research Tools

The purpose of this research is to gain an in-depth understanding of behaviors and cultural beliefs on a problem that affects both urban and rural communities. A qualitative study in a variety of communities in 3 regions of Afghanistan, involved:

Preliminary Research: literary review and field research

A preliminary period of 10 days was allocated for a research expert to observe and participate in fieldwork together with an organization conducting projects with people with disabilities. During this period, a number of individual cases were analyzed (2 cases per type of disability was targeted) in different environments. This allowed the research expert to gain first-hand insight on the typologies of disability and attitudes generated within families and communities. This allowed researchers to build accurate questionnaires and guidelines, and direct illustration of the problems being addressed along with a strong understanding of the environments.

Survey with In-Depth Questionnaires

Four hundred and eighty (480) questionnaires were sent in the regions in order to get a reliable picture of general awareness, beliefs and attitudes among different audiences and in different socio-cultural and cultural environments.

Focus Group Discussions

Forty-eight (48) focus groups were organized in various locations and among different audiences to provide strong qualitative information. These discussions and dialogues complemented the 480 interviews and followed an approach as outlined in the guidelines developed for the research.

Case Studies

Four case studies were conducted by two socio-anthropologists to obtain an in-depth understanding of the behavioral and cultural beliefs and perceptions of people with disabilities, both in rural and urban areas in the regions of Kabul and Herat.

Note Bene: Interviews were conducted in Dari and Pashto. When necessary, interviews were held in homes, this particularly with women interviewees.

2.2 Locations

The research was conducted in the following areas:

- Central Afghanistan (Kabul and neighboring districts): Tadjik/Pashtoun ethnic group mix.
- Southeastern Afghanistan (Jalalabad and neighboring villages): Dominant Pashtoun ethnic group with influence from Pakistan.

- Western Afghanistan (Herat – mainly urban): Tadjik group was dominant, Hazara among the community of returnees with an influence from Iran.

2.3 Stakeholders

In-depth interviews and focus groups were conducted among 7 different stakeholders:

1. Disabled people in the following 5 main categories of impairment
 - 1a. People with visual impairment
 - 1b. People with hearing and speech impairment
 - 1c. People with mobility impairment
 - 1d. People with a physical deformity
 - 1e. People with intellectual disabilityFor each category of disability, an equal number of men and women were interviewed, both in rural and urban settings.
2. Families of all people with disabilities (including the same categories of disability, gender and age as above).
3. General public (community members), including potential employers
4. Opinion leaders in communities (influencers)
 - Mullahs
 - Wakils/Malik
 - Teachers
5. Social workers in disability projects
6. Medical practitioners (orthopedist, physiotherapist, doctors, etc.)
7. Traditional practitioners (hakim, bonesetter, daiyas, etc.)

2.4 Categorization of Disabilities

It was not always easy to identify the nature and cause of a disability. At times, the interviewees would often not know themselves. Sometimes the interviewees would not tell the ‘truth’ or more often would indicate a particular disability that was not apparent to the interviewer. But since the interview team did not include a physician, specific diagnosis could not be made. However, through the detailed questionnaire, all attempts were made to ensure that the interviewee was in a ‘handicap situation’ rather than suffering from a medical ailment (e.g. arthritis, etc.).

For the purpose of the research, we used the following categorization to classify the interviewees:

- Disability related to learning/intellectual impairment
- Disability related to physical/mobile impairment
- Disability related to sensorial impairment (visual, hearing and speech)
- Disability related to physical deformity²

² A majority of people, men and women, from Kabul or Khak I Jabar, told interviewers that physically deformed people were not really ‘disabled’, as ‘they can still work’. In essence those people whose disability does not affect their capacity to fulfill the expected role within the family, are not considered disabled. “Physical deformities are not important; she can work and take care of people”. (Shirin, 35, wife of amputee, Kabul) Later, when asked about

This stereotyping categorization might be controversial but is it as close as possible as to what Afghan people consider as disability. Because there is an understanding that ‘as long as disability is made more handicapping by the neglect, prejudiced attitudes and discriminatory practices of society, it is society which needs treatments and rehabilitation, not the person with disability’ (Berry & Dala, 1996). Therefore, in this research, it was decided to understand and stick to community perceptions and definitions of the issue.

2.5 Constraints and Difficulties Encountered

People with mental and hearing and speech disorders

Interviewers could not interview people with mental disability and hearing/speech disorders on an individual basis for obvious reasons. People with hearing/speech impairments needed translator and it was often very difficult to find sign language translators for this purpose. Despite this, a group discussion with this audience during the field research was managed. Within the sector of people with mental disability, interviews were mostly conducted with their available family members.

Disability is a sensitive issue

In a general way, talking about disability is a very sensitive issue, especially among women. Women, especially those who are unmarried, found it hard sometimes talking about their lives as people with disabilities. Some interviewees cried with regards to certain questions.

“Why do you ask us so many questions? It is like putting salt on our wounds.”

Female Interviewee

Difficulties during training

Interviewers sometimes felt ashamed and embarrassed to talk with people with disabilities and ask questions about particular issues. During their training, it was observed that the interviewers’ own perceptions on disability were filled with misconceptions and prejudice.

Security in Herat

Two case studies were supposed to be conducted in the region of Herat, one in the urban area and the other one in the rural area. However, during period intended for fieldwork in this area, armed conflict began between conflicting regional factions. The fieldwork in urban Herat was interrupted for several days and security measures did not allow the social-anthropologist to conduct research activities in the rural areas. Therefore only urban area case-studies were conducted the Herat region.

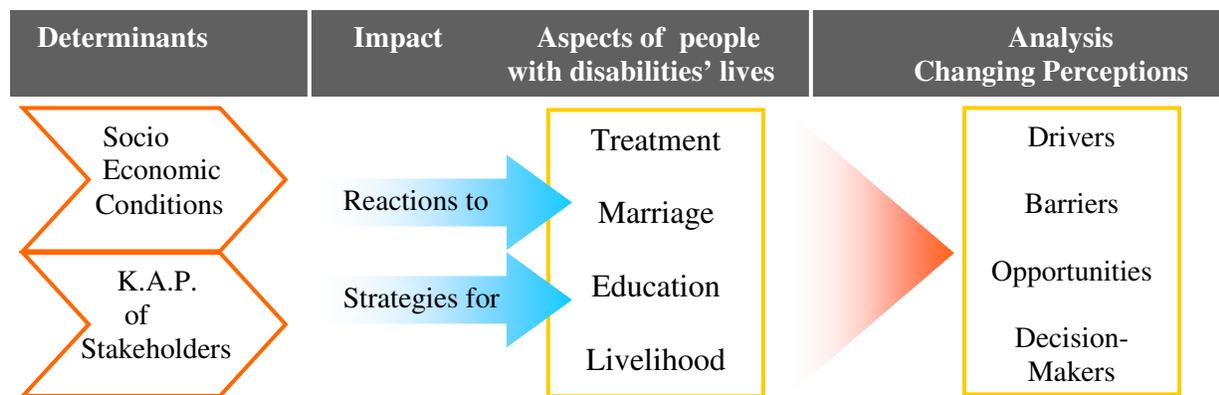
marriage and disability, Shirin said that a physical deformed person can get married: “because either s/he can still be cured or because s/he can still work and take care of his/her family”.

3. Results & Findings

3.1 Research Approach

The **actionable** objective of this study was to gain an understanding of the perceptions of disability in Afghanistan and its impact on the livelihood of the people with disability. Because there is the belief that “disability is often what we perceive; it is in the mind of the perceiver. Disability policies, programmes and practices of any country are manifestations of the attitudes which the people in different cultures share” (Berry & Dalal 1996), to this end, the ‘perceivers’ social representations of disability were analyzed.

To meet this objective, we adopted the following research approach:



- First the determinants that impact various aspects of people with disabilities were investigated:
 - Socio-Economic Conditions
 - Knowledge, Attitudes and Practices (also reflecting cultural issues) of key stakeholders:
 - The people with disabilities themselves,
 - Families of people with disabilities, and
 - The community-at-large (including potential employers)
- The impact of these determinants was then explored in terms of the reactions and strategies stakeholders adopt with respect to the following core-aspects of people with disabilities' lives:
 - Treatment
 - Education
 - Marriage
 - Livelihood

- Based on this understanding of the interaction between socio-economic conditions and the KAP of stakeholders; and the resulting perceptions, reactions and strategies associated with the core-aspects of people with disabilities’ lives, the following was identified:
 - Key perceptions that need to be challenged (or strengthened),
 - Triggers/drivers of these perceptions,
 - Barriers and opportunities to address these perceptions, and
 - Key decision-makers who need to be focused on

3.2 Determinants

3.2.1 Demographic Variables

In addition to the different types of disabilities, socio-economic indicators were taken into consideration for the analysis of the results of the research. The indicators considered are as follows:

- Economic Situation: Based on the ownership of the house, land property (mainly in rural area), the profession or regular income generating activities.

The economic level of a family is a pivotal factor that impacts the degree for which a person with disability is integrated within the family and the community. For example, a person with disability having an income or property will have more chances for marriage and to participate in the dynamics of social interactions, such *trabgani* (see further).

- Level of Education

Education provides higher status and is perceived as enabling. Additionally, education affects how people with disabilities and their families understand the causes of disability and what kind of actions and strategies they need to have to cope with disability.

Education combined with the economic situation has an impact on how the people with disabilities deal with their disability and how they are treated and integrated into society.

- Location: Rural/Urban

Location (rural vs. urban) is heavily linked with access to opportunities (education and economic) and services (health, rehabilitation, etc.). In rural areas, cultural norms and networks like *Trabgani* (see below) are stronger. Location also has an impact on the attitudes and practices of people with disabilities and their families but also the community perceptions and support structures vary too.

- Age

The way families and communities perceive an individual with disability depends on and evolves with the age of that individual. As will be explained later, a disabled child does

not suffer nor benefit from the same perceptions as a disabled adult. Also, the understanding of and responses to disabilities vary with respect to the age of the disabled person. For example, in many cases, a child who has speech/hearing impairment is often perceived as having mental disability.

- *The Position in the Family*

The hierarchal position of a disabled person within his/her family has influence on how the person is treated. In our study we came across some families, who had several offspring with disability: the eldest, especially if male, was privileged when it came to invest in treatments.

- *Gender*

Throughout the research, special attention was paid to the gender aspects of disability. Gender is definitely a determinant factor to be taken into consideration when doing research, especially in the Afghan context where women are inherently and traditionally in a difficult position.

When asked for whom is it more difficult to be disabled, for women or men, there were two contradictory responses:

- It is more difficult for women with disability because they are the “weak part of society”. Often they are considered weaker and more vulnerable:

“malul women are more incapable than malul men”

Focus Group with men from Herat

- The situation of men is seen as more difficult because the man, as a breadwinner, has more responsibility, so life is harder for a man with disability. It is *‘easier as they (women) stay in the house anyway’*.

Indeed, the issue of women with disability relates to the general situation of women in Afghanistan. The rules of Purdah are still in effect for Afghan women, especially from within the Pashtun culture. To one degree or another, women are usually kept quite secluded behind the family compound walls.

However, as Hunt (1991) observes, women might be more or less secluded, but “regardless the location, they are active participants in social exchange, visiting neighbors or meeting at shrines, weddings, etc...”

When speaking with women about their disabilities, the discussion very often led to gender issues in a broad way.

Example of a Focus Group discussion with women with disability in Kabul:

Question: “What is the most difficult situation for person with disability?”

Women's Answers:

The disability itself is the worst thing for people, particularly when they remember healthier days of their lives.

Some women say that when they want to say something, the whole family says: 'shut up, take your meal and say nothing'.

"I recall a time she was practicing in Paghman. I saw women picking up wood from the mountain in a knapsack. They had severe neck and waist pain and some of them were paralyzed because of the heavy work. They did not have enough food to eat and they were very weak and malnourished. I suggest equal rights should be given to women and to men."

"I agree with her! Some men do not allow the women to go out of the house or work in society. Not allowing a woman to work makes the disabled women worst."

"I agree with all others. Despite the fact I lost my hand and my husband is blind of one eye and one leg is crippled, when he is coming back from work, his leg bleeds because of work and he has pain from his disability. This is a tough situation for both of us".

The gender of the people with disability does not only affect the way s/he is perceived, but also how the community at large treats him/her socially and practically. For example, with regards to medical treatment:

"Women are usually referred to the general surgery department. Men are stronger and can tolerate the pain – you know, a surgery can last up to 6 hours. Women are not strong enough to stand such pain",

Orthopedic surgeon in Herat

This surgeon noted above would usually send his female patients to the general surgery department, as he perceives women as not *strong enough* to go through an orthopedic surgery. This implies that there are cases where practitioner's approach will differ according to the gender of his patient. Women will not necessarily benefit from the same treatments as men.

3.2.2 KAP of Stakeholders

3.2.2.1 General: Definition & Causes

The basic definition and categorization of disabilities in Afghanistan is based on the 'interpreted' causes of disability: *mayub* vs. *malul*. These interpretations occasionally vary, and therefore in turn result in mixed categorizations and varying perceptions regarding people with disabilities.

- Definition of Mayub and Malul

The first aspect of disability in Afghanistan is the difference between *mayub* and *malul*. In Dari they are the two words that are translated and are related to the English word 'disability'. Officially, the definitions of *malul* and *mayub* are the following:

***Malul:* is a person who became disabled because of an accident (war, mine, car accident, disease etc.)**

***Mayub:* is a person who is disabled at birth.**

However, a person's interpretation of *mayub* and *malul* can have different meanings. In general, people know that one of the terms is related to birth-caused disability and the other term to accident-caused disability. However, very often all mental disability and sensorial disability are considered in the category of birth-related disabilities and all physical disabilities in the category of accident-related disabilities. Additionally, people occasionally qualify an amputee a *malul* and the deformed – when the body members are “dry” {*khushq*} – a *mayub*.

As the wife and the brother of Raheem, a man with mental disability disabled, said:

“malul are those who do not have arms, feet nor sight. But Raheem is complete, people call him mayub, everything is ok but not working. Deaf and dumb are mayub.”

So the *mayub* and *malul* in colloquial terms can be related to the physical aspect of the disability.

In other words, the social interpretation is as follows:

Malul: The body physically misses limbs or eyesight

Mayub: The body looks normal but does not function well.

There is generally more compassion for *malul*, as *malul* used to be “normal” or “healthy”.

“Physically there might not be so much difference between malul and mayub but if we dig about it, in this case, malul are more affected than mayub. Because mayub are sick since the day they were born. But malul used to be fine and healthy and because of an accident, they become malul”

Malik, 42, rural Herat (Sea Oshan) – all the participants of the FG agreed.

It appears to be easier for the non-disabled people to sympathize with problems faced by a *malul*. A *mayub* was always in the same state of disability; whereas a *malul* is in “deep suffering because he can remember when he was normal”. In conclusion, a *mayub* does not know what being normal is so he cannot suffer from that feeling. So *malul* are more pitied than *mayub*.

- Etiology of Disability in Afghanistan

The only people who could give a clear explanation of the cause of their disabilities were the ones who were victims of an accident (war-related, by mines or car accident). In most other cases it was difficult to gain a clear medical explanation for the disability.

The causes mentioned by both *mayub* and *malul* can be summarized as follows:

- Accidental causes – including war-related causes
- Medical causes – including diseases, illnesses
- Pregnancy and delivery-related causes
- Inherited causes
- Religious reasons
- Spiritual/supernatural reasons

A special focus is given here to the causes related to *mayub* disabilities, as the causes are misunderstood most often and also because of the varying perceptions that are associated with them.

Mayub disabilities are more difficult to understand. The most quoted explanations for the causes of *mayub* disabilities were:

- Related to God's will
- Fate {kismet}
- Person affected by a *jinn* or a *pari*
- Mother careless or unhealthy during pregnancy
- Mother affected by *jinn* or shadow of *jinn* {saya}: “*she passed ashes and became possessed by jinn and became a jinn-i.*”
- ‘Blood did not match’, ‘wrong blood’
- Parents are disabled

A factor that makes it difficult for people to identify the causes of *mayub* is that often a *mayub* person has ‘normal physical appearance’. Popular beliefs have been created to explain the cause and the nature of the disabilities. As Frey & Campbell (2002) underline, “for many cultures it is not the impairment per se which the culture considers but rather what the impairment implies about the impaired person's relation to the culture's religious, cosmological, and meaning-making systems” and also “in terms of how it impacts the actions etc. the person performs”.

From all the explanations that people gave for *mayub* disability, practically no one gave a purely medical reason for the disability despite that fact that many have sought medical assistance. This phenomenon can be partly explained by the facts that doctors do not always explain clearly what the cause of the disability is or what the nature of the disability is. Some respondents said that they “were not getting any answers from doctors”

“When I was pregnant with Akhmat Shukran, it was during the war, I went to the hospital to give birth. At the same time a rocket attack occurred and I fell to the floor and gave birth there. Because of the attack everybody was so busy, nobody could look after him. After 15 days, my grandmother said that something was wrong with the child; the doctors however said no, every thing was fine. After one and half years we fled to Pakistan where the doctors said he

was disabled but there was nothing to be done. There they said he has mental problems, but he does not have a mental problem”.

Shikeba (27) – mother of four, of which two are disabled children, and one died

Religious Explanations

- “It is God’s intervention, ‘God’s will’”
- “An examination, a test from God”
- “Punishment from God because the parents ‘did something wrong’, ‘did not respect God’, ‘laughed at disabled’”

In most of the cases, this explicatory type of discourse is given by the community (individuals without any personal contact with people with disabilities) but seldom by the people with disabilities themselves or their families. Furthermore, this ‘divine’ attribution is not restricted to *mayub* cases. Even for *malul* disabilities, the misfortune of an accident or a disease is explained in these terms.

Supernatural Causes: Jinns (spirits) / Jado (magic) / Pari (fairy)

While supernatural causes for *mayub* disabilities are not readily mentioned, they did come up after the interviewees became comfortable during the case studies and the focus-group discussions. Though women mentioned the fear of *jinns* and how they affect people more often than men, men also think *jinns* can cause harm to people.

There is a common belief that pregnant women, women who just gave birth, young children and the elderly are the most vulnerable to *jinns*. The different forms and effects of *jinns*:

- *Shaya*, the shadow of a *jinn* on which one can step
- ‘passing the ashes’ can make you possessed because ashes or dust are where the *jinns* live at night
- Having the *jinn*’s babies inside the body
- simply fearing *jinns* can make the person possessed

Jinn and *pari* are often used to explain diseases like epilepsy or paralysis and especially mental diseases. They are also used to justify the birth of disabled children.

These supernatural phenomena are considered not harmful per se but “if you disturb them, they will disturb you back”. The common belief goes, that *jinns* and *pari* often manifest in nightmares, when disturbed by passing near ashes or the dust of a grave, plucking flowers at night or when someone does something bad to somebody else.

Many people did acknowledge the existence of black magic (*jadu*) or evil eye (*nazar-i-bad*), but there was practically no reference to either causing disability. The difference between *jadu* and *nazar-i-bad*:

- *nazar-i-bad*: people can cause harm to other people unintentionally.

- *Jado*: people use its power intentionally. *Jadu* can make someone become “*dewana*”.

The wife of a *diwana* (*person with mental impairment*), Mohmmad Raheem, said that his family had used black magic on him “because he was chasing the girls from the field”.

These explanations of the causes of the disability have a great influence on how people look for treatment that will be analyzed further in this report.

○ War-related Disabilities

War-related disabilities are often considered differently. There is prestige and respect associated with war-related victims. However from the victims’ perspective becoming a *malul* due to war can be very frustrating. Being a martyr is seen as a better situation.

“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 – it is better to die. Martyrdom is more respected than mayub”

Chakari, leg amputee, rural Kabul

Justifying disability as an accident of war or landmine became more acceptable for many people with disabilities and their families. Researcher became aware that some mothers who would say that their child became blind or physically disabled because of a mine explosion; though later in the next meeting it became clear that the cause was congenital or related to a disease. It appears more socially acceptable and more legitimate for people with disabilities and their families to characterize disabilities as accidents (especially war-related) rather than birth-related disabilities.

Two respondents mentioned the fact that those people who became disabled during the ‘Jihad against the Russians’ are more respected than the others.

“Those people who have become malul during Russian occupation are more respected”

Amputee man from Khaki-i-jabar

“Disabled which happened during jihad are more respected than disabled which happened during the internal fighting [when mujahadeen groups fought each other]”

Blind and handless man from Malang

○ Consanguinity & Genetically Caused Disabilities

No one mentioned disability being caused by consanguinity or congenital diseases even though many people were married to a first cousin. However there was some idea that genetics played a part in disability:

- ‘The parents’ blood did not match’; ‘the mother had bad blood’; etc. While consanguinity is acceptable and not questioned, in certain cases people do attribute congenital disabilities to lineage and hereditary.
- That there is danger of having disabled children when both parents are also *mayub* disabled
- That there is danger of having disabled children when one parent is *mayub* disabled. This was mainly mentioned when the *mayub* was mentally disabled, hearing impaired, spastic or had cerebral palsy and could not communicate ‘normally’.

- Perceptions: Malul vs. Mayub

There is a definite bias in favor of *maluliat* rather than *mayubiat*. While there is more sympathy and respect for *mayubiat* from all audiences, there is more hope and expectations associated with *maluliat*.

Occasionally people with disabilities and their families attributed *mayub* disabilities to *malul* causes in order:

- To keep up hope that the disability can still be cured
- To avoid jeopardizing future marriage opportunities
- To avoid bad talk or speculations on the causes of the disability by the community

In the case of children born with disabilities: few parents are aware of the disability of their child at the moment of birth. They discover the disability of their child much later, when he/she starts growing up and when the symptoms start showing up. This contributes to the confusion and the lack of understanding of the causes of disability.

Conclusion:

Key points about general understanding and perceptions.

Knowledge:

- General lack of understanding of causes of disabilities, especially for ‘*mayubiat*’
- Though formal medical care is sought in many cases, medical causes are rarely applied to disability
- Very little awareness of consanguinity and genetically caused disabilities
- Understanding of *mayub* causes strongly rooted in culture and folklore.

Attitudes

- Attitudes are based on the interpreted cause of disability: *mayub* vs. *malul*
- Bias in favor of *maluliat* over *mayubiat*.
- More sympathy and respect for *mayubiat* from all audiences, but there is more hope and expectations associated with *maluliat*.

Practices

- Doctors cannot always explain clearly the causes of disability, especially birth-related disabilities
- Occasionally people with disabilities and their families disguise *mayubiat* as *maluliat*

3.2.2.2 Communities

Often the common discourse among people is that they have no problem with attitudes towards people with disabilities. But, once taken into confidence, people especially those with disabilities; admit being affected by the behavior of others, which is overtly and subtly negative. According to the survey results, more than half of the people with disabilities experienced problems with people within the community.

- Verbal & Physical Abuse

Name-calling and derogatory words are commonly used with respect to people with disabilities. Even in focus groups and case studies, people with disabilities were often referred to as “half-body”, “half-human” or “not complete” and therefore “unable”, “weak”, “needy” and sometimes “useless”. In addition, having a disability is construed as “being unhealthy”.

Common terminology that are considered insults by the person with disability :

- Blind: Kor. The appropriate and politically correct word should be Nobinâ.
- Lang-losh: Amputee or person with a disability on his/her leg
- Chumta: A person who is amputee or disabled of the hand
- Diwana: A person who is mentally disabled

The survey revealed that people with disabilities felt that verbal abuse and then indifference were the main negative attitudes they have to deal with in society. Interestingly, children are considered to be the main perpetrators of these negative aspersions against the disabled. Though physical abuse is rarely mentioned and is mainly associated with family dynamics, 10% of the women and 8% of the men who participated in the survey said that they also faced physical persecution from society.

In addition to this direct barrage of negative attitudes towards people with disabilities, many study-participants also mentioned the destructive nature of “community gossip”. Cases of disability within a family are speculated about by the neighborhood, and this ‘bad talk’ leads to disrespect for the person with disability and his/her family.

Due to all these forms of direct and indirect social hostilities, people with disabilities not only find it difficult to socially integrate with the community at large, but these hostilities also directly affect their willingness and ability to engage in social activities. In the words of a mother of two blind children in Herat:

“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”.

Disabled children, in particular, are kept inside the home, because parents do not want them to suffer from these societal abuses.

- Different attitudes for different disabilities

People in general believe that disabilities can be prevented and cured. This seems to apply to all types of disabilities. However, when it comes to attitudes about capabilities, respect, community support, etc. the attitudes vary for the different kinds of disabilities. Persons with vision impairment command the most respect while the mentally disabled are considered ‘lost causes’ and are ignored.

- Vision Impairment:

“The Eye is the lord of the body. Anyone who doesn’t have this treasure deserves everything in his life so we should respect blind people a lot”,
Malik (42), Sea Oshar, urban Herat.

When asked who is the most respected, the visually impaired are almost unanimously preferred. Compared to other disability, there seems to be more compassion for blindness than any other kind of disability, even from people with disabilities themselves.

People often perceive the blind person as someone who only sees “black”, who “cannot distinguish day from night”. Interestingly, one person also said that a blind person, who has lost his/her sight, has “*the best blessing from Allah*”.

The social representation of the blind person is very much linked to the character of the Qori -- someone knowledgeable and wise. The survey-question “who is closer to God”, is most answered, “the blind” (*malul* as well as *mayub*):

“According to Islam, when you can recite the Koran, you are closer to God as you have the Koran forever in your heart”
Tailor, rural Kabul

When blind children, especially the boys, were asked what you want to be when you grow up, they all answered “*Qori*” or “*Hafiz*”.

As Miles mentions (Frey & Campbell, 2002), “in some cultures where important teachings are learned through careful listening and memorizing, blind people are thought to have an advantage over sighted people”.

This acceptability and respect at times creates untenable pressures and expectations from blind men. These men are expected to be ‘knowledgeable’ and ‘cultured’. Moreover, the only form of employment people with vision impairment is considered fit for is being a Qori or a Mullah. Some people said that ‘an ignorant blind man goes to hell... they are more prone to God’s judgment.’

Within the research, little insight was gained with regards to the status of blind women. However, from meetings with members of the Herat Blind Association, it appears that blind women are difficult to reach and that the social acceptance and respect given to blind men does not necessarily apply to women. In one focus group discussion, two mothers of blind girls said that the only possibility/future for their girls was to get them married to older or disabled men.

Though people with vision impairment might be better respected and despite having interviewed married blind people, the research shows they have a lesser chance than other disabled people to get married. On this matter, many of the participants put blind people in the same category as mentally disabled: in the focus groups, participants would say that most disabled people are able to marry except those with vision impairment and the mentally disabled.

○ Physical Impairments:

Malul whose hand or leg is missing; Mayub whose hand or leg is dried.
Physical disabled woman (25), rural Kabul

People usually differentiate physical disabilities into two types, following the pattern of *mayub and malul*:

- A person whose body looks complete but does not work (because their limbs are ‘dry’) is considered *mayub*, and
- An amputee is considered *malul*

Additionally, the community perceives these two physical impairments differently. Though both groups suffer from verbal abuses, the ‘crippled’ (*khushq*) and the ‘lame’ (*lang losh*) are considered to have different physical capabilities. The *malul* amputees, paradoxically, are seen as more capable of working than the *mayub* physical disabled, especially because of the help of prosthesis:

Now if the lame has prosthesis leg, he can work and gain more respect.
Male tailor (50), Kabul

There are mixed feelings about amputees. On the one hand, they receive sympathy and respect from people because they are often considered to be war or mine-victims.

People respects mobile disabled a lot because when they were healthy they were serving the people.
Traditional practitioner (75), rural Kabul

But on the other hand, they are often linked to the negative representation of beggars, especially in urban areas, like in Kabul: “*Amputees can only beg!*” as one man from Kabul said.

The *mayub* physically disabled, in general are subjected to only discriminatory attitudes. This can partly be explained by the fact that these disabilities cannot be attributed to obvious causes like war-injury, etc. and therefore this leads to people speculating and blaming the disabled person and his/her family for the people with disabilities’ ‘fate’.

My mother-in-law insulted me very much. They called me crippled. It was my fault.

Hand amputated female tailor, Jalalabad (23)

○ Physical Deformities:

The majority of people, men and women, said that physically deformed people were not really disabled, as ‘they can still work’. In essence, those people whose ailment does not affect their capacity to fulfill the expected role within the family are not considered disabled. However, physical deformity does affect one’s potential to get married or marry a good partner; this is especially true for girls. Some women of Kahk-I-Jabar described the criteria for a good bride as: beautiful, white, tall and fat. With women ‘beauty’ does increase their chances in finding a good marriage partner. For men it does not seem to matter how one looks as long as one can provide in a satisfactory way for a family income. When asked about marriage, many survey participants said that only the physically deformed could get married: “*because either she could still be cured or because she can still work and take care of her family*”.

○ Speech/Hearing Impairment:

According to social workers dealing with disability issues, hearing and speech impairments in children are often confused with intellectual or learning impairments. That is why these children often are treated as being intellectually or learning challenged and left behind. However, social workers also pointed out that once families have been given an explanation of their child’s impairment, they integrate the child more. Because aurally impaired individuals look ‘complete’ physically, they are perceived as more capable than people with any other disabilities in terms of working and being able to get married.

“Dumb and deaf have the chance to marry because they can work and they are not seen as burden”

Physical disabled woman, rural Kabul

Also, their capacity to think is recognized; it is just that “they cannot express themselves”. That is why there is relatively more compassion towards people with speech and hearing impairments.

“Deaf and dumb also have more chances for wedding because they are very intelligent and also they don’t have any difficulty having children”

As an adult, the hearing or speech-impaired person seems to suffer less from negative attitudes. However, when it comes to education, people generally put the speech and hearing impaired children in the same category as intellectual or learning disabled children. They cannot go to the same schools as 'normal' children; not because they do not have the capacity to understand, but because they need special treatment and 'different methods'.

○ Intellectual and Learning Disability:

The *diwana* as they are called in Afghanistan, are the most stigmatized group among the disabled. They therefore face the most difficulties in terms of integration within their families and the society.

Diwana is a colloquial term that refers to any impairment related to *asab* (mind). It is used as much for people who are depressed as for those with Down Syndrome. When asked, "In which category would you place mentally disabled," a majority of people with disabilities, their families and practitioners answered, 'a separate category'.

People with mental impairment receive the least amount compassion from society: When questioned 'to whom would you give one Afghani', no one surveyed said *diwana* because a "*diwana* does not understand"; "is not conscious" or "he doesn't realize" what an Afghani is.

A mother of a 16 year-old mentally disabled child living in rural Kabul said: "*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'.*"

Individuals with intellectual or learning disabilities are frequently ignored and left aside. As mentioned above, there is a lack of understanding about the causes of mental disabilities and compounding the situation is the lack of support and awareness about how to interact and treat individuals with mental disabilities. People also perceive mental disabilities as incurable. Even at the family level there is a lack of knowledge and capacity to take care of person with mental impairment. This lack results in callousness at the very least, and in some cases, physical abuse.

A stark example of how the society views and treats people with mental disabilities is the *maristoon* (governmental hospice) near Kabul. Many mentally disabled women are abandoned there. The hospice is essentially an asylum without any adequate medical support or sanitation. The women there are said to be *Shukhe asabi* (traumatized by war) and *diwana*.³

³ Further research should be done on the women put in *maristoon* as this could give us a good insight of what women, especially affected by mental/intellectual disability, go through and how they are treated in their families.

Conclusion:

Key points about the KAP of Communities:

Knowledge:

- General knowledge that disabilities can be prevented and cured
- Hearing and speech impairments of children are often confused with intellectual or learning impairments
- Confusion between the different types of mental disorders
- Lack of knowledge and capacity to interact with and care for people with mental disabilities
- Amputees are differentiated from those physically disabled and are believed to be more physically capable

Attitudes

- Prevalent negative attitudes exist (verbal abuse and indifference) within society against people with disabilities
- Attitudes vary for different types of disabilities: mental disabilities stigmatized the most; visual impairment the least
- Hearing impaired individuals are considered most capable
- Indifference towards and isolation of disabled women, especially blind women.
- Children considered to have the most negative attitudes towards people with disability

Practices

- Though not pervasive, physical abuse of people with disabilities is a harsh reality
- Families tend to be at a loss in taking care of members with mental disabilities, and in certain cases abandon them at *maristoons*
- Blind boys and men are expected and trained to be Qori. No other professions are readily considered for them.

3.2.2.3 Families of People with Disabilities

How the person with disability is perceived and treated within the family depends on the stage of life of the disabled person and the evolving capabilities of the person with disability to take care of him/herself and others over time:

- Childhood
 - Single adult
 - Married adult
 - Parent
- Childhood

In general, but in particular from the case studies, research found families quite supportive to children with disabilities. Some relatives really involve themselves in the support of their

disabled family members. Within the Herat Blind Association, family members (mostly mothers, brothers and sisters) came and helped organize the association.

Most of the successful people with disabilities seemed to succeed professionally or have a good confidence in themselves due to significant support from their mothers or fathers. Furthermore, the immediate older sibling generally assists a disabled child.

In some families, parents were over-protective of their children with disabilities. And because of this over-protection, families tended to keep their child indoors. This situation can lead to a complete isolation from the outside world.

Isolation can also be provoked by the shame of one having a relative with a disability. Many people with disabilities complained that when they were children their family wouldn't bring them to social events like weddings or picnics on Fridays because they would be too much of a burden.

The main reasons given by families for not taking a disabled child to 'public'⁴ places include:

- The child will be made fun of, laughed at or be scolded
- The child will be pitied by people
- The need of assistance, the child cannot be left alone
- Shame of being responsible for the child's disability (see next section on 'the guilty mother')

Often in families there is also a lack of direct communication with the disabled child. This leads to under stimulation of the child (Coleridge 1998). As the case below illustrates this is often due because of a lack of knowledge. In particular, in the cases of mental or sensorial disabilities, parents and relatives do not know how to communicate with the child.

Because of a car accident, Asifa, a 5-year old girl, went through a surgical operation and both of her legs were amputated. The mother thought she was going to die and that there was no hope. Then they were referred by regional hospital of Herat to the ICRC orthopedic hospital where Asifa went to rehabilitation and received prosthesis. After her operation, her parents didn't know what to do with her. They didn't talk to her and didn't even touch her. It was difficult for the parents to adjust to the new situation of their child. *"Everybody felt so sorry for her. She wasn't saying anything, she wasn't laughing"*. As she couldn't play with other children, she was left home. The doctor explained to the parents that they needed to pay more attention to her. Now, her parents communicate with her and bring her out. The child started talking again.

○ The Guilty Mother:

The shame of having a child with a disability, in particular in birth-related cases, may often be blamed on the parents, especially the mother. This is especially true when cultural causes of disability are considered. As mentioned earlier, birth-related

⁴ I.e. outside the household compound.

disabilities, *mayubiat*, are seen as punishment of God on parents or the fault of the mother because she has done something wrong during pregnancy.

“People always say that disability caused at birth is by jinn or bad eye. But it is not true. Or they say it is the fault of the mother or father. And it is mostly the fault of the mothers, because they take medicine when the husband is not around”.

Mother of 12 children, dai’a in Khak I Jabar.

Within two families in Kabul where they openly acknowledged the fact that ‘their blood did not match’, the mother of a disabled child in one family said: *“I know it is because of me, because I have given birth to two disabled children”.*

It seems that this ‘burden of guilt’ is transposed also to modern medical discourse. Within the group that did not attribute disability to supernatural causes, they said it is because the mother did not take care during her pregnancy, did not get vaccinated or did not take the right medication. Some say it is because the mother did not have “good blood”.

In Kabul, a mother of four ‘good’ children, who’s youngest child has paralyzed legs and is mentally disabled according to her, replied to accusations of the disability being her fault; *“I do not take it seriously whose fault the disability is. I know that all other pregnancies went normal and the doctor told me so. I know it is not my fault. But the father and the community say yes, it is my fault. They say my health was not good during that pregnancy”.* She further explains that before she was pregnant with her youngest child she was sick. *“Now my husband thinks that his son is disabled because I did not have enough blood”.*

- Adulthood: Taking care of oneself versus taking care of others

“For children with a disability 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.

As an adult with disability, the support required becomes greater and this can be seen as a burden to the family. The role of an adult, be it female or male, is to take care of someone. Adult responsibility differs for men and for women. Men are expected to work in order to earn an income or food while women are expected to take care of the household. This naturally does not mean that women have no part in income generating activities or that men have no role in bringing up the children, but these are the basic expectations of both men and women, single or married.

This is where life becomes difficult for disabled people. In general, people think that individuals with disabilities have difficulties in taking care of themselves, meaning that someone else needs to assist them or take care of them full time. Many respondents, when

asked which disabilities were ‘less respected’ than others, answered with regards to ‘the ones who cannot take care of themselves, how can they be respected?’ As it will be elaborated further in the report, this is why employability is very much linked to respectability.

“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 him/her all the time, then this person cannot work”.

Village Doctor, Khak I Jabar

“So many problems exist. If there is a mayub in a family, everyone looks at him as a headache. They say that this kind of person should be sent to a maristoon [governmental hospice] or a hospital so they can feed that person. No one helps a mayub in a family”

Physically disabled woman, urban Jalalabad, when asked about family attitude

Women hold this opinion too. When asked what is more important for people with disabilities, ‘that they are able to take care of themselves’ or ‘to take care of others’? They answered in general:

“Taking care of others, like my husband, he can take care of me and the children. He earns money.”

Wife of an amputee, Kabul

Clearly it is perceived that a individual with disability should first be able to take care of him/herself before being able to take care of others. But, like other poor social groups, “survival in a subsistence economy in Afghanistan depends primarily on cooperation and mutual support within the kin group. The extended family is the prime source of social welfare. Contributing to the family is prized much more than making one’s way in the world” (Coleridge, 1998).

○ Process of Marginalization

Fundamentally, the inability to work means that an individual can no longer fulfill their traditional expected role within society. A man provides for income and food and a woman takes care of the house and children. Once a person with disability cannot fulfill their role his/her position in society changes. This is noticeable in many ways⁵:

- Loss of respect within the family
- Loss of respect within the community
- Inability to marry
- Inability to have offspring

⁵ These sets of developments should be the same for women too, although they were never stated as such as the men did.

Mohmad Aslam (50), Amputee, Kabul explains;

“For a disabled person there is a big difference between working and not working. Family or spouses do not like people with disabilities, who do not work. First problem is the disability itself, next problem is that you cannot work or have to beg, your status and prestige decreases in society”.

Mohmad also tells about a childhood friend, a very respected old man, a white beard, who started to cry the first time he saw him just after the accident when he became disabled...

“He said to 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 than 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”.

The next day, his wife, Shirin (35), recalls the situation as follows:

“In the military he received so much respect... but after he became malul, within his family they started to think less and less of him. His brothers, father and uncles, since he is malul they think of him as dead, they do not care for him anymore. At the moment we have no contact with his family anymore even though they also live in Kabul.”

When asked if people respected her husband after he started working as a tailor’s apprentice, a new activity to earn money, Shirin and her daughter replied: *“No, they did not respect it! Still people think bad”.*

This example has a very dramatic outcome and will not happen to all people who become disabled. Most likely there were other things contributing to Mohmad Aslam’s circumstance then solely becoming disabled. However, this situation does illustrate that the respect an individual enjoyed prior to becoming disabled diminishes, affecting position the family, position in the community and ultimately the position the family has within the community.

Trabgani

The marginalization described above affects and is affected by the familial norms called *Trabgani*.

As Wardak (2002) explains:

“Norms of reciprocity are governed by trabgani. Trabgani refers to the established patterns of behavior which guides members about who to co-operate with, who to compete with, who to marry, and in a word how to live as tarboor - an equal and

respectable member of the kin group; it is both a source of cohesion and divisive rivalry among members of a *plarina* in different circumstances”.

In Pashtoon culture, but also Tadjik (where it is called *awdar zardagi*) exist a positive competition between males of extended families on the father’s side, especially between cousins. Having a person with a disability can disrupt this competition and marital-arrangements because a disabled family member disrupts normalcy and can bring shame on the family. This results in further marginalization of the person with disability within the family.

“We are Pashtoons, we have a culture of trabgani. In a village it is therefore very bad to beg, it is bad for your trabdoor”,

Amputee man, Malang

- Being a woman with disability

In Afghan society, the expectancy on women to bear children cannot be overemphasized. This is a challenge for women with disability, as they are also perceived as reproductively challenged and incapable of taking care of children. This in turn affects their eligibility for marriage. Most often, women with disability either are not married or are married to a lower social class relative or another disabled person.

When she was 12 year-old, Jaina (physically impaired) had an arranged marriage with her first cousin, who was an orphan and 10 years older than her. He is now a baker and they are very poor, while her maternal family seems well off (they own two houses in Herat).

Jaina remembers crying a lot because she did not want to get married at the age of 12 to a poor man who was 10 years older than her. She despondently compares herself to her sisters who are still studying, and one of them who got married at the age of 18 (to her 22 year-old first cousin) by a “marriage of love”.

Women with disabilities, who are not married remain within their maternal homes and are given roles of domestic helpers provided they are able to do some chores. Though we did not come across any specific cases of disabled women being admitted/abandoned at *maristoons*, people did mention that this occurred occasionally, depending on the socio-economic condition of the family.

In the case of an able-bodied married woman acquiring a disability, a major consequence is likely to be that of the husband taking a second wife. This relegates the woman with disability as a dependent and impacts the respect the woman held in the family. This may also decrease the status and care of her children.

Homeira has set up a shura for disabled women in rural Herat. After an accident, Homeira was disabled by severe arthritis in her hands and feet that has crippled her. Her husband, who is around 60 years old, took a 14 year-old wife.

“Look at him (pointing at him as he was in the room), he has no shame, he gets a 14-year old wife!... Because I am now crippled and I cannot do the house chores anymore!”

A critical problem that women with disabilities face is domestic violence. Though this issue was not dealt with directly, both men and women highlighted it in surveys.

“Females are prohibited to even use one-fourth of their rights. Last night I was beaten so much that I cannot explain, although my husband is educated. I only asked my husband why he came late at home ...”

Female physiotherapist with physical disability, Kabul

Studies have show that women with disability are more likely to be victims of physical and sexual abuses than their non-disabled sisters (WHO 1989). Research and intervention will be required to explore further this serious issue further.

○ Having Children

The number of children, especially the number of sons, reduces the marginal status people with disabilities have. The more a person with disabilities can actually function as other non-disabled people in building a family, the more their status within the family and the community will improve. However, this process can be counterproductive if disabled children are born.

Arifa (35) blind, married to blind man has 8 children of which one son is mentally disabled, she says about her situation: *“It is enough that two people are blind and got married, why did God give us this much hard time? People were making jokes about us both being blind, but I do not pity ourselves, I only have pity for my son who is mentally disabled. People always call him diwana”*.

Conclusion: Key points about the KAP of People with Disabilities’ Families:

Knowledge:

- Parents lack awareness on how to take care of and communicate with children with disabilities.
- People with disabilities are considered to be incapable to taking care of themselves and therefore, even less capable of taking care of others.
- Women with disability are believed to be reproductively challenged or incapable to bearing children.

Attitudes

- Parents in general are quite supportive of their disabled children; however this often

results in over-protection.

- Respect and status of people with disabilities within their family depends on their ability to fulfill their traditional roles: to support others and bear offspring.
- Mothers of people with disabilities bear the 'burden of guilt' for their children's disability.
- An individual's disability has an impact on the whole family's status in society.
- Bearing offspring (especially sons), reduces the marginal status of people with disabilities.

Practices

- The eldest sibling often helps a child with disability.
- The overprotection of disabled children sometimes leads to isolation and under stimulation.
- Disabled women are rarely eligible for marriage.

3.2.2.4 People with Disabilities

Families' of people with disabilities and their community's attitude has an impact on their self-perceptions. The strongest feeling expressed by people with disabilities is "shame" {sharm}. Many said that they were afraid to go out and be insulted by others. Therefore they avoid social contact as it reinforces negative self-perceptions. Also, the negative self-perception is based on their perceived inability to fulfill their role within the family and being a burden to others. Self-worth is measured in terms of contribution to the family by way of income and having children.

Like the rest of the society, people with disabilities do not understand the causes of disability or the possibilities that exist with respect to their disabilities (i.e. what they can do in terms of ability to work and to acquire an education). There are virtually no sources for this knowledge and support for people with disabilities in the area of information. For medical support people with disabilities rely more often on traditional healers and 'alchemists' than medical doctors, this may be due to the fact that they rarely have access to medical facilities. In terms of psychological and livelihood support, very few NGOs or social networks include people with disabilities to any extent that can be depended on.

All of the above often result in a fatalist resignation that attributes everything to kismet {fate}; and the manifestation of self-pity. For many people with disabilities nothing can be done to rectify the low quality of life and self-pity justifies their dependence and refusal to take on personal risks⁶. As one member of a focus group in Kabul mentioned,

"I cannot walk. When my family goes to some party or marriage ceremony I wish I could walk there. Or I wish I could go to the rest rooms, or drink a cup of tea or water. I am the poorest person in the world, because I have to be carried on other people's back".

⁶ Jacobs calls this phenomenon 'victimization': "[...] the serious flaw of perception of the person who plays a role of victim is that they remain a stranger to a stranger" (2002)

Housewife (15), physical disabled (arm and leg) due to congenital disease, Kabul

These attitudes of shame, low self-worth and resignation are prevalent across most types of disabilities, especially those that prevent an individual from becoming a bread-winner, a mother or a father. Those individuals with hearing impairments and some with physical disabilities have more opportunities and hope in participating in familial and community life.

Conclusion:

Key points about the KAP of people with disabilities ...

Knowledge:

- Low knowledge and understanding of their disabilities – in terms of causes, treatment and support.
- Low knowledge and understanding of their abilities and possibilities – in terms of treatment and other supportive opportunities.

Attitudes

- Feeling of shame, low self-worth and resignation. A reflection of the negative attitudes of the society around them.

Practices

- Prefer to isolate themselves

3.3 Impact on the Lives of People with Disabilities

The crucial issues for People with disabilities are as follows:

- **Treatment:** how people with disabilities and their families react and cope with the impairment is an important issue. The way in which a person with disabilities chooses to treat or cope with his/her disability is relevant because it will affect his/her well-being and also how he/she is integrated into society.
- **Employment and Livelihood:** the productive capacity of a person with disabilities plays a major role on the position of that person within family and on the status within the community.
- **Marriage:** the fact a person is eligible to marry or not is important in order to conform to social norms of acceptance.
- **Education:** this is determined the capacity of the individual, in terms of literacy and skills or to participate in daily life. For example, disabled children accessing formal schools is extremely limited due to lack of family understanding of disabled peoples' abilities and of the school environment.

3.3.1 Treatment & Management of Symptoms

The knowledge, attitudes and practices studied in the previous sections of this report have a strong influence on how people with disabilities and their families react to and formulate strategies for treatment.

For example, there is a widespread perception that *mayub* are not treatable or curable as they have never been seen as 'normal' or 'healthy'. For example, the relatives of a boy who has hearing and speech impairments in Khak-i-Jabar say, "*as it is by birth there is nothing you can do about it. God made them like that.*"

Additionally, doctors seldom provide a clear answer to the nature or cause of the disability because:

- they too do not know, or
- the subject is considered to be a cultural taboo

A doctor in Khak-I-Jabar explains why he does not explain to people that some disabilities are genetically caused: "*If I tell them, they will be disappointed and will not come back. ... It is not good in our culture. Also not having sons is not good in our culture*".

3.3.1.1 Treatment Responses & Strategies

Three types of treatments exist:

- Modern medicine
- Traditional medicine: *shakistaband, ra gir, hakim, daiya*
- Spiritual/religious treatments: *mullah, wasita*

Many families combine medical and religious/spiritual treatments simultaneously. Two reasons support this:

1. Families lack an understanding of the causes and treatments related to various disabilities, therefore they seek out diverse methods for curative measures; and
2. Strong cultural traditions compel people to seek spiritual and religious treatments that are seen as mandatory to address the supernatural causes of disabilities (as mentioned before).

In many cultures, "systems of explanation, responsibility and treatment [are] based on local religious or spiritual beliefs" and often these healers are directly associated with the explanation the family has selected as the cause of disability (Frey & Campbell, 2002). Therefore it would be interesting to explore the issues of treatments and spiritual assistance for a fuller understanding on how a person with disabilities approaches his/her own disability and how the community perceives it in this context.

- Miracle Pills vs. Traditional Healing

More than three quarters of people with disabilities and their families who participated in the study have been to the hospital. When asked, "Who would you go for treatment?" a general

doctor or specialists, most replied that there is a lot of expectancy from those doctors, especially for perscribing “miracle pills”⁷. Also, many people with disabilities and their families expressed a wish to be sent abroad for treatments or to be cured by a foreigner doctor. Some of them, the ones who could afford it, pursued treatment in Pakistan or Iran.

Though not many respondents readily mentioned going to the *hakim*, these traditional practitioners are still a popular and current practice.

“To know which doctors cure better the mayub and the malul, we have to refer first to the medical doctors and if we don’t get better then we have to refer to traditional practitioners and mullah”

Relative of person with disabilities (32), rural
Herat

Medical service providers and hakims (providers of traditional *dawa-i-unani* [Greek medicines]), do not accept each other. However both medical and traditional practitioners do accept religious/spiritual practitioners, as “they have a more psychological influence”. There are many complaints from medical practitioners, especially from orthopedist and physiotherapist, about traditional practitioners.

“The Shakistaband when they manipulate the bones, [...] make it worse and they make it more difficult for us to treat. Sometimes patients arrive at the center and when we remove the plaster, it is completely infected. And this can result in a disability situation” (orthopedist, Herat).

Some of the medical practitioners who were interviewed were even more uncompromising:

“These traditional practitioners, like hakim, shakistaband or raggir, shouldn’t even be allowed to work.”

Despite doubts about their skills to cure/ameliorate disabilities, traditional practitioners will continue to play an important role. People will visit them when modern doctors cannot cure or fail to adequately address the concerns of their disabled patients. People with disabilities will try a second chance with hakim, shakistaband, ragir, or a tabib, particularly when they financially cannot afford a modern doctor in a hospital/clinic.

- Spiritual/religious treatment: Mullahs and Ziarat

As indicated earlier, there is a general idea that *mayub* disabled cannot be cured. Or that some disabilities are not considered to be treatable, especially the ones linked to hearing and speech impairment or mental diseases. In these cases, which are often considered related to ‘*asab*’ {mental} causes, too incomprehensible, or spiritual in nature, most people will:

- Consult a mullah, tawiz nawis, and/or
- Seek the spiritual help of wasita (shrine with specific powers).

A substantial majority of people, urban/rural and literate/illiterate believe in and respect Wasita over other spiritual/religious treatments.

⁷ Quoting from an interview with a doctor in an orthopedist hospital in Herat.

○ Mullah with Tawiz

After medical doctors, mullahs with tawiz are the next most popular service-providers for people with disabilities. Women tend to consult a mullah more often than men. Rural people consult mullahs twice as often as urban people. Many educated people do not have faith in mullahs with tawiz. They believe the mullahs only steal money from their patients. However, mullahs are key influencers in the community. Their roles can sometimes go beyond giving amulets and prayers and they can play the role as social advisers.

“I encourage them [blind, lame or amputees that come to visit him] and sometimes give them advice to go to Ministry of Martyrs and Disabled. They ask me about their future and the future of their children”. ‘We listen to people’.

Qari Mohamad Gul Wesal, a blind mullah, in Kabul

It was often reported that mullahs would be consulted in cases of paralysis, epilepsy, mental impairment, and problems related to a *jinn* possession or God’s will. Mullahs use prayers, *shoeist*, *tawiz* {amulets} and *dam* {infuses} to heal.

The physically disabled or people who know the cause of their disability do not consult mullahs to acquire a tawiz. As a young blind man from Herat said: *“because I know that my loss of sight is due to a mine explosion, the mullah cannot do anything for me”.*

“We did not go to the mullah; the mayub go to mullah. Malul go to the doctor because there are some chances of treatment. Going to mullah depends on your belief of God. God makes people disabled by birth, ...but only God decides if he will change anything”.

Grandfather (60) of mobility and visually disabled person,
Khak I Jabar.

○ Ziarat {Shrine}

Going to the Ziarat to pray to the wasita⁸ (graveyard saints) is an important aspect of Afghan culture. Though some people, educated or non-educated, say that they do not believe in the mullah with the *tawiz* or other traditional practitioners, most people believe in *wasita* and the power of shrines. Several shrines are known to cure specific illnesses and diseases. For instance in Malang there is a shrine that cures polio. Two other *wasita* famous among people with disability are the graveyard of *Sakhi-Jan* in Mazar-e-Sharif, having the virtue of giving sight to blind people and the graveyard of *Mia Ali Sahib* in Jalalabad.

Going to the shrines is always accompanied by a series of rituals that depend of the virtue of the saints. The site in Jalalabad is believed to cure *diwana* and other disabilities related

⁸ Wasita mean two different things in the region of Herat and the region of Kabul. In the region of Herat, the term of wasita relates to the shrines. In the region of Kabul, wasita means more social connections. But in general, wasita stress the idea of mediator. One is mediating with God, the other one with influential actors of the community.

to *asab*. People with disabilities are usually brought to the graveyard by their family where they are chained to trees and fed with millet bread and tea for several days (the duration varied from 6 to 40 days). The success of this shrine in curing the *diwana* of their illness is reported as questionable.

“In Pakistan, the doctor was too expensive, and the mullah didn’t work. But every year he was sent to the shrine in Jalalabad, Milli Saeb. That helped a bit. And he also had electroshocks. That helped too [...] We also sent him to a lady who had jinns inside her, but she said ‘I cannot do it but the Milli Saeb shrine can’. He stayed there for 40 days and only got bread and hot pepper, and black tea. Nowadays you have to pay 4000-to-5000 Afs. We will send him again after his brother earns some money in Pakistan”

Mother of mentally disabled teenager, rural Kabul.

“I do refer people to the shrine and it works because people themselves believe in it. It is not treatment but people believe in it”.

Doctor from Shak-i-Jabar

- Prosthesis

Orthopedic hospital patients felt that prosthesis emphasized disabilities and were thereby perceived as being more stigmatizing. Additionally, some physically disabled participants who were prescribed prosthesis said that they only wore them for only a few days or a week. They gave up wearing them because they found them heavy and uncomfortable.

- Prevention

There is very little awareness about the prevention of disabilities, most probably because the majority of people still see disability within the family as ultimately “God’s will”. The only preventive measures women mentioned, was the avoidance medicine use, carrying heavy things during pregnancy, and giving children appropriate vaccinations after birth. Within the general public, the only known way to prevent *mayub* disabilities was vaccination. Despite the lack of knowledge, within the Focus Groups interviewed there was a general eagerness to know more about the different disability preventative measures.

Key Points:

- People with disabilities and their families choose a combination of treatments: medical, traditional and spiritual to treat disabilities
- There is a conflict between medical and traditional practitioners
- Mullahs with tawiz and Wasita are the main means of traditional/spiritual treatment
- Prosthesis are seen as more stigmatizing
- There is a lack of knowledge about prevention and care

3.3.2 Marriage

“What are the most difficult conditions for mayub and malul? Being sad and not having anyone”.

Woman in Batee Kot, rural area Jalalabad.

To the question, “does disability affect your chances of getting married?”

- Less than half of the interviewed people with disabilities and their families answered ‘no’.
- Within the community, most people answered ‘yes’.
- In the male population, almost 100% of them said ‘yes’.
- In the female population, slightly more than 75%.

To the question, “would you marry a disabled person?”

- Less than twenty percent of the community answered ‘yes’.

During Focus Groups discussions, participants expressed quite strong positions. Many said that they would never marry a disabled person because “they cannot afford marriage”. Some of them even said that *mayub* shouldn’t marry anyone. Many people say that they wouldn’t give their daughter to a disabled man, because a disabled man cannot be a breadwinner and sustain a family. Indeed for a man with disability, eligibility for marriage depends very much on his ability to earn an income and to his social status.

3.3.2.1 Importance of Social Status

Marriage is an important step in a person’s life towards gaining status within the family and within society. The ultimate status of a man is to be the head of an extended family, a family where he lives together with his married sons and their wives and children. As Coleridge (2002) states: “Inability to marry because of disability deprives a man of the possibility of ever reaching such a position and therefore reduces his status, either potential or actual”.

This can be applied to women with disability as well, although the nature of their status is different from men. Grima (1992) mentions that a woman is not respected when she is single, as she has still not experienced the full burdens of life that come with marriage and child bearing. Motherhood, especially resulting in many married sons gains a woman not only status and respect but also gradual increased influence within the family. Therefore, marriage for both sexes is a step towards full respect and provides the opportunity to overcome marginalization due to disability so long as no disabled children are born.

Stor is 45-50 and is speech impaired and has a leg deformity. People said she was also *diwana*. She could not get married. When asking her about marriage, she explains how “*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*”.

With the ability to work and to take care of others, marriage is a way for disabled people to improve their position in life, family and community and therefore to overcome their marginal status. However, very few people are willing to marry their children to people with disabilities.

Nevertheless, there are married people with disabilities. These disabled people, predominantly men, were able to get married because of the following reasons:

- An agreement between families for arranged marriages, i.e. sister exchange and first cousin marriage.
- The family of the person with disability is well-off, thus considered a good party for less wealthy families
- The persons with disability's family has work with sufficient income and status
- The marriage between two disabled people

“One of my teachers taught me how to make tawiz nawis and with this profession I got married and so far we have been making a living”.

Blind mullah, married to a blind woman, Kabul

“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

These situations also depend on the livelihood of the bride's family. If they are poor, marrying an earning disabled man might be a strategy to at least guarantee **sustainable welfare**.

In addition to the difficulties faced by individuals with disabilities, their families, in particular siblings or children find it difficult to secure suitable marriage partners. This is mostly in the case of *mayub*. The following case study illustrates this type of stigmatization also occurs with family members of *malul*. As the daughter of a disabled amputee in Kabul said; *“If you are the daughter of a person with disability , they think your family will give you for free or for a cheap price”*.

3.3.2.2 Marriage Eligibility by Disability Type

The people with disability that are most eligible for marriage are people who have speech and hearing impairments. The recurrent reasoning for this is that they are “very intelligent”, “don't have difficulties”, “physically, they are not *mayub* or *malul*, and they can do everything”, “they are physically normal or physically good”, “they look healthy”, and are “apparently sound”. In other words, *“dumb and deaf have more chances of getting married because they can work and they are not seen as burden”* (disabled woman from rural Kabul).

3.3.2.3 Kismet: Women Married to Disabled Men

It seems that disabled men can get married more easily than disabled women. In most cases marriage is either between a disabled man and non-disabled woman or between two disabled people.

Non-disabled women married to disabled men, describe their situation as being their fate {kismet}.

The wife of a man with disability, Zakia (20), said she believed in *kismet*. *“That is why I married a disabled. If I am happy with my life or not, it does not matter because I am the wife of a disabled”*.

Sharifa, the daughter of an amputee in Kabul, was asked if she would want to marry a disabled person: *“No, but it is my kismet whether I marry a disabled or not”*.

However, there is one case where a blind woman said she was her ‘own *wasita*’ [meaning she made it happen, she was the facilitator] for her marriage. The family of her husband, who is also blind, wanted to get him married to her sister, but it was she who ended up marrying him.

“I felt pity for him and was always kind to him. Then I became the wasita for my husband. His mother was always coming to our house for proposing to my older sister. But my sister rejected him, and I accepted him”.

Arifa (35), blind woman married to blind man, Kabul.

Both Arifa and her family were most probably eager to marry her to the blind man, as it would have been difficult for Arifa to get married otherwise. As her husband mentioned in a separate interview; *“My wife comes from a poor family”*. Thus her blindness and the poverty of her family gave her little chance of other possibilities.

Later in the interview, Arifa who now has 8 children of which one is mentally disabled, mentioned in regard to her son’s marriage possibilities: *“No one will accept a marriage proposal on behalf of our son. Also I do not want to destroy a girl’s life as I have faced lots of problems”*.

3.3.2.4 Strategies for Marriage

With arranged marriages like sister exchange and first cousin marriages, it is often the extended family that helps out in getting a disabled family member married.

Shirin married her husband when he was already disabled. They are first cousins. She explains; *“Nobody else wanted to marry him. My father was close family and also a friend, therefore he offered me to his nephew”*.

A mother explains how her son who stepped on a mine and lost a leg a few years ago; he *“does not work now, but we are planning to get him married soon”*. She pointed at a young girl sitting in the doorway. *“We want to exchange his sister for a wife for him”*. She added later *“If there is no sister to exchange you have to pay a lot of money”*.

When Paghonta married her husband, his brother said: *“Do not marry her, she is disabled”*. But she was very beautiful at the time, with the tattoo spot between her eyes, she was white and fat, and her husband too was disabled”. When asked if marriage with disabled people still happens? She answered, *“It is kismet”*. Pointing to Shafiullah, Paghonta’s deaf and mute son; *“If he did not have a sister, he could not get married. If his sister becomes beautiful, tall and white, he can get married”*.

Zahar, relative of a hearing and speech impaired person, Khak I Jabar

Some of these marriage practices have negative consequences due to consanguinity.

Key Points:

- The self-worth and status of people with disabilities depend on how the community perceives them. This perception is dependent on the ability people with disabilities marry and have offspring. Any person’s position in society is defined in terms of his/her ability to have and sustain a family.
- Disabled men have a better chance of marriage if they can demonstrate economic independence, which in turn depends on their ability to find employment and earn an income.

“Everything is related to economy: if they are wealthy, they will have good opportunities in their lives. He can have a good life partner [i.e.spouse] and he can have a good job. He will have lots of respect from society too. But conversely, if a mayub has economical problems, he will not have the opportunity to marry someone because he will not be able to pay all the expenditures needed and also, he will not have any respect from society” Malik of Sea Oshan, rural Herat.

Many focus group participants voiced the same point of view.

- Like all women in Afghanistan, disabled women’s status depends on the number of able children they have.
- Women with disability are often considered to be ‘reproductively challenged’, and find it very difficult to marry.
- Among all people with disabilities, persons with hearing and speech impairments are considered more eligible for marriage.

3.3.3 Education

In answer to the question “do you think there should be a special school for children with disability?”

- Almost half of those who were surveyed answers ‘yes’.
- Nearly all families of people with disabilities answered ‘yes’
- Positive answers were more prevalent in rural areas than in urban areas.

3.3.3.1 Children’s Education

There is a high rate of drop out among children with disability. Many respondents mentioned that education is the only way a disabled person can actually learn a skill to improve their working

chances later. However, there were very few cases of parents or relatives taking the child to school. For most *malul* cases, the child was taken out of school as soon as the accident or illness caused the disability. For *mayub* the chance that they will ever go to school is slim. Also, girls with disability are less likely to be sent to school than boys. This is also related to the broader issue of girl's education in Afghanistan.

Parents seem to be the most reluctant to send their children to regular formal schools. They prefer to invest more on non-disabled children. Parents have a low opinion of and expectations from their disabled children's abilities. The main responses given to why they don't send their children to school were (by order of importance):

- The child will not be able to follow the classes
- Other children will mistreat their child and they 'don't want people to laugh at him/her and feel pity
- The school is too far away.

"In Pakistan he [her disabled child] went to school. However, we are also scared children will laugh at him and feel pity. We do not want him to feel bad".

Mother of a ten-year-old disabled child, Kabul.

In the words of a *malik* from Kabul:

"It depends on the family finance -- if the father is disabled a child cannot continue his studies and must make a living for the family. If a child is disabled he can go on with his/her studies. For example my brother is malul; he has one leg. He could study, now he is a journalist. But income plays a major role. All families prefer to send their children to school be they disabled or not disabled. People think that when they are disabled studying is the only good way for them to get good money in the future. Here usually amputees beg. The few ones who work are because their employers trust them".

3.3.3.2 Barriers to Education

Most of the *malul* interviewed have stopped attending school after the accident that made them disabled. A young blind man from Herat said: *"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".*

Many people with disabilities were affected by insults they received as a child from other children. Even adults today said that verbal abuses often come from children when they walk in the streets. In the questionnaire, children were cited as having the worst behavior towards people with disabilities.

In all regions, the attitude of the community towards disabled children is generally good. People with disabilities would say that adults easily take pity on children therefore adults treat these

children well. However, it is the attitude of other children towards disabled children that poses a significant barrier to the education of disabled children. Many mothers expressed the fear that their child might be laughed at or treated badly. That is why many parents and people with disabilities themselves prefer specialized schools.

Key Points:

- Education is seen as an opportunity for disabled people to gain an edge and make an income
- Two critical barriers to disabled children receiving an education are:
 - Parents' low expectations regarding their disabled child's abilities, and
 - Negative behavior of other children towards disabled children
- Parents prefer to send their disabled children to special schools

3.3.4 Livelihood

37% of the people with disabilities who were directly interviewed and 15% of the people with disabilities whose family were interviewed had a job. The potential of being employed is very low. Practically all people with disabilities who were interviewed were illiterate. Those who were literate were disabled by accident. In Khak-I- Jabar, only two in a group of around 50 men had learned a skill after becoming disabled (tailoring and embroidery).

There is a high rate of unemployment throughout Afghanistan. A barrier to employment for disabled men is not only their impairment but also the attitude of employers towards disabled people. Many disabled people and some non-disabled people interviewed mentioned that many people do not regard a disabled person 'as valuable as a non-disabled person', people think that they cannot work as hard or as well as a non-disabled person. As a result people with disabilities do not get hired and if they were to get hired they often earn half as much money.

"I cannot work in the government ministries because I am disabled. They think we cannot work according to the value of our wage because we are disabled. ... Another problem with the government is that you only get hired if you have a good connection (wasita) and money. One of my old classmates works with the government and he has provided jobs for other classmates but he refuses to talk to me. This is the big community but it is the same in the small community".

Mohmad Aslam (50), Amputee, Kabul

3.3.4.1 Expected Role of Persons with Disabilities

People with disabilities are often seen as incapable of working:

“Healthy people cannot find work, so how it is possible for disabled people. Mayub are unable people, they cannot work, a part from begging”

35 year-old teacher from Kabul

As many NGO workers dealing with disability observed, many persons with disability “ignore their own capabilities” or “were not aware of their capacities”. But as a blind shopkeeper said: “there should be jobs according to their ability”. When asked what kind of position people with disability could have, the answer would often be: shop keeping, office work and tailoring. The blind and mentally disabled are perceived as the least capable to work.

When asked, “what do you expect from your *mayub/malul* family member?” Most families answered ‘income’. In fact, more than half of the people with disabilities and their families interviewed are indebted. So there is pressure on people with disabilities to contribute to the household livelihood.

Indeed, work plays an important role in the lives of disabled. On average, all men and women are expected to engage in specific gender defined role, housework (non-paid) or work for income provision. Being able to fulfill ones expected role in society, different per gender but equal in significance, is an important way for a disabled person to be accepted as an equal as non-disabled or at least gain more respect within the family as well as within the community.

However, as a Comprehensive Disabled Afghans Programme report observed, more and more women are forced to increase their involvement in income-generating activities because of a worsening economic situation. And this is often the case for women with disability or women married to men with disability, especially in urban areas. **Jainda** from Herat uses her social and family network in the neighborhood to sell knitting, sewing and tailoring services. Her customers bring the materials at her home, as she cannot walk properly.

3.3.4.2 *Employment: A Confidence Booster*

Employment can boost confidence and help guard against depression. For many people with disabilities, once they have acquired a job, they do not consider themselves as having a problem anymore.

“I work as a programme 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.

Employment and income helps to relieve people with disabilities from the feeling of being a burden to their family.

Receiving charity is considered a “shame.” This contributes to feelings of guilt towards the community in general way. That is why when asked if they received zakat or khairat, many people with disabilities would often be very embarrassed or ashamed to answer. Rresearch

interviewers also expressed feeling ashamed when asking this question. As a man from rural Kabul said “we are Afghan and we never like to eat the meal that someone else has provided us”. But sometimes people with disability are forced to ask for charity. Jamila, a women whose husband became *dewana* during the war, was sometimes “obliged to beg under her burqa, hidden from her relatives” in order to have some income.

Wahdat (1998) states, “Employment and economic rehabilitation in Afghan society in most of the areas and even among the family is considered as sign of empowerment, dignity and a symbol of good luck”. Indeed, the importance of being an active participant/member of society is very crucial for the self-esteem of people with disabilities. Many people expressed their wish of being “self-reliant” and “energetic”. And when asked what would ameliorate the situation of people with disabilities, they would unanimously answer give more opportunities to work⁹.

“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

“Even for a non disabled person who does not work, nobody likes him, it is the same for a disabled person. People say bad words to them, like landa ghaar¹⁰ even for the non disabled who do not work.”

Alam (28), an amputee from Kabul

There was also a general agreement among other audiences that a person with disabilities, who works, gains respect. It “*shows his courage and shows that he solves his problems, that he is different from other people with disabilities and therefore is respected a lot*” (52 year-old man from rural Herat).

“Working is better for mayub in order to provide for their wives provision. Working has benefit and helps you to have power. People respect those who work. One day two people sitting in a car passed by me and they offered me some cash. I didn’t want to accept but my mother encouraged me to saying that they were just having pity on me. So I accepted but I felt ashamed”.

Mayub Female tailor, 45, rural Kabul

3.3.4.3 Traditional Support Systems

For a family with a disabled member there are currently two forms of assistance possible, social networks and NGOs. Practically all respondents reported that although they had often consulted clinics supported by NGOs for medical service or for the provision of prosthesis, very few of them had actually benefited from support programmes such as community rehabilitation projects. The first and primary provider of assistance to people with disability is the extended family and/or the community.

⁹ The Comprehensive Disabled Afghans Programme report on “Economic Integration of Disabled People, The Afghan Experience” have also observed that people with disability themselves would give priority to their economic rehabilitation rather than physical rehabilitation.

¹⁰ *LandanGhaar*: colloquial word for someone who does not work and is considered insulting.

Many respondents complained about the lack of help and consideration from the government, especially from the Ministry of Martyrs and Disabled (MMD). They often said that MMD favors war-victims and does not take into consideration other types of disabilities. Furthermore, they consider the allowance given to people with disabilities as not legitimate. Some do not even bother to go and get their allowance because it would not even cover their traveling cost.

There are several mechanisms developed by the communities to support needy families that can be considered a traditional social assistance network. The extent to which families use this network and mechanisms varies per region. As observed by Coleridge (1998), commitment to Islam is common to all Afghans as both a belief system and as a social programme: “Islam itself brings a sense of responsibility, evident in such things as *zakat* and *ushr*, both forms of charity to those who have less [...] including disabled people”.

Traditional forms of assistance provided in the urban and rural areas of Afghanistan:

- *Ushr*: 10% of lalmi harvest (rain fed) and 20 % of abi harvest (irrigated)
- *Zaka*: obligation, religious tax when you own house, property, have savings and can be money, food (depending on your commodities)
- *khairat*: ‘combination of goodness and giving’ can be water, food, clothes, money, but depending on your own will
- *sadaqa*: you give direct to beggars or indirect through community work, bringing up a child, or making a road *etc*
- *sar saya* (shadow around the head): money or food for the mullah (in the north *qalapuli*)
- Small events where food and clothes are distributed amongst the needy families in the community:
- *chadori bibi*: (like *nazr*) women give a *shirin*, a party and invite all other women to eat and to distribute clothes if they have the opportunity, this will give God’s blessing to cure a sick family member or other wishes.
- *nazr I bibi*: when old woman nears her death she distributes clothes to close relatives and poor, to give back just in case she has any outstanding borrowing

However assistance, asking for assistance is considered a shameful act. As one respondent recited: “*When you stretch out your carved hand to someone, you make a bridge for your honor and reputation to cross*”.

And added: “*When I became disabled I kept on working, never went to organizations. I was ashamed I needed help, because I can work*”. In essence if one can actually provide for himself by work or is educated as we saw above, people consider it shameful to ask or receive assistance, especially through traditional mechanisms.

“Many families who have disabled family members become sad if you help them financially or send them food. They say ‘we are not beggars’”.

Nasir Ahmad, Malik, Kabul

- Eroding Traditional Support Systems

When asking *shura* members about the *zakat* system and if it was still in place, one of the elders said “Before Saur Revolution [1978], there was the *zakat* system and everything was green, we had maize and wheat’. Someone added; “and we also had less disabled”. The local economy has also been drastically affected by the six years of drought, which has impoverished many families. Moreover, every month someone steps on a mine.

Another development that sets in and which causes imbalance between the wealthy and the needy is the migration of many wealthy landlords to Kabul. Although they still have land and still receive money from the tenants, they do not fulfill their community obligations of distributing *zakat*, *ushr* or *khairat* to the needy families of their village anymore.

Many complaints from all three regions cited that the alms are often given to the mullahs and that they did not necessarily redistribute them to the most vulnerable people in the community.

“Here people don’t give zakat, ushr, or khairat to disabled, the people just give zakat and khairat to mullahs”

Shakar Khan (70), brother of deaf/mute, Khak I Jabar.

Overall, this erosion of the social support network can be attributed to the following¹¹:

- Pervasive impoverishment due to over two decades of war and displacement
- Relatives are also poor
- A large numbers of vulnerable families in need of assistance
- Less neighborhood coherence
- More disabled people in need and growing
- *Zakat* and *khairat* are more and more given directly to the mullah
- Impoverishment due to six-year drought (rural areas)
- Absence of wealthy landowners that had traditionally provided assistance (rural areas)

Mohammed Hanif is 18 years old and lost a hand and his sight during a mine explosion when he was a child. He is jobless but is *hafiz* of Koran (Koran teacher). His family have no land and even some one else owns their house. “My father is also jobless, only relatives give us *zakat*, *usher* and run our life. ... Our economic situation is bad. And there has been a drought for the past 8 years so all people are weak and there is nothing to give as *zakat*, *khairat* or *ushur*. There are no rich men in our village, and if they are there they assist their own relatives. If there is extra work and men are needed for work, the *malik* will introduce their own relatives to their work”.

Key Points:

- Illiteracy, low-skills and unemployment are key barriers to people with disabilities

¹¹ For more information on the urban livelihoods see the study from Stefan Stratte of AREU in which vulnerable families with disabled are mentioned often.

participating in society

- Employment and income-generation are confidence boosters
- Traditional support systems involve extended families and the whole community. This system however is eroding.

4. Analysis & Recommendations

4.1 Key Perceptions

This analysis includes the following steps:

- A) Identification of the key perceptions that need to be challenged (or strengthened),
- B) Recognition of the triggers/drivers of these perceptions,
- C) Assessment of the barriers and opportunities to address these perceptions, and
- D) Identification of the key decision-makers who need to be focused on

1. Mayubiat are the most stigmatized people with disabilities

Trigger: Lack of comprehension, knowledge and understanding of what causes congenital disabilities.

Barriers: Perceptions linked to religious/spiritual explanations.

Opportunities: An expressed desire to know about causes of the disability. People think that disability can be prevented or cured.

Key influencers: Medical/health staff, traditional practitioners, family

2. Low self-esteem in the self-perception of people with disabilities.

Trigger: Lack of understanding of disability and capacities people with disabilities have. The reality and perception of people with disabilities is that of dependent and not have the ability to contribute to their families.

Barriers: People's attitude, especially verbal abuses and offenses. Poverty and limited economic and employment opportunity.

Opportunities: Existing disability structures can enhance self-esteem and confidence to people with disabilities by involving them in diverse activities. Employment is a confidence booster.

Key influencers: Community as a whole, i.e. family, teachers, NGOs, disable persons organizations, mullahs, malik, potential employers

3. Intellectual/learning impairment is considered the worst type of disability

Trigger: Lack of understanding and comprehension about these impairments within family and society.

Barriers: Lack of specialists and communication on the issue of mental disorders. This is confusion between the different types of mental disorders.

Opportunities: Traditional informal resources and practitioners dealing with this issue¹².

Key influencers: Parents, health/medical staff, traditional practitioners, spiritual healers.

¹² Though those practices are often not to the benefit of people with mental disorders, they can be used as a channel to address this issue.

4. *Families of children with disability tend to isolate the child with disability which decreases chances to access education*

Trigger: Overprotective and under-stimulating attitude from the parents towards the child with disability. Fear that the child might be laughed at or scolded.

Barriers: Lack of belief in the capacity of the child. Shame. Negative attitudes from non-disabled children. Lack of understanding on how to take care of the child.

Opportunities: Changes in parents' attitude once they were shown how to take care of the child. Parents do care about their child's well being.

Key influencers: Parents, teachers, community, health workers

5. *Guilt put on the mothers of children with disability*

Trigger: Blame on the mother is encouraged by traditional as well as modern medical discourses.

Barriers: Shame and embarrassment of the whole family.

Opportunities: An expressed desire to understand what caused disability.

Key influencers: Family, traditional practitioners, religious healers, mullah, health/medical staff

6. *Society, and people with disabilities themselves, think they do not have the capacity and the ability to work*

Trigger: Lack of confidence from people with disabilities and their environment (family, community and potential employers) in the capacity to take care of him/herself and his/her family.

Barrier: Overall unemployment problem in Afghanistan.

Opportunities: Expected role and therefore pressure on the person with disability to contribute to the household livelihood. An expressed desire to participate in the household economy. Shame of being 'recipient of charity'.

Key influencers: Family, potential employers, community

7. *Parents think that their child with disability does not have the capacity to go to school*

Trigger: Very few people, especially the parents of people with disabilities, consider that children with disability have the capacity to attend regular formal school. Lack of knowledge of children's potential and development

Barrier: Attitude of non-disabled children. Little chance for girls with disability to access education. Lack of facilities (e.g. distance) makes it difficult for disabled children to attend schools.

Opportunities: Having an education is a way for people with disabilities to gain status, and become part of society

Key influencers: Teachers, malik, mullah, parents

8. Children seem to have the harshest attitude towards people with disabilities

Trigger: This issue needs to be researched. It could be that children indiscriminately mimic adults who look down on and treat people with disabilities harshly.

Barrier: None

Opportunities: Can easily be reached through schools

Key influencers: Teachers, parents

9. People with disability are perceived as not eligible for marriage

Trigger: Men are perceived as not being capable of bringing an income to the household. Women are perceived as reproductively challenged or not being able to take care of children.

Barrier: Cultural traditions and socio-economic realities.

Opportunities: Having an education and/or employment is a way to gain status. Traditional systems of marriage can be supplemented by matchmaking services.

Key influencers: Family, malik, mullah

4.2 Principles of Action

This research confirms the statement of Lancet (1999): that the lives of individuals with disability are usually far more limited by prevailing social, cultural and economic constraints than by specific physical, sensory, psychological, or intellectual impairments.

As we have seen, people with disabilities are marginalized in different aspects of their lives. The negative attitude that one can have in a family and in the community is reinforced by the underestimation of people with disabilities' ability:

- to work and provide an income,
- to get a regular education,
- to get married.

How is it possible to improve the integration of the people with disabilities in society and how can society adapt to people with disabilities?

As Coleridge (1998) has observed, it is difficult to talk about social integration in a country where segregation is the norm. The same goes for the notion of empowerment. Empowerment, if such a thing can be applied in the Afghan context, should first begin with reinforced self-confidence of the people with disabilities, as they themselves have accepted "an inferior position in the social hierarchy as the normal state of things" and have internalized segregation (Coleridge 1998).

So the aim of an awareness communication campaign should be to:

- Improve the self-perception of people with disabilities,
- Encourage positive social perception of people with disabilities, and
- Encourage inclusive attitudes.

In order to do this, the integration process should go through:

- Increasing opportunities for integration for segregated individuals (e.g. employment)
- Changes in the family representation and attitude towards the person with disability, especially focusing on abilities.

This research also confirmed the findings that people with disabilities seek more economic rehabilitation than physical rehabilitation, though the latter still remains an important issue. The stigma imposed on the people with disabilities, and the status he/she has, are closely linked to the productive role within the family. This is why changing the perceptions of disability should also be accompanied by macro level programmes, focused on developing indigenous economic and support systems. As seen in the research, disability is a crosscutting issue. Messages concerning disability should be incorporated in all development programmes and projects, including existing health and education sector programmes.

‘It is not limitations, of whatever kind, which are the cause of the problems but society’s failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organization’ (Oliver, 1996)

Special attention should be given to each type of disability. As mentioned throughout this report, people with different types of disability suffer from different stigmas and discriminative attitudes. Therefore the issues need to be undertaken for each type of disability, especially for the intellectual/learning disabilities, which might need some special attention¹³ in different ways.

4.3 Tools & Concepts for a Communication Campaign

a) Communication tools¹⁴ :

- Radio is considered the best way to sensitize the general public on disability issues. Different formats can be used to propagate messages on disability awareness through poetry, songs, dramas, talk shows, etc.
- Newspaper and TV for educated and well-off people, who might be potential employers or decision makers
- Outreach workers for home visits to women and their networks¹⁵ and the ‘hidden’ people with disabilities.
- Materials should be prepared for:

¹³ Further research is needed especially on intellectual/learning disability, as well as women with disability.

¹⁴ These results come from Focus Groups discussion. Questions asked:

- What is the most important/pressing issue to discuss in awareness campaign?
- ‘What media should be used?’
 1. To sensitize on disability issues?
 2. To reach the different kind of disabled people?

¹⁵ “Females may be secluded but, regardless of location, they are active participants in social exchange, visiting neighbors or meeting at shrines, public baths, weddings, etc.” (Hunt, 1991)

- Mosques (with the participation of the mullah)
 - Schools (with the participation of teachers)
 - Health centers/clinics/hospitals (with the participation of health workers)
- b) Focus on people with disabilities' self-esteem by highlighting their abilities and the accomplishments of people with disabilities
- Childhood:
 - Encourage inclusive education by making parents aware that their disabled-children are capable of attending formal schools
 - Stimulate the participation of the child with disability within schools
 - Adulthood:
 - Make more visible the abilities and capacity of persons with disability
 - Encourage the formation of local structures for people with disabilities¹⁶ or empower the existing ones (disable persons organization, shuras for people with disabilities, unions, etc.)
 - Give a voice to the individuals with disability themselves and involve them in the process as much as possible¹⁷.
- c) Focus on integration of people with disabilities within their family
- Childhood
 - Need to improve families' awareness regarding child development
 - Improve the knowledge of parents and relatives on how to communicate with a child with disabilities and on how take care of them.
 - Adulthood:
 - Encourage family participation in activities that involves people with disabilities
 - Show how people with disabilities can contribute to their families' livelihood and welfare
- d) Focus on inclusive attitudes and services within the communities
- Childhood:
 - Encourage inclusive attitudes from non-disabled children towards people with disabilities
 - Adulthood:
 - Change potential employers' attitude towards people with disabilities by showing the valuable capabilities of disabled people
 - Create income-generating activities for people with disabilities
 - Target prejudices that hinder the eligibility of people with disabilities to marriage
- e) Focus on the approach of health workers/practitioners towards disability:
- Childhood:
 - Improve communication skills of health workers to inform families on how to take care of children, especially those with intellectual and learning disabilities

¹⁶ Many of Focus Group participants, especially men, suggested that Persons with Disabilities organize themselves in union, in order for them to have a place for exchange, to solve their problems and defend their rights.

¹⁷ As Paulo Freire states, the problem for people with disabilities attempting to maximize their potential is partly identified as a 'culture of silence' that perpetuates the oppression of disadvantaged minority groups including people with disabilities.

- Adulthood
 - Train health workers and traditional practitioners on the different types of mental disorders.
 - Communicate dangers of consanguinity as a cause of disability and as a way to remove the incomprehension about disability. Consanguinity will cause ‘bad blood’ or ‘wrong match of blood’.
 - Involve traditional practitioners as much as possible in awareness campaigns
 - Spread information on the causes and nature of disability and the ways of prevention



4.4 Examples for a Communication Campaign

Target: Self-esteem of people with disabilities:

- Coordinate a platform of different actors working on disability issues in order to facilitate exchange between Disable Persons Organizations, NGOs, International Organizations and Governmental Organizations.
- During events like the International Day of Disability, make the successful individuals with disability and their skills more visible.
- Through radio broadcasts and mosques, change the attitudes by encouraging a politically correct way of addressing individuals with disabilities.
- Involve people with disabilities in the creation of radio programmes, e.g. educational programmes for the blind.

Target people with disabilities and their families:

- In health centers, hospitals, and clinics, through posters and flipcharts and trained medical staff, inform and sensitize in an accessible way on the causes of disability taking care not to represent mothers as guilty and giving responsibility to all the family and the community on how to take care for a disabled child or adult.

- Through radio, billboards, local mosques and trainings for religions leaders, disseminate information on how to access facilities that help people with disabilities.
- Through radio and local mosques, show that people with disabilities can contribute to the family livelihood.
- Involve families in activities organized by disabled person's organizations.

Target children:

- Train teachers to stimulate participation of children with disabilities within schools.
- Invite people with disability in schools to talk about the issue.
- Involve children in schools with activities organized by disabled person's organizations.
- Create entertaining activities for children: theatre/puppet plays, mobile cinema, traditional singers to sensitize on disability.
- Involve children in radio programming.

Target potential employers:

- Create a communication network between disabled person's organizations, job placement services¹⁸ and potential employers.
- Through TV, create an awareness campaign of what people with disabilities are capable of doing. Give examples of jobs they can accomplish: an amputee making a mattress, a computer-literate person who has hearing/speech impairments, a visual-impaired English teacher, etc...
- Elevate the image of employers who hire people with disability through events like the International Day of Disability, and/or other means used in communication campaigns (TV, radio spots, newspaper, and billboards).

Target the community as a whole:

- Spread positive images of 'heroes' with disabilities through radio (like characters in radio dramas or songs) and billboards: people with disabilities who have made it professionally (and not necessarily war or mine victims).
- Spread information about the causes of and means of prevention of disability in health centers, hospitals, clinics and mosques.
- Use theatre plays, singers/players and/or mobile cinemas to reach remote areas.
- Target prejudices against the competence and abilities of people with disabilities in order to improve their eligibility for marriage.
- Use verses of the Holy Koran in the different means of communication and in posters for Ziarat and mosques to encourage an empathic attitude towards people with disabilities.

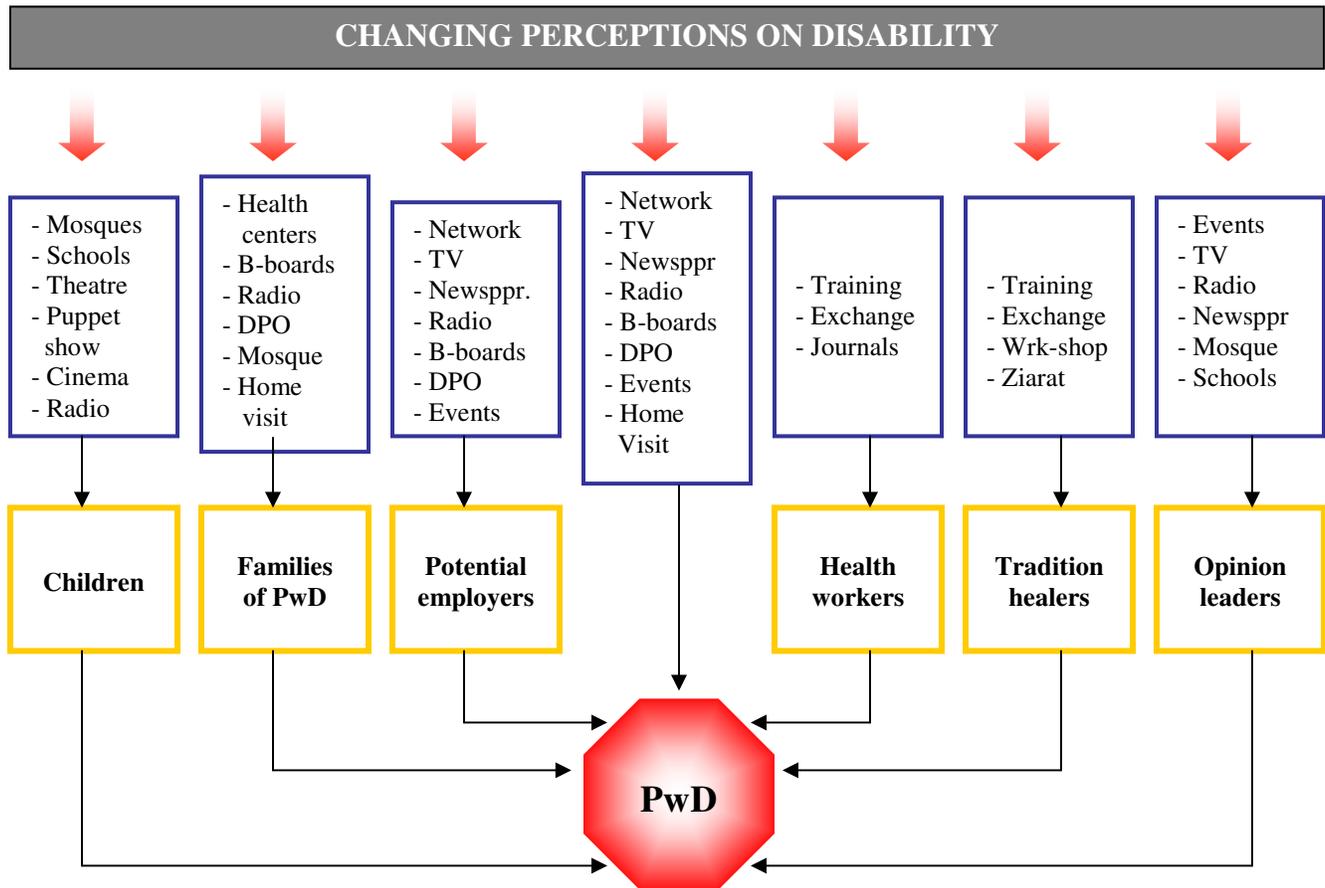
Target medical/health workers and traditional practitioners:

- Train them on the causes and nature of disability and to present this information in an accessible, simple format (local vernacular) to the people, e.g. talking about consanguinity in the terms of "wrong match of blood".
- Need of collaboration and exchange between medical/health workers and traditional practitioners in order to deepen their knowledge about disabilities issues: how the people with disabilities react towards their disability, what are their practices, etc.
- Train shakistaband and ragir to have more hygienic practices in order to avoid infections.

¹⁸ Some organizations working on disability issues already have a job placement service for people with disabilities. This type of initiatives should be encouraged.

All awareness communication campaigns should encourage and use Braille and sign language.

Media & Audiences:



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6. Glossary

Asâb

Mind/mental

Asab-i

Emotional, angry

AsâbKharab

Bad/angry mind – colloquial term for ‘crazy’. Can be an insult.

Ashar

Volunteer collective work, e.g. cleaning the rivers/streams, irrigation canal, the village (“because it is for everyone”), the farm. Especially in the villages. Any collective work where the person needs to ask for the help of his relatives because he cannot do it alone.

Awdar Zardagi

See *Trabgani*

Hazrat Ali

Son-in-law of the prophet, 4th right friend {*yor-e-charam*}.

His shrine is in Mazar-e-Sharif, in the Sakhi-jan (other name of Hazrat Ali – Sakhi means generous, free-handed person) graveyard. At the beginning of the Muslim new year (around end of March), there is a pilgrimage to his shrine, especially Blind people go there to ask ‘for their sight to be returned’.

Balâ

Sort of djin with a long hair. Kind of a witch.

Chumta

Disabled of the hand

Dam

Infusion/blow given by mullahs and traditional practitioners as a treatment while they recite Koran.

Dawa-i- unani

Literally “Greek medicine” which are prescribed by *tabib/hakim*. Mostly herbal.

Daiya

Traditional mid-wife.

Dewana

Crazy – [insulting word]

Falaj asob

Mentally paralyzed.

Goonga

Mute

Hafiz

A person who knows the Koran by heart.

Hakim

Traditional doctor

Jadu

Black magic. Can be the cause of an illness but also of negative social relations.

Jinn

(Arabic) singular jinniy, plural jinn; also genii. In the Koran, a class of beings, both male and female, between angels and human kind and represented as being created from smokeless fire. Popularly *jinn* are regarded as being able to appear to mankind in the form of domestic animals or of human beings of gigantic size, the benevolent ones appearing in beautiful shape, the malevolent in horrible guise.

There is a belief that *jinn* live in ashes {khakistar} and dust. If you step on ashes, you disturb the *jinn*. If a pregnant woman disturbs the *jinn*, especially at night, it affects her pregnancy.

Jinn-i

Person affected/visited by a *jinn*.

Kar

Deaf

Kor

Blind – [insulting word]

Qari

Someone, usually a blind person, who can recite the Koran by heart. It is a traditional occupation for blind man¹⁹.

Kismet

Fate. [from Arab *qismat*, from *qasama* to divide] Fate, destiny; used by Muslims to designate all the incidents and details that occur to a person during life -- what is commonly called one's lot, but implying that this is foreordained and irrevocable.

Khairat

Alms, something you do as a good will. Water, food, clothes, money, depending on your own will.

¹⁹ Miles (2002).

Khushq

Dry

Landa Ghaar

Person who doesn't work – [insulting word].

Lang (losh)

Lame – [insulting word].

Malul (adj.) – Maluliat (n.)

Disabled by accident

Mayub (adj.) – Mayubiat (n.)

Disabled by birth

Miâ-Ali Sahib graveyard

Graveyard in Jalalabad who has the reputation to cure the mentally disabled, the 'madmen'. The families bring the mentally disabled relative, chain them to trees, and feed them with millet bread and tea, during a lapse of time that varies between 6 to 40 days, depending on the cases.

Mirgee

Epilepsy

Nazar-i-Bad

Evil eye

Nazr-e-Bibi

When an old woman is near death, she distributes clothes to close relatives and poor, to give back just in case she had outstanding borrowings.

Nabinâ

Visually impaired.

Pari

Spirits of pre-Islamic Persian folklore, similar to the Arabic *jinn*. An invisible being opposed to demons. In later Persian literature, used as the symbol of perfection, and the beauty of the beloved is compared to it.

They live in clean places, especially flowers and trees. There are innocent, but if you disturb them at night, they can be harmful.

Purdah

Seclusion rules that regulate women's life, in Pashtu culture.

Ragir

Masseur / vein setter

Ruhani

Spiritual guide/saint (close to *wasita*)

Sadaqa

Voluntary charity (as opposed to *Zakat*)

Sarsaya

Literally “Shadow around the head”

Money or food given to the mullah.

In the North, *Qalapuli*.

Saya

Shadow of the *jinn*. Stepping on *saya* can causes illnesses.

Shahid

Martyr. In the Muslim world, it is the will of Allah to die as a martyr.

Shakistaband

Bone-setter. Common practice: he/she spreads egg yolk on the affected part, and with pieces of wood and wraps the member in pieces of clothes s/he restore the broken bones.

Shal

Paralysis or ‘crippled’.

Shal lak

Footless

Shoeist

Verses of the Koran written on a piece of paper. There are usually used to accomplish rituals. Examples: to be worn, drank, eaten or burnt.

Shishak

Sort of *jinn* with a long hair. Kind of a witch.

Shukhe asabi

Traumatized by war

Shuras

Village council

Tabib

Traditional doctors/practitioners (same as *hakim*).

Taklife Rawani

Mental problems

Taqdeer

Fate (see *Kismet*).

Tarboor

<Pashtu: an equal and respectable member of the kin group²⁰. Usually, it refers to male relative on the father's side.

Tasbi

Muslim rosary.

Tawiz Nawis

Mullah who has the power to heal using, *shoeist*, *tawiz* or *dam*.

Tchador-i-Bibi

When women give a *shirin*, i.e. a party where they invite all other women to eat, they distribute clothes (if they have the mean) and this will give God's blessing to cure a sick member of the family, or other kind of wishes.

See *Nazr-i-Bibi*.

Trabgani

In Pashtu tradition: competition between male cousins, people who are blood related. This is explained as one should not do anything shameful that could harm or affect his competition with his relatives, especially in *tarboor* relationship.

In Pashtu culture:

“norms of reciprocity are governed by *trabgani*. *Trabgani* refers to the established patterns of behavior which guides members about who to co-operate with, who to compete with, who to marry, and in a word how to live as *tarboor* - an equal and respectable member of the kin group; it is both a source of cohesion and divisive rivalry among members of a *plarina* in different circumstances (*Trabgani* is mistakenly interpreted as rivalry/enmity)” , Wardak (2002)

In Tajik: *Awdar Zardagi*

Trabdar

Literally *Knock the door*.

Expression to understood as “Don't go and knock on everyone's door”. i.e. it is shameful to ask help from others.

Ushr

<Arabic : Once a year, you have to give 10% of your properties to the poorest.

OR 10% of *lalmi* harvest and 20% if *abi* harvest

Wasita/wasila

This is not related to Jalalabad or Kabul, but it is what people use in both cases, therefore it can be referred to as case 1: The wasita is a connection to reach Allah, a mediation between God and the people. They are like prophets. The people go to shrine to the tomb of religious and virtue people, holy people, who are close to Allah. They are a better way to communicate with Allah.

This is not related to Herat, but it is what people use in both cases, therefore it can be referred to as case 2, it has more administrative aspect. Often it is related to

²⁰ Wardak (2002)

work/employment. A person wasita can help in that way to be the connection to acquire jobs/employments. In the judicial court, someone who can testify for someone and support the innocence of the person he also called a wasita.

According to the Fahrang Moaser dictionary:

« intermediary ; medium ; go-between ; agent ; middleman ; cause »

Zakat

< Arabic: Literally 'purification' and 'growth'. One of the five pillars of Islam. Religious tax: it is obligatory upon all Muslims to give 2.5 % of wealth and assets each year (in excess of what is required) to the poor. Giving the Zakat is considered an act of worship because it is a form of offering thanks to God for the means of material well-being one has acquired. Can be given to directly to the needy people or to the mullah.

Ziârat

Shrine