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Conducting Surveys on Disability: A Comprehensive Toolkit

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HANDICAP INTERNATIONAL
Vivre debout

Islamic Republic of Afghanistan

CONDUCTING SURVEYS on DISABILITY

A COMPREHENSIVE TOOLKIT

Parul BAKHSHI
Jean François TRANI
Cécile ROLLAND

NATIONAL DISABILITY SURVEY IN AFGHANISTAN, 2005

HANDICAP INTERNATIONAL
Vivre debout

Islamic Republic of Afghanistan

CONDUCTING SURVEYS on DISABILITY

A COMPREHENSIVE TOOLKIT

NATIONAL DISABILITY SURVEY IN AFGHANISTAN 2005

European Union

SWISS AGENCY FOR DEVELOPMENT AND COOPERATION

United Nations

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ICRC, International Committee of the Red Cross
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MADERA
Médecins du Monde
National Afghan Disabled Women Association
National Association for Disabled of Afghanistan
National Disability Union
Sandy Gall's Afghanistan Appeal
SERVE
Swedish Committee of Afghanistan

Abbreviations

AFAs	:	Afghanis
BPHS	:	Basic Package of Health Services
CI	:	Confidence Interval
CSO	:	Central Statistics Office
DPO	:	Disabled Persons Organisation
GoA	:	Government of Afghanistan
HDR	:	Human Development Report
Hrs	:	Hours
ICF	:	International Classification of Functioning, Disability and Health
IDPs	:	Internally Displaced Persons
IED	:	Improvised Explosive Devise
ILO	:	International Labour Organization
MDGs	:	Millennium Development Goals
MICS	:	Multi Indicators Cluster Survey
Mins	:	Minutes
MMDSA	:	Ministry of Martyrs, Disabled and Social Affairs
MoE	:	Ministry of Education
MoWA	:	Ministry of Women's Affairs
MoPH	:	Ministry of Public Health
ND	:	Non-Disabled
NDSA	:	National Disability Survey in Afghanistan
NGO	:	Non Governmental Organisation
NRVA	:	National Risk and Vulnerability Assessment
MTM	:	Master Trainer Monitor
NHSPA	:	National Health Services Performance Assessment
PPS	:	Probability Proportional to Size
PwD	:	Person with Disability
RTM	:	Regional Team Manager
UN	:	United Nations
UNDP	:	United Nations Development Programme
UNICEF	:	United Nations Children's Fund
UXO	:	Unexploded Ordnance
WFP	:	World Food Programme
WHO	:	World Health Organization

Preface

My involvement with the National Disability Survey in Afghanistan started at the very beginning of this challenge, three years ago, when two members of my research team told me they were planning to launch a national household survey on disability. This project was motivated by a strong ideal, to better understand the living conditions and the needs of Afghans with disability. In order to design the methods and tools to achieve this, a number of experts from various origins came together to generate a strong team spirit; it has been an interesting challenge to be part of this team.

This comprehensive toolkit gives the basis for the design and the implementation of household surveys on disability. It is an instrument that can be used for all those interested in knowing how to look at disability within a specific political, cultural, religious and social context. The six fact files of this document detail the various steps required to design, conduct and analyse a survey focusing on similar issues. These steps include: understanding the socio-economic context in order to specify the survey objectives, setting up appropriate methodologies including the sample selection and the design of questionnaires, training the interviewers teams, conducting field operations to collect the data and, finally, analysing and disseminating the relevant information.

This toolkit was not written for a specific profile of persons. It argues that commitment of all partners, at all stages, is a pre-requisite to ensuring that scientific findings are translated into relevant policy decisions. In order to carry out any form of action research, bridging the gap between the various actors working in the field of development, be it researchers and academicians, non-government organisations or policy designers and practitioners, is a must. In the pages that follow, academicians and researchers defined a set of methodologies, which were successfully tested in the field in order to observe and measure issues related to disability. The role of the policy designers and practitioners is to then suggest relevant policy measures, through a participatory mechanism. In order to do this, they need to know the underlying assumptions, understand the methodologies used to collect the data in the field, and grasp the socio-economic reality. This is the only way to ensure that the results will not be misinterpreted or misused, and that they will be accepted and considered valid.

It has been a pleasure to be part of the team. The discussions and debates around the NDSA have helped better understand the issues related to vulnerable groups in general, and disability in particular. This project is a real success for the Ministry of Martyrs, Disabled and Social Affairs of Afghanistan and the teams of Handicap International who commissioned and implemented the study. To all those who would like to undertake such challenges, one can only hope this toolkit be of a great help. Firstly, to better understand the daily situation of the persons with disability. Secondly, to implement relevant policies that improve their capability and help them to lead the lives that they value.

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Introduction

Carrying out a survey on disability is always a perilous endeavour. A myriad of questions arise regarding definitions, methodology, training of surveyors... This toolkit has been compiled following the National Disability Survey in Afghanistan (NDSA), the fieldwork for which was carried out between November 2004 and July 2005. It brought together people from different walks of life, in Afghanistan or around the world, who contributed to make this task possible.

The present document is an attempt to compile a variety of documents, experiences and discussions that took place during the many steps of the NDSA, the lessons learnt regarding the sampling process, tools, as well as the organisation. Some questions were omnipresent and still remain unanswered; however they did lead to some very interesting discussions: this document attempts to present these debates, as well as some solutions that were chosen for the NDSA. The comprehensive toolkit has been designed to help answer some of these queries that are intrinsic to a majority of surveys and studies carried out in the field of disability, by making recommendations on how to proceed. It was designed following the experience gained from the NDSA, carried out by Handicap International for the Government of Afghanistan. This applied research was implemented in one of the most dangerous post-conflict contexts in the world today. However, at a time when policies are being decided in the country, it seemed essential to have a comprehensive view regarding the multitude of issues that impact the lives of Afghans with disability.

The NDSA was a household survey that covered all 34 provinces of the country and was conducted in close collaboration with the Ministry of Public Health of Afghanistan, the Ministry of Martyrs, Disabled and Social Affairs and the Central Statistics Office under the Ministry of Economics and in partnership with the local team of the Johns Hopkins Bloomberg School of Public Health, Baltimore, USA. The project was commissioned in view of the need to provide evidence regarding persons with disability, required by all partners working in the country. Economic and political decisions were being made on very local and sporadic estimations of the prevalence rate, which varied from 3% to 10% of the total population. There was no information regarding the numbers, profiles, living conditions and coping strategies of persons with disability. Programmes that were run by national and international organisations were often based on intuition and depended largely on accessibility to populations. As a result there was a demand, both on part of the government and organisations working in the field of disability, for a more complete knowledge regarding this population in order to tailor and adapt policies and programme to the needs of the beneficiaries.

The suggestions and guidelines presented in this document are general, and are based on the lessons that were learnt in the field regarding the specificities of carrying out a survey on disability. The aim here is not to provide a pre-defined method for conducting a similar project, but to offer certain elements that can help avoid biases and errors when carrying out a survey on vulnerable groups. All the elements that are presented here will need to be re-thought and adapted to the socio-cultural context within which the survey is planned. Moreover, this document presents the various steps that were devised for a national-level or large-scale survey. However, a number of recommendations made can be used for smaller scale or local surveys and studies. The toolkit aims to facilitate the task of anyone who is planning to carry out a survey on disability, be it small-scale or nationwide.

The present document is divided into six different fact files that may be used as a whole or independently:

- Fact File 1: Understanding the Context, Defining Objectives;
- Fact File 2: Defining the Methodology, Selecting the Sample;
- Fact File 3: Elaborating Relevant Tools;
- Fact File 4: Training the Survey Team;
- Fact File 5: Field Organisation;
- Fact File 6: Analysis and Dissemination of Information.

Each fact file consists of examples from the NDSA. It also contains technical files which can be used as a checklist for other surveys. These files summarise all the questions that need to be asked before starting a survey on disability.

General Considerations – How to Get Started

Crucial questions need to be asked, and answered, at the very onset, before starting the survey. These may be related not only to the very need for a survey, its aims and objectives, but also to the social and cultural norms, the political situation, the financial possibilities within a given context, as well as the expectations and queries of all the various stakeholders and governmental bodies and international as well as local organisations who will use the results and findings.

The first question that may be asked is **why a survey**? A survey is necessary when a given finite population, or a sub-population, i.e. the disabled people of Afghanistan, has to be studied. The survey provides information about this population. This information is gathered through variables, which give the population characteristics or parameters. A sample, which is a subset of elements of the population, is selected and studied.

It is important to state here that the NDSA was carried out in a very unique context- the recent history of Afghanistan has categorised it under the "post-conflict" label. However, the transition from a post-conflict stage to a development and rehabilitation stage is the main challenge that the country faces today. The successive wars and the despicable security conditions in most regions have contributed not only to a paucity of comprehensive rehabilitation services but also to the lack of any overall picture regarding disability in the country. Added to that, very complex political and international dynamics have led to an unstable situation. The NDSA has been the first household survey that is nationally representative, and which attempts to look at the overall situation of persons with disability in the country.

There are two main methods of conducting a national survey on disability:

- By using a national sample of households and screening them for disability: this was the case of the NDSA;
- By screening for disability in a national census or a national survey (about health, education, labour…)

In order to compare the situation of persons with and without disability, the survey should include a sample of non-disabled persons as well. This makes it possible to assess the differences between the two groups, as well as to evaluate the opportunities that seem open to each one of them in terms of education, health, employment, livelihood, social participation…

Any survey, small or large, entails a clear and detailed planning of a number of diverse aspects, which in turn will shape the organisation of the study as well as the use of the results provided by it. Technical File A asks some general questions regarding the survey and its implications, for the researchers, the decisions makers, the organisations working in the field and for persons with disability.

Getting Started

Make sure that you have certain facts regarding the study clearly in mind:

- Do you need a survey, or would another type of study be more appropriate?
- Who is the study being carried out for, who has commissioned it?
- Who is funding the study?
- Which organisations, groups, NGOs will be able to use the results of the study?
- What is the overall aim of the study?
- What are the specific objectives?
- What is the time frame?
- What is the allocated budget?
- What are the needs in terms of time and human resources?
- What are the general socio-cultural specificities of the country and how will these influence a survey on disability?

Fact File

1

Defining Objectives, Understanding the Context

Surveys on disability are carried out not only for research purposes but also to help with the implementation of programmes. The first objective is to provide general understanding of the situation of persons with disability, whereas the second aim is to provide insights regarding specific living conditions, the immediate and long-term needs of the persons with disability and the means to implement relevant programmes to meet these needs. The defining of the overall objectives is usually done in view of the demands of the main partners, their programmes and policies, and their expectations. For a national survey these partners may include the government, as well as the donor agencies. There might also be considerable pressure from existing lobbies and organisations of persons with disability, which may influence crucial aspects of the survey, such as the very definition of 'disability' and the conditions that should be included under this heading. The challenge then is to strike a balance between specific demands of the partners and decision makers on one hand, and scientific validation and neutrality on the other. However, this balance must be found in order to guarantee that the results and findings of the study are taken into consideration when strategies and policies are being defined and implemented.

The lesson that was learnt from the NDSA experience is to ensure that the following two aspects are not ignored at any time:

- **The scientific validity,** guaranteed by researchers who are not involved in the organisations, donor agencies or the decision making bodies in a direct way.
- **The political validity**, which is ensured by persons in charge of liaising with the different stakeholders and making sure that the results of the survey are not misinterpreted or misused, but also that they are utilised in a relevant and appropriate manner.

Defining Specific Objectives, Ensuring Political Grounding

The clear defining of the general outcomes of the survey as well as the specific questions that the study will provide answers to, is the first step towards implementing a sound and useful study. What questions is the survey attempting to answer? What are the overall goals of the study and what are the specific objectives? This very crucial aspect of the process is closely related to the funding bodies that the reports will be submitted to of course, but the researchers can be clear about the independence of carrying out their fieldwork as well as analysis. The donors and other decision makers provide the general framework of what questions and fields are addressed by the study; they cannot have their say in what the results should be.

Whatever the context, the overall goal set by all the stakeholders is improving living conditions and enhancing choices of vulnerable groups in general and persons with disability in particular. In order to make 'evidence-based' decisions and define policies and programmes, there is a need to have reliable insights into the living conditions of these groups.

Before starting the survey process on the field, researchers will need to think about the use of the results that their work will provide. At the end of the project a question that often arises is: **and now what**? One of the major concerns of researchers is to see their results and policy recommendations translated into effective policies and programmes. However this final phase can only be ensured if the various partners are aware of the project and of how their programmes can benefit form it. Within a given context, are the

Objectives of the NDSA

For the NDSA the main aim was to provide a comprehensive picture of disability in the country, prevalence rates and information regarding all the major issues concerning access to public services (school, health care facilities), livelihoods and social participation of persons with disability. However, the objectives were also dependent on the expectations and demands of the funding agencies as well as the political partners. Although the overall goal of the survey seemed clear, its political implications and consequences were less explicit. The results of the survey would impact the disability scene in the country by putting forward findings that would not always be in line with the beliefs that programmes and policies have been based on to date. The political side of the survey was trickier to handle. The study was aimed at providing insights and recommendations for the Government of Afghanistan even though other NGOs and organisations would also benefit from it.

However from a research perspective the objectives were clear:

- To measure prevalence of disability by type of disability;
- To provide insight into the needs and opportunities of persons with disability in Afghanistan. These may include needs in terms of rehabilitation, education, employment, vocational training, social integration and political participation;
- To identify barriers, difficulties and stigmatisation that persons with disability face in everyday life;
- To provide strategic guidelines on how to overcome main difficulties faced by persons with disability.

conditions necessary to ensure this next phase in place? Once the knowledge is available, who is responsible for translating it into sustainable public action? How can researchers ensure that the will to expand choices and freedoms is a priority throughout: from the very conception of the study to the implementation of policies? These questions will be constant and will need to be considered and worked upon alongside the research if the results are to be used for the intended purpose.

Understanding Beliefs and Realities in a Given Context

Understanding the dynamics that influence the living conditions of vulnerable groups within a given context is yet another hurdle to cross. This requires an in-depth analysis of the religious, cultural and social aspects of a given country, a task that is often rendered more complex by gender and ethnic implications as well as economic factors. No valid and reliable study can be

Political Ponderings for the NDSA....

"Afghanistan is now 3 years post-conflict and has been in the throes of rapid policy and infrastructure development. With this period of brisk growth the need for information on which to base decisions has been clearly outlined in at least 2 different offices of the GoA, the MoPH and the MMDSA. Until now, there has not been an environment conducive to the development of evidence-based decisions or the funding available for establishment of baseline data in the field of disabilities. The will and need has been there within the programmes. With the NDSA close to providing quality research and data in the field of disability for the first time, one must stop to ask, where does the onus fall to carry the mantle of the information from research to policy? Who takes on the responsibility for translating this information to action? Does this fall on the researchers or on the policy developers and implementers? One may argue that the limited capacity of the GoA in this field precludes them from taking the more active role in the use of this data, but that the UN agencies and international partners, who have an understanding of the field of human development which is derived from the capabilities approach, should carry forth this function. Since the GoA has the ultimate responsibility for the development of sustainable and practical solutions to the problems inherited after over 20 years of conflict, one could easily argue that it is they who have the burden of carrying this research forward to programme and policy development in partnership with the development partners; the question is, will they?"[1]

[1] TRANI J. F. et. al, (2005), "Disability in Afghanistan: Taking a Capabilities Approach to Look at Research Challenges and Policy Implications", paper presented at the *5th International Conference of the Capabilities Approach*, UNESCO, Paris.

carried out without first understanding the underlying socio-cultural elements that form the frame within which tools should be conceived and results understood.

If the researchers do not belong to the country of survey, they need to familiarise themselves with the history, culture and religious aspects of people's lives in order to determine what is acceptable and what is taboo, and avoid the trap of ethnocentrism. Here it becomes necessary to comprehend group dynamics and gender relations, even more so in what are broadly known as 'traditional cultures' where collective identities tend to be much more salient and influence the way people act and interact.

The first step towards comprehending the cultural norms and beliefs is by conducting open discussions regarding cultural practices, religious beliefs, and ways of life using basic qualitative methods:

- Life stories;
- Focus group discussions;
- Open-ended, one-to-one interviews;
- Word association techniques;
- Case studies.

Conducting these preliminary sessions precedes any defining of questions and tools. Researchers need to determine what is relevant, what is acceptable and what is sensitive. It is important also to approach various types of groups within a given population and not just the target group for the study in order to have a comprehensive view of disability in a given context:

- Persons with disability;

Complex Social Representation of Persons with Disability in Afghanistan

A study on "Afghan's perceptions on disability" that was carried out in 2004[2] showed a complex picture of the beliefs, knowledge and attitudes related to different types of disability. According to the study, there is a common belief that war-related disabled are viewed as courageous heroes, having made a sacrifice for their country. These persons are not only a socially visible group (more so than in a number of other countries), but they also constitute an influential political group. Moreover, the results of this study clearly show that there is no real consensus on how to term disability in Dari.

Mayub, Malul, Diwana...as defined in the study
"The first aspect of disability in Afghanistan is the difference between *mayub* and *malul:* in Dari, they are two words that relate to the English word 'disability'. Officially, the definitions of ***mayub*** and ***malul*** commonly given 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 became disabled 'by birth'. This category can include disability due to congenital factors, as well as related to birth accidents, disease, malnutrition…anything that occurs in the first months."

There is clearly an overall confusion between types and causes of disability when it comes to common beliefs.
"But in people's interpretation, *mayub* and *malul* can have different meanings. In general, people know that one of these terms is related to 'birth-caused' disability and the other term to 'accident-caused disability'. However, they very often put mental disability and sensorial disability in the category of birth-related disabilities, and the physical disabilities in the category of accident related disabilities. Also, people occasionally qualify an amputee a *malul* and the deformed – when the body members are 'dry' *(khushq)* – a *mayub*. So the *mayub* and *malul* in colloquial terms can be related to the physical aspect of disability."

Finally, "the *diwana* is the colloquial term that refers to any impairment related to *asab* (mind). It is used as much for people with mental illness as for people with intellectual disability". The *diwana*, are the most stigmatised; they face the most difficulties in terms of integrating within their families and society.

[2] THAKKAR M., CERVEAU T., DAVIN E. (2004), "Afghan perceptions on Disability", *Altai Consulting Report for UNICEF/UNDP*, 2004, 61p.

- Disabled persons' organisations;
- NGOs working with persons with disability;
- Decision makers at the state-level;
- Religious leaders and community leaders;
- Experts and researchers;
- Lay persons in general, including men and women.

The social representations that are linked to disability are sometimes difficult to understand; what is valorised? What is hidden? What are the reasons behind stigma and discriminations? Who is the most discriminated against? What is the plight of women with disability? Researchers need to get a sound idea of what type of belief systems and social practices they are dealing with.

Researchers have to be careful of the use of the right word and of the several meanings it may have. The choice of words and their implications are an inherent element for designing a survey in a language the researchers are not familiar with. Usually a variety of terms refer to various realities. For example in Afghanistan, the war disabled often have a much more valorised place within society and are the main recipients of public attention and the target group for compensation programmes. The risk that may then arise is to have this category over-represented in the study while the other, less visible categories would be under-estimated. As a result, for the NDSA, the research team had to derive a tool that would work around this problem and not just look at the more accepted forms of disability.

This information can be collected through different methods: focus groups with persons with disability, discussions with experts, individual interviews... It will form the basis of the questionnaire and other tools.

A Simple Theoretical Framework as a Basis for Defining Disability

This phase ensures that the survey methodology is built on a stable basis that, in turn, will provide the framework for the interpretation of results. A very complex set of social representations are usually infused into the social fabric and affect all spheres of life. As a consequence, vulnerable groups such as persons with disability are valorised or shunned, admired or hidden, according to the perceived causes. The challenge then is to have a framework that encompasses all these differences. In order to elaborate the tools for a survey it is necessary to review the various definitions that have been put forward on the subject of disability and to consider all work previously done. Once the first hurdle of coming to a consensus on what is called disability in terms of definitions and theoretical considerations has been crossed, the main task remains of translating these definitions into tools that can be used to detect disability within households and communities. This needs to be done while keeping in mind cultural and social specificities of the socio-cultural context. Drawing on different schools of thought can contribute to defining an adapted framework within which the survey is elaborated.

Based on the abundance of literature that exists on the concept of disability, before reaching a definition, researchers need to bear in mind two main aims:

- Firstly, **the need to be functional** in order to be able to design a questionnaire that takes into account individual, institutional, societal and environmental factors: "*Disability is multidimensional, thus, we cannot ascertain the single "true" disabled population. Different purposes are related to different dimensions of disability or different conceptual components of disability models*[3]".

Understanding the Context

This technical file can only be completed with interviews and focus group discussions with persons with disability as well as lay people from the general population that the survey looks at. This step is essential to the design of tools and methods and for ensuring that the questions are relevant to the lives of the interviewees.

- What are the terms that translate the term 'disability'?
- What are the different types of disabilities identified by the people?
- How do people categorise disability? In terms of physical impairments? In terms of causes? According to a variety of different factors?
- What are the sensitive subjects that people feel uncomfortable talking about?
- What differences do they perceive between persons with and without disability?
- What is the general reaction of lay people towards persons with disability? Compassion? Pity? Discrimination?
- What are the major problems identified by people in everyday functioning? What are the main barriers?

[3] See WASHINGTON GROUP (WG) (2005), *Report of the on Disability Statistics*, December 30th 2005, p. 2., *http://www.cdc.gov/nchs/citygroup.htm*, accessed September 9th, 2006.

- Secondly, the view on disability **needs to be relevant to the context** and allow space for gender, ethnic and religious factors, which come into play in the lives of persons with disability.

For long, two main models have been presented as having contrasting views. The medical view, based on the individual and his/her impairment considers the physical or mental 'problem' that a person has. This view, which entails approaching the subject of disability by focusing on the individual, has often been considered to be biased by disability activists and organisations. The latter put forward the argument that persons are 'disabled' because of the structure of the society in which they live, which does not accommodate their impairment. Thus, it is the environment, physical and social, that makes a person with impairment, a person with disability. This view, which has been put forward by a number of disabled persons' organisations, looks at the barriers that exist within the social context and that prevent a person from achieving the same level of functioning as a non-disabled person. In this perspective it is society that needs to be reviewed in order to take into account the disabled person's needs. Mainstreaming disability concerns is a progressive and sustainable way of redesigning society in order to include people with disability.

In terms of definition, the World Health Organization has defined the International Classification of Functioning, Disability and Health (ICF). This document looks at disability as a combination of different types of factors that influence the environment within which persons with disability evolve. "*In the ICF, the term functionings refers to all body functions, activities and participation, while disability is similarly an umbrella term for impairment, activity limitations and participation restrictions*"[4].

This definition is based upon two main concepts:

- **Body functions and structures** focus upon personal factors which correspond to the personality and characteristic attributes of an individual,
- **Activities and participation** focus upon the environmental factors, including the physical environment, the social environment, the impact of attitudes etc.

In the past decade, the capabilities approach put forward by Amartya Sen has placed the definition of disability within the wider spectrum of human development. The capabilities approach provides further insight into the issues related to disability since it proposes to look, not at what a person actually does (functionings), but at the range of possibilities that he/she chooses that specific functioning from – this is the capabilities set. This view is based of "beings and doings that an individual has reason to value", thus shifting the focus from the specificities of the disabling situation to how to look at establishing equality in terms of possibilities and choices. This perspective looks at the interplay between individual characteristics and social restrictions and proposes to measure outcomes in terms of the expanding of people's choices, and thus, freedoms. Limiting the definition to merely a quantitative, or income and institutional access would be ignoring the dynamics that exist between the individual and the community. The focus on human diversity within the capabilities approach is also particularly important in view of the research: "*Within this view of human diversity as central, therefore, according to the capability approach, it makes a difference whether someone is a man or a woman and if he or she has physical and mental prowess or weaknesses; if someone lives in a temperate physical environment or in more adverse climatic zones, and in certain social and cultural arrangements rather than in others. And the difference entailed by these variations has to be accounted for, when addressing the demands of equality*"[5].

There are evidently similarities between these various definitions of disability, the emphasis being on the interplay between the individual and the collective. Within the human development perspective, the definition of disability devised for the NDSA needed to take into account these diverse aspects:

- The individual's potentialities and vulnerabilities;
- The opportunities offered by the environment the individual lives in;
- The agency role of the individual or communities, which looks at the extent to which the person (or the group) considers him/herself as the main actor and decision maker in his/her own life.

[4] WORLD HEALTH ORGANIZATION (1987), International Classification of Impairments, Activities and Participation, Geneva.
WORLD HEALTH ORGANIZATION (2001), International Classification of Functioning, Disability and Health, Geneva.

[5] TERZI L. (2003), "A Capability Perspective on Impairment, Disability and Special Needs: Towards Social Justice in Education", paper presented at the *3rd Conference on the Capability Approach, From Sustainable Development to Sustainable Freedom*, 7-9 September 2003, University of Pavia, Italy.

Definition of Disability in the NDSA

The NDSA questionnaire is designed to place emphasis on the individual and societal factors that influence the lives of the disabled. The institutional factors will be addressed to a lesser extent; the aim of the survey being to provide policy guidelines for the GoA in a country where the state support structures need to be set up in most parts of the country. The definition utilised for the survey draws on all the definitions stated:

Disability is thus the condition that results from the interaction between an individual impairment in functioning and the community and social resources, beliefs and practices that enable or prevent a person from participating in all spheres of social life and taking decisions that are relevant to his/her own future.

Fact File 2

Defining the Methodology, Selecting the Sample Size

There are a number of ways to proceed when carrying out a survey on vulnerable groups in general and disability in particular: these range from localised qualitative surveys, limited to a specific target group, to nationwide quantitative surveys which require a representative sample of the target populations.

Why Choose to Survey?

A survey is a procedure for systematically collecting information about attitudes, preferences, knowledge, or behaviour by asking people questions. Some people distinguish between applied and research surveys, the purpose of the latter is to increase scientific knowledge, by testing theories for example.

Major Characteristics

Surveying has three major characteristics:

- Asking people questions using a formal procedure;
- Using a quantitative method that collects standardised information;
- Obtaining information from a sample that is representative of the population that the sample was drawn from.

Surveys are used because:

- They are cheaper in comparison with a census, for example;
- They are more practical (they take up less time and interview a limited number of persons);
- They are accurate (the results can be valid for a wider population if certain statistical principles are respected).
- They provide more information than a census.

Defining the methodology that will be followed throughout the survey process will lay down a road map for each step. The choice of the type of survey done will depend upon the objectives of the survey. There are various possibilities depending upon the expected outcomes. For a survey on disability these options could include:

- A census that includes questions on disability;
- A nationally representative survey with screening questions for detecting disability;
- A regionally or provincially representative survey with screening questions for detecting disability;
- A local qualitative survey that looks at a specific limited population (women with disability, for instance).

The steps that have been presented in this toolkit refer to a large scale, probability proportional to population size (PPS) survey. The NDSA falls into this category and was carried out in all the provinces of Afghanistan. Smaller scale and more qualitative surveys would use some elements that are described in this section.

The choice of the methodology will, in turn, determine the types of results that will be derived from this survey and will have major implications in terms of the financial and human resources possibilities.

Sample, Results, Method and Specificities for Various Surveys

Type of Survey	Survey Sample	Results Valid for	Methods	Specificities
Census	Entire population	Entire Population	Closed/pre-coded questionnaire	Very costly in terms of organisation and analysis
National PPS[1]	**A statistically representative sample**	**Entire population**	**Closed/pre-coded questionnaire**	**Cost-efficient to establish national prevalence rates**
Regional/Provincial PPS	A statistically representative sample	Entire population	Closed/pre-coded questionnaire	Cost-efficient to establish regional prevalence rates
Qualitative theme-based survey	Target sample	Target group	• Open Questionnaire; • Focus group discussions; • Interviews; • Life stories; • Observation...	In depth study of selected themes regarding disability for a chosen group having specific characteristics
Participatory Observation	Chosen individuals/ communities	Individuals/ communities	• Open Questionnaire; • Focus group discussions; • Interviews; • Life stories; • Observation...	In depth study of selected themes regarding disability for a chosen group having specific characteristics

The Sampling Frame

A number of documents present the survey methodology in detail. They also look at surveys on disability specifically. Two documents among others that provide a comprehensive view of survey techniques are:

- L. Kish, *Survey Sampling*, New York, Wiley, 1965.
- *Guidelines and Principles for the Development of Disability Statistics*, Department of Economic and Social Affairs, Statistics Division, Statistics on Special Population Groups, Series Y No. 10, United Nations, 2001.

The aim in the present document is not to go into sampling detail, but to try and explain certain simple steps that help ensure that the survey on disability provides valid prevalence rates and a look at comprehensive coping strategies.

Why Sample?

Sample surveys do not aim to enumerate or list every individual or household in the country but to be representative of the population under study. A sample is chosen for various reasons:

- Because it is close to impossible to include everyone in terms of time, the distances and the resources (human and financial).
- But more importantly, because including everyone is not necessary; in fact, statistically the same results can be obtained from a small part of the entire population.
- Because surveying each and every individual is not always possible.
- Because the knowledge required to reach the goals previously defined needs to be based on a wide range of questions. This information cannot be obtained by a limited number of questions, which is the case in a census.

A sampling method is used for all these reasons and can be done in many ways, depending on what the expected results of the study are. So first, the research team must be clear on what the aims and objectives are.

When sampling, the major task is to select a **representative sample**. This means that the group of people that are interviewed will have a very high chance of representing (having similar characteristics as) the target or "parent" population: for a national survey this is the entire population of the country.

Any sampling frame is based on two principles:

- Everyone has an equal chance of being included in the sample;
- In order to avoid bias, researchers need to ensure that the sample selected has the same characteristics as the parent population.

Defining the Sample Size

The question that then arises is **how big should the sample size be**? This is again closely linked to the objectives of the survey. **The more general the results, the smaller the sample requires to be.** A national survey on disability requires a sound sampling

[1] PPS survey refers to a survey methodology where the random sampling is done according to the population size. This means that in provinces with high number of inhabitants there are more clusters and the remote areas have fewer clusters. For example for the NDSA, Kabul city had the highest number of clusters, being the most populated region of the country.

methodology that allows the establishing of valid prevalence rates at the national, and sometimes at regional/provincial, or even local levels. As a result the conclusions that would be made for the sample would be relevant at the national and sub-national levels. If results are required at a more local level, the sample size would be larger in order to provide regional, provincial or district-level results.

How large should the sample size be in order to be nationally representative?

The defining of a precise sample that allows the research team to reach the defined objectives requires the expertise of statisticians specialised in sampling and survey methodology. In the case of the NDSA, partners at the Johns Hopkins Bloomberg School of Public Health in Baltimore carried out the necessary calculations and came up with the number of households that would need to be surveyed in order to obtain the rate of prevalence. The calculations to determine the number of households take into account three factors:

- The estimated rate of prevalence of disability;
- The confidence interval;
- The level of precision that is selected[2].

In the case of small population groups such as very vulnerable groups (women alone with children, persons with disability…), it is necessary to define a relatively large sample to be sure to include a sufficient number of interviewees having the characteristics of the group studied.

However, the random sampling survey method does present a few limitations:

- A very large sample is required to detect and interview an adequate number of interviewees identified as having a disability. This is also important if the researcher wants to sub-divide the population of persons with disability into sub-groups (by types of disability for instance) or carry out complex analysis (for instance rate of employment by age classes, or school retention by level of education…).
- If the survey is not a representative sample survey, the sample will not be representative of the whole population of persons with disability. As a result, the conclusions made for the sample will not be considered to be statistically valid for the entire parent population.
- The coverage of specific locations or circumstances is challenging at best and impossible at worst. This may be the case for persons living in institutions (such as jails, schools or hospitals…), nomadic population or refugees living in camps, homeless persons...

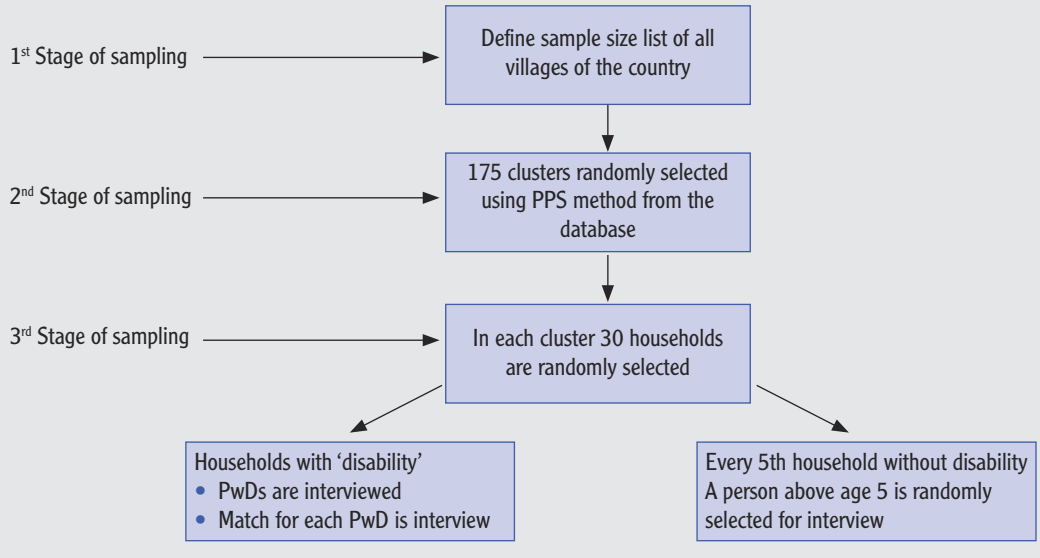
The 3-Stage Sampling Method Used for the NDSA

In order to provide rates and results that were reliable, it was essential that the random method be followed at every step of the sampling frame for the NDSA: as a result at every step of the process, each household had an equal chance of being selected.

First Stage of Sampling

For the NDSA, the first stage of sampling is **the district**. Two sources of population data were used to define the district population frame. Afghanistan consists of 34 provinces. For 30 of these, the 2003-2004 population pre-census figures were available. As a result the districts were ordered based on the population size. For the remaining 4 provinces, which were not covered by the pre-census due to security issues, the Central

Sampling Design



[2] Annexure 1

Statistics Office provided projections for 2003-2004 calculated based on the 1979 census and the same ordering was done. The required number of districts to be included in the survey was then selected following the same method for both lists. As a result the NDSA was carried out in 175 districts throughout the country and including all 34 provinces.

The first stage of sampling consisted in defining the size of the sample as well as its distribution into the number of clusters. As a result the NDSA sample consisted of 5250 households, with 30 households in each selected cluster. This represented a sample of 175 clusters throughout the 34 provinces of the country. The following steps were followed:

- All the districts in Afghanistan were listed with their population;
- From this list 175 clusters or "neighbourhoods" were chosen;[3]
- Big provinces had more clusters;
- Smaller provinces had fewer clusters;
- All provinces had some clusters.

Second Stage of Sampling: Finding the Villages[4]

All the villages were listed according to the Central Statistics Office population data and the villages were then selected. For the 4 provinces were the pre-census has not been completed, village populations were not available, and the villages had to be randomly selected.

Third Stage of Sampling: Finding the Household[5]

The accepted number of households per cluster varies between 25 and 40. For the NDSA the number of households per cluster was constant at 30: these also needed to be randomly selected. In order to do this in an appropriate manner each and every step of the sampling process was defined with precision, and all possibilities were thought of:

- The survey team proceeded to the centre of the cluster;
- The team chose a direction by spinning the pointer;
- They numbered the houses from 1-30 in that direction in chalk;
- One household between 1 and 30 was randomly selected: this is the first household where the interview was carried out;
- That household, and the nearest 29 were selected for interview;
- The next 29 households of the cluster were chosen using the "nearest front door" method.

The Control Groups

In order to understand the living conditions and coping strategies of any vulnerable group it needs to be compared to those who are considered less vulnerable. This helps understand if a given problem is specifically linked to the vulnerability that the survey is looking at, or whether the problem is shared by the family and the community as a whole. For surveys on disability, researchers need to define which groups without disability will be interviewed for meaningful comparison of living conditions.

Identifying Households with a Person with Disability

It is essential not only to identify persons with disability but also to look at the situation of family and the household that they belong to. How does this collective unit function in this case? In order to answer these questions two different types of groups for comparison: **the in-household 'Match' and the 'Control' from a household that has no person with disability living in it**.

Sample Selection for the NDSA

- The disability prevalence rate was estimated at 6%;
- The number of households selected for the NDSA is of 5250;
- If 6% was in fact the real rate, the NDSA would have to survey close to 6000 households with the confidence interval, precision required;
- 5250 households represents close to 47,000 persons.

[3]Annexure 1

[4]Annexure 1

[5]Annexure 2

The Intricacies of the Sampling Procedure....

"The survey team goes to the centre of the cluster", not that simple.

1. Here we had two methods for determining the centre of the cluster.

- In Kabul for example, where each selected cluster was in fact a *nahia*/district, we asked AIMS (Afghanistan Information and Mapping Services) to calculate the GPS centres for each of the *nahias* selected. Because AIMS did not have the adequate software, this calculation was very approximate. However one major problem that arose was the fact that sometime the GPS coordinates of the geographical district were on a mountain top which might have been mined. So we re-defined the lines of the district, restricting it to the residential areas in order to be sure that our centre would be within a place where people were actually living.
- In smaller clusters, villages, small towns, it was usually the person in charge who determined what the centre was.

2. The survey team spins the pointer for the first numbering of households...

This determines the direction in which the first numbering of the households would be done. Once the direction is indicated, then the team marks households 1-30 **in that direction**, in chalk for the first numbering. Once the team finishes this numbering it then randomly selects the starting point.

3. The random selection of the first household...

The team has slips of paper numbered from 1-30. They put them in an opaque plastic bag and select one number: this will be the first household that will be surveyed. If the number selected is 15, then the team goes back to the house numbered 15 in chalk and proceeds to number it the first household for survey. This is done in black felt with the inscription 'NDSA' under it for the verification teams.

4. The application of the 'nearest front door' method

From then on the team starts the survey of 30 households. They follow the method of the 'nearest front door', which consists in seeing which door is closest to the house that they have just surveyed. They proceed till they have completed 30 households in total in the village. The team does not leave the cluster without completing a total of 30 households.

The 'Match' is Found Within the Household of a Person with Disability

Interviewing the match person allows comparison between the situation of a person with disability and a non-disabled person **within the same household**. Ideally, the 'Match' has similar characteristics as the person with disability, primarily in terms of gender and age. In order to ensure this, a number of 'rules' need to be clearly set-up in order to find the most appropriate 'match' within the household. In a country like Afghanistan, the gender variable seems the most essential since gender differences are the most salient and determine relations within the family and the community in general.

The 'Control' is Found Within a Household Without any Person with Disability

The aim of choosing a 'Control' person is to compare the situation of a person with disability with that of a non-disabled from a household without any person with disability living in it. This allows comparison at the individual level but also at the household-level to see how disability impacts the family as a functioning entity.

From the NDSA Field Manual...

In each selected village the chief of the household in each of the 30 households will be interviewed with module 1 (household questions) and module 2 (screening questions) to determine if a person with disability resides within the house. If a person with disability is living in the household then the entire questionnaire will be administered to that individual or to the caregiver. In the advent that the person with disability is not home at the time of the interview, the team must return to that house before they leave that cluster to check for his/her presence.

Identifying the 'Match'

In houses where a PwD is found, a similar ND person must also be interviewed with module 3-20 for adults or 3-7 for children. Similar age and gender characteristics must be met for both individuals, PwDs and ND if possible.

For every PwD interviewed, a matched individual with no disability must also be interviewed. At minimum, **females must be matched with females and males matched with males**.The following criteria must be implemented in order.

1. If there is a ND person within 2 years difference (above or below) from the **PwD and of the same sex** then select that individual as the match and fill out modules 3-20 for adults or modules 3-7 for children. If there is more than one person within a 2-year age gap, then select the one closest in age. If there are two individuals of equal distance in age then randomly choose one individual to interview.
2. If there is no ND person within a 2-year age gap then the interviewer must randomly select a ND person of the same sex within the same age category (14 and below for children, or 15 and above for adults).
3. If there are no ND individuals of the same sex within the same category, then randomly choose an individual of the same sex in the other age category.

Identifying the 'Control'

Within the 5th ND household, one person must be randomly selected from all those individuals present to complete modules 3-20 for adults or 3-7 for children. The 5th ND household is only determined after module 2 (screening questions) has been completed by the head of the household/or person answering questions for the head of the household. All names must be placed in a basket and one name is randomly selected.This individual will be the control for the 5th ND household. (If a match for a previous PwD is needed then this will be done after this selection process). Continue to the next 5th ND house and repeat this process.

Annexure 1

The Stages of Sampling of the NDSA

There are several ways to select a sample. For the NDSA, the disability rate estimate has been based on existing estimations. The estimations of the number of persons with disability in the country vary from:

- 3% according to UNDP/UNOPS estimations in 1999, i.e. 700,000 Afghans with a disability.
- 4% that is, 800,000 people according to International Labor Office (ILO) and
- 10% according to WHO estimates, which is a population of 2 million Afghans.[1]

In the current situation, the best choice is random sampling, which means that at the outset, all possible items included in the population have an equal chance of being selected. This implies a very careful pre-selection plan of the population, which would be drawn up to ensure that all items in the parent population have the same chance of appearing in the sample.

The First Stage of Sampling at the National Level

The first stage of sampling was to determine the sample size that would help us establish the numbers that would be needed for this survey.

The NDSA sample size was defined keeping in mind an estimated prevalence rate of 6 to 8%, different estimates of disability in the country range from 3% to 10%. We estimated that a minimum of 1915 persons with disability would need to be interviewed, with a confidence interval of 95%, an alpha of 0.05 and a precision of 15% considering design effect. Based

	Precision 10%	Precision 15%	Precision 20%
Assuming a "true" 4% prevalence of disabilities			
True value in this range	Range 3.6-4.4 %	Range 3.4-4.6 %	Range 3.2-4.8 %
90% confidence	6,492	2,886	1,623
95% confidence	9,216	4,097	2,305
99% confidence	15,915	7,075	3,980
Assuming a "true" 6% prevalence of disabilities			
True value in this range	Range 5.4-6.6 %	Range 5.1-6.9 %	Range 4.8-7.2 %
90% confidence	4,328	1,884	1,060
95% confidence	6,017	2,675	1504
99% confidence	10,391	4,619	2,598
Assuming a "true" 8% prevalence of disabilities			
True value in this range	7.2-8.8 %	6.8-9.2 %	6.4-9.6 %
90% confidence	3,111	1,383	778
95% confidence	4,417	1,963	1,104
99% confidence	7,628	3,918	1,907
Assuming a "true" 10% prevalence of disabilities			
True value in this range	9-11%	8.5-11.5 %	8-12 %
90% confidence	2,435	1,085	609
95% confidence	3,457	1,536	864
99% confidence	5,970	2,654	1493

[1]The number of persons with disability are based on estimates of the total population provided by the organisations themselves.

on CSO population database 2003-2004 the sampling method for the next stage was established.

The number of households that would be needed was determined on the estimations of the CSO population database in order to obtain our sample size for persons with disability. Keeping in mind that the cluster effect is maximal with 30 households within the cluster, this would require doing a total of 5000 to 6000 households.

The Second Stage of Sampling: Choosing the Clusters

The sampling for the NDSA was carried out with a random selection method. As data was available only for 30 provinces out of 34 regarding population figures, 2 different methods were used:

- One for the 30 provinces for which we had the population pre-census;
- The other for the 4 provinces for which the population pre-census data is not available. For these provinces the sampling level was defined according to district-level estimations and the sampling interval was different.

The province wise-estimates for population, using the Central Statistics Office projections for 2003-2004, are available at this level for the 4 provinces. From this list clusters, for the 4 provinces for which this information was not available in the pre-census, the sampling was done using a separate methodology.

For the particular case of the new provinces, Panjsheer and Daikundi, which were initially part of other provinces Parwan and Uruzgan respectively, there was representation for the population because these provinces were part of other provinces.The use of the PPS method ensured that we included these provinces in the sample selection.

A sample of 150 clusters was defined, with a requirement for over-sampling, which came to a total of 175 clusters.

The estimated population being of 20.691 million, the interval for determining the choice of clusters was of 118,237 (20.691 million/175).

Of these, according to the population, 11 clusters fell within the 3 missing provinces:

- 2 in Zabul Province;
- 3 in Paktika Province;
- 6 in Helmand Province.

In the remaining 30 provinces 164 clusters were selected.

Choice of Clusters for the Provinces Where Population Estimates were Available

- First the list in alphabetical descending order for sampling (at province-level and at village-level) was organised.
- The population for these clusters was of 20006246.
- The sampling interval was 20006246/164= 121989.3
- A random number gave the starting point, chosen through the ALEA method[2].
- The first village chosen was where the x^{th} individual lived
- We thus proceed with the selection, always adding 121989 to the last selected number. Each village where the chosen number individual lived was a selected cluster for the NDSA.

Choice of Clusters for the Provinces for Where Population Estimates were **not** Available

We considered the provinces as stand-alone, or based on the number of clusters already determined. This meant that each province was considered as a separate entity and we selected the number of clusters in each one according to our method. For the population's estimates, the projections that had been made on the 1979 census data for these provinces were taken into consideration and the cumulative population was calculated.

Then, for the provinces where we did not have the data, we proceeded in the same manner as for the other provinces.

For the Province of Helmand

- The total population is at 756400;
- 6 clusters in this province have to be selected;
- The sampling interval is 126066.667 (756400/6);
- The random number selected through ALEA is Y^6.

For the Province of Paktika

- The total population is 357300;
- 3 clusters in this province have to be selected;
- The sampling interval is 119100 (357300/3) ;
- The random number selected through ALEA is $Ƶ^6$.

For the Province of Zabul

- The total population is 249100;
- 2 clusters in this province have to be selected;
- The sampling interval is 124550 (249100/2);
- The random number selected through ALEA is W^6.

At the end of this sampling frame, a list of 175 clusters was selected according to population size and represented all the provinces of the country.

[2]For confidentiality reasons these numbers are not specified here

Third Stage of Random Sampling: Choosing the Households

There were 30 households selected within a cluster, statisticians affirm that beyond this figure the cluster-effect is relatively decreased. Therefore, in order to have more reliable figures and sub-regional level data, it had been decided to keep the number of clusters stable at 30 households per cluster.

The selection of the households within a cluster was also determined according to a strict methodology.

1. The Survey Team went to the Centre of the Cluster

Here two methods for determining the centre of the cluster were applied:

- In Kabul for example, where each selected cluster was in fact a *nahia*/district, AIMS (Afghanistan Information and Mapping Services) calculated the GPS centres for each of the *nahias* selected. Because AIMS did not have the adequate software, this calculation was very approximate. However one major problem that arose was the fact that sometime the GPS coordinates of the geographical district were on a mountain top which might be mined. So the lines of the district were re-defined, restricting it to the residential areas in order to be sure that our centre would be within a place where people were actually living.
- In smaller clusters, villages, small towns, it was usually the person in charge, the Elders, representatives of the *Shura* who determined what the centre was.

2. The Survey Team Spinned the Pointer for the First Numbering of Households

This determined the direction in which the first numbering of the households was done. Once the direction was indicated, then the team marked households **1-30 in that direction**, in chalk for the first numbering. Once the team finished this numbering, it then randomly selected the starting point.

3. The Random Selection of the First Household

The team had slips of paper numbered from 1-30. They put them in an opaque plastic bag and selected one number: this was the first household that would be surveyed. If the number selected was 15, then the team went back to the house numbered 15 in chalk and proceeded to number it the first household for survey. This was done in black felt with the inscription 'NDSA' under it for the verification teams.

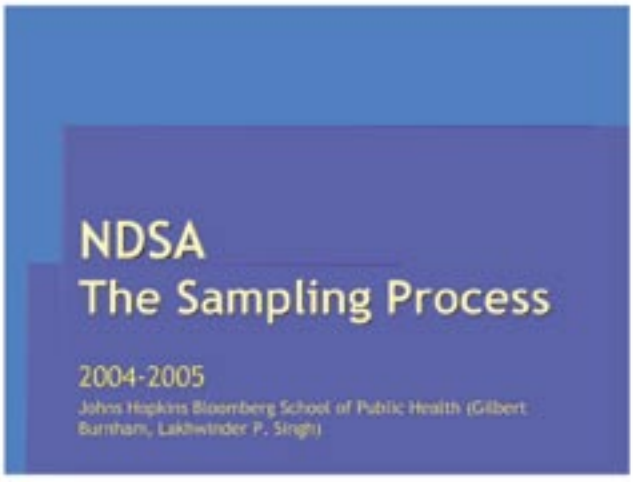
4. The Application of the 'Nearest Front Door' Method

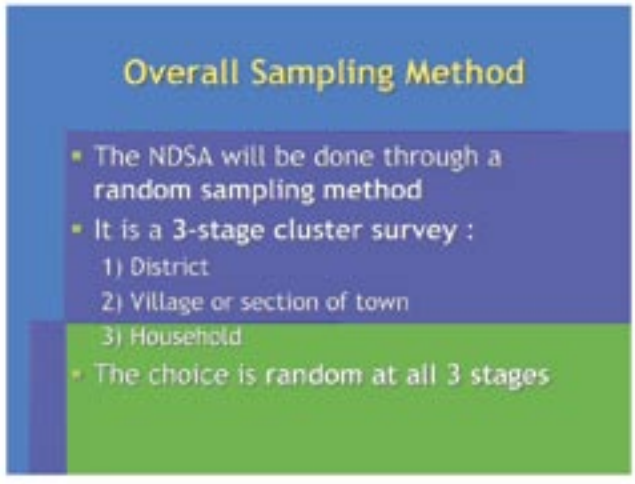
From then on the team started the survey of 30 households. They followed the method of the 'nearest front door' which consisted of seeing which door was closest to the house that they had just surveyed. They proceeded till they had completed 30 households in total in the village. The team did not leave the cluster without completing a total of 30 households.

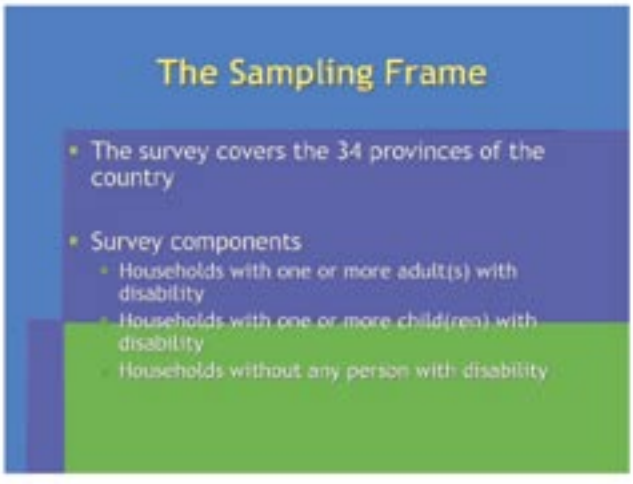
Annexure 2

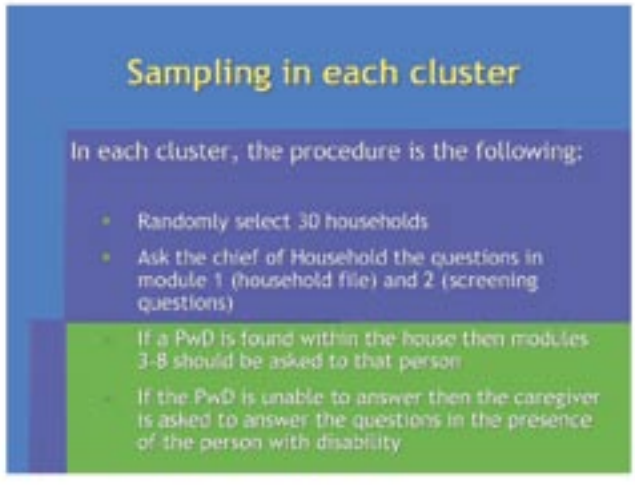
Details of the Third Stage of the NDSA Sampling Process

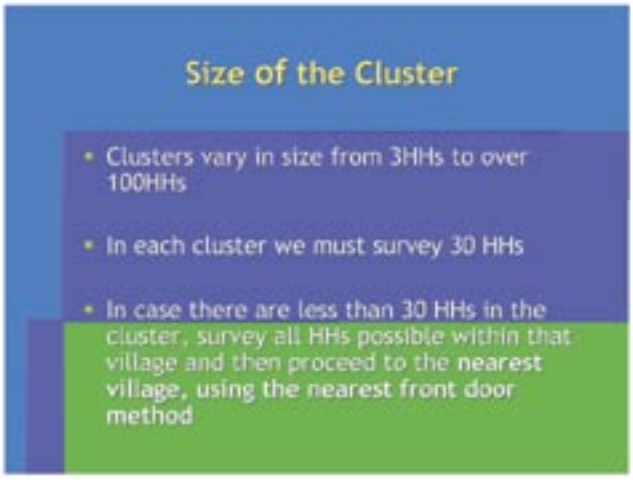
Document Used for Training of the Survey Team

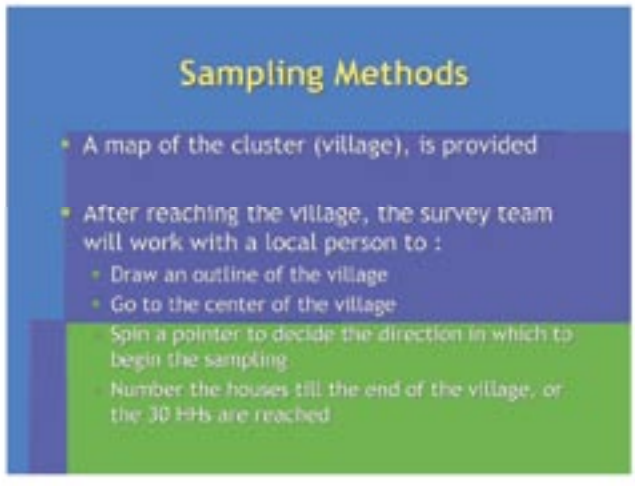












Sampling Methods Continued

- Pick a random start number from the number table without looking
- From that house proceed to the nearest front door and begin the survey until you reach 30 HHs
- If you run into the end of the village before 30HHs have been reached then spin the pointer at the end of the village to obtain a new direction and proceed to the next nearest front door until all 30 HHs have been surveyed

Villages with less than 30 HHs

- Survey all those HHs in that village
- Proceed to the nearest village and the next nearest door until all 30 HHs have been surveyed

Overview of Interview Process

- All the PwDs above 4 years old in the 30 households are interviewed with an adult or child questionnaire
- We interview for comparison the same number of Non-disabled (ND) persons in the *SAME* house
- In every 5th ND HH a randomly chosen individual must be interviewed

Sampling Households

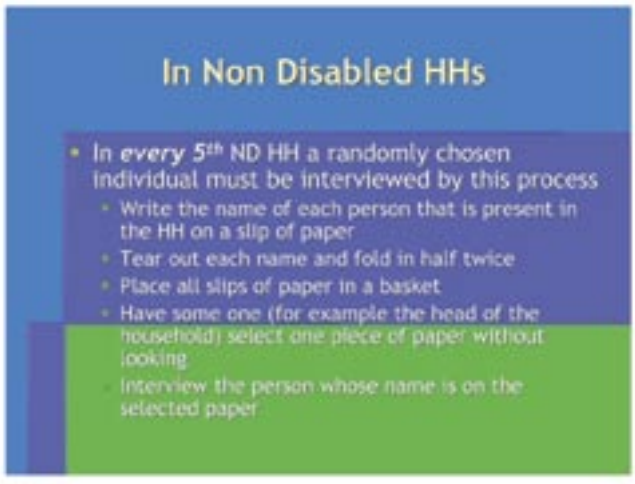
- Start from the first randomly selected house
- Interview the Chief of Household about the presence of a PwD, adult or child, in the Household using the screening questions
- If a PwD is present then continue with the questionnaire
- In this same HH interview a Non-disabled (ND) person with module 3-8 that is approximately the same age, and sex as the PwD

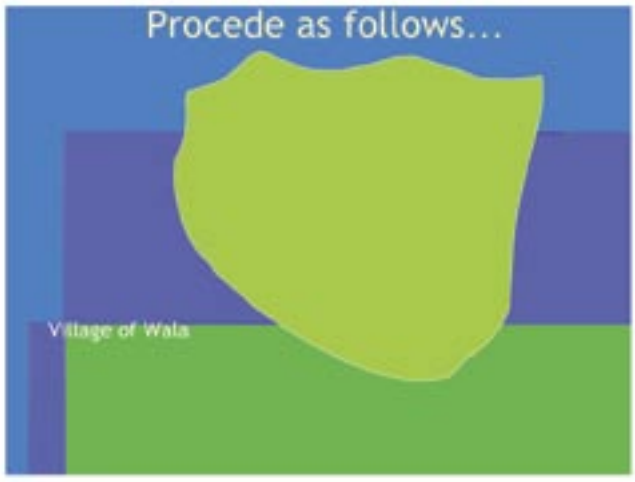
Sampling Households

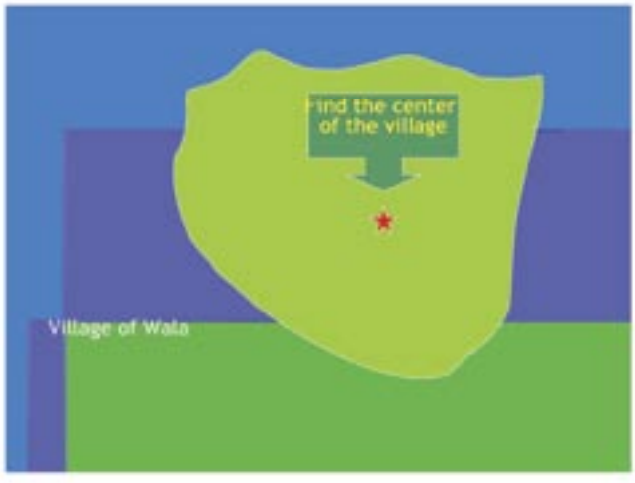
- If No ND person with the ***same sex*** and/or age as the PwD then randomly choose one of the other present members of the family to complete module 3-8
  - Write the name of each person that is present in the HH on a slip of paper
  - Tear out each name and fold in half twice
  - Place all slips of paper in a basket
  - Have some one (for example the head of the household) select one piece of paper without looking
  - Interview the person whose name is on the selected paper

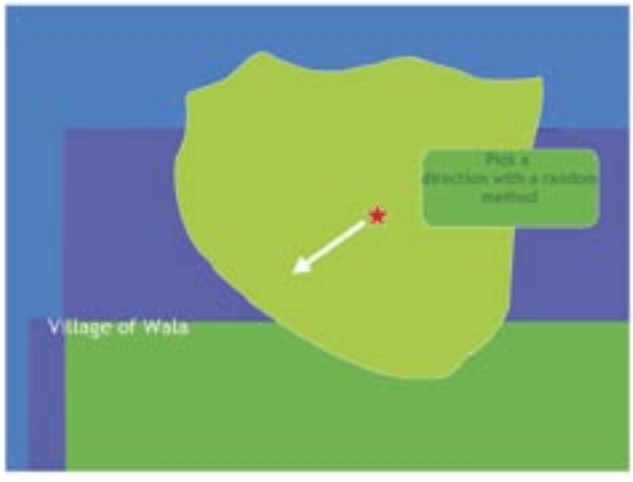
Matching ND and PwDs

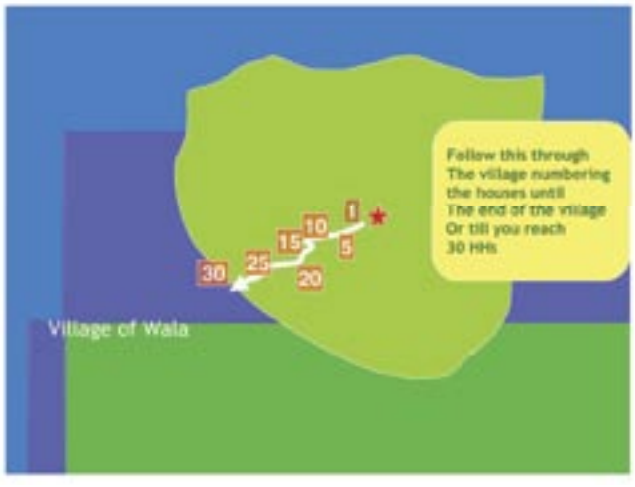
- It is important to have approximately equal amount of males and females for ND and PwDs with similar ages
- Make a list of all NDs and PwDs with age and sex as you interview in order to match them
- EX. If in one HH you interview a female PwD that is 15 years old and interview a female ND that is 30 years old, in the next house try to survey a female 15 year old ND and a female 30 year old PwD

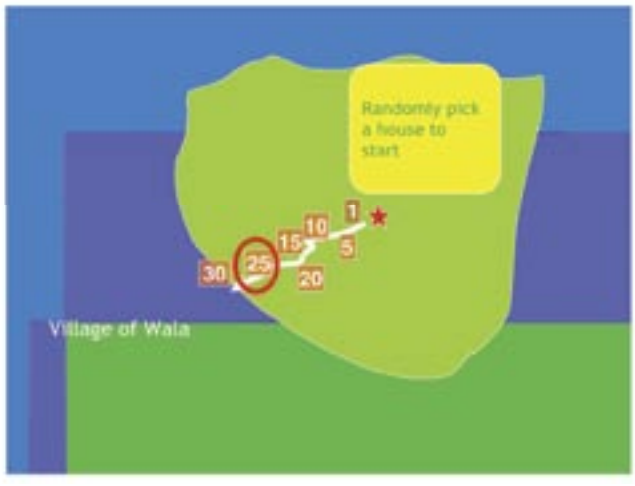

In Non Disabled HHs
In every 5th ND HH a randomly chosen individual must be interviewed by this process
Write the name of each person that is present in the HH on a slip of paper
Tear out each name and fold in half twice
Place all slips of paper in a basket
Have some one (for example the head of the household) select one piece of paper without looking
Interview the person whose name is on the selected paper

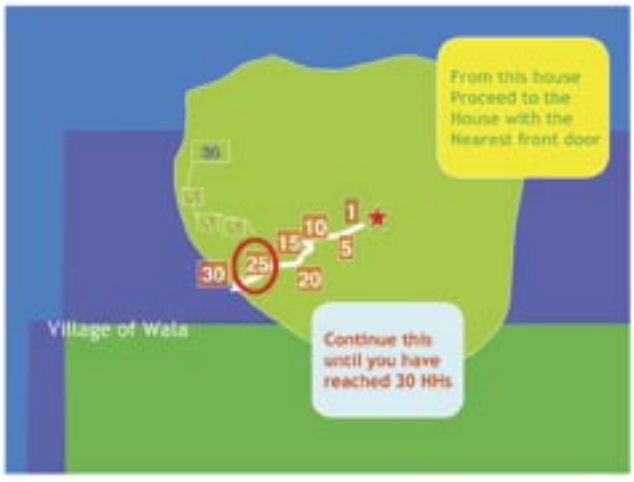

Procede as follows...
Village of Wala


Find the center of the village
Village of Wala


Pick a direction with a random method
Village of Wala


Follow this through
The village numbering the houses until
The end of the village
Or till you reach
30 HHs
1
5
10
15
20
25
30
Village of Wala


Randomly pick a house to start
1
5
10
15
20
25
30
Village of Wala


From this house
Proceed to the
House with the
Nearest front door
Continue this
until you have
reached 30 HHs
Village of Wala

If you reach the end of the village before
you get 30 HHs
Village of Wala

If you reach the end of the village before
you get 30 HHs
Spin the pointer
to find the new
Direction
Village of Wala

If you reach the end of the village before
you get 30 HHs
Village of Wala

If the village has less than 30 HHs total
Survey all HHs
Village of Wala

If the village has less than 30 HHs total
Village of Wala

Elaborating Relevant Tools

This stage of the survey process is the one that is the most time consuming and the most subtle. Here the objectives of the survey that have been defined along with the various stakeholders need to be specifically taken into consideration, while maintaining cultural and social relevance and acceptability. The conception of the tools of survey, mainly the questionnaire, is of great importance in disability assessment in order to avoid conceptual error, which is the major type of non-sampling errors (with a high level of non-response for instance) and can jeopardise the validity of the survey results. Conceptual errors result from inadequate definitions of disability, irrelevant phrasing of questions, non-respect of survey protocols, poor translation into local languages and insufficient training of surveyors.

The request to provide comments from a variety of partners and specialists (disability activists in the country and those working in other countries of the region; researchers, donors and decisions makers), can be a long and sometimes tedious process. Of course there are certain subjects where the debate is ongoing worldwide and where the researchers will have to take a decision in view of the characteristics of the field and the objectives.

Looking at Tools that Already Exist

Some institutions specialised in disability surveys have developed a set of questions that are used with specific adaptations in different contexts and for specific objectives. These tools can be useful for drawing up a questionnaire and can be adapted to the specificities of the context. This section looks at the tools that are used as well as the ICF and its advantages for surveying.

Existing Tools for Detecting Disability

1) **The Hopkins Symptoms Checklist 25(HSCL-25)** is an instrument for detecting anxiety and depression in torture and trauma victims.
2) **The Hopkins Symptom Checklist-90-revised (SCL-90-R)** is a self-report instrument designed to screen for a broad range of psychological problems and symptoms of psychopathology, it can also be used as a progress or outcomes measurement instrument.
3) **The Harvard Trauma Questionnaire** is the first culturally validated instrument to measure trauma/ torture and psychiatric symptoms of post-traumatic stress disorder in refugee populations. It is being used worldwide, having been translated into over 30 languages.
4) **The World Health Organization Disability Assessment Schedule II (WHODAS II)** assesses day-to-day functioning in six activity domains. Results provide a profile of functioning across the domains, as well as an overall disability score. This instrument is available in 16 languages and 11 versions adapted to cultural contexts.
5) **The Washington Group set of questions.** The Washington Group on Disability Statistics was formed as a result of the United Nations International Seminar on Measurement of Disability that took place in New York in June 2001. An outcome of that meeting was the recognition that statistical and methodological work was needed at an international level in order to facilitate the comparison of data on disability cross-nationally. The Washington Group has developed a short set of questions on disability that address the issue of assessing equalisation of opportunity. The question-set is intended for use primarily in census formats but also in national surveys and to provide international comparability of the resulting

data. Pre-tests of these questions have been initiated in approximately 11 countries. The group also addresses the implementation problems and methodological issues that arise in censuses and national surveys. Two sets of questions are developed, one about basic activities and one related to aspects of participation including considerations about environmental factors.

Using the ICF

The ICF framework provides the conceptual basis for the establishment of a set of questions adapted to a given cultural context. It is organised in 4 parts:

- **Body Functions** composed of 8 chapters looking at each and every type of body functions: mental, sensory, cardiovascular, haematological, immunological and respiratory systems, etc.
- **Body Structures** look at the physical and mental constitution in 8 chapters: structure of the nervous system, eye system, voice and speech, etc.
- **Activities and Participation** composed of 9 chapters looking at all activities from learning activities to communication and domestic activities and community, social and civil life.
- The last part is related to **environmental factors** and is composed of 5 chapters from product and technology to natural environment, support and relationship attitudes, services, systems and policies.

The ICF is a very comprehensive document providing a detailed classification of body functions and structures, activities and environmental factors in a 300-page document. It is a good basis for construction of a questionnaire and must be used as a dictionary/guide to help the designing of questions for a screening tool, aiming at identifying impairments and disabling situations. Some of the information can be used for other modules of the questionnaire aiming at understanding access to school or health services, livelihood, or social participation of persons with disability within a given socio-cultural context. For instance, chapter 8 in part 3 (Activities and Participation) related to major life areas provides a checklist of matters to consider for each field: education, work and employment...

However, because it is in fact very comprehensive, it must be used carefully:

- It is not a tool initially elaborated for survey purposes but for use by medical and other types of staff working in the medical or disability field. **It does not provide the questions to put in your questionnaire**.
- **It covers matters that might be irrelevant for a given purpose.** In an Afghan survey, questions about "maintaining vehicles" or "taking care of plants, indoors and outdoors[1]" are not relevant.
- **It provides principles, not in-depth consideration**. For instance, it does not consider cultural issues such as stigma. In the chapter on attitudes the ICF provides general considerations and definitions related to attitudes and social norms. It does not provide guidance on how to understand attitudes in a given context.
- **Some elements cannot be measured in a survey,** especially in a country that does not benefit from an effective health system reaching the whole population: this is the case of almost all body structures presented in the second part. It does not make much sense either to have the information concerning the structure of the eye socket or the structure of external ear when the target population is in priority the very severely impaired persons.
- In some countries, or some remote parts of countries where literacy level is low, **the "qualifiers" used in the ICF to measure the extent or magnitude of the functioning or disability in a given question, are not relevant**. Interviewees are not able to determine if the difficulty they have is absent, mild, moderate, severe or complete. The same problem occurs when identifying a level of ability with similar qualifiers. Absence or existence of a given ability might be meaningful, providing a degree of ability or difficulty may not.

Finally, a questionnaire is a set of limited questions. Out of a set of hundreds of items listed in the ICF, the researchers have to make choices about which disabling conditions they want to identify, related to the issues and the context they are dealing with.

Detecting Disability: the Screening Questions

Various surveys that have been carried out on a large scale in developing countries have shown a number of weak points. One of the major ones relates to the methods used for the "detection" or identification of persons with disability.

In a survey on disability, the respondents that need to be included must be identified: how to proceed with the selection of respondents is matter for ongoing debates among specialists. The definition of disability[2] has to be translated into precise and relevant questions that constitute **the screening tool**. The tool used by the NDSA is a questionnaire that consists of 27 distinct and simple questions[3]; each one can be answered by **Yes** or **No** and relates to:

- Signs, conditions or symptoms associated with physical or mental difficulties;
- Limitation or difficulty in performing certain activities.

[1] WORLD HEALTH ORGANIZATION (2001), op. cit. p. 156-7.

[2] Annexure 4, P 70.

[3] Annexure 4

Various Sources of Information for Detecting Disability

The design of the "screener" for disability can rely on different methods. It is, however, essential to rely on existing tools that have been tested and used worldwide as they offer consistency for identifying and measuring disability.

The screening tool aims to identify the different types of disability that might exist within a given household. It is composed of several sections related to different types of difficulties. Each section consists of a series of questions. The design, phrasing and choice of questions in the screening are based on existing bibliography and tools, discussions with experts in the country and abroad, as well as interviews and pre-tests with persons with disability. For the NDSA the screening tool was based on:

- Advice and inputs from experts on disability and persons with disability, and organisations of Afghans with disability;
- Use of documents, mainly the ICF and the WHODAS II;
- Pre-tests on the field to ensure that the wordings of the questions were understood and did not reflect stigma and prejudice.

A large number of surveys have made the mistake of relying on one person as a source for detecting the presence of a person with disability within a given household. The surveyors, more often that not, have limited experience with disability, or, when they are health and social workers, have experience with specific types of disability. Moreover, the training of the survey team is often too short, limited to visible disabilities or those that are culturally accepted and easily identified. All this can lead to an under-evaluation of the disability prevalence rates.

For a survey on disability that aims at establishing prevalence rates, researchers need to devise a screening methodology that is not based on the judgement of one or more surveyors only. The screening questions can be determined according to different sections: physical, psychological, intellectual and sensorial. These questions relate to the concept of what is **disabling** in order to lead a fulfilling life within the community and in society. In defining the screening process there may be various considerations. The term itself is often disabling: 'disability' in many cultures refers to socially acceptable forms of disability, ignoring other forms, such as mental disability.

The designing of questions that are not stigmatising and that are presented in a non-threatening manner for the interviewees and their families, remains a difficult task.

As a result various sources can be used to validate the detection of a person with disability within the household:

- The screening tool;
- The opinion of the surveyor

These may be confirmed (or not) by the interviewee's point of view.

- The interviewee's opinion regarding his/her own condition.

Detecting disability through an adapted and unbiased tool is one of the main pre-requisites to carrying out any survey on the subject of disability. Examples of surveys that have been carried out in other countries have shown that there is a serious risk of wrong estimation or underestimation if the screening tool is dependent solely on the survey team, especially if the training was insufficient or inadequate.

Using a screening tool does, however, present a limitation, which seems difficult to avoid. The questions of the screening tool are asked to the head of household. Therefore, there is a risk of underestimating the existence of disability conditions among household members. The ideal solution would be to interview each member of the household with the screening tool. This is practically impossible for a survey, more so in a country like Afghanistan. People are out in the fields, villages are often

Different Sources of Information to Determine the Presence of a Person with Disability within the Household:

- The opinion of the surveyors was important and allowed us to curb the risk of families stating having a person with disability in the hope of getting some state support.
- The screening tool which consisted of a list of 27 simple questions that addressed different types of disability.
- Self-perception of the interviewee: this was asked for persons who were interviewed after having been screened as having some form of disability. At the end of the entire questionnaire, he/she was asked if she/he saw her/himself as disabled or not.

difficult to reach, and security is a major concern. One possible way to overcome this bias is to ask another member of the household to confirm the answers of the head of household; this, however, is a tedious and time-consuming task.

The Choice of Terms in View of Lay Beliefs and Attitudes

While developing the tool, it is necessary to determine the terms that will be used in order to ask the questions that relate to screening. In a number of cultures, the equivalent of the term "disability" is closely linked to a range of social representations, beliefs and practices. Before using the term it is essential that researchers understand what stereotypes the term 'activates' in a given social and cultural setting. Moreover, in a number of languages, various terms refer to different realities.

The tool permits comparison and can be used with all persons. When elaborating this tool, one must keep in mind that the translation of the disability terminology is a difficult dilemma[4]. The stereotypes and the prejudices that were linked to disability need to be curbed as much as possible in order to:

- Avoid getting stereotyped answers that are often activated by the use of the term itself;
- Ensure that no specific types of disability are left out, especially the mental forms and those resulting from stigmatised or hereditary causes.

The use of the accepted and familiar terms only brings out the types of conditions, which are already culturally recognised as being disabilities. This does not allow space to find the different types of problems which are not collectively identified as a disability but that none the less lead to persons being disabled in their everyday lives. For example, after the age of fifty, persons who have serious difficulties seeing and need help to move around, are often not seen as disabled but just as being old.

The Various Sections of the Screening Tool[6]

The elaboration of the various sections of the screening tool is a long and complex process. It needs consultation with a number of specialists, review of existing frames for screening, associations between impairments, functioning, environment and the wording of specific questions. The types of disabilities that the survey attempts to identify within each cluster can be elaborated using lists and categorisations that already exist in the country. Needless to say, these will need to be adapted, re-phrased, and allow space for people presenting multiple and complex forms of disability. However, contrary to a number of lists that have been established previously, which have been based on a categorisation according to causes of disability, **the screening should not have reference to why or how the disability appeared.** This tool merely looks at the present situation of the members of the household. Asking the questions about existing disabilities is also a way of avoiding the glorification of certain persons with disability (the war-related and land mine survivors) and the shame linked to types of disability resulting from congenital or birth-related causes and which are considered to be worse due to their social implications. The screening tool of the NDSA comprised of various questions that related to the types of disability listed below. However, each disability was

'Disability' vs 'Difficulty'

In view of these points the NDSA made the choice, like a number of other surveys that have been carried out, to use the term "difficulty" or "*mushkel*" in Dari. This term is less threatening and constitutes less of a 'label' for the persons concerned, thus making the reference to disability easier. Lastly, the use of this more neutral term would discourage persons who believe that there were direct cash or goods benefits linked to the survey.

The debate on the advantages and the drawbacks of the use of the term is still continuing; researchers supporting the use of this term placing the need to find the various, and the more hidden persons with disability; on the other hand the organisations of persons with disability as well as other structures that are working on these issues were concerned that not using the term "disability" would mean denying their identity as persons with disability[5]. The elaboration and the testing of the NDSA tool showed that the latter argument, important as it is from a rights perspective, was not a drawback for conducting research in a respectful but non-biased manner.

[4] In order to determine the questions and the terms that would be used in the questionnaire the NDSA team carried out discussions with persons with disability as well as the general population. At least three different terms came up in Dari: *mayub*, *malul* and *diwana*, the last one for the persons with mental disability. There was often a disagreement between people on what these terms referred to and their meaning seemed to change according to dialects and regions of the country.

[5] This concern was voiced by the National Policy for Action of Disability (NPAD) of the UNDP in Afghanistan.

[6] Annexure 4: Screening tool

screened through a specific question, studies having shown that the aggregation of several disabilities into one question leads to serious underestimation.

The screening tool of the NDSA is composed of five sections

Section A: Physical and Sensorial Difficulties

This section consists of a series of questions regarding physical and sensorial types of disability. For each question the surveyor lists the people who have a particular problem who will be afterwards interviewed, depending on his/her age, with the adult or the child questionnaire.

For this section, a **Yes** to any **one** of the questions 2.1 to 2.6 will suffice to presume that a person may be disabled. The questions screen for lacking a limb, deformity, movement limitation and all sensorial impairments.

Lack part of/entire member(s) of the body

- Left leg below the knee;
- Left leg above the knee;
- Right leg below the knee;
- Right leg above the knee;
- Right arm below the elbow;
- Right arm above the elbow;
- Left arm below the elbow;
- Left arm above the elbow;
- Hand amputee (thumb and at least 2 entire fingers);
- Foot amputee (more than the toes).

Difficulties that impede movement and mobility[7]

- Left leg;
- Right leg;
- All body;
- Lower part of body;
- Both legs;
- Right side;
- Left side;
- Right arm;
- Left arm.

Visual impairments

- Both eyes blind;
- One eye blind;
- Both eyes low vision.

Hearing impairments

- Both ears deaf;
- One ear deaf;
- Both ears low hearing.

Speech Impairments

- Total;
- Severe;
- Partial.

Section B: Intellectual and Learning Difficulties

This section consists of four questions, 2.9 to 2.12. The procedure is the same than for the previous section but the person has to have at least **two** of the 4 signs in order to be considered as having a disability. A **Yes** to only one question does not suffice.

- Later/slower speaking patterns compared to other members of the family;
- Later/slower walking, mobility development compared to other members of the family;
- General retardation in development patterns, behaving much younger that the given age.

Section C: Behavioural and Psychological Difficulties

This section looks at some behavioural patterns that persons of the household might have. It consists of 8 questions. The procedure is the same than for the previous section, the person must show at least **two** of the 8 signs in order to be considered as having a disability. A **Yes** to only one question does not suffice.

- Difficulty or impossibility in expressing needs, using language that no one understands;
- Difficulty or impossibility in being with people who are not familiar;
- Difficulty or impossibility in keeping still, staying in one place;
- Difficulty or impossibility in keeping quiet, talking all the time in presence of others or alone;
- Violent behaviour regarding yourself (banging head against the wall, self-mutilation, biting own hand etc.).

Section D: Communication and Social Functioning Difficulties (Linked to Identifiable Reason)

This sections looks at some attitudes and interaction patterns that persons of the household might have. It consists of 6 questions. The procedure is the same as for the previous section; the person has to have at least **two** of the 6 signs in order to be considered as having a disability. A **Yes** to only one question does not suffice.

- Having repetitive, stereotyped body movements (rocking back and forth);
- Sudden and unpredictable physically violent behaviour towards other person (hitting, biting, scratching, spitting, pulling hair...) without reason;

[7] One of the limitations here is too much focus on extremities. All surveys on disability should include various types of spine problems that lead to a disabling situation.

- Sudden and unpredictable verbally violent behaviour towards other person (abusing, using foul language constantly...) without reason;
- Getting angry very easily and screaming/yelling without reason, when touched.

Section E: Fits and Seizures

This section looks at some specific fits that persons of the household might have. It consists of 3 questions. The procedure is the same than for the previous section, the person has to have a **Yes** to **two** of the questions in order to be considered as having a disability.

- Fits, seizures;
- Epilepsy signs;
- Fainting or passing out without reason.

This module of the questionnaire is essential for the rest of the survey. The screener is the tool from which the prevalence rate is estimated. This is why it has to be filled out with great care and sensitivity. For example, if someone seems to hesitate a lot, the surveyor has to be convincing and non-threatening in order to ensure that the persons of the household do not feel that they are being judged.

Filling out the Screening Questionnaire

The screening questionnaire is used to identify the persons with disability for follow-up. In the case of the NDSA, it was asked theoretically to the head of household, who is also the person that answers the family questionnaire, providing the main information for the demographic items (age, sex, place of birth, civil status, activity…) about each and every member of the household. The head of household can be encouraged by the surveyor to request help from another member of the household in case of difficulty or hesitation in answering any of the screening questions.

It might be argued that asking the head of household about abilities and difficulties or signs of disability for any of the household members is a major risk for missing a person with disability, thus underestimating their number. Nevertheless, a complex sample selection procedure might not be adapted to a country such as Afghanistan because:

- There is no possibility to proceed with a systematic medical diagnostic (only 54% of the population declared having access to a health centre);
- A majority of persons with disability do not have any medical contact, and never received any treatment or support;
- Some persons do not need to be identified because they will not be taken into consideration in policies at this stage: dyslexia, for instance is not a problem in a country with less than 30% of literacy rate.
- In some parts, the entire cluster needed to be surveyed with a limited team in a day period to avoid security threat. Priorities need to be clear in such cases!

To limit this risk, the NDSA team proceeded as follows:

- The head of household was asked to request help from the women of the household when he had a doubt about the ability of a person to perform a given task: this has proved to be an efficient solution to avoid underestimation or non-cooperation.
- The Monitor MasterTrainer, usually a medical doctor, in charge of the supervision of the team was called upon in case of a contentious case and the person concerned in the household was met.
- Surveyors were trained to reformulate questions and explain the signs.
- Above all, questions were made very simple, culturally friendly, and composed with neutral words to avoid stigma.

The Other Modules of the Questionnaire

Once the screening has been carried out, surveyors can move to the next step: filling out the questionnaire that looks at living conditions. This tool is composed of a variety of questions that can be used as indicators of the issues in focus. The questions are ordered in thematic modules. Inside each module, questions are organised from the most simple to the most complex type of information required. Order of questioning always follows a logical pattern. **Sometimes, questions asked are similar to those of other surveys carried in the country to allow comparison** over time and/or with different sub-groups of the national population.

One of the aims of general surveys is to look at the living conditions of persons with disability in comparison with that of non-disabled persons. **As a result the tool should be adapted for interview of the control groups of non-disabled persons as well.** Keeping this in mind, the questionnaire devised would need to be valid for the match within the household of a person with disability and the control group outside the household of a person with disability. In a number of developing and transition countries, where the structures and services are non-existent in most parts of the country, it is important that the results presented establish whether the problems found are specific to persons with disability (or certain types of disabilities) or whether they are more general problems shared by the community; the policy implications are of course very different in both these cases.

The major principles to be followed are presented here. The questionnaire is the most important tool as it will provide the

information needed to reach the objectives defined. The quality of the information collected relies mostly on the validity, reliability and accuracy of the questions asked, as well as on the general pattern followed in the questionnaire.

Principles for the Design of a Questionnaire

In view of the defined objectives, the questionnaire will be designed to provide insights into the various issues that have already been mentioned above. Within each field (health, education, income...) the questionnaire will look at the following aspects of the living conditions of the persons with disability:

- Identifying the resources (family, community and state level) that are available;
- Looking at the access to these resources;
- Identifying the existing barriers that prevent persons with disability from accessing these resources, these can be physical, social, environmental and/or psychological;
- Defining effective ways to overcome these barriers;
- Identifying the range (or limitations) of choices that persons with disability perceive as open to them;
- Identifying ways to enhance capabilities of persons with disability, by defining coping strategies that expand real choices.

The questionnaire is thus designed to reflect the hard facts of the everyday lives of persons with disability regarding issues such as health and education. **But it also looks at their view of reality and the changes that they would like to see in their living conditions**. Finally, questions should be designed to reflect the prejudice and discrimination faced by this vulnerable group and to propose ways to ensure long-term changes.

A comprehensive questionnaire can be composed of different units or modules focusing on elements that help understand the opinions and perceptions of persons with disability on matters of concern:

- Family and demographic characteristics;
- Health conditions and accessibility to existing services;
- Education;
- Labour market, job accessibility, unemployment, under-employment;
- Livelihoods, level and sources of income;
- Social networks and participation.

The survey can thus provide very basic statistics (means, distributions and cross tabulations by age, sex, ethnic group, areas...) as well as more complex multivariate analyses. Descriptive statistics are a starting point to answer the questions that the data was collected for.

While developing the tools that will be used for the survey, it is essential to ask what information each and every question is going to provide. This can be done by first defining the fields of interest for the survey, and then by determining what type of information will be required in each field. The box below may help to devise the relevant questions. Of course, the survey tool may be limited to only one field.

Step 1: Define the fields of interest for the survey;
Step 2: Define the type of information that the survey is aimed at collecting;
Step 3: For each field and each type of information define the precise indicator(s) that will be calculated;
Step 4: For the given indicator (s) define the most appropriate question (s).

Pattern for Drawing up the Questionnaire

Information Fields	Identifying the Resources	Access to these Resources	Barriers to these Resources	Identifying Ways to Overcome Barriers
Health	Indicator(s): Question(s):	Indicator(s): Question(s):	Indicator(s): Question(s):	Indicator(s): Question(s):
Education	Indicator(s): Question(s):	Indicator(s): Question(s):	Indicator(s): Question(s):	Indicator(s): Question(s):
Employment and Income	Indicator(s): Question(s):	Indicator(s): Question(s):	Indicator(s): Question(s):	Indicator(s): Question(s):
Livelihoods	Indicator(s): Question(s):	Indicator(s): Question(s):	Indicator(s): Question(s):	Indicator(s): Question(s):
Social Participation	Indicator(s): Question(s):	Indicator(s): Question(s):	Indicator(s): Question(s):	Indicator(s): Question(s):
Awareness	Indicator(s): Question(s):	Indicator(s): Question(s):	Indicator(s): Question(s):	Indicator(s): Question(s):

Asking Questions in a Logical Order: the Example of Education

The questions follow a logical order, as for instance, in the Education Module.
The question about reading and writing comes first.
Then, it is logical to respect the following order:

- *Ask about having received education; this induces conditional questioning. Thus a skip pattern is used to filter the question that is not relevant.*
- *If the answer is **No**, ask why the person did not receive education;*
- *If the answer is **Yes**, ask about which type of institution provided education;*
- *If the person has been to a formal public or private school (i.e. was not educated at home, in a Madrasa…), ask about the class reached.*

Example:

4.1 Do you know how to read and write (for instance a little note) ?

1 =YES 2 = NO /___/

specify choice

My name is (specify). I am from (specify the village or town). I am (X) years old. I would like to tell you about my situation.

_____

_____

_____

N.B.: Code again in the box below 1=YES if the interviewee could write the entire text, and 2=NO if he/she could not write the entire text

/___/

specify choice

4.2 What kind of education did you receive or are you receiving mainly ?

(2 answers possible) /___/___/

specify choice

1 = government school
2 = private school
3 = training centre
4 = religious school (Madrasa)
5 = in the family/or with someone
6 = no education

N.B. : For s . answer 1 go to Q 4.4

4.3 Why did you receive no formal education ?

/___/

specify choice

1 = being disabled, I was refused
2 = absence of school
3 = lack of money
4 = need to work
5 = education not very useful
6 = doesn't like school
7 = too much work in the house/field
8 = useless for girls
9 = family does not allow girls to be educated
10 = no school for girls in the village
11 = quality of school is not good
12 = bad political situation

N.B. : For all answers ----------> go to Q. 4.10

4.4 Upto which class did you reach as a student?

1 = class 1	6 = class 6	11 = class 11	16 = PHD, more than 5 years
2 = class 2	7 = class 7	12 = class 12	17 = other, specify_____
3 = class 3	8 = class 8	13 = class 13 _____	
4 = class 4	9 = class 9	14 = Bachelor's s Degree, 3 years	
5 = class 5	10 = class 10	15 = Master's s Degree, 4/5 years	

/___/

specify choice

Major Steps in the Design of the Questionnaire

A certain number of principles must be considered when designing a questionnaire. The quality of information gathered relies mainly on the efficient and easy use of this tool.

Logical Order of Questions and Skip Patterns

The quality of the information gathered depends largely upon the way the questionnaire is designed (see box, p30).

Single Meaning of Questions

In a well-organised questionnaire, each question should have **a unique meaning and a single possible interpretation**. This is the ideal goal to pursue. Multiple meanings inevitably lead to incorrect and useless information. This does not allow for any kind of valid results during the analysis phase.

Possible Link between Questions

A question can be linked to a previous one. Usually, it is better to have a pattern inside the questionnaire itself which will explain the link (see box below).

Keep Sensitive Questions for the End

Since disability topics are sensitive in many cultures, particularly for certain types, the order in which questions are asked is extremely important for several reasons:

- It reduces non-response and even hostility in some places like south Afghanistan. The sensitive questions should be asked at the end of the interview;
- It prevents the interviewee from becoming defensive or suspicious from the very beginning of the interview, thus jeopardising the collection of reliable information;
- More generally, it avoids loss of interest and ensures a higher level of cooperation.

Sensitive questions are not only those about disability. These can be also questions about:

- Income and loans;
- Sexuality;
- Ill-treatment;
- Access to adequate food, the omnipresence of hunger.

Different Respondents

The design of the questionnaire must take into consideration that different people will answer the questionnaire. Usually, the person screened or chosen through random sampling (for controls) is the one who is interviewed. In a household survey related to disability, the person with disability is generally the interviewee. There are some exceptions to this rule:

- The questionnaire is composed of a family module that consists of general questions about the household. In this case, the head of household can answer or any adult member of the household.
- The questionnaire includes a screening tool used to identify a specific issue: in the case of the NDSA, the screening tool is a set of questions to identify persons with disability. Usually, the screening questions are asked to the head of household. There is a risk of underestimating

Clarity of Meaning in a Question: the Example of the Screening Tool

In section D of the screening questionnaire Q. 2.19 is worded as follows:
"Does any member of your family make the same gesture over and over again (rocking, biting their arm, hitting their head…)?"
During the training, a discussion arose among trainees about the notion of gesture. The phenomenon of palsy was considered by some of the trainees as a repetitive gesture. If we consider that a gesture is "the use of motion of the limbs or body as a mean of expression", (Merriam-Webster Online Dictionary), then it does exclude an uncontrolled tremble of the hand for instance.

Link Between Questions

In the Adult Questionnaire, health module, Q. 3.11 asks about the time required to reach the closest available health care facility.
This question depends on the type of means of transportation used to go to this health care facility, as asked in Q. 3.10.
It also depends on the type of health care facility declared available in Q. 3.8.
The goal of the training is to familiarise the surveyors with this kind of pattern.

disability in doing so. Nevertheless, it is time-consuming and practically difficult to administer the screening to all members.

- The target person is not able to answer him/herself for different reasons (child under a certain age, person with mental, intellectual, behavioural difficulties, etc.). In this case, a proxy or assisted response can be used.
- The person is not present at the time of the interview.

In the last two cases, an adult "proxy" respondent can be interviewed. A proxy is the response provided by another person. This was often the caretaker in the case of the NDSA. Assisted response is used whenever the person is not able to answer her/himself. This is useful for mentally challenged respondents or for younger children.

Pilot Survey and Pre-Test

Once the design of the questionnaire has been completed, using the tools available and after discussion with experts and persons with disability, it needs to be tested in the conditions of the survey.

In a national survey like the NDSA, it is highly recommended to test the questionnaire in both rural and urban clusters. The test can be done within households after applying the methodology for systematic selection of households. Researchers accompany the interviewers as observers and watch respondents answering questions and interviewers completing the forms. Another possibility is to test the tool using the focus-group method where the researcher leads the group of participants through a structured discussion around the questionnaire used for the survey.

These methods provide feedback useful to check that:

- Surveyors have understood the training on disability concepts, interviewing procedures, and meaning of questions;
- Respondents are not offended by sensitive questions, thus that the wording and phraseology are adequate;
- Questions are clear and unambiguous and not misunderstood by the respondents.

Training of the Survey Team

The importance of the training of the survey team is often underestimated in surveys on disability. As a consequence, the length and the quality of the training phase is not always sufficient. The quality of the data obtained, largely depends on the understanding and the commitment that the team has with regards to the objectives of the survey as well as the comprehension of the tools and the methodology. In fact, non-response occurs mainly when surveyors do not fully understand the survey goals and concepts, ask the questions inconsistently, record answers inadequately which leads to a general lack of uniformity in the way the survey is implemented.

This section of the toolkit focuses on the month-long training that was carried out for the Master Trainers and Monitors of the NDSA, who in turn, were in charge of training the survey teams on the field. These training sessions were elaborated with the help of a number of persons working in the field of disability and with the participation of persons with disability within the training sessions. However, the confrontation between scientific requirements of neutrality and inclusion of organisations of persons with disability remained constant throughout the survey.

Who Should Survey?

This is a difficult question to answer. The decision depends on the socio-cultural and economic context that the study is being carried out in; it also depends upon the education level in the country. When defining the survey plan, a number of questions need to be taken into consideration and explained to the partners and the stakeholders in order to be accepted.

Persons with Disability as Surveyors

Whatever the context of the survey, the decision to include persons with disability needs to be taken at the very onset, when budgets and methodologies are being decided. In certain settings, surveyors with disability might encourage families to talk about the members of their own households and facilitate dialogue, whereas in other situations this might highlight certain types of disabilities and still stigmatise other forms, making it even more difficult to find disabilities that are not socially and culturally accepted. In a number of traditional societies the concept of disability is still closely linked to that of ability. There is a belief that certain categories of persons with disability can and should be helped because they have the potential to become contributing members of society. The inclusion of persons with disability needs to be systematic in order to ensure that they are part of the process at every stage and the required measures need to be taken in order to minimise the barriers that impede their work.

In the case of the NDSA, the decision to include persons with disability was strongly influenced by the geographical setting as well as cultural and social norms. Of course the barriers and inaccessibility of certain remote areas needed to be taken into account: a number of clusters selected for the NDSA were situated in mountainous areas and could only be reached after several days on foot, on horseback or by donkey.

Moreover, in a country like Afghanistan, where the level of education is very low in the general population, it was extremely difficult to find persons with disability having the required level of education and who did not already have a stable job. In each regional centre, the NDSA team interviewed persons with disability and trained the ones that had the minimal qualifications. However, it was not possible

to employ more than a handful of them in view of the lack of education and the complexity of the survey tool, which required high literacy skills.

Lastly, the persons with disability who were recommended as surveyors by the local authorities were usually from affluent families, having a political agenda in the region, and thus, presenting a huge bias for the neutrality of the survey process. A number of persons were from powerful families and had a clear tendency to influence the results of the survey in favour of getting aid for their region. The individuals who were disabled due to war or victims of landmines, extremely visible and socially accepted within the Afghan context, also shared lay beliefs and prejudice towards other categories of persons with disability that are less valorised because they result from other causes (congenital, disease, malnutrition etc.).

Should Persons Working on Disability with National and International Organisations be Included?

Here again the decisions taken will depend upon the context. Within the NDSA team this did lead to a certain amount of debate. The experience obtained through interviews and training sessions showed a number of concerns regarding the understanding of disability. Persons having prior experience in the field of disability were trained; however there was still a bias towards certain types of disability that were more visible. In Afghanistan the large visibility of persons with war-related disabilities results in the setting-up of a few rehabilitation and physiotherapy centres and programs. As a consequence persons working on disability in the country have a very commendable picture of the particularities of physical disabilities, very often they do not even consider for example mentally disabled persons as being in the same category. In these cases, it may be easier to work on training of persons who share the social and cultural beliefs that are present in a given society rather than working with persons who have heightened awareness about one aspect of disability and are sometimes more difficult to sensitise regarding the forms and types of disability that they are not familiar with.

> For the NDSA it was decided to work with persons who had the qualifications required in order to fill out the questionnaire: minimum requirement being having completed school. Some surveyors had prior health experience (a number of the MTM were doctors), almost all of them had already participated in a national survey and were working under one of our partners namely the Ministry of Public Health. Some of the surveyors were however teachers and university students. A great part of them were civil servants; this ensured their availability since the survey was carried out on behalf of the Government of Afghanistan.

Sensitisation: Changing Set Ideas and Vocabulary

Sensitisation entails looking at the mechanisms of stereotypes and prejudices, understand the dynamics of their creation as well as the cultural dimensions that firmly keep them in place. If the aim of a sensitisation is in fact to fight the discrimination that results from these, then the first step is to try and understand these processes from a social, psychological and behavioural point of view. Although this may seem like a huge effort just for the survey, these beliefs strongly influence the attitudes of the survey team and impact the way the questions are asked, and in consequence, the quality of the answers that are obtained.

What Are the Specific Aims of the Training Sessions?

What are the specificities of training for a survey on disability? A particular type of sensitisation is required in this case, based on very technical elements and geared to obtain a very precise outcome: **carrying out an interview in the most respectful and unbiased way possible.** Moreover, the time-frame for the training for a survey is usually shorter than a sensitisation campaign, which can rely upon the repetition of information and reactivate messages time and again in order to achieve a long-term result. For a survey, the sensitisation is somewhat different. In order to be efficient in a short time, it is imperative to define certain objectives that will be essential for the data collection exercise.

The training sessions look at the following aspects:

- A first sensitisation regarding the concept of disability;
- Work on existing prejudice (working through the vocabulary that is used);
- Understanding the similarities that exist between persons with disability and persons without disability and trying to work along with the perception of differences.

The main aim remains to create a vision of a '**person**' and not just a person with disability, make the surveyors take interest in the lives of the persons and see what types of difficulties they are faced with.

First Step: Understanding the Concept of Disability

Fact file 1 already specified the social representations of disability in Afghanistan. There are a variety of terms that translate disability into Dari and Pashto; these refer to different beliefs, realities and attitudes towards persons with disability. It is important to fully understand the meaning of these terms, how they are used and what they imply within a specific context.

It is difficult to explain and to make people interiorise the distinctions between impairment and disability, the next step being to look at the individual first and not the impairment.

In order to achieve this we followed a simple three steps method:

- Bringing out the **stereotypes** and the related beliefs, which are often based on real facts.
- Understanding the **prejudice** that is often related to a given stereotype. A prejudice is the act of assigning a positive or negative belief to a given stereotype.
- Fighting **discrimination**, which is the fact of taking action that is based on the prejudice.

Example of the Three Steps Method

Stereotype:	A person who is a landmine survivor often lacks a limb.
Prejudice:	The fact of lacking a limb makes it impossible for the person to go to school.
Discrimination:	Such persons are not sent to school.

While a stereotype can be, and usually is, based, on real life facts, very often it is accompanied by negative prejudice and discrimination. The training for the surveyors should look at this dynamic process and focus first and foremost on fighting discrimination and negative prejudice, which are at the source of differences in living conditions between persons with disability and those without. The aim is not to ignore the differences that are real, but to understand that most of the beliefs that derive from the perception of these differences are not only unjustified but often contribute to the discrimination that persons with disability and their families face.

In the NDSA training, the theoretical definitions and the differences between concepts were explained: impairment-disability-handicap. Any training session will need to ensure beforehand that **the translators know which term they should use for each of these concepts in the local languages. If there is no satisfactory term, trainers should continue using the term in English and explaining it**. The most important element is to stress the fact that a number of situations can be disabling, and that this is not always linked to a permanent impairment. The examples that we did use for the Afghan survey were that of our project manager who was unable to communicate in the training sessions without the help of the translator, who happened to have a visual impairment. In this case who would be considered disabled?

A Well-Planned, Comprehensive and Diverse Schedule

In order to achieve the complex aim of sensitising the survey team on disability, a variety of methods can be used at different stages of the training sessions. The combinations of various methods that use different cognitive and affective mechanisms ensure that the message is not just understood on one level but also experienced. In order to assess what the lay beliefs are among the group of surveyors, it is important to ask them a few questions at the beginning of the training. These questions may be the following:

- How would you translate the term disability into your language?
- How would you define the term?
- Please state the different types of disability that you are familiar with;
- Please think of a person with disability that you know or you have seen. What three terms would you use to describe her/him?
- What do you think is the most evident similarity and the main difference between you and that person?

Defining a Training Schedule

This is a point that cannot be stressed enough: training for a survey on disability cannot be done adequately in just a couple of days. Although there is no ideal training period, it is essential to ensure that all aspects of disability have been addressed and that survey techniques (interview, questionnaire, organisation…) have been over-viewed. What this document presents is not the ideal training schedule. However there are some core aspects that are inherent to any training.

First week of Training for NDSA

Fields addressed during the first week of training by the occupational therapist, physiotherapist and psychologist were:

- The concept of disability, discussing definitions;
- Physical and sensorial disabilities;
- Mental disabilities;
- Children with disability;
- Interviewing techniques (attitudes, vocabulary, respect).

Although the NDSA did allot one day to each of these themes, there is no right way to proceed. The important fact is to address all these through different means.

The NDSA training followed a pattern for the issues addressed during the first week:

- Theoretical definitions and discussion about how to translate the terms;

- The detection of these disabilities, the questions that can be asked in order to detect these;
- Visit of centres in order to meet with persons with diverse disabilities, discussions, underlining the similarities between the surveyors and the persons with disability;
- Discussion and de-briefing about the visit, what did they remember about the person, what did they feel;
- Sometimes role-play exercises can be used in order to explain that communication is possible even when the disability is severe and affects speech and movement.

Throughout the sessions, trainers were especially attentive to the vocabulary being used and the attitudes of the surveyors. Attitudes shown by trainees were used as example for discussion over stigma.

Example of Stigma and Discriminatory Attitudes during the Training Sessions

During the training session on children with disability, the surveyors visited a cerebral palsy ward for children. The aim of the session was to have a discussion with the families that bring their children to the service and try and understand their difficulties. Most of the surveyors being from a medical background, it was very unfortunate that during this visit one of the groups of trainees did actually persist in asking questions to the mother about why the child was disabled, what caused the disability, did the mother have other children with disability. The idea that somehow, the cause had to be identified remained very strong. The facilitator was not present for a few minutes and could not stop this line of discussion. The mother of the child, faced with these questions from a group of persons was close to tears...

The trainers and facilitators tried to talk with the mother to try and apologise.

Second Week: Tools and Interview Techniques

The second week of training can then be more centred on the methodology and the tools of survey (questionnaires, field manual, sampling frame etc.). Explaining the questionnaire can seem relatively simple depending upon the length and the complexity of the tools. The NDSA methodology and tools were extremely complex: three stages of sampling and various questionnaires that could consist of up to 44 pages for an adult.

The order of modules and of questions was examined and each question within each module defined, explained and debated about.

Moreover, the researchers took this second week to discuss the meaning behind each and every term as well as its adequate translation into Dari and Pashto. This was done for two main reasons:

- This was an opportunity to change the translation of the questionnaire as well as check that all the options were given for the pre-coded questions.
- It was essential that the survey team, and more specifically the Master Trainers/Monitors, who would be in charge of training the surveyors in the regional centres, know what kind of information each and every question was trying to obtain. This could only be done if they felt that they understood the aims of each and every question. The importance of this has been stressed in a number of surveys. If the distance between the researcher and the survey team is too great and the training time too short, these can seriously jeopardise the quality of the data collected. **The training for the NDSA was carried out by the researchers, who had designed all the tools.**

Second Week of Training

As we stated, this week consisted of discussion of the methods and tools. Some aspects were specifically addressed by the training:

- Sampling methods;
- Security on the field;
- Checklist and household file;
- Health module;
- Education module;
- Employment module;
- Livelihoods;
- Social participation and inclusion.

Third Week of Training: Getting on the Field

The third week consisted of field tests for the survey team. These field tests were progressive, starting with a relatively easy population and moving onto more remote areas and difficult interviewees. These consisted of:

- 1 day of training with medical students;
- 3 days of field test in an organisation that provided training and employment for persons with disability;
- 2 days of field test on the field in urban and rural clusters.

The main aim of this week of training was to make the surveyors familiar with the complexities of filling out the questionnaire and

avoid reading out the items each and every time. During this phase special attention needs to be paid to:

- Attitudes and behaviour of the surveyors;
- Vocabulary and capacity to re-formulate questions in simple terms;
- Patience and respect for the interviewee;
- Accuracy when completing the questionnaire.

Specific Aspects of Training for Surveys on Disability

As stated earlier, this specific form of training does entail paying attention to certain aspects of disability. Some of the points were seen to be sensitive during the training for the NDSA. The first one was looking at the beliefs and stereotypes that exist within the group and to work on these. The second aspect was to look specifically at mental disability. Lastly it would be advisable not to ignore the gender aspect during the training sessions.

First Steps Towards Sensitisation....

For large-scale surveys, more often than not, surveyors do not have a background in disability. Even when they do, they often work in specialised areas, dealing with a specific category of persons with disability. The first sessions are meant to break the ice, bring out the prejudice and even discrimination that the surveyors carry with them, knowingly or unknowingly, and that reflect the beliefs that are present within society as well.

The first phase of training can be achieved through many different methods, group discussion, word-association exercise and through role-play. The aim remains the same, whatever the means, to make people aware of their own beliefs regarding disability, of their reactions and their attitudes. This in turn will be used throughout the training to assess changes in attitudes and reactions.

Special Attention Given to Forms of Mental Disability

If detecting disability within the household is a difficult task then finding people who have a mental disability is sometimes close to impossible without proper training and adapted tools. Surveys that are aimed at providing information regarding disability, more often than not, largely under-estimate the rate of mental forms of disability, be it mental illness or intellectual disability. This can be explained by various reasons:

- There is a lack of knowledge regarding these forms of disability, which goes hand-in-hand with a lack of visibility within society.
- Mental disabilities are often surrounded by common beliefs and religious superstitions, which result from the overall inability to identify a specific cause. As a result it is believed that there is some mysterious or divine intervention; in traditional cultures, mental disability is often viewed as a punishment that a person had to endure for his/her acts.
- The language often used is negative; stereotyped terms refer to these forms of disability (often the equivalent of 'mad' or 'crazy').
- Like disability that results from congenital causes, mental forms have an effect on the image of the family and can have serious consequences on the marriage of siblings, for instance.

Breaking the Ice

Ice-breaker exercises for the training of the surveyors of the NDSA included various games and role-play exercises. One of the interesting discussions was brought on by carrying out a quiz that was designed by our occupational therapist working in the country. The aim of this exercise was to see what beliefs were behind discriminatory behaviour towards persons with disability. Some experts were also present during this session to explain why certain beliefs were not based on any sound facts.

QUIZ QUESTIONS

- I would buy cakes from a person who has leprosy…
- I would help start a home-group for 5 children with mental disability next to the local school…
- I would allow my child to marry a person who is blind…
- There should be special rules for people with physical disability so that they can get jobs more easily…
- I would feel happy if 6 disabled children (some visually and some hearing impaired) joined my child's primary school class of 45 students…
- A person who has been in a mental hospital can drive a car…
- I would not be surprised if a person who has a spastic arm and leg took my order at a restaurant…
- Disability is sent from Allah to a person…
- A person who is in a wheelchair should get special help from the government to go to university…
- I would leave my three-month old baby with a neighbour who uses two crutches to walk…

All these reasons result in household members hiding the presence of a person who has a mental illness or intellectual disability. The prejudices are often well-rooted in society; the survey team is not exempt from this. What makes it even more difficult to convince teams to take the time and energy required to make sure that persons with mental disability are included, is that people can easily comprehend the programmes that can be set-up for persons with physical and sensorial disability in terms of access to health services and education as well as the setting up of effective employment opportunities and quotas for reservations in public services. For persons with mental disability the needs and requirements are often seen as being too costly, demanding too much effort. There is a more or less implicit hierarchy that exists within persons with disability as a group. In developing and transition countries there is a common belief that the limited resources should be used where they can be most efficient and make people 'productive' and integrated members of society.

The Experience of the NDSA

Keeping in mind all these facts there are two elements that any training sessions must consist of in order to ensure that mental forms of disability are not grossly under-estimated:

- The training should integrate modules that address the issue from a human rights perspective. This of course is more effective if there has been some form of awareness-raising.
- The other aspect that should be stressed is the necessity to help persons with mental disability as well as their families, in order to lessen the burden on the family as a unit.

An effective training on mental disability will stress both these points.

Gender Sensitivity: a Constant Battle

A number of training sessions on disability only briefly address the gender aspect, which remains crucial in all contexts. The social fabric is not divided into clear-cut and independent variables; various factors interact constantly to create complex social relations. Gender is a major factor that influences relations within the family and the community. It defines social roles and the expectations that are linked to these. In each context the aspects of gender that need to be worked on in view of carrying out a survey need to be defined. The main challenge then is to carry out a session on women with disability, looking at the specific problems of this vulnerable group. In certain cases a more extensive sensitisation on gender issues in general may be necessary.

For the NDSA Training the General Aims of this Session Were:

- To make the trainees understand the differences between sex and gender;
- To make them aware of the differences, which derive from discriminatory attitudes;
- To help them understand the double discrimination that women with disability endure in society;
- To make them realise that there are solutions that can improve the situation (without being culturally offensive).

From Sensitisation to Awareness: Maintaining Quality and Sustainability of the Training Session

The path from sensitisation to efficient and long-lasting awareness is difficult. For surveys, we have to admit that the main aim is not to raise awareness regarding disability within the team. The necessity to re-activate the knowledge and attitudes acquired during the first training cannot be stressed enough.

'Booster' Sessions: Re-activating the Messages

A survey can be carried out over a short period of time or can continue over several months. As time passes, survey teams have a tendency to retain merely the technicalities of filling out the questionnaire. In order to ensure that the quality of the interview situation is not deteriorating, it is important to do short reminder training, focused on the following points where the tendency to go fast and cut corners is most likely. If the surveyors are in the field everyday, short "re-activation" trainings should be carried out **every month.** The aim of these sessions is to ensure that the main aims and messages of the initial training do not wear off with time and the constraints of the field. These are of course shorter than the initial training and are tailored to suit each group of surveyors. The themes that need to be re-addressed during these sessions can be very different and will depend closely upon what was observed on the field. The difficult task of the monitors/master trainers and researchers then, is to evaluate what the weaknesses of the survey team are and design the booster session in function of these.

For the NDSA, this step of the fieldwork and training was not adequately taken into consideration due to time and security constraints. In addition, the regional team managers could not be on the field often; as a consequence it became very difficult to become aware of the weaknesses of each team. However,

during the verification of the questionnaires, it did become clear that certain themes needed to be included in various consecutive sessions.

- **Mental Disability** (Mental Illness and Intellectual Disability). This aspect of disability is a challenge in any training, not only those related to survey. As time and security constraints increased during the fieldwork of the NDSA, the effort and patience that were required to detect these 'hidden' forms of disability also deteriorated.
- **Gender Issues:** the need for a further booster training session in this aspect is also recommended, as with time, the common beliefs and attitudes towards women in general, and women with disability in particular re-surface. For the NDSA this was even more salient as in certain regions, where long days of travel were required, families would not allow the women to go. The male surveyors then had to carry out all the interviews, sometimes across closed doors…
- **Sampling Procedures:** As the sampling of the NDSA was a tedious task, there was a tendency to cut corners when the households in the clusters were too far apart or when another village needed to be included to complete the required 30 households per cluster. Survey teams need to be reminded of the importance of this step. In the NDSA, the researchers also informed the teams that random checks of clusters would be carried out.
- **Place of the Interviewee with Disability.** As time and fatigue wear out the surveyors, the efforts required to interview people with very severe and multiple disability also deteriorated. As a result, in cases where the person with disability cannot answer for him/herself and the caretaker needs to be interviewed, the actual respondent gets ignored. The surveyors should not forget that the main focus remains the person with disability and he/she needs to be present during the interview and included and acknowledged as often as possible.

The Challenge Faced During the NDSA

The challenge that we faced on the field was the need to strike the balance between tackling dangerous situations with regards to security of the teams and the quality of the interview situation.

In fact, in certain regions bad security made it impossible to stay in a cluster for more than a day (the fact of returning to the same location increasing the risk of an attack). However, the surveyors were required to remain patient during the sensitive questions and reformulate when the interviewee did not understand the terms and not rush the interview.

We realise that in certain cases security considerations did take precedence…

- **Final Questions.** The NDSA questionnaire was a lengthy one and the most sensitive questions, those related to ill-treatment for instance, were asked at the end so that they did not influence the rest of the answers. However, surveyors may have had a tendency to rush through the final questions. Booster sessions can also look at maintaining a patient and respectful attitude till the very end of the interview.

De-Briefing Sessions for the Surveyors

Lastly, it is essential to organise de-briefing sessions with the survey team that have been on the field for long stretches of time. These sessions are aimed at creating an opportunity for the surveyors to express their frustrations and thoughts with regards to their experiences during the fieldwork. The teams invariably will be faced with difficult situations on the field, be it security or dealing with the expectations of people, their living conditions, their frustrations… It is important to create a time and space for these experiences to be heard and discussed.

Experiencing Dialogue and Feedback During the NDSA Fieldwork

One major and interesting team interaction during fieldwork was the discussion about responses to queries given by interviewees in a village. A recurring debate was about the help that should be given to the people. Frequently, the chief of the village or the Elder members of the *Shura* (Council) wrote a letter, with their signatures or fingerprints, requesting the Ministers providing support to the survey to provide help to the village.

For surveyors, who sometimes took non-negligible risks to reach some areas, who walked long distances or endured several days of car travel to reach remote villages, simply collecting data did not make a lot of sense.

This is why it is imperative:

- To provide repeated explanation why data collection can change order of priorities in implementation and designing of programmes;
- To give feedback on the results to the interviewees and their families;
- To train part of the team on data analysis so that they better grasp the use that can be made of data collection work that they are doing;
- To ensure follow-up for action on disability: make sure things do not stop at the survey level but results are disseminated and translated into action.

Training for Surveyors for a Study on Disability: the Experience of the NDSA

This section details the training sessions that were carried out for the Master Trainers Monitors (MTM) of the National Disability Survey in Afghanistan (NDSA). This training, prepared and carried out by various experts working on disability in the country, was done over a period of one month, in Kabul during November 2004. **The aim of this document is not to present a polished manual that explains what should be done, but to share an experience that took into account the cultural specificities of the country in order to sensitise a group of persons who were not experts in the field of disability.**

The one-month training that was carried out for the MTM had a clear objective: training the team in order to carry out the required survey in an adequate and respectful manner. This training session, one of the longest carried out for such a study, brought together a series of experts working in the field of disability in Afghanistan. A number of tools were put together and these needed to be respectful of the culture and the context, use words that were accepted as well as work towards changing prejudiced beliefs regarding persons with disability.

Even if this training was carried out for surveyors, the tools and methods can be of use for more general sensitisations on disability. In fact, the MTM and the surveyors, though in majority from the medical field, had never received any such training. Even the trainee who was a physiotherapist, and had been working for a number of years with an NGO, had certain strong prejudices when it came to persons who had non-physical disabilities.

The present annexure details that first phases of the training for the NDSA: understanding disability. The last two weeks of training are not detailed here, and were more focused on the survey tools and methodology, as well as on improving the interview skills and attitudes of the surveyor towards the person with disability.

Getting Started

Contacting the Partners

Needless to say that training is a team effort. Any training on disability will invariably be done with the collaboration of other partners working in the country. These can be local and international NGOs or government structures such as hospitals, schools and other bodies. Moreover, visits to institutions as well as schools and vocational training centres is a crucial component of the training. Discussion with these partners should be done beforehand in order to explain the training and decide upon the interventions and visits that can be organised. The NDSA training had support from partners in the various fields.

Some Pointers for Trainers and Facilitators

Here are some pointers that the trainers need to bear in mind throughout the training. Most important of all, the trainers need to be **reactive**. You never know what the group dynamics are going to be like, methods and exercises will be adapted to the group constantly; some things will work well, other will fall on their face.

Dear Training Team:

- Know your trainees well.
- Listen to your trainees.
- Evaluate and re-evaluate your sessions each day and make changes if necessary.
- Be aware that at some point you will begin to sort through these various ideas and evaluate their appropriateness in the environment you are in (religious or cultural limitations, economic situation, access to limited materials).
- You must be open to alternative solutions as they occur. There are several ways of delivering the same message, but which one is the best for your target population?
- Allow time for trainees to ask questions. It is important that your trainees be aware that you are willing to change things and be flexible. Be accepting of all questions.
- At the end of each day, give trainees 15 minutes to give their reactions to the day. This can provide feedback on doubts, or questions that students were afraid to raise. This is also a good way to sum-up what has been acquired during the session.

Clarifying Roles, Duties and Expectations

In any project on disability it is important to be convinced of the commitment of the entire team to the project. In order to establish a good relationship with the trainees, **it is advisable to write down what is expected of them, and what they will receive out of the training, in a formal contract.** The obligations of each and every member of the team are stipulated in a written document that is signed by the concerned parties. This is even more important in a fast-changing environment such as Afghanistan.

It is also important to think about the monetary aspect: will the trainees receive any kind of payment, or other remuneration for the training? For the NDSA it was clear that the training was considered to be 'part of the job', it was required in order to carry out the study on the field. **We advise that this point be discussed and made clear in the very beginning of the survey.**

Points that need to be specified and agreed upon in the contract for the trainees:

- The purpose of the training;
- The duration and daily timings of the training, venue;
- Transport (to the training venue as well as to the centres for visits);
- Provision of lunch;
- Evaluation of training session (this can be done in the form of a test at the end of the training);
- Validation through a certificate for the trainees who pass the test at the end;
- Attending the subsequent "booster" sessions.

Here is an example of the contract that we signed for the NDSA. Thought it might seem tedious, our experience showed that putting down the expectations and compensations as well as the sanctions in writing, can be of great use in case of contention.

Example of Contract

Contract Between

Name of the Organisation and Its representative in Afghanistan
And Mr/Ms. _____
Hereafter referred to as the trainee,

According to the condition stated hereafter, in accordance with the legislation in Afghanistan and general conditions within the organisation.

I. General Terms and Conditions

1. The trainee will attend the workshop on Sensitisation on Disability.
2. *Here you can specify any other commitments that might follow.* For the NDSA it was the carrying out of the survey on the fields in specific provinces.

II. Duration

The present contract comes into effect on its date of signature.
It is a short-term contract for the training/survey on disability carried out in the city of _____ _____. The contract is on a daily basis. Fridays are paid if the trainee is called and accepts to come.

III. Termination or Modification of The Contract

1. The trainee declares that he/she is aware that a humanitarian aid association is not a company. It operates in a context where security and funding conditions may be unstable.
2. The trainee is informed and accepts the fact that:
   - The contract may be terminated by the association in the event of force majeure (such as troubles forcing the association to withdraw).
   - In the event of insufficient funding, the organisation of the mission may be modified,

or the mission forced to close. In such an event, employment contracts will be terminated automatically.

3. At the end of the training session, the trainee must return anything given to him/her upon arrival and belonging to the association (equipment, keys etc...).
4. The organisation has the right to terminate the contract without prior notice in the case of serious professional misconduct or negligence affecting his/her work, or if the trainee neglects one of the clauses of this contract.

IV. Payment

1. The wage is _____ a day for training, with_____ more for food. The total amount is of _____ for a day of training.
2. In case of absence the day will not be paid.
3. In case the trainee arrives more than an hour late of leaves more than an hour early, the day will be considered as a half day.
4. At the end of the training and if the trainee passes the final test, he/she will receive a certificate.

V. Working Hours

1. The trainee will attend sessions according to the schedule set up. The typical day will start at 8 A.M. and last till 4 PM. With a one hour lunch break at 12 P.M.
2. If there is delay in returning from lunch, the afternoon session will be extended proportionately.

VI. Contention

1. In the event of contention regarding the interpretation of this contract, the English version will serve as sole reference.
2. In case of the trainee stopping before the completion of the session, the contract will be terminated and no remuneration or compensation will be given.

This contract formalises the employee's agreement with the terms and conditions stipulated.

In _____, on _____

Signatures should be preceded by the annotation "read and approved"

Organisation Trainee

Clarifying the Terms with the Translators and Interpreters

Before the beginning of the training you will need to look at the translation of documents. The documents used for the NDSA were translated into Dari and Pashto for the regional training sessions. However it is recommended to go through the documents and to ensure that any new documents are translated. It is also essential to go through **all the documents** with the interpreters, or other persons who will be carrying out the training in the local languages.

Be sure that you agree on how the main terms of the training will be translated: Disability, Impairment, Sensorial Disability, Mental Disability...

For the NDSA training the term disability was used only to explain theory. During visits to centres, discussions and other activities trainees had to use the term difficulty.

Devising the Schedule

This is a point that cannot be stressed enough: **training for a survey on disability cannot be done adequately in just a couple of days**. Although there is no ideal training period, it is essential to ensure that all aspects of disability have been addressed. What we present in this document is not the ideal training schedule. However there are some core aspects that should not be left out.

Fields addressed during the training by our occupational therapist, physiotherapist and psychologist were:

- The concept of disability, discussing definitions;
- Physical and sensorial disabilities;
- Mental disabilities (mental illness and intellectual disability);
- Children with disability;
- Interviewing techniques (attitudes, vocabulary, respect);
- Women and Disability;
- Talking about Human Rights;
- Mine-Risk and Security Information.

Although the NDSA did allot one day to each of these themes, there is no right way to proceed. The important thing is to address these through different means. The NDSA training followed a pattern for the issues addressed during the first week:

- Theoretical definitions and discussion about how to translate the terms;
- The detection of these disabilities, the questions that can be asked in order to detect these;

- Visits of centres in order to meet with persons with diverse disabilities, discussions, underlining the similarities between the surveyors and the persons with disability;
- Discussion and de-briefing about the visits, what did they remember about the person, what did they feel;
- Sometimes role-play exercises can be used in order to explain that communication is possible even when the disability is severe and affects speech and movement.

Throughout the training we were especially attentive to the vocabulary being used and the attitudes of the surveyors.

The following schedule gives the skeleton of the training sessions. This is of course flexible and will need to be adapted to accommodate any specificities of the training.

Day	Subject	Facilitator(s)/ Partners
Day 1: Morning	Introduction, Expectations, First Test	
Day 1: Afternoon	Disability Concept: Breaking the Ice	
Day 2: Morning	Disability Concept: Role play	
Day 2: Afternoon	Physical Disability: Theory	
Day 3: Morning	Physical Disability: On the field	
Day 3: Afternoon	Sensorial Disability: Theory	
Day 4: Morning	Sensorial Disability: On the Field	
Day 4: Afternoon	Mental Disability: Theory	
Day 5: Morning	Mental Disability: On the Field	
Day 5: Afternoon	Mental Disability: Sharing Experiences	
Day 6: Morning	Children with Disability: Theory	
Day 6: Afternoon	Children with Disability: On the Field	
Day 7: Morning	Working on Attitudes	
Day 7: Afternoon	Attitudes: Role play	
Day 8: Morning	Women with Disability	
Day 8: Afternoon	Lets talk about Human Rights	
Day 9: Morning	Security and Mine Risk	
Day 9: Afternoon	Some Useful Information	
Day 10: Morning	Working on Objectives	
Day 10: Afternoon	Assessment	

The last 10 days of the three-week training were devoted to the explanation of the questionnaire and to interview techniques, both in theory and on the field, both in urban and rural settings.

Disability Concept

Objectives

- Introduce the concept of disability;
- Bring out some negative prejudices and lay beliefs;
- Initiate a discussion;
- Experience a disabling situation;
- First steps towards sensitisation;
- Express Feelings.

Notes for Trainers and Facilitators

While a stereotype can be based on real life facts, very often it is accompanied by negative prejudice and discrimination, which are not justified. The training for the surveyors should look at this dynamic process and focus first and foremost on fighting discrimination and negative prejudice, which are at the source of differences in living conditions between persons with disability and those without. The aim is not to ignore the differences that are real but to understand that most of the beliefs that derive from the perception of these differences are not only unfounded, but often contribute to the discrimination that persons with disability and their families face. It is difficult to explain and to make people interiorise the distinctions between impairment and disability, the next step being to look at the individual and not the impairment.

In order to achieve this, we followed a simple three-step method:

- Bringing out the stereotypes and the related beliefs which are sometimes based on real facts;
- Understanding the prejudice that is often related to a given stereotype. A prejudice is the act of assigning a positive or negative belief to a given stereotype;
- Fighting discrimination which is the fact of taking action that is based on the prejudice.

At the end of this first session, trainees should be clear about what vocabulary to use and what not to use.

They should have a first grasp of the difference between the concepts of impairment and disability.

They should also have no doubts about which terms can be used in the interviews for the survey, and which ones are absolutely unacceptable.

Physical Disability

Objectives

- Provide theoretical information regarding physical forms of disability;
- Sensitise trainees to physical disability;

- Visits to centres;
- De-briefing sessions and discussion.

Physical disability is probably the aspect, which is easiest to address since people in general feel familiar and comfortable with this notion. But is it important to bear in mind that physical disability is often dominated by amputees, war-disabled and land mine survivors in Afghanistan.

However, during this session we chose to work on lay conceptions and attitudes that the trainees might have and that are a reflection of the prejudices and stereotypes that exist within society in general.

You will have a fair idea of these by looking at the responses given to the test carried out on the first day.

Looking at Theory

A study on Knowledge, Attitudes and Practices of various groups of persons regarding persons with disability[1] showed that:

Knowledge on disability is characterised by:

- General lack of understanding of causes of disabilities, especially for birth-related disability;
- Formal medical **care** is often used. But medical **causes** of disability are rarely mentioned;
- Very little awareness of consanguinity and genetically caused disabilities.

Attitudes regarding disability are characterised by:

- Importance given to the interpreted cause of disability (from birth or accident);
- More sympathy and respect for accident-related disability from all audiences.

Practices regarding disability are characterised by:

- Doctors cannot always explain clearly the causes of disability, especially birth-related disabilities;
- Occasionally, persons with disability and their families disguise birth-related as accident-related disability.

The aim of this session is to present the various forms of physical disability without focusing too much on the causes. During the session it is important to keep in mind the following points:

- Pay **attention to vocabulary**, a lot of terms that can be prejudices will come up and will need to be corrected (interpreters have to be briefed about this). It is therefore a helpful choice to have a person with disability as translator.
- Different groups will focus on different aspects. For the NDSA training there was a tendency to '**try and diagnose**' as well as a strong feeling of '**pity**' for persons with disability. The facilitators tried to work in order to canalise these tendencies. We found that using the word **disability** stressed the divide between the persons with disability and the non-disabled. The word **difficulty** not only had the advantage of being usable for everyone, but also showed the similarities in the situations that people experienced. For example everyone, at some point or other, either due to accident or other health problems, had experienced inability to move a part of their body. We tried to work on what trainees felt when they faced these difficulties.
- The third problem that we faced was what we called the **'merit-efficiency aspect'**. This is very closely linked to the perceived cause of disability; war-victims and landmine survivors "should be helped" –merit aspect. Moreover, when the effort is considered too much (for a total paralysis for example), then trainees did express their disagreement with the need to make the effort – efficiency aspect.

The first step towards fighting these attitudes is **not to let a single such remark go by without comment.**

The second step is to evoke **rights**, but not in isolation. **Rights must always be linked to a context and its consequences**. For example "persons with disability have the same rights as other Afghans" has little impact. But asking the trainees, "What does employment mean for you and your family?" "How would/did you feel if/when you had no employment?" and then "How did it affect your family?" Then the transition can be made more easily towards the employment efforts needed for all Afghans, whatever their difficulty may be.

Visits to Centres

For the NDSA training the aims of the visit to these centres were:

- To meet with the persons with disability as well as their families;
- To talk with them;
- To understand what their problems are and how they deal with these problems;
- To understand how they deal with their problems and what solutions they find to these problems.

De-briefing Sessions

You will need at least 30 minutes for this. If you are working with several groups at the same time you will probably need close to an hour at the very least.

[1] THAKKAR M & el. (2004), op. cit.

Before starting this session, at the end of the field visit, it is advised to have a brief talk with the facilitators in order to get an idea of what the problems were regarding the attitude, behavior and the questions asked by the trainees.

The de-briefing should be done immediately after the field visits and not the next day.

The aim of the de-briefing session is to ensure that the trainees express their feelings and their opinions about the visits to the centres.

Some questions that can be used for the de-briefing sessions:

- **Who did you meet?**

This is perhaps the most essential and the most sensitive question. **Here you need to avoid a description on symptoms first**. If the trainee starts by saying "we met an amputee, or a paraplegic" interrupt immediately by "what was the person's name? Age? Colour of eyes?", any question that has no link with the impairment.

If a trainee starts by saying "we met a person **who could not walk**", the facilitator should immediately ask the counter question "what could he/she do?".

The aim is to look at the person first, not at a person with disability first.

- **How did the persons/people you met resemble you? What were the similarities?**

Here facilitators will need to focus and even over-focus on the similarities. These could be aspects of family life (he/she has children), interests (likes movies), or just general aspects.

- **What difficulties did he/she face?**

Here again the trainees will have a tendency to talk about the impairment. Facilitators should focus on the term **difficulty**. We are not talking about the physical condition but difficulties regarding household tasks, education, employment, access to buildings.

"**She has no arms**" is not a difficulty. "**She cannot cook for herself or dress herself**" is a difficulty. Trainees will feel distant to the first affirmation because they have not experienced it, they may identify more easily with the second, which relates to activities that they carry out also. The main goal remains to create a vision of a 'person' and not just a person with disabilities, make the surveyors take interest in the lives of the persons and see what types of difficulties they are faced with.

Sensorial Disability

Sensorial disability, like physical forms, are relatively easy to talk about in Afghanistan. Moreover, the beliefs and stereotypes that are linked to sensorial disability can be positive, even if they are linked to a variety of religious and cultural aspects. The overall pattern followed was the same as for the previous section.

However, facilitators need to be attentive to certain aspects of sensorial disability. The study carried out on perceptions of disability showed that:

- Hearing/speech impairments of the children are often confused with intellectual/learning impairments;
- Attitudes vary for different types of disabilities: mental disability stigmatised the most; blindness seems to be stigmatised the least;
- Speech impaired individuals are considered the most capable;
- There is general indifference towards and isolation of disabled women, especially blind women.

The theory regarding these forms of disability was very brief. For the NDSA trainers decided to centre the training on sensorial disability on the notion of **special needs** and **inclusion**. This was mainly done on the field visits.

For the NDSA training the aims of the visit to these centres were:

- To meet with the children and young persons with sensorial difficulties as well as their families;
- To talk with them;
- To see various methods for learning to read and write and solutions for education in general;
- To understand how they deal with their problems and what solutions they find to these problems.

Mental Disability (Mental Illness and Intellectual Disability)

If understanding disability in general is a challenging task then understanding mental disability is even more difficult without proper training and adapted tools.

This can be explained by various reasons:

- There is a lack of knowledge regarding these forms of disability which accompanies a lack of visibility within society;
- All forms of mental disability are often surrounded by lay beliefs and superstitions. This is closely linked to the inability to identify a specific cause. As a result it is believed that there is some mysterious or divine intervention; in traditional cultures, mental disability is thus viewed as a punishment that a person had to endure for his/her acts.
- The language often used negative, stereotyped terms to refer to these forms of disability (often the equivalent of 'mad' or 'crazy').

- Like disability that results from congenital causes, mental forms have an effect on the image of the family and can have serious consequences on the marriage of siblings, for instance.

All these reasons result in household members hiding the presence of a person who has a mental form of disability.

These prejudices are often well-rooted in society; the trainees are not exempt from this. What makes it even more difficult is that people can easily comprehend the programmes that can be set-up for persons with physical and sensorial disability in terms of access to health services and education as well as the setting-up of effective employment opportunities and quotas for reservations in public services. For persons with mental disabilities the needs and requirements are often seen as being too costly, demanding too much effort. There is a more or less implicit hierarchy that exists within persons with disability as a group. In developing countries there is a lay belief that the limited resources should be used where they can be most efficient and make people 'productive' and integrated members of society.

Breaking the Ice

Keeping in mind all these facts there are two elements that any training sessions must consist of in order to ensure that forms of mental disability are not grossly under-estimated:

- The training should integrate modules that address the issue from a human rights perspective. This of course is more effective if there has been some form of awareness-raising.
- The other aspect that should be stressed is the necessity to help persons with mental disabilities as well as their families, in order to lessen the burden on the family.

Before going through the theoretical presentation, we decided to start with a general discussion regarding mental disability. The aim of this exercise was to bring out the prejudice and the lay beliefs that often surround persons with mental disability. The questions that were used to initiate and orient the discussion:

- **How would you translate mental disability in Dari/ Pashto?** (The response that often comes up is *Diwana/ Lewana*).

The *diwana*, as they are called in Afghanistan, are the most stigmatised and therefore they face the most difficulties in terms of integrating within their families and society.

- **Can you think of a person that you know or that you have met who has a mental disability?**

Here we try and talk about life stories. There were certain members of the training team who had family members and close friends who had mental disability. They told their stories, the problems faced as well as the way the family deals with it. Of course, this was thought about before and the facilitators agreed to talk about their experience. It was a little more difficult to get the trainee to talk about their own acquaintances, but some of them did refer to neighbours and friends.

- **What are the different types of mental disabilities that you can think of?**

This is a time when trainees realise that, contrarily to other types of disability, they do not have a precise idea of the different types of difficulties that might exist. They will describe the symptoms, but when asked "what is this type of problem?", they often do not have any idea.

After this discussion, facilitators can go through the theory, taking time to give examples of the different kinds of signs and symptoms that characterise mental disability as well as the different degrees of difficulty.

For the NDSA training the messages that we wanted to deliver were:

- Mental disability is not a fatalistic state where nothing can be done.
- There are ways of coping with certain symptoms, especially violent episodes.
- The problems that the families face can be very similar to those faced by families of other persons with difficulties.
- These persons and their families can be helped no matter what the problem and the degree of the difficulty.

The facilitators did need to fight against certain tendencies:

- The tendency to look for the causes of these forms of difficulties.
- The need to know if there is a definite cure for these difficulties.

Visits and Discussions

If there is a visit of an institution and discussion with persons with mental disability (mental illness and intellectual disability) and their families, some questions can be useful for de-briefing sessions

Some questions that can be used for the de-briefing sessions:

- **Who did you meet?**

This is perhaps the most essential and the most sensitive question. **Here you need to avoid a description on symptoms first**. If the trainee starts by saying "we met a mad person, or a person with mental problems" interrupt immediately by "what was the person's name? Age? Colour of eyes?", any question that has nothing to do with the impairment.

If a trainee starts by saying "we met a person **who was looking at the ceiling all the time**", the facilitator should immediately ask the counter question "what could he/she do?".

Here also, **the aim is to look at the person first, not at a person with disability first**.

- **How did the persons/people you met resemble you? What were the similarities?**

Here facilitators will need to focus and even over-focus on the similarities. There could be in terms of family life (he/she has children), interests (likes movies), or just general aspects.

- **What difficulties did he/she face and her/his family face?**

Here again the trainees will have a tendency to talk about the impairment. Facilitators should focus on the term **difficulty.** We are not talking about the mental condition but difficulties regarding household tasks, education, employment, and the social acceptance. This last component is essential when talking about mental disability, how others view the person and his/her family. Trainees will feel distant from persons with mental disabilities because they cannot imagine what the experience is like, they may identify more easily with the family members and the problems they face and the solutions that they have found. The main aim remains to create a vision of a 'person' and not just a person with disability make the surveyors take interest in the lives of the persons and see what types of difficulties they are faced with.

One last aspect needs to be taken into consideration with regards to mental disability: what can really be done?

Trainees will easily see the ways of setting up initiatives, policies and programmes, for persons with physical and sensorial disabilities in terms of education, employment, accessibility... For mental disability, especially the more severe forms of mental disability, it will be more difficult to convince the trainees of the necessity to set-up similar initiatives for the individuals and their families. This training will touch upon the rights based perspective but the message needs to be delivered using a different language.

Using Films

After a number of discussions, and more specifically discussions with an Indian NGO, Jan Madhyan, which runs centres for intellectually disabled girls in New Delhi, India, and which has extensive experience in awareness-raising in developing contexts, it was suggested that we use films. The films had been created by the NGO and had the advantage of being set in India, a context and a society that the trainees from Kabul felt close to; most of them spoke Urdu and understood the commentary. To add to the familiarity, the background music was from Bollywood!

The first film explained the signs of intellectual difficulties at a very early age as well as how it can evolve. It was centred on early detection and finding solutions to help the child with the problem. It then went on to interviews with parents, their fears and their difficult moments. They explained how they suffered from the lack of social acceptance and the isolation that they felt due to attitudes that people had. However the film does contain certain subjects that facilitators might chose to omit or address later, in one of the booster sessions.

- One mother expressed her embarrassment when her teenage daughter decided to undress during a public function.
- The psychologist interviewed addressed the need for certain behaviour in order to release tension (masturbation for young boys).

The second film, maybe easier to use, shows the experience of the NGO with girls who have intellectual difficulties, specially Down Syndrome .This film shows the various vocational activities that have been set-up, and how these girls contribute to the income of the family, they are not burdens on their loved ones. This is a way of opening up a discussion regarding what the possibilities for these persons are and how they can be helped in a context like Afghanistan.

Assessing the Trainees

Finally, we asked the trainees to answer a few questions in writing; these questions were in line with the aim of the training which was to show people how to carry out a survey on disability:

- According to you, in Afghanistan, how does it make people feel when they are asked questions on disabilities?
- According to you, in Afghanistan, how does it make people feel when they have disabled people in their family?
- Depending on your previous answers, what attitude should we adopt when asking questions of the survey?
- What kind of false ideas could people have on mental difficulties?
- What kind of attitudes do people usually have towards people with mental difficulties?

Children with Disability

This section was extremely important for the NDSA training as one of the main challenges of the surveyors was to talk with adult household members and ask them questions about the presence of children with disability in the household. The second objective was to train the surveyors to ask questions to children

with disability with the same respect and consideration that they would show to an adult. As a result, the training on this session was aimed at "detection" and "respect".

Any sensitisation regarding children with disability needs to address the following issues.

- To give information on the broad picture of child disability – how they are more likely to live in poverty, suffer more abuse and neglect than other children and only about 2% have access to education. It is a good idea to have a few numbers as example of the huge gap that exists between children with and without disability.
- It is important to then explore the reasons why disabled children are treated differently –the rejection comes deep from within society from feelings of guilt, shame, disappointment and superstition. These feelings are often shared by all the family members.
- Too often children are seen for the impairment and not as a child with the same needs as any other. So during the training try to impart a child-centred approach throughout. This translates into considering the child as more able than just the limitations of his/her impairment.

Although the theory part of the training was done through PowerPoint slides, it was made as interactive as possible by asking participants what they observed from the photos of different disabilities, and whether they had known any such children. Then the group discussed what problems they thought the children would face, particularly in everyday activities.

For the NDSA training the messages that we wanted to deliver were:

- Children with disability are to be treated with the same respect and consideration as adults;
- Do not look for causes, or someone to "blame" for the difficulty;
- Make trainees understand that a lot can be done for children whatever their difficulty;
- Realise that the difficulty of the child impacts the family as a whole.

To be very honest, the discussion session was not a success for the training of the NDSA. One of the reasons might be that the trainees were mostly from a medical background and where more focused on the medical aspects of the children with disability that on the human aspect. Facilitators should keep in mind certain facts, especially during the visits of centres for children with disability:

- It is important when working with children to see the whole child and not just the impairment.
- There may be a tendency for many to immediately handle the child without prior warning or permission from either the child or mother. Attention and respect in addressing them first need to be ensured.
- People may be more interested in diagnosing the condition, looking for reasons and causes as to why "this happened to the child" rather than finding out the abilities of the child, his/her likes and dislikes, whether he/she goes to school, has friends etc. It takes strong guidance to try and prevent this from happening, and instead demonstrate a more family and child-centered approach by addressing questions either directly to the child where possible, or one of the parents.
- We also tried to stress the importance of approaching a child through play and toys first and not just grabbing them.
- This approach was also highlighted when actually carrying out the survey in the household, so that interviewers would obtain a much more accurate idea of what kind of disability might be present.
- The final part of the training was to give guidelines on how to communicate with children and their families during the interviews.

Field Organisation

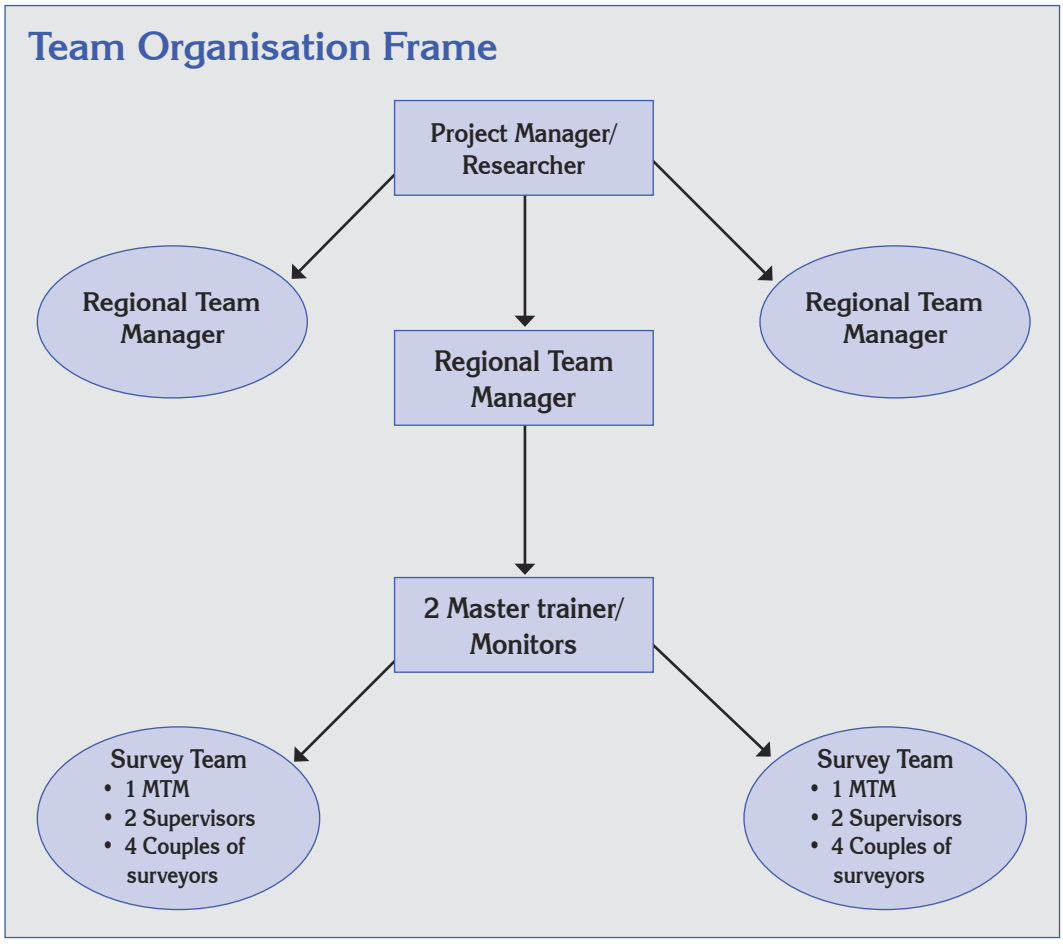
Once the tools and methodology defined, the next step is to prepare for the fieldwork. This entails a myriad of elements to be managed simultaneously: human resources management, recruitment, fieldwork preparation and organisation, security supervision and data quality.

Human Resources: The Team

The human resources are the first element towards ensuring the quality of the research carried out. In a survey on disability, the commitment of the entire team to the project is a pre-requisite. In order to formalise this, it is advisable that the rights and obligations of each and every member of the team are stipulated in a written document that is signed by the concerned parties, thus explaining the duties of each one.

The following table shows the organisation of the NDSA teams on the field.

Team Organisation Frame



Being On the Field

The presence and implication of the researchers who have developed the tools and methodology, at all stages of the survey, from the definition to the final analysis, is the main guarantee of quality. Regarding surveys on disability in particular, the presence of the researchers at the household-level

Looking for the Appropriate Answer

In question Q. 15.11 (for men) and Q. 19.15 (for women) of the social participation module, "If No, why did you not participate in ceremonies", some interviewees have a tendency to answer: "because I am disabled".
For surveyors, it was sometimes a valid answer.
This was the opportunity for the researcher to explain that the interviewee was to be asked further: "Why is your disability a barrier for participation in ceremonies?" in order to obtain the useful information explaining the stigma or the lack of social participation, or lack of transport or assistance needed to get to the venue.

Weaknesses of a Questionnaire: the Risk of Standardisation

In question Q. 4.10 of the education module, the question "Would you like to go or return to school, if possible", the inadequacy of the question appeared clearly in a village lost in the mountains of Faryab province.

The 60 year-old woman interviewed just starred at the surveyor and asked him "What do you think I should answer?" and laughed. It had taken us one day of walk to get to the cluster from the district centre where the closest school was situated.

can have a considerable effect on the screening and the detecting of persons with disability. Presence on the field is also the way to show commitment, interest, and consideration for the fieldwork done by the teams of surveyors who are collecting data.

This presence of the researchers is also useful for the following step: cleaning and re-coding the data. The researcher knows how to proceed because s/he observed the answers given by the interviewee. As a result, if new codes need to be added they become easy to identify.

Finally, participation in the fieldwork allows the researcher to take notes of what he/she sees or hears. This makes the weaknesses or inconsistencies of the responses coherent and understandable. It also provides examples of real situation to illustrate the facts provided by the figures.

Team Leaders: Regional Team Manager/ Researchers

The Regional Team Manager is responsible for implementing and analysing the survey in coordination with other researchers and under the leadership of the project manager. Ideally the researchers who define the tools and methodology are also in charge of their application on the field as they have a clear overview of the questions and the indicators that lie behind them.

As a result, the responsibilities of the RTM can cover a wide range of activities that require a comprehensive overview of all aspects of the survey. These may include:

- Contributing to the writing of survey material (questionnaire, field manual, checklists, security documents…);
- Training of surveyors and supervisors;
- Liaising with provincial and local authorities, and community leaders in areas under his/her responsibility;
- Meeting with stakeholders to facilitate survey implementation in areas under his/her responsibility;
- Managing the teams on the field in terms of coordination and organisation;
- Reading and checking completed questionnaires for control and returns on the field; they are the ones who carry out the final check for completeness and accuracy;
- Intervening to solve all problems during field research in areas under his/her responsibility;
- Organising analysis on the issues under his/her responsibility;
- Managing budgetary requirements;
- Assisting the project manager in writing of reports in his/her field of research/specialty/knowledge.

Guarantee of Quality: Master Trainer/ Monitors

The specific responsibilities of the MTM may be:

- To train the surveyors from the different provinces that have been selected;
- To make the necessary preparations for the fieldwork;
- To organise and direct the fieldwork, and
- To monitor and maintain the quality of collected data.

The MTM ensures that the supervisors are well-trained in scrutinising the questionnaires and checking the consistency once filled in. They are also the ones who make sure the questionnaires are completely and accurately filled for all the households **before leaving the cluster**. They follow and record the field process using a monitoring list.

Recruiting and Training the Teams in the Regions

One essential aspect of the responsibilities of the MTM is to recruit and train the supervisors and the surveyors for the fieldwork. This includes selection of the persons, their training session and their monitoring on the field.

To prepare for the fieldwork, the MTM must:

- Obtain maps for each area in which his/her team will be working and check these locations with local people who know the area and the community. **The NDSA maps were drawn by hand** by the staff of the CSO, after obtaining indications given by the staff who went in the clusters for the pre-census.
- Become familiar with the area where the team will be working and determine best arrangements for travel and accommodation.
- Contact local authorities to inform them about the survey and gain their support and cooperation. Letters of introduction are provided, but natural tact and sensitivity in explaining the purpose of the survey helps in obtaining the cooperation needed to carry out the interview correctly.
- Obtain all monetary advances, supplies, and equipment necessary for the team to complete its assigned interviews. Careful preparation is important for facilitating the work of the team in the field, for maintaining the interviewers' morale, and for ensuring regular contact with the central office throughout the fieldwork.
- Ensure that the travel plan is discussed with all team members.

During the Fieldwork, MTM Role

The MTM is in charge of coordinating the work in the field. S/He takes the major decisions regarding the collection of data in the cluster. His/her tasks are multiple:

- Locate the cluster that has been selected during the sampling process. If the MTM has any questions about locating the community, s/he checks with local authorities and key persons before the surveyors part ways.
- Assign work to the interviewers.
- Make sure that all assignments are correctly carried out.
- Carry out the quality control work.
- Regularly send progress reports to the provincial office and keep headquarters informed of the team's location.
- Communicate any problems to the RTM.
- Take charge of the team vehicle, ensuring that it is kept in good condition and that it is used only for the project work.
- Arrange lodging and food for the team.
- Maintain a positive team spirit.
- Check all forms before leaving the area to ensure that they are filled out correctly.

The Backbone of the Team: Supervisors and Surveyors

The supervisor and moreover the surveyors are the major actors of the collection of data. There are the ones who make the difference by ensuring quality data.

The Supervisors

- Ideally the supervisor has at least finished school and preferably has some kind of higher qualifications.
- It would also be preferable that the supervisors be from the area of survey and have extensive work experience in the regions, if possible in the field of disability (CBR workers or other community workers) or in health programmes (health workers).
- They have field experience (survey work would of course be an advantage).
- They have the capacity to take charge of a team on the field (ability to take decisions fast and be uncompromising when it comes to security issues).
- They show a commitment to contributing to this project.

The Surveyors

The surveyors are of course directly in charge of the data collection through the interviews they carry out. They receive a quota of questionnaires to complete during the day of survey. Certain conditions are important to respect to guarantee quality of data collection.

- One team of surveyors always consists of one man and one woman (regardless of the relationship between them). This is justified by the fact that some questions are sensitive (ill-treatment). Moreover, in a context like Afghanistan social norms dictate that women and men unknown to each other do not communicate.
- The surveyors have at least finished school.
- They have some kind of field experience, either working with persons with disability and other vulnerable groups, survey experience, and/or other relevant field experience.
- They should belong to the region and if possible belong to the communities where the clusters are located.
- They should show a commitment to contributing to the project.

A two to three weeks training was carried out in the regional centre for the supervisors. This training was carried out by the MTM, according to a programme that was designed and organised by the researchers and RTMs. This included presentation by experts or professionals working in the field of disability such as physiotherapists, psychologists and occupational therapists, as well as visits to rehabilitation centres, hospitals or special needs classes. Discussion with families, focus groups with persons with disability, de-briefing sessions with trainers were carried out.

One or more of the RTMs was also present during the training in the regional centre. This training looked at specificities related to disability, extensive explaining of the questionnaire, the process on the field as well as practice.

Preparing for the Fieldwork[1]

In a country like Afghanistan, preparation of the fieldwork first of all means **to ensure all guarantees for the security for the team**. In terms of quality of data collection, this phase is also essential. The team must have all the equipment required. Accommodation and food must have been organised. Official documents to introduce the team in the cluster must be provided to the MTMs and supervisors in charge of the given cluster.

Material Required for Fieldwork

Before leaving for the field, the MTM and the supervisors are responsible for collecting adequate supplies of the materials the team will need in the field. These items are listed below.

Fieldwork Documents

These may include:

- Copies of the Field Manual for each member of the team plus one (1) additional copy;
- Maps showing the location of clusters;
- Monitoring checklist to follow the survey process in the cluster;
- Letters of introduction to local authorities;
- Survey questionnaires in all relevant languages.

Supplies

These may include:

- Black pens for interviewers;
- Blue pens for the supervisor;
- Red pens for MTM;
- Clipboards, briefcases, and backpacks;
- Paper clips, scissors, string and clear plastic tape;
- Plastic bags to store completed questionnaires;
- First aid kit.

Funds for field expenses

The usual field expenses are the following:

- Sufficient funds to cover expenses for the team;
- Funds for fuel and minor vehicle repair;
- Contingency funds for hiring a vehicle in case of serious breakdown of original vehicle;
- Advances for per diem allowances for the team.

Arranging Transportation and Accommodation

The RTM based at the regional level provides detailed, accurate information to the team on driving routes and accommodation. The RTM is, however, based at a distant location and must keep track of many different teams. The ultimate responsibility for arranging transportation and accommodation therefore falls on the MTM and supervisors. It is the MTM's responsibility to stay in touch with the RTM and to make final decisions on where to stay. Lodging should be reasonably comfortable, located as close as possible to the interview area, and provide secure space to store survey materials. The MTM and supervisors are responsible for maintenance and security of the vehicles. The vehicles should be used exclusively for survey-related travel, and when not in use, it should be kept in a safe place. The driver of the vehicle takes instructions from the MTM or supervisor who are also responsible for figuring out how and where the team is going to take its meals.

Contacting Local Authorities

It is the MTM's responsibility to contact the (provincial, village) officials **before** starting work in an area. Letters of introduction may well be provided, but tact and sensitivity in explaining the purpose of the survey is essential to ensure the cooperation needed to carry out the interviews.

In the NDSA process, letters from the Minister were delivered to each of the 34 Governors of provinces. Then the Governor wrote letters for the Heads of District where the selected clusters were situated. Finally, the Head of District provided letters for village Elders and Shura (council) members.

Contacting the Regional Team Manager

Each MTM must arrange a system of frequent and regular contact with the RTM before leaving for the field. This is compulsory in order to inform the RTM of any developments in a timely fashion, to arrange for payment of team members, and to return completed questionnaires for efficient data processing.

Using Maps to Locate Clusters and Households

A major responsibility of the MTM and supervisor is to assist interviewers in locating households within the clusters. In some villages this may be relatively simple, in more remote areas this could turn out to be a complex task. In countries where database

[1] This section has been derived from the National Health Services Assessment of Afghanistan's field manual. This survey was led by the Johns Hopkins Bloomberg School of Public Health in 2003-2004.

and listings are inaccurate, when they are unable to find a given village, the survey teams often have to rely on local people to locate a village whose name may resemble the one they have on the list.

Organising and Supervising Fieldwork

Once all the steps that are required for the preparation of a cluster have been taken and the local authorities have been informed about the survey, the actual work starts within the cluster. The MTM and supervisors then proceed with the sampling stages in order to determine which households will be included in the sample.

The MTM's Checklist for Each Cluster

This is the **field organisation document par excellence** and is used as a logbook for each cluster. The MTM's checklist is used on the field, in the cluster to organise the work of the team. But it is also referred to during all stages of the quality checks as well as during the data cleaning process.

This checklist records information regarding the survey for each household in the cluster. It may comprise of the elements listed in the box below.

Assigning Work to Surveyors

The following tips may be helpful for the MTM and the supervisors in assigning work to the team members:

- Make daily work assignments for each surveyor. Ensure that each interviewer has all the required information and materials for completing the work.
- Make sure that all households have been interviewed before leaving an area.
- Finally, it is the responsibility of the MTMs and the supervisors to make sure that the interviewers fully understand the instructions given to them and that they adhere to the work schedule. The work schedule is prepared in advance by the RTM, and following it closely is crucial to avoid overruns in the total amount of time and money allocated for the fieldwork. MTM and supervisors should also monitor the work of each interviewer to assess whether she/he is performing according to the standards set by the RTM.

Reducing No Response

One of the most serious problems in a sample survey of this type is no response—that is, failure to obtain information for selected households. A serious bias could result if the level of no response is too high. One of the most important duties of both the MTM and the supervisors is to try to minimise this problem and to obtain the most complete information possible. The **two major causes of no response are:**

- No one being home;
- The respondent refusing to be interviewed.

If no one is at home in a sampled household throughout the period of the survey in the clusters, then these households should be replaced.

Linguistic and ethnic barriers between the respondent and the interviewer can sometimes lead to refusal – it is best to limit this possibility by selecting interviewers with the same linguistic and ethnic background as the surveyed community members. In case of incapacity of the interviewee to answer part or the entire questionnaire, a proxy respondent is used. Of course, the proxy respondent has to be aware of the subject of the interview, thus be the caregiver for instance or another member of the

Cluster Monitoring Checklist

Province code :
District code :
Cluster/village code:
Name of MTM in charge :
Date(s) of survey:
Total number of persons with disability:

Household number in cluster	National household number	Name of surveyor	Number of persons with disability	Name, sex and age of PwD	Name sex and age of match in same household	Name sex and age of control in a ND household	Problems
1							
2							
3							
4							
5							

household, close to the person selected. It is better if the person selected for interview is present during the interview.

When the rate of non-response becomes high, the representative character of the sample can be lost. This is mainly due to the fact that the situation of the persons not interviewed can differ significantly from the ones included in the sample. Estimation of non-response bias has to be calculated. The non-response is part of the non-sampling error. It is more difficult to evaluate than the sampling error and it cannot be reduced by increasing the sample size. At all stages of the NDSA preparation and implementation, the maximum has been done to avoid and minimise non-responses.

Maintaining Motivation and Morale

The MTM and supervisors play a vital role in creating and maintaining motivation and morale among the interviewers—two elements that are essential to good-quality work. To achieve this, supervisors must ensure that the interviewers:

- Understand clearly what is expected of them;
- Are properly guided and supervised in their work;
- Receive recognition for good work;
- Are stimulated to improve their work;
- Work in positive and secure conditions.

While working with the interviewers it may be useful to adhere to the following principles:

- Rather than giving direct orders, try to gain voluntary compliance before demanding it.
- Without losing a sense of authority, try to involve the interviewers in making decisions, and at the same time, see to it that the decision remains firm.
- When pointing out an error, do so in private, in a tactful and friendly manner. Listen to the interviewer's explanation, show him/her that you are trying to help him/her, examine the causes of the problem together and finally explain your plan for improvement and correction.
- When interviewers voice complaints, listen with patience and try to resolve them.
- Try to foster team spirit and group work.
- Under no circumstances show preference for one or another of the interviewers.
- Try to develop a friendly and informal atmosphere.

The guarantee of the respect of these simple principles is an important step towards reduction of measurement error. Motivation of interviewers is compulsory to obtain:

- Good explanation to, thus good understanding of the questions and concepts by the respondent;
- Maximum effort to limit under-coverage when a cluster is in a remote place and it is necessary to walk a long way to reach it;
- Respectful manners and encouragement of respondents to limit refusal and/or partial answers, irrelevant answers given;
- Strict respect of prescribed procedures for random selection.

Security Concerns

Fortunately this aspect is not always as primordial in all countries as it is in a post-conflict and insecure environment such as Afghanistan. However it does need to be taken into consideration and should never be underestimated.

Preparing the Field

Assessing and taking decisions regarding the security on the field is a complex and delicate task. However, it is necessary to reduce risk of under-coverage, which increases the non-sampling error. This task requires a clear comprehension of the national and local situations as well as a wide and diverse network that can provide diverse sources of information. As a consequence, one identified person, for example the regional team manager, should be in charge of gathering all the relevant information.

In high security risk countries the decisions regarding the security conditions within a given region should be taken after discussion with the local authorities as well as with the survey team (which ideally comes from the region).

Moreover, the socio-cultural aspects as well as the political implications of the given context take utmost importance. The team managers of the survey will need to understand:

- The inter-group relations within the region (what the dominant socio-ethnic groups are and what the dominated groups are). This can have serious implications on the survey situation.
- The gender relations that can have implications on security of the survey team.
- The political positions;
- In number of traditional societies, it is imperative that the survey team seeks the agreement and the support of the village elders and the religious leaders in order to ensure that they are well received by the inhabitants and ensure their cooperation.

The Security Document

All security rules and regulations need to be stipulated in a formal document that each member of the survey team should be familiar with and have in case he/she needs to refer to it. This document must take into account all types of situations that the survey team may run into, the measures that need to be taken and the persons that they can refer to in case of a problem regarding security.

Example of Security Concern During the NDSA in 2005: a Constant Threat to the Data Collection

Security constraints may create some problems for conditions of interview. When the team goes into an area controlled by Taliban, or opponents of the government, then it becomes difficult to respect all our principles. In such areas, one cannot explain the survey will provide scientific knowledge for governmental policies, because any kind of perceived involvement of the government would jeopardise the security of our survey staff.

An explanation of the rules adopted by a MTM of the survey: "When it was time to go to a village controlled by Taliban, we always asked persons from the community to go with us and we rented the cars within the community, therefore diminishing the risk of being attacked".

The on-going conflicts and rivalries do not only pose a challenge to our team, but vice versa, the presence of our team at times have a direct security related impact on the local population. Consider for instance the situation of one of the villages the team went in a district of Samangan province. The village is situated in a valley, wedged in between the high peeks of Bamyan and Samangan. It is a 2-day hike from the district centre. In the same valley are other villages. The main problem is that each village is made up of different ethnic groups – in this valley Pashtun, Hazara and Uzbek. As in so many cases in Afghanistan, the inhabitants of each village are in conflict with the inhabitants of the other villages. Thus, the villagers in our cluster did not want the data collection work to take place at all for fear the neighbours might anticipate material betterments for the people in the village we survey, become envious and take violent action against the people in our cluster village in due course. Therefore, our team was faced with a moral question as to whether the data collection should take place at all. The MTM decided to discuss with the elders of the other villages. After informing the neighbouring villages of the purpose of the survey and pointing out the results of the survey would benefit all people with disability throughout the country, they felt reassured and the data collection could go ahead.

The document can have separate sections on the following:

- **Road security;**
- **Confrontation, robbery and assault;**
- **Car hijackings;**
- **Gunfire;**
- **Checkpoints;**
- **Ambush;**
- **Improvised explosive devise (IED);**
- **Landmines and unexploded ordnance (UXO)[2];**
- **Grenades;**
- **Shelling;**
- **Bombing.**

Contact Lists and Security Tree

The teams on the field need to have a clear idea of who they need to inform in case of danger or problems. In case of an incident the time of reaction is essential in order to respond in the most efficient way possible.

Ensuring the Quality of the Data Collected

All the steps that have been described above contribute to ensuring that the data collected is of good quality. In a relatively safe context this can be ensured by the presence of the research team and the managers on the field. There is always a tendency of the survey team to cut certain corners that are considered as being tedious. For the NDSA these "tedious" aspects of the fieldwork were:

- **The sampling methodology**, the different stages of sampling can be long, depending upon the geographical structure of the village. Moreover, the surveyors did not always understand the importance of the random sampling methodology that had been explained to them during the training session.
- **The screening questions** were another area that required time and patience. This section of the questionnaire was long and often needed a lot of

[2] This aspect was specifically addressed during the training programme for the survey team.

reformulation and explaining in order to obtain the information sought. In a context where other concerns such as security are a major issue, it is plausible that this section was not carried out in the best possible conditions.

Of course the most adequate solution would be to have a member of the research team present in the field at all levels to make sure that the methodology is followed as closely as possible. But this is not always possible.

Coherence of the Answers in the Questionnaire

The coherence between the questions concerning disability was checked by comparing:

- The opinion of the surveyor;
- The screening questionnaire;
- The health section that looks at what a person can and cannot do.

Questions are repeated in different modules of the questionnaires or some answers are consistent with the answer to another question. These are simple rules to enforce to make sure that the surveyor asked the questions properly and comprehensively to the respondent. Therefore, the level of education and the reason why the person did not receive any education were asked both in the family module (household file) and in the education module. Some questions were linked. For instance, it was compulsory to ask questions about secondary activity and time spent at work to persons having answered "yes" to the question on a possible income-generating activity, even if this was only one hour a week, done within the home.

Financial Incentives and Field Checks of the Survey Team

Other methods can be suggested in order to ensure that the major aspects of the methodology are followed by the survey team when on the field.

One of these is to **include a checking clause in the contract of surveyors**. This stipulates that a percentage (50% for instance) of their salary will be paid after a quality control of the questionnaires has been done by the regional team manager and after there has been a field check regarding certain clusters, randomly selected, that attests the fact that the survey team actually went there. This is done by sending someone to check the markings on the doors and ask the village elders the exact dates that the survey team came to the cluster. The checking of the accuracy of the data is done by asking a few questions regarding the names of the heads of households, their age and profession as well as the number of persons living in the household and checking all this information against the paper forms that the surveyors have returned with.

Checking of the Questionnaires at Each Stage of the Fieldwork

The most important aspect of data quality checking is to ensure that it is carried out at all stages of the survey. The first check should be carried out on the field, in the cluster. This can ensure that the missing information is minimal. The questionnaires are checked again for coherence before being entered into the database for analysis.

Mastering the field organisation is a major challenge and a major achievement. In a country like Afghanistan, the life of the team itself depends on good planning. But this is an extreme case. Good planning also means that the fieldwork will finish on time, that the driver will not have to drive back to the place of stay at night and thus, will not have an accident… Good field organisation is ensuring that collection of data is of good quality, and that the questionnaires were filled out adequately by a motivated team who was accepted in the cluster. This also means that no questionnaires are missing or destroyed by bad weather.

Analysis and Dissemination of Results

The final phases of a survey consist of the analysis of the data gathered on the field and the dissemination of results. This process can be long, depending upon the quality of the data, the data entry process, the corrections and cleaning requirements, as well as the intricacies of the analysis carried out. Simpler research work will look at a descriptive analysis whereas more complex research work will look at multidimensional analysis. The former is the most useful for stakeholders working in the field of disability and requiring basic indicators to better target the population and better prioritise their interventions. Tabulations should be planned with users of the data at the very beginning of the process, once objectives have been defined. This ensures that the survey meets requirements of stakeholders working in the field of disability. It also avoids ineffective duplication of studies that are resource and time consuming.

Analysing the Survey Data

There are various levels of analysis possible, ranging from the most simple (calculation of means, average and cross-tabulations) to the highly complex (multivariate analysis and calculations of various indexes). Although the first analyses can be carried out on any survey, the more elaborate ones do need a large-scale sample for statistical validity. The analysis phase, just as all the others, needs to be defined at the very onset.

Primary Analysis

The first report invariably consists of the primary analyses that are carried out on the data of the survey. This gives quite a clear picture of the population that was the target of the study. The first report may present general profiles of persons with disability by type of disability, gender, standard age groups, as well as the basic information regarding education, health, employment and income... The scope of the results will depend upon the objectives of the study. However complex and elaborate the survey, it must invariably provide both very basic statistics (means, distributions, cross tabulations…) and more complex multivariate analysis. Descriptive statistics are a starting point to answer the questions that the data was collected for, these first findings are accessible to all the stakeholders and hold utmost importance in policy planning. It is essential to ensure that the reports, especially the primary report compiled for decision makers, be simple and comprehensive in order to be taken into account in the defining of programmes.

Primary Report: Descriptive Statistics

The first (and sometimes only) report usually provides basic descriptive statistics to all stakeholders. As a basic requirement, data by disability status is presented by age and sex, employment status, level of education, level of income… A series of basic indicators (i.e. percentage distributions, medians, means and standard deviations) are also provided to donors, development agencies and the government according to the main themes addressed by the survey.

Other specific issues can furthermore be considered by producing tabulations on persons with disability. Cross-tabulations of educational characteristics with age, sex, and type of disability would reveal any differences among persons with different types of disability in educational achievement, school attendance, or literacy. Data on employment, when cross-tabulated with age, sex and type of disability, can measure the extent to which persons of either sex with different types of disability are being integrated into the labour market. Income data cross-classified by age, sex and type of disability can provide an indication on income security. Marital status and living arrangements, when cross-tabulated with age, sex and type of disability,

can measure the extent to which persons with disability are living alone or living with others[1]. A better understanding of the situation of persons with disability is also given by comparison with the data for persons without disability.

These tabulations are a first understanding of the general living conditions of persons with disability; further insights can be provided through more complex analysis. The descriptive indicators provide basic knowledge in main fields of concern for policy makers: demographics, education, health, social network, livelihood, community role, etc.

Specific Gender Analysis

Sex-disaggregated data is required wherever possible. Results seen through a gender lens provide insights into the living conditions of women with disability, regarded as the most vulnerable among the vulnerable. These findings can be used to put forward solutions that take into account the family structure, and respect social and cultural norms. The understanding of gender-roles and how these have evolved over time is not only important to comprehend the present situation but also to define programs that are acceptable to the persons concerned and who can be supported by the community and the family. A survey on disability must shed some light on the specific situation of women with disability and improve the understanding of whether and how women can better impact on family and community-level decision-making processes. Comprehending the gender dynamics contributes to effectively taking into account the specific needs of these women according to the type of difficulties that they face. There again, comparisons with women without disability is an important means to better comprehend inequality of situation.

More Complex Secondary Analyses: Looking at the Dynamic Coping Strategies

The second phase of analysis is in close link with the objectives and expectations of the various stakeholders. Although certain calculations can be defined beforehand, these analyses can also be carried out to answer a specific question that partners might have and that require further calculations. If the tools and the methodology developed allow more complex variables, this analysis may bring into light the reasons behind certain behaviour as well as coping strategies, which are used by vulnerable groups in contexts of very limited resources. These economic modelisations help understand profiles as well as the dynamics behind the decisions taken and the choices made.

Poverty and Disability

Disability and poverty are closely related. The analysis of the situation of persons with disability, furthermore the definition of a typology, the measure and the characteristic of poverty will rely not only on a traditional one-dimensional approach but also on multidimensional ones. The complex reality of the situation of persons with disability makes it difficult to capture the nature of their situation and of the phenomenon of poverty via a one-dimensional approach. A multidimensional approach shows the relationships between a set of more than three variables using tools (multidimensional exploratory analysis such as analysis of multiple correspondences, factorial analysis[2]… but also principle component analysis) that permit both the understanding of the underlying relationships and the methods for displaying them in simple tables or graphs.

A national level survey needs to provide political leaders with a battery of socioeconomic indicators that will give information about level of poverty. Poverty will be studied in link with the situation of persons with disability according to different issues: access to labour market, access to education, social exclusion and access to the healthcare system, access to food and shelter. These indicators will give a first overview of the situation of persons with disability in different fields as well as a perception of the level of poverty according to income. The absolute level of poverty will therefore be defined as a lack of income to satisfy the essential requirements for survival. The relative level of poverty can be measured to obtain the average standard of living in the given society. This analysis is an attempt to provide a more comprehensive view of the situation of the persons with disability. Multiple-dimensional analysis might be an adequate tool to study the situation of persons with disability with the lens of the capability approach of Amartya Sen.[3]

Multi-Dimensional Analysis

The multidimensional approach is a way to establish a possible link between the functionings (beings and doings of the capabilities approach) achieved by a person and his/her intrinsic characteristics (age, gender, health and type of disability) as well as the environmental factors (at different levels, household, community and socioeconomic or institutional level). The characteristic of poverty for persons with disability is the lack of fundamental capabilities to attain basic functionings. We will therefore focus, through econometrics, on the identification of factors such as social obstacles or individual situations that limit the capabilities of persons with disability and prevent them from participating fully in society.

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[1] UNITED NATIONS, Department of Economic and Social Affairs (2001), *Guidelines and Principles for the Development of Disability Statistics*, United Nations, New York, 2001.

[2] For an overview of these techniques see BENZECRI, J.P. (1992) *Correspondence Analysis Handbook*. New York: Marcel Dekker.

[3] SEN A. (1992), op. cit.

Development Indexes

There are different indexes that can be calculated in order to measure poverty levels[4] based on income:

- **The Head Count Ratio** which indicates the proportion of poor people in the national population;
- **The Poverty Gap** which measures the intensity (deepness) of poverty;
- **The Sen Index** which compiles, on the same scale, the information concerning the incidence of poverty, the intensity of poverty and the inequality among the poor;
- An **aggregate of elementary indicators** to obtain an overall evaluation of well-being.[5]

Complex Econometric Analysis

The success of public policies addressing needs of persons with disability relies on a comprehensive knowledge of behaviour. Econometric analysis such as multinomial logistic and probit models[6] will provide new and fundamental insights to the understanding behaviour of persons with disability. The modelisation of data constitutes a comprehensive means to understand the influence of various characteristics. Analytical statistics examine the relationships among variables looking for the causal linkage. Different qualitative regression models, based on the variation from one type to the other with the disability typology as the dependent variable, will try to find the influence of a set of potential explanatory or independent variables contributing most significantly to the various types of disabilities. Such modelling methods will be relevant to understand the rationale and dynamics of existing behaviours or the socio-economic situation of persons with disability.

Dissemination of the Information

Once the fieldwork is finished and the analysis well under way, the question of dissemination of results arises. Although the different partners may have an idea about the survey methods, having provided comments on the tools and methods, when it comes to results, they may have very specific expectations in line with their agenda and priorities. The research team must then ensure that these expectations are met and the results and findings are understood and included in the ongoing work. However, it is important to bear in mind that **results may not be in compliance with the policies and programmes in place, they might even point out certain inadequacies and inefficiencies...** that is why the dissemination process needs to be planned and carried out in a participatory way.

Setting up an Advisory Group

One of the ways of ensuring that the demands and expectations of the various partners have been taken into account is to set up an advisory group that gives recommendations and puts forward the queries that stakeholders might have to the research team. This group may also ask for specific analyses regarding a particular problem. **The setting-up of a space and time where the partners can express their concerns is of utmost importance in order to ensure the utilisation of the results and the credibility of the survey process;** the various partners will ultimately be responsible for translating the finding ways to translate results into relevant action. It is important to hand over ownership for the implementation phase to the persons on the field; the research team then takes on an advisory role at the final stages of the survey. For a national survey aimed at making policy recommendations to the government, this advisory group must consist of the reference persons and advisors of each ministry. For smaller scale surveys this group can comprise of the organisations working on disability in the given area.

Reporting to Partners and the People

Reporting to the various partners and the major stakeholders is an ongoing process. **Briefs and short progress reports should be shared on a regular basis with the partners in order to keep them informed regarding the different aspects of the study:** the methodology, the field progress, the respect or delay in the time-frame, the problems encountered.

The first report, as we stated, is aimed at making the findings of the survey accessible and understandable by the various partners. This of course requires an effort on the part of the researchers, to simplify their terms and concepts and explain them in a field implementation perspective. The primary report is usually the document which is the most widely distributed and used. It was used by the NDSA team in major workshops in ministries for instance. It could be used also in feedback meetings organised in the places where the teams went for survey and received support. In Afghanistan, the research team had planned to carry out workshops in Governors' offices of the major regions in presence of the chiefs of districts. This allowed the local representatives to provide feedback in their district to chiefs of villages and to village Shuras. Meetings in provincial health directorates were also organised.

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[4] For a good overview of poverty analysis see, RAVALLION M., (1992) *Poverty Comparisons. A guide to concepts and methods, Washington, LSMS*, working papers n° 88, World Bank, 1992 and BOURGUIGNON F. and PEREIRA DA SILVA L. *(Eds) (2003), The Impact of Economic Policies on Poverty and Income Distribution: Evaluation Techniques and Tools*. New York: Oxford University Press.

[5] CHIAPPERO-MARTINETTI E. (2000), "A Multidimensional Assessment of Well-Being based on SEN;'s Functioning Approach", Societa Italiana di Economia Pubblica, *Rivista Internazionale di Scienze Sociali*, vol. 3, pp. 207-239.

[6] See MADDALA G.S. (1984), *Limited-dependent and qualitative variables in econometrics*, Cambridge University Press, 2nd edition, Cambridge.

Any further analyses are more specific and complex in nature and provided to a narrower audience. These secondary reports are usually more targeted and aimed at specialists of a certain field, such as landmine survivors, for example.

Interpreting the Recommendations, Using the Results of the Survey

A void may exists between the view that the research team has of the survey and its findings and the understanding that the field partners may have of these; this is even more true in post-conflict situations. While understanding the indicators and the information provided seems relatively simple, the translation of these into targeted recommendations for the various actors is often a more complex endeavour.

Workshops can be organised in order to discuss the results in a usable manner, making them simpler to understand along with explaining what the findings mean for defining and re-defining of programs and projects. These workshops can be focused on the specific questions that were expressed in the advisory group and present the results of the surveys to answer them. The series of sessions can be centred on specific themes (education, livelihoods) or discuss the influence of more cross-cutting themes such as social participation, stigma and discrimination.

The importance of this final phase of the survey should not be underestimated at the risk that the efforts of the survey remain unused because of lack of communication.

Conclusion

In developing and transition countries, the overall goal set by stakeholders is of improving living conditions and of enhancing choices of vulnerable groups in general, persons with disability in particular. In order to make 'evidence-based' decisions and define efficient policies and programmes, there is a need to have reliable insights into the living conditions of persons with disability in the country.

The National Disability Survey in Afghanistan was the first of its kind to be carried out in a post-conflict country. The support for this project showed the will of donors and decision-makers to take relevant and effective decisions. A survey like the NDSA aims at providing relevant knowledge for the defining of adapted public action. The costs of disability are borne not only by the individuals but also by the family and the community as a whole. The lack of preventive measures and adapted responses based on low-cost interventions within a country like Afghanistan, partly explain the high prevalence of severe disability. Inadequacy of the public infrastructures and the increasing cost of public services such as health and education systems, employment support and livelihood policies, etc, make the situation even more challenging. Families continue to bear the financial burden resulting from the disability, reduction of living standards and often, social exclusion and stigmatisation from within the community. The need for an integrated policy approach that covers prevention, detection, rehabilitation and inclusive programs, will be necessary to reduce and better serve the needs of disabled Afghans.

However, gathering the knowledge needed, through surveys and studies, remains a challenge in terms of conceptualisation, organisation as well as analysis. The present toolkit is an attempt to answer questions regarding ways of implementing field survey research on disability. The approach adopted here is less theoretical and conceptual than practical, putting into perspective theories and definitions with the help of a field experience in Afghanistan.

A unique perspective, which has emerged in the interaction between research in the disability field and policy development, has been the use of research in determining government agencies' standing and future role in the disability field. This has been clearly demonstrated recently with the National Disability Survey in Afghanistan. A significant illustration of this is the discussion about the estimation of persons with disability which varies greatly. As a result any research which attempts to further clarify this picture with the inclusion of prevalence data, is bound to run into controversy. If the prevalence number is shown to be lower than expected or larger than thought, this could have serious programmatic implications. Key to the question of prevalence of disability is the larger issue of definition of disability and where to put the threshold. Thus a wide definition or too narrow a definition can have drastic effects on the results of the research and subsequent policy development.

The question that arises then is: what next? One of the major concerns of any research team is to see how the results and recommendations will be translated into effective policies and programmes. Are the conditions necessary to ensure this next phase in place? What is the role of the research team in ensuring this final phase? Who should be responsible for making results accessible and understood by all partners, whatever their mandate may be? The researchers for the NDSA remain convinced that associating all partners, and specially Disabled Persons Organisations with the choices made all along the research process and including these partners in any dissemination plan, are two major means of ensuring follow-up of research and its conversion into relevant, effective and sustainable action.

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Annexure 4

Tools for the NDSA

Introductory Process

Introduce yourself and the survey

We are the members of a survey team working with the Minister of Public Health and the Minister of Martyrs and Disabled. (Optional)
This survey looks at the situation of Persons with Disability (PwDs) in Afghanistan.
We would like to speak with the head of household or the person who knows the most about the persons in the household.

To the head of household and again to the person with disability surveyed:

We would like to gather information about persons with disability whatever the cause of disability or the type of disability might be. Your participation in this survey and your answers will help the government and the NGOs to better define their programmes in all fields (health, education, employment, defense of rights).

We would like to speak to you and to the persons with disability living in the house and some other members too.
We are conducting this survey in many households of Afghanistan.

The survey will take approximately 60-90 minutes to complete. You will not get anything, such as money or food, for being in this survey, but the information you give us will help define programmes for persons with disability. Your answers are confidential and will not be shared with any other person.

The records of this study will be private. Only the people who are doing the study will be able to look at the answers that you give to the questions. Whether you choose to be in the study is up to you.

There will be no effect on your family. Only those people who are doing the study will know that you are in the study. They will not tell others in the village, district or province.

You have the right not to be in the study or to stop at any time.

If you do not understand a question, please ask me to explain it to you. You are free to stop at any time during the interview. If a question makes you uncomfortable, we will skip the question and go to the next question.

Do you have any questions before we start?

Are you willing to be a part of this study?

Consent to interview

1 = YES 2 = NO

/___/
specify choice

If NO, ask why?

1 = refused
2 = no one at home to give permission for interview
3 = no one at home

/___/
specify choice

If refusal, estimate, if possible, number of persons living in the house

/___/___/
specify number

Check List for All Respondents

Check List

National Household Code /___/___/___/___/___/
Number of Household within the Cluster /___/___/
Province Code /___/___/
District Code /___/___/
Village/Town (Block) Code /___/___/___/___/___/___/

Person giving information about household
Surname/First Name _____ /___/ code native language
Native Language_____ /___/

1 = Pashtun
2 = Dari/Parsi
3 = Tajik
4 = Uzbek
5 = Hazara
6 = Aimaq
7 = Pashaee
8 = Turkoman
9 = Arab
10 = Hindi/Urdu
11 = Punjabi
12 = Qezalbash
13 = Other, specify_____
88 = Don't know
99 = No response

/___/ code native language

N.B.: Rest of the check list must be filled after unit 2 (screening questionnaire)

Interviewee
Surname/First Name _____ /___/___/ code interviewee
Native Language_____

Control person for interviewee with difficulties /___/___/ code for the control person

Language of interview 1 = Pashto 2 = Dari/Farsi 3 = Uzbek /___/ code language

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Type of disability (according to the criteria of the survey, 2 answers possible)

N.B.: Only to be filled after screening questions if interviewee has difficulties

1 = lacking one limb
2 = lacking more than one limb
3 = partial paralysis
4 = total paralysis
5 = other mobility
6 = visual
7 = hearing
8 = speech
9 = mental
88 = don't know
10 = chronic pain
11 = physical deformity
12 = facial deformity
13 = other, specify_____
99 = no response

/___/ /___/ code type

N.B.: The person with difficulty, answers the questionnaire him/herself, if possible. If not, answers should be given by the caregiver in the presence of the PwD

Caregiver
(if interviewee is too young to answer or is unable to answer by him/herself)
Surname/First Name _____
Native Language_____ /___/ code language

Surveyor
(to fill at the end of the interview)
Surname/First Name _____ /___/___/___/
Date of interview (mm/dd/yy) /___/___//___/___//___/___/
Time of interview (strike out not applicable answer: am or pm) /___/___/___/
Duration of interview (hours and minutes) /___/___/___/

Supervisor
Surname/First Name _____
Date of supervision (mm/dd/yy) /___/___//___/___//___/___/

Comments of the Surveyor and the Supervisor

National Household Code	/___/___/___/___/
Number of Household within the Cluster	/___/___/
Province Code	/___/___/
District Code	/___/___/
Village/Town (Block) Code	/___/___/___/___/___/___/

Comments of the surveyor:

Comments of the supervisor:

Household File Asked to Head of Household

National Household Code /___//___//___//___/

Number of Household within the Cluster /___//___/

1 Household File

N.B.: Listing members of household from the head to the youngest member respecting the type of relationship

col 1	**Situation of the Person**	1 = person with difficulties 2 = person without difficulties interviewed	3 = Other members of the household	
col 3	**Relationship to the Head of Household**	1 = head of household 2 = spouse 3 = child	4 = sibling 5 = mother/father 6 = other family member	7 = member of spouse family 8 = friend 9 = other, specify_____
col 5	**Presence of Members**	1 = present (A member spending at least 6 months per year in the household is considered as present)	2 = absent	3 = visitor
col 6	**Civil Status**	1 = single 2 = married, monogamous 3 = married, polygamous	4 = divorced 5 = engaged 6 = widow(er)	7 = separated 8 = other, specify_____
col 8	**Place of Birth**	1 = in the present family house 2 = in the cluster of survey 3 = the main city within the province 4 = a village within the province	5 = the main city of other province 6 = village of other province 7 = Pakistan or Iran 8 = Other foreign country	
col 9	**Employment Situation**	1 = working 2 = seeking job 3 = person, in charge of household tasks	4 = student 5 = too old to work 6 = too young to work	7 = long disease, not looking for a job 8 = not working, not looking for a job 9 = others, specify_____
col 10	**Status of Employed Activity**	1 = landowner/mortgager 2 = daily/weekly wage worker 3 = contract worker	4 = occasionnal worker 5 = apprentice 6 = family helper	7 = self employed 8 = employer 9 = other specify_____

N.B.: The occasional worker works only on irregular period, the daily wage worker is working on regular period

0	1	2	3	4	5	6	7	8	9	10
For all members of household										**(col 10 to 14**
N°	**Identification** *(to be filled by the surveyor after unit 2)*	**Name**	**Relationship to the head of household**	**Sex M/F 1 = M 2 = F**	**Present status of member**	**Civil status**	**Age**	**Place of birth**	**Employment of the person the month before**	**Under which of the above status categories does the person fall?**
/_1_/	/___/	__ __ __ __ __	/___/	/___/	/___/	/___/	/___/	/___/	/___/	/___//___/
/_2_/	/___/	__ __ __ __ __	/___/	/___/	/___/	/___/	/___/	/___/	/___/	/___//___/
/_3_/	/___/	__ __ __ __ __	/___/	/___/	/___/	/___/	/___/	/___/	/___/	/___//___/
/_4_/	/___/	__ __ __ __ __	/___/	/___/	/___/	/___/	/___/	/___/	/___/	/___//___/
/_5_/	/___/	__ __ __ __ __	/___/	/___/	/___/	/___/	/___/	/___/	/___/	/___//___/
/_6_/	/___/	__ __ __ __ __	/___/	/___/	/___/	/___/	/___/	/___/	/___/	/___//___/
/_7_/	/___/	__ __ __ __ __	/___/	/___/	/___/	/___/	/___/	/___/	/___/	/___//___/
/_8_/	/___/	__ __ __ __ __	/___/	/___/	/___/	/___/	/___/	/___/	/___/	/___//___/
/_8_/	/___/	__ __ __ __ __	/___/	/___/	/___/	/___/	/___/	/___/	/___/	/___//___/
/_9_/	/___/	__ __ __ __ __	/___/	/___/	/___/	/___/	/___/	/___/	/___/	/___//___/
/_10_/	/___/	__ __ __ __ __	/___/	/___/	/___/	/___/	/___/	/___/	/___/	/___//___/
/_11_/	/___/	__ __ __ __ __	/___/	/___/	/___/	/___/	/___/	/___/	/___/	/___//___/
/_12_/	/___/	__ __ __ __ __	/___/	/___/	/___/	/___/	/___/	/___/	/___/	/___//___/
/_13_/	/___/	__ __ __ __ __	/___/	/___/	/___/	/___/	/___/	/___/	/___/	/___//___/
/_14_/	/___/	__ __ __ __ __	/___/	/___/	/___/	/___/	/___/	/___/	/___/	/___//___/
/_15_/	/___/	__ __ __ __ __	/___/	/___/	/___/	/___/	/___/	/___/	/___/	/___//___/

Province Code /___//___/

District Code /___//___/

Village/Town (Block) Code /___//___//___//___//___//___/

Number of Persons in the Household /___//___/

col 11	**Name of Profession**	Please write the name given by the person
col 12	**Code of the Profession**	write the code of the sector in which the person works (list of 64 professions in the manual)
col 13	**Code of the Sector of Activity**	1 = agriculture (farming, etc.) 2 = mining 3 = manufacturing (textile, crafts, carpet weaving, etc.) 4 = manufacturing (carpentry, spare parts machinery manufacturing) 5 = land and Construction (house building) 6 = transport (taxi, bus, train, airplane) 7 = trade (sales, commerce, bazaar, clothes shops, food shops, etc.) 8 = education or health 9 = state and Administration (office, Mullah, army) 10 = hunting or gathering 11 = banking services 12 = communication (Roshan, AWCC...) 13 = other services
col 15	**Absence of Education (persons above 5)**	1 = absence of school 2 = lack of money 3 = child too old to go to school 4 = school not adapted to girls 5 = need to work 6 = school useless for girls 7 = school not very useful (for children in general) 8 = doesn't like school 9 = because of war and bad political situation 10 = I was refused 11 = too young to go to school 12 = because of disability/my difficulty 13 = other, specify_____
col 16	**Level of Education**	1 = class 1 2 = class 2 3 = class 3 4 = class 4 5 = class 5 6 = class 6 7 = class 7 8 = class 8 9 = class 9 10 = class 10 11 = class 11 12 = class 12 13 = higher education 14 = other, specify_____

11	12	13	14	15	16
Only for people coded 1 in col. 9)			(For all members above 7)		
What is the name of the profession ?	**What is the code of profession? (*supervisor will indicate the code)***	**Sector of activity *(supervisor will indicate the code)***	**Does (has) the person receive(d) some education? 1=Yes 2=No**	**If NOT, why?**	**If YES, which level of schooling did the person reach?**
___ ___ ___ ___ __	/__/__/	/__/__/__/	/__/	/__/	/__//__/
___ ___ ___ ___ __	/__/__/	/__/__/__/	/__/	/__/	/__//__/
___ ___ ___ ___ __	/__/__/	/__/__/__/	/__/	/__/	/__//__/
___ ___ ___ ___ __	/__/__/	/__/__/__/	/__/	/__/	/__//__/
___ ___ ___ ___ __	/__/__/	/__/__/__/	/__/	/__/	/__//__/
___ ___ ___ ___ __	/__/__/	/__/__/__/	/__/	/__/	/__//__/
___ ___ ___ ___ __	/__/__/	/__/__/__/	/__/	/__/	/__//__/
___ ___ ___ ___ __	/__/__/	/__/__/__/	/__/	/__/	/__//__/
___ ___ ___ ___ __	/__/__/	/__/__/__/	/__/	/__/	/__//__/
___ ___ ___ ___ __	/__/__/	/__/__/__/	/__/	/__/	/__//__/
___ ___ ___ ___ __	/__/__/	/__/__/__/	/__/	/__/	/__//__/
___ ___ ___ ___ __	/__/__/	/__/__/__/	/__/	/__/	/__//__/
___ ___ ___ ___ __	/__/__/	/__/__/__/	/__/	/__/	/__//__/
___ ___ ___ ___ __	/__/__/	/__/__/__/	/__/	/__/	/__//__/
___ ___ ___ ___ __	/__/__/	/__/__/__/	/__/	/__/	/__//__/
___ ___ ___ ___ __	/__/__/	/__/__/__/	/__/	/__/	/__//__/

Screening Questions Asked to Head of Household

National Household Code /___/___/___/___/___/
Number of Household Within the Cluster /___/___/
Province Code /___/___/
District Code /___/___/
Village/Town (Block) Code /___/___/___/___/___/___/

2 Screening Questions for Identification of Different Types of Disability

N.B.: ***These questions are asked to the head of the household for all the members of the family. Everytime that he/she answers positively, then we ask the identity of the member who has that particular difficulty, write it down and proceed to the next question for the entire family. All the questions are thus asked to the chief, for all members of the household. It is important to say that we do include the chief/head in these questions.***

Section A

2.1 Does any member of your family lack part of one or more limbs? (the smallest level of amputation is the amputation of the big toe/thumb, we will not consider the other toes/fingers)

Who is it? 1 = YES 2 = NO /___/
Names:_____ specify choice

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

1 = YES 2 = NO /___/
Who is it? specify choice
Names:_____

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

Who is it? 1 = YES 2 = NO /___/
Names:_____ specify choice

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

1 = YES 2 = NO /___/
Who is it? specify choice
Names:_____

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

1 = YES 2 = NO /___/
Who is it? specify choice
Names:_____

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

Who is it? 1 =YES 2 = NO /___/

Names:_____ specify choice

N.B.: ***Yes to at least <u>1 out of 6 questions</u>, we ask the questionnaire to the concerned persons or to the caregiver. We try asking the questions to the person first. If this is not possible we ask the question to the caregiver in the presence of the person.***

Section B

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

Who is it? /___/

Names:_____ 1 = YES 2 = NO specify choice

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

1 = YES 2 = NO /___/

Who is it? specify choice

Names:_____

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

1 = YES 2 = NO /___/

Who is it? specify choice

Names:_____

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

Who is it? 1 = YES 2 = NO /___/

Names:_____ specify choice

N.B.: ***Yes to <u>at least 2 out of 4 questions</u>, we ask the questionnaire to the concerned persons or to the caregiver. We try asking the questions to the person first. If this is not possible we ask the question to the caregiver in the presence of the person.***

Section C

2.11 Is anyone in the family "asabi"?

Who is it? 1 = YES 2 = NO /___/

Names:_____ specify choice

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

1 = YES 2 = NO /___/

Who is it? specify choice

Names:_____

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

1 = YES 2 = NO /___/

specify choice

Who is it?

Names:_____

For all respondents

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

1 = YES 2 = NO /___/

specify choice

Who is it?

Names:_____

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

1 = YES 2 = NO /___/

specify choice

Who is it?

Names:_____

2.16 Does any member of your family refuse to be with family or people and remains alone?

1 = YES 2 = NO /___/

specify choice

Who is it?

Names:_____

2.17 Does any member of your family become angry and aggressive without any adequate reason?

1 = YES 2 = NO /___/

specify choice

Who is it?

Names:_____

2.18 Does any member of your family have a tendency to physically hurt him/herself?

/___/

1 = YES 2 = NO

specify choice

Who is it?

Names:_____

N.B.: ***Yes to 2 questions at least out of 8, we ask the questionnaire to the person or to the caregiver. We try asking the questions to the person first. If this is not possible, we ask the question. to the caregiver in the presence of the person.***

Section D

2.19 Does any member of your family make the same gesture over and over again (rocking, biting their arm, hitting their head)?

1 = YES 2 = NO /___/

specify choice

Who is it?

Names:_____

2.20 Is any member of your family extremely active and cannot sit in one place ?

1 = YES 2 = NO /___/

specify choice

Who is it?

Names:_____

2.21 Does any member of your family seem to not care at all, not be aware of the feelings of others?

1 = YES 2 = NO /___/

specify choice

Who is it?

Names:_____

2.22 Does any member of your family not notice when someone is speaking to him/her, not be aware of the presence of others?

1 = YES 2 = NO /___/

specify choice

Who is it?

Names:_____

2.23 Does any member of your family scream loudly when they are touched or hear a noise that they do not like?

1 = YES 2 = NO /___/

specify choice

Who is it?

Names:_____

2.24 Does any member of your family have trouble adjusting to change and always want to do things in the same way?

1 = YES 2 = NO /___/

specify choice

Who is it?

Names:_____

N.B.: ***Yes to at least 2 out of 6, we ask the questionnaire to the persons or to the caregiver. We try asking the questions to the person first. If this is not possible we ask the question to the caregiver in the presence of the person.***

Section E

2.25 Does any member of the family suffer from "Mirgi" ?

1 = YES 2 = NO /___/

specify choice

Who is it?

Names:_____

2.26 Does any member of your family have sudden jerking of the parts of the body with loss of consciousness?

1 = YES 2 = NO /___/

specify choice

Who is it?

Names:_____

2.27 Does any member of your family bite his/her tongue often, froth at the mouth?

1 = YES 2 = NO /___/

specify choice

Who is it?

Names:_____

N.B. : ***Yes to at least 2 out of 3, we ask the questionnaire to the persons or to the caregiver. Once you identify special needs, please complete column 1 of the household file "Identification" of module 1 Information about household. We try asking the questions to the person first. If this is not possible we ask the question to the caregiver in the presence of the person.***

3 Health

3.1 Are you able to do the following for yourself without assistance or equipment? (read out the statements)

I	= bathing/ablutions	1 =YES	2 = NO	3 =YES, with difficulty	I. /___/
II	= getting dressed	1 =YES	2 = NO	3 =YES, with difficulty	II. /___/
III	= preparing meals for yourself	1 =YES	2 = NO	3 =YES, with difficulty	III. /___/
IV	= going to the toilet	1 =YES	2 = NO	3 =YES, with difficulty	IV. /___/
V	= eating/drinking	1 =YES	2 = NO	3 =YES, with difficulty	V. /___/
VI	= moving around	1 =YES	2 = NO	3 =YES, with difficulty	VI. /___/

specify choices

N.B.: For men go to Q.3.3.for women answer ALL the questions

3.2 Are you able to do the following inside the house/compound without assistance or equipment? This question is to be asked only to women (read out the statements)

I	= sweeping, cleaning the house	1 =YES	2 = NO	3 =YES, with difficulty	I. /___/
II	= cooking meals for everyone	1 =YES	2 = NO	3 =YES, with difficulty	II. /___/
III	= washing dishes	1 =YES	2 = NO	3 =YES, with difficulty	III. /___/
IV	= looking after younger children	1 =YES	2 = NO	3 =YES, with difficulty	IV. /___/
V	= looking after elder members	1 =YES	2 = NO	3 =YES, with difficulty	V. /___/
VI	= doing the laundry	1 =YES	2 = NO	3 =YES, with difficulty	VI. /___/

specify choices

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

I	= climb stairs	1 =YES	2 = NO	3 =YES, with difficulty	I. /___/
II	= go to the bazar/shop on your own	1 =YES	2 = NO	3 =YES, with difficulty	II. /___/
III	= carry heavy things (water…)	1 =YES	2 = NO	3 =YES, with difficulty	III. /___/
IV	= work in the field	1 =YES	2 = NO	3 =YES, with difficulty	IV. /___/
V	= ride a bicycle/or animal	1 =YES	2 = NO	3 =YES, with difficulty	V. /___/

specify the choices

3.4 Do you have any of the following difficulties?(read out the statements)

I	= finding the way to express what you need	1 =YES	2 = NO	I. /___/
II	= feeling comfortable with people	1 =YES	2 = NO	II. /___/
III	= keeping calm, staying in one place	1 =YES	2 = NO	III. /___/
IV	= concentrating on more than one thing at a time	1 =YES	2 = NO	IV. /___/
V	= going out of the house because you feel scared	1 =YES	2 = NO	V. /___/
VI	= going out of the house because people look	1 =YES	2 = NO	VI. /___/
VII	= having repetitive, stereotyped body movements	1 =YES	2 = NO	VII. /___/
VIII	= learning new things easily	1 =YES	2 = NO	VIII. /___/

specify the choices

3.5 In the past 6 months have you experienced the following? (read out the statements)

I	= fits/epilepsy	1 =YES	2 = NO	I. /___/
II	= physically violent behaviour towards another person without any reason	1 =YES	2 = NO	II. /___/
III	= verbally violent behaviour towards another person without any reason	1 =YES	2 = NO	III. /___/
IV	= violent behaviour regarding yourself	1 =YES	2 = NO	IV. /___/
V	= fainting or passing out	1 =YES	2 = NO	V. /___/

specify the choices

3.6 In general do you have difficulties to… (read out the statements)

I	= remember things	1 =YES	2 = NO	I. /___/
II	= talk easily to other men/other women (NB: for women talk to women)	1 =YES	2 = NO	II. /___/
III	= understand what people say	1 =YES	2 = NO	III. /___/
IV	= make yourself understood	1 =YES	2 = NO	IV. /___/
V	= hear clearly someone calling you in the house	1 =YES	2 = NO	V. /___/
VI	= see clearly someone in front of you	1 =YES	2 = NO	VI. /___/

specify the choices

3.7 In general, do you ever… (read out the statements)

I	= want to stay locked up inside the house	1 = YES	2 = NO	I. /___/
II	= feel very sad/cry without a specific reason	1 = YES	2 = NO	II. /___/
III	= not feel hungry for long periods of time	1 = YES	2 = NO	III. /___/
IV	= feel afraid for no reason	1 = YES	2 = NO	IV. /___/
V	= sit for a long time and think	1 = YES	2 = NO	V. /___/
VI	= want to live somewhere else, away from family	1 = YES	2 = NO	VI. /___/
VII	= have rapid changes of mood	1 = YES	2 = NO	VII. /___/
VIII	= feel oppressed for no particular reason	1 = YES	2 = NO	VIII. /___/
IX	= feel suffocated for no particular reason	1 = YES	2 = NO	IX. /___/
X	= feel angry and resentful for no particular reason	1 = YES	2 = NO	X. /___/

specify choices

3.8 What kind of health services are available for you ? (3 answers possible)

1 = health centre
2 = hospital
3 = physiotherapic and/or orthopedic centre
4 = private clinic/ doctor
5 = pharmacy/chemist
6 = female professional available
7 = other, specify_____

1. /___/
2. /___/
3. /___/

specify choices

by order of importance

3.9 What kind of health services are more useful for you ? (2 answers possible)

1 = health centre
2 = hospital
3 = physiotherapic and/or orthopedic centre
4 = private clinic/ doctor
5 = pharmacy/chemist
6 = other, specify_____

1. /___/
2. /___/

specify choices

by order of importance

3.10 How do you get to the closest available health care facility? (2 answers possible)

1 = by foot
2 = by motorised vehicle (car, tractor…)
3 = by bicycle
4 = on an animal (donkey…)
5 = other, specify_____

1. /___/
2. /___/

specify choices

by order of importance

3.11 How long does it take to get to the closest available health care facility?

/___/___/___/

(in case of no answer leave in blank)

specify number of minutes

3.12 During the past one year, how many times have you used health facilities?

specify the number of times

/__ /___/___/

(in case of no answer 999)

specifiy number

3.13 Have you tried any traditional or religious cures for your problem during the past year?

/___/

1 =YES
2 = NO--------> **go to Q.3.16**

specify choices

3.14 If Yes, what kind of cure did you try? (2 answers possible)

1 = bonesetter
2 = tabi unani
3 = mollah
4 = other spiritual leader/old woman
5 = pilgrimage/prayer
6 = traditional healer who uses magic
7 = other, specify_____

1. /___/
2. /___/

specify choices

by order of importance

3.15 During the past one year, how many times have you tried the traditional cures you mentioned ?

specify number of times /___/___/___/

(in case of no answer leave in blank) specifiy number

NB. : For each line in the table, indicate one type of cure (it can be several regular visits to the same centre)

How much did you pay for these ?

col.1 Indicate the Type of Service

1 = health centre
2 = hospital
3 = physiotherapic and/or orthopaedic centre
4 = private clinic/ doctor
5 = pharmacy/chemist
6 = bonesetter

What kind of difficulty did you face ?

7 = tabi unani
8 = mollah
9 = other spiritual leader/old woman
10 = pilgrimage/prayer
11 = traditional healer who uses magic
12 = other, specify_____

col. 2 In which month did you last go for treatment during last 1 year (Indicate the number of the month)

col. 3 col. 5 col. 7 Type of Expense(s)

1 = fees, donation
2 = medication (modern or traditional)
3 = medical tests
4 = food
5 = transportation
6 = amulates (taweez) other rituals
7 = care taker
8 = equipment (crutches, devices…)
9 = other, specify_____

col. 4, 6, 8 col. 9 Cost of the service

col. 10 What Kind of Difficulties Faced ? (3 answers are possible)

Financial difficulties

1 = I was refused because I had no money (or not enough)
2 = I had difficulty to get the food for myself during my stay
3 = I didn't have money for fees/donation after treatment
4 = I didn't have money for medication /amulates/ objects
5 = I had to go into debt

Transport, access difficulties

6 = there was no available transportation/it's very far away
7 = I had difficulty to find the money for transportation
8 = I had difficulty to find someone to go with me because nobody had time to take me
9 = I did not ask anyone because I felt that it was a waste of time
10 = I had difficulty to find someone to go with me because nobody thought it was important

Difficulties at the hospital

11 = there was no available medication
12 = there was no doctor to take care of me
13 = I was refused because I am disabled
14 = attitude of the medical staff was very negative
15 = the equipment that they gave me is not very useful (heavy, difficult to use…)
16 = there is no female professional
17 = no difficulty
18 = other, specify_____

(in case of multiple answers, please state by order of importance)

1	2	3	4	5	6	7	8	9	10
Type of health service used	**Month of use/ visit**	**What was the first type of expense?**	**What was the cost of the 1st expense? (in Afghanis)**	**What was the second type of expense?**	**What was the cost of the second expense? (in Afghanis)**	**What was the third type of expense?**	**What was the cost of the 3rd expense? (in Afghanis)**	**What was the total cost per visit? (in Afghanis 4+6+8)**	**What difficulties were faced? (by order of importance)**
/___/	/___/	/___/	/__//__//__//__/	/___/	/__//__//__//__/	/___/	/__//__//__//__//__/	/__//__//__//__//__/	/___//___//___/
/___/	/___/	/___/	/__//__//__//__/	/___/	/__//__//__//__/	/___/	/__//__//__//__//__/	/__//__//__//__//__/	/___//___//___/
/___/	/___/	/___/	/__//__//__//__/	/___/	/__//__//__//__/	/___/	/__//__//__//__//__/	/__//__//__//__//__/	/___//___//___/
/___/	/___/	/___/	/__//__//__//__/	/___/	/__//__//__//__/	/___/	/__//__//__//__//__/	/__//__//__//__//__/	/___//___//___/
/___/	/___/	/___/	/__//__//__//__/	/___/	/__//__//__//__/	/___/	/__//__//__//__//__/	/__//__//__//__//__/	/___//___//___/
/___/	/___/	/___/	/__//__//__//__/	/___/	/__//__//__//__/	/___/	/__//__//__//__//__/	/__//__//__//__//__/	/___//___//___/
N.B.: The supervisor will calculate the total cost of health expenses						/___//___//___//___//___//___//___//___//___/			**(in Afghanis)**

4 Education

4.1 Do you know how to read and write? (for instance a little note)

1 = YES 2 = NO /___/

specify choice

My name is (specify). I am from (specify the village or town). I am (X) years old.

I would like to tell you about my situation.

_____

_____

_____

N.B. : Code again in the box below 1=YES if the interviewee could write the entire text, and 2=NO if he/she could not write the entire text

/___/

specify choice

4.2 What kind of education did you receive or are you receiving mainly ? (2 answers possible)

1 = government school 3 = training centre 5 = in the family/or with someone

2 = private school 4 = religious school (Madrasa) 6 = no education

1. /___/
2. /___/

specify choice

For answer 1 go to Q. 4.4

4.3 Why did you receive no formal education ?

1 = being disabled, I was refused
2 = absence of school
3 = lack of money
4 = need to work
5 = education not very usefull
6 = doesn't like school
7 = too much work in the house/field
8 = useless for girls
9 = family does not allow girls to be educated
10 = no school for girls in the village
11 = quality of school is not good
12 = bad political situation

/___/

specify choice

For all answers go to Q. 4.10

4.4 Upto which class did you reach as a student?

1 = class 1 6 = class 6 11 = class 11 16 = Ph.D, more than 5 years
2 = class 2 7 = class 7 12 = class 12 17 = other, specify_____
3 = class 3 8 = class 8 13 = class 13 _____
4 = class 4 9 = class 9 14 = Bachelor's Degree, 3 years
5 = class 5 10 = class 10 15 = Master's Degree, 4/5 years

/___/

specify choice

4.5 Did you ever have to interrupt your studies ?

1 = YES 2 = NO----------**go to Q. 4.8**

/___/

specify choice

4.6 From which year to which year ?

from /___/___/___/___/ to /___/___/___/___/

specify year specify year

N.B.: Less than 1 year/1 year, specify the same year twice.

4.7 For what reason ? (2 possible answers)

Political reasons

1 = because of the political regime
2 = because the school was destroyed
3 = because the school was shut down

Reasons linked to the school

4 = because teachers were not paid and did not teach
5 = because I was not well treated by the teachers
6 = because I was mistreated by other children
7 = because I was rejected by parents of other children
8 = because I was disabled, I was refused in school although I could continue
9 = because I was disabled and school was too difficult

Family, personal reasons

10 = because I have to look after somebody in the family
11 = because of illness
12 = because too much work at home
13 = because there was no money to pay for my education
14 = because there was nobody to take me to school
15 = because I had to work to get money
16 = other, specify_____

1. /___/
2. /___/

specify 1st and 2nd choice by order of importance

4.8 How old where you when your education stopped ?

age : /___/___/

specify age

N.B.: Code 77 if the interviewee is still going to school, and go to 4.12.

4.9 Why did you stop your education? (2 answers possible)

1 = school was shut down
2 = lack of financial means of the family
3 = didn't have the right to go to school
4 = death or inactivity of earning member
5 = switched to apprenticeship
6 = studies completed--->**go to Q.4.12**
7 = failed at school
8 = didn't like school
9 = found a paid job
10 = didn't learn anything
11 = because I became disabled, I was refused by the school
12 = because there was too much work at home/in the field
13 = because of war or/and bad political situation
14 = other, specify_____

1. /___/
2. /___/

specify 1st and 2nd choice by order of importance

4.10 Would you like to go (back) to school/university ?

1 =YES 2 = NO---------->**go to Q. 4.12**

/___/

specify choice

4.11 If YES, what prevented or prevents you from going to school ?

1 = I have to work and feed my family
2 = I am too old to go back to school/university
3 = there is no money for school/university at home
4 = I have to earn money to start a family (dowry)
5 = there is no school closeby
6 = there are no female teachers in the school
7 = there is too much work at home/in the field
8 = no one can help me inside the school
9 = no one can take me to school
10 = other, specify_____

/___/

specify choice

4.12 Do you think education is useful ?

1 =YES 2 = NO---------->**go to Q. 4.14**

/___/

specify choice

4.13 If YES, for what reason ?

1 = because it is useful for everyday life
2 = because it improves the prospects for finding a job
3 = because I like school myself
4 = because I have a better position in society
5 = because I want to be independent
6 = because I want to be less burden on others
7 = because I want to be someone
8 = because it is better for getting married ---------->**go to unit 5**
9 = because it is important for progress
10 = other, specify_____

/___/

specify choice

4.14 If NO, for what reason ?

1 = because it is not useful for everyday life
2 = because it does not improve prospects for finding a job
3 = because school is boring
4 = because I am happy with the level I have completed
5 = because I was ill-treated by the teachers
6 = because I was ill-treated by other children
7 = other, specify_____

/___/

specify choice

5 Activity and Inactivity

5.1 Do you do any household tasks yourself ?

1 = YES 2 = NO-----> **go to Q. 5.4** /___/

specify choice

5.2 How many hours per day do you spend on household tasks ?

Specify the number of hours /___/___/

5.3 Which tasks do you mainly do?
(in case of multiple answers, please state according to the time spent)

1 = cooking
2 = cleaning
3 = fetching water/fill tanker
4 = taking care of other members of the family including children
5 = laundry
6 = chopping the wood
7 = doing the grocery shopping
8 = other, specify _____

1. /___/
2. /___/
3. /___/
4. /___/
5. /___/
6. /___/

specify choices by order of importance

N.B.: You ask the interviewee to evaluate the most time consuming

5.4 Do you do any income generating activities inside the house ?

1 = YES 2 = NO /___/

specify choice

N.B. : If YES, after completing unit 5, please complete units 6 to 8

5.5 Do you currently have work (regular or irregular)?

1 = YES 2 = NO /___/

specify choice

N.B.: If the interviewee is working go to unit 6.

5.6 Have you ever done paid work ?

1 = YES 2 = NO-----> **go to Q. 5.8** /___/

specify choice

5.7 What difficulties did you face in your work place ?
(in case of multiple answers, please state by order of importance)

1 = it was very difficult to reach my work place
2 = the position(s) of work was(were) too tiring
3 = the tasks demanded were too difficult
4 = it was dangerous (risky for me)
5 = I was rejected by my co-workers
6 = I was ill-treated by my employer
7 = I was paid less than other workers for the same job
8 = I had no particular difficulties
9 = bribery (bakshish) and corruption
10 = the bad weather
11 = along with work outside, I had to do other work at home
12 = other, specify_____

1. /___/
2. /___/
3. /___/

specify choice by order of importance

5.8 Did you work or have a job for at least one hour per day during last week?

1 = YES -----> **go to unit 6** 2 = NO /___/

specify choice

5.9 Did you work or have a job for at least one day during last month ?

1 = YES -----> **go to unit 6** 2 = NO /___/

specify choice

5.10 If you are not working, for what reason ?

1 = physically incapable of working
2 = mentally incapable of working
3 = nobody would give me a job because I'm disabled
4 = long illness (more than 1month)
5 = I am looking for my first job
6 = no job opportunities in the area
7 = doing duties/work inside the house
8 = too old/retired
9 = don't need to work/rent collector
10 = student
11 = I quit my job---------->**go to Q. 5.12**
12 = I was dismissed/fired---------->**go to Q. 5.11**
13 = other, specify_____

/___/
specify choice

For answers other than 11 and 12 go to Q. 5.13

5.11 For what reason were you dismissed/fired ? (in case of multiple answers, please state by order of importance)

1 = because of my health problem (disability)
2 = because my place of work has shut down
3 = because of re-organisation
4 = because I was not productive enough
5 = because I was pregnant or had a child
6 = because I committed a mistake
7 = because I was too old
8 = because I didn't get along with other workers or the boss
9 = because of accessibility problems
10 = other, specify_____

1. /___/
2. /___/
3. /___/
specify choices by order of importance

For all answers go to Q. 5.13

5.12 For what reason did you quit your job ? (in case of multiple answers, please state by order of importance)

1 = because of my health problem
2 = my family was against my working
3 = I had to take care of my children
4 = I had to take care of another person in my family
5 = because of lack of transport
6 = because transport has become too expensive
7 = I recently moved
8 = I went back to school/training
9 = because I was not paid
10 = because the work was dangerous
11 = because of bad working conditions
12 = because of an accident
13 = for political reasons
14 = no particular difficulty
15 = other, specify_____

1. /___/
2. /___/
3. /___/
specify choices by order of importance

5.13 Even if you stated that you have not worked last month, have you carried out one of the following activities to help your family? (state the activity)

1 = work for myself (selling, daily wage worker…)
2 = making products for sale
3 = worked for a member of the family
4 = occasional work as a student
5 = other paid activity, specify_____
6 = no such activity
7 = household tasks

/___/
specify choices

N.B.: Unemployed persons looking for a job go to unit 9, for codes 1 to 5 please go to unit 6

6 Main Employment/Job

N.B.: If the person is a student and works after class, then please answer this unit 6

6.1 What is the name of the job or employment that you have ?

Activity no. 1 = _____ /___/___/___/

give the detailed name — profession code

N.B.: The supervisor will indicate the code of the profession

6.2 What is your professional status ?

Employee:

1 = manager, engineer, doctor
2 = employee chief of staff/unit
3 = employee
4 = qualified labourer
5 = unqualified labourer
6 = paid trainee

Non Employee:

7 = self employed (can have family helper not paid) (always has capital in equipment, raw material…)
8 = employer (my own company/shop with staff)
9 = worker paid per task and daily/occasional worker
10 = seasonal worker
11 = unpaid apprentice
12 = family helper

/___/ specify choice

6.3 What difficulties do you face in your work place ?

1 = it is difficult to reach my work place
2 = the position(s) of work is(are) too tiring
3 = the tasks demanded is(are) too difficult
4 = the work is dangerous/risky for me
5 = I don't get on with my co-workers
6 = I am ill-treated by my employer
7 = I am paid less than other workers for the same job
8 = I have no difficulty
9 = insufficient wage
10 = bribery (bakshish) and corruption
11 = bad weather
12 = other, specify_____

1. /___/
2. /___/
3. /___/

specify choices by order of importance

7 Secondary Employment/Job

N.B.: All workers with multiple activities must answer the questions of this unit. If the interviewee has only one activity, go to unit 8

7.1 In addition to your main activity have you had one or many others ? (by order of importance, according to the time of work)

Activity no. 2 = _____ /___/___/___/

give the detailed name — profession code

Activity no. 3 = _____ /___/___/___/

give the detailed name — profession code

Number of secondary jobs /___/

N.B.: The supervisor will indicate the codes of profession

specify number

7.2 In addition to the activities you have already quoted above have you had one or many others during the past month ? (by order of importance, according to the time of work)

Activity no. 4 = _____ /___/___/___/

give the detailed name — profession code

Activity no. 5 = _____ /___/___/___/

give the detailed name — profession code

Activity no. 6 = _____ /___/___/___/

give the detailed name — profession code

Activity no. 7 = _____ /___/___/___/

give the detailed name — profession code

Number of secondary jobs /___/

N.B.: The supervisor will indicate the codes of profession

specify number

7.3 What is your professional status in the secondary activity? (activities stated in Q. 7.1 and Q. 7.2)

Employee:

1 = manager, engineer, doctor
2 = employee chief of staff/unit
3 = employee
4 = qualified labourer
5 = unqualified labourer
6 = paid trainee

Activity no. 1	1. /___/
Activity no. 2	2. /___/
Activity no. 3	3. /___/
Activity no. 4	4. /___/
Activity no. 5	5. /___/
Activity no. 6	6. /___/

specify status

Non employee:

7 = self employed (can have family helper not paid)
(always has capital in equipment, raw material…)
8 = employer (my own company/shop with staff)
9 = worker paid per task and daily/occasional worker
10 = seasonnal worker
11 = unpaid apprentice
12 = family helper

7.4 Why do you have more than one job ? (2 answers possible)

1 = my job changes with the seasons
2 = all the jobs I find are temporary jobs
3 = I can't sustain/help my family with my main job only
4 = I need more money for a specific expense/purpose: wedding (dowry), funerals, disease
5 = I created activities to give a job to a member of my family who is unemployed
6 = other, specify_____

1. /___/
2. /___/

specify choices

8 Duration Of Activity

8.1 Please give the duration of work by activity and by period of work (starting with the main activity)

1	2	3	4	5	6	7
Profession code (see manual of the supervisor)	**Name of activity/job (name)**	**How long have you been working in this activity/job (in months)**	**How many hours per day do you usually spend on the job? (in hours)**	**How many days do you usually spend on this job per week? (in days)**	**Do you remember how many days you spent on this job last month? (in days)**	**Do you remember how many weeks you spent on this job last month? (in weeks)**
/__/__/__/		/__/__/__/	/__/__/	/__/	/__/__/	/__/__/
/__/__/__/		/__/__/__/	/__/__/	/__/	/__/__/	/__/__/
/__/__/__/		/__/__/__/	/__/__/	/__/	/__/__/	/__/__/
/__/__/__/		/__/__/__/	/__/__/	/__/	/__/__/	/__/__/
/__/__/__/		/__/__/__/	/__/__/	/__/	/__/__/	/__/__/
/__/__/__/		/__/__/__/	/__/__/	/__/	/__/__/	/__/__/
/__/__/__/		/__/__/__/	/__/__/	/__/	/__/__/	/__/__/
/__/__/__/		/__/__/__/	/__/__/	/__/	/__/__/	/__/__/

8.2 If you have the opportunity, would you like to work more than you do?

1 =YES ---------->**go to Q. 8.3** 2 = NO -------> **go to Q.8.4** /___/

specify choice

8.3 If YES, in which activity/job ?

If it is one of the surveyed persons activity/job, give its number:

If it is another activity/job, give the name :_____

_____

(the supervisor indicates the profession code)

activity number	profession code
1. /___/	/___/___/___/
2. /___/	/___/___/___/
3. /___/	/___/___/___/
4. /___/	/___/___/___/

8.4 Are you currently looking for another job?

1 =YES ---------->**go to unit 9** 2 = NO -------> **go to unit 10**

/___/

specify choice

9 Employment Seeking and Unemployment

N.B. : The section 9 concerns all unemployed persons and employed persons looking for another job. If the person is not looking for a job, please go to unit 10

9.1 How long have you been unemployed ?

number of months of unemployment (for unemployed person) /___/___/___/

specify number of months

9.2 How long have you been looking for another job ?

number of months of looking for another job (for employed person) /___/___/___/

specify number of months

9.3 When was the last time you looked or asked for a job?

number of weeks since you have been looking for a job /___/___/___/

specify number of weeks

N.B.: If the surveyed person says 1 day to 1 week, the surveyor writes 1. **Code 0 if not actively seeking for a job**

9.4 Why are you looking for a job/activity? (in case of multiple answers, please state by order of importance)

1 = I need a job to earn my living
2 = I need to help my family by working
3 = I can't sustain my family with my main job only
4 = my job is temporary
5 = I want/need a better paid job
6 = I need better work conditions
7 = other, *specify*_____

1. /___/
2. /___/
3. /___/

specify choices

9.5 What will you now do to find a job/activity ? (in case of multiple answers, please state starting from the most recent action)

1 = I will ask a member of my family for a job
2 = I will ask a friend/neighbour/colleague
3 = I will ask people I meet, in the street or going from door to door
4 = I will check offers proposed in AKBAR and other agencies
5 = I will ask my family/friends for money (lended or given) to start an activity
6 = nothing, I will wait for a proposition
7 = other, specify_____

1. /___/
2. /___/
3. /___/

specify choices

9.6 How long are you willing to work (per day and per week)?

number of hours per day

number of days per week

1. /___/___/
2. /___/___/

specify number

9.7 What minimum wage do you expect to earn in a month for such a job ?

minimum wage for a month /___/___/___/___/___/___/___/___/

specify amount in Afghanis

10 INCOME

10.1 What is your monthly income in each of your activities ? (keep the same order than in Q. 6.1 and Q. 7.1 and Q. 7.2, activity 1 being your main activity)

Activity no. 1 /___/___/___/___/___/___/___/
Activity no. 2 /___/___/___/___/___/___/___/
Activity no. 3 /___/___/___/___/___/___/___/
Activity no. 4 /___/___/___/___/___/___/___/
Activity no. 5 /___/___/___/___/___/___/___/

specify the amount in Afghani

Activity no. 6 /___/___/___/___/___/___/___/
Activity no. 7 /___/___/___/___/___/___/___/

specify amount in Afghanis

Total : /___/___/___/___/___/___/___/

specify amount in Afghanis

N.B. : For income in goods, please evaluate the amount by month

10.2 Have people (including your family) given you money during the last year ?

1 =YES 2 = NO ---------> **go to Q.10.3** /___/

specify choice

A) Who gives you money for each of the 3 main donations ?

1 = husband/wife
2 = father/mother
3 = brother/sister
4 = other family member
5 = friends
6 = state pension
7 = local leader
8 = religious leader
9 = other people, specify_____

1. /___/
2. /___/
3. /___/

specify choices

B) What is the frequency of each of the 3 main donations ?

1 = daily
2 = weekly
3 = monthly
4 = quarterly
5 = annually/this year
6 = irregular

1. /___/
2. /___/
3. /___/

C) Please give the amount of money for each of the 3 main donations ?

1. /___/___/___/___/___/___/ 2. /___/___/___/___/___/___/ 3. /___/___/___/___/___/___/

10.3 Have people (including your family) given you goods during last year ?

1= YES 2 = NO-------> **go to unit 10.4** /___/

specify choice

A) Who gives you goods for each of the 3 main donations ?

1 = husband/wife
2 = father/mother
3 = brother/sister
4 = other family member
5 = friends
6 = state pension
7 = local leader
8 = religious leader
9 = other people, specify_____

1. /___/
2. /___/
3. /___/

specify choices

B) What is the frequency of each of the 3 main donations ?

1 = daily
2 = weekly
3 = monthly
4 = quarterly
5 = annually/this year
6 = other, specify_____

C) What are the type of goods you received for the 3 main donations ?

1 = livestock
2 = equipment for work
3 = equipment for household
4 = mean of transportation
5 = food/grain
6 = clothes
7 = gold/jewellery
8 = other, specify_____

10.4 Did you take a loan in the past 5 years ? (five main loans)

1 =YES 2 = NO -------> **go to unit 11** /___/

specify choice

A) From whom did you borrow money ?

1 = husband/wife
2 = father/mother
3 = brother/sister
4 = other relative
5 = friend
6 = local leader/religious leader
7 = bank /saving and loans
8 = boss/employer
9 = professional money lender
10 = NGOs
11 = Other people, specify__
_____

1. /___/
2. /___/
3. /___/
4. /___/
5. /___/

specify choice

B) When did you borrow money ?

specify date
mm/yy

1. /___/___//___/___/
2. /___/___//___/___/
3. /___/___//___/___/
4. /___/___//___/___/
5. /___/___//___/___/

specify mm/yy

C) How much did you borrow ?

(specify amount)

1.	/___/___/___/___/___/___/___/
2.	/___/___/___/___/___/___/___/
3.	/___/___/___/___/___/___/___/
4.	/___/___/___/___/___/___/___/
5.	/___/___/___/___/___/___/___/

(in Afghanis)

D) How much have you repaid already ?

(specify amount)

1.	/___/___/___/___/___/___/___/
2.	/___/___/___/___/___/___/___/
3.	/___/___/___/___/___/___/___/
4.	/___/___/___/___/___/___/___/
5.	/___/___/___/___/___/___/___/

(in Afghanis)

E) For what purpose did you borrow money ?

1 = food
2 = school expenditure
3 = health expenditure
4 = professional equipment
5 = house equipment
6 = ceremony
7 = dowry
8 = land purchase/rent
9 = property purchase
10 = good purchase for business
11 = Other, specify_____

1.	/___/
2.	/___/
3.	/___/
4.	/___/
5.	/___/

specify choice

F) What is the duration of the loan ?

specify number of months

1.	/___/___/___/___/___/___/___/
2.	/___/___/___/___/___/___/___/
3.	/___/___/___/___/___/___/___/
4.	/___/___/___/___/___/___/___/
5.	/___/___/___/___/___/___/___/

specify number of months

G) What is the status of repayement ?

1 = totally repaid
2 = repaid less than 50%
3 = repaid half or more than 50%
4 = not at all repaid -------> **go to unit 11**

1.	/___/
2.	/___/
3.	/___/
4.	/___/
5.	/___/

specify choice

H) What is the form of repayement ?

1 = in cash periodically
2 = in cash irregularly
3 = in kind periodically
4 = in kind irregularly
5 = both cash and kind
6 = all repaid in one time

1.	/___/
2.	/___/
3.	/___/
4.	/___/
5.	/___/

specify choice

11 Livelihoods

11.1 Where is the main source of drinking water located?

1 = within the coumpound/house ---------> **go to Q. 11.3**
2 = outside the coumpound/house

/___/
specify choice

11.2 If it is outside the coumpound, how long does it take to fetch drinking water? (time per return trip)

specify time per return trip (in minutes)
888 = don't know **999 = no response**

/___/___/___/
specify choice

11.3 What are the main sources of drinking water for your household ? (multiple answers possible)

N.B.: ***The order of importance is determined by the number of times you go for water to each source. Need to prompt for a second source***

Piped water
1 = piped into residence/ coumpound/ plot
2 = public tap/tap in the neighbourhood
Ground water
3 = hand pump in residence/coumpound/ plot
4 = public hand-pump
Well water
5 = well in residence/coumpound/ plot
6 = covered well
7 = open well and kariz
Surface water
8 = spring
9 = river/ stream
10 = pond / lake
11 = still water: dam
12 = rain water
13 = tanker/ truck
14 = other, specify_____

1. /___/
2. /___/
3. /___/
specify choices
by order of importance

11.4 What is the main source of lighting for your household ? (3 answers possible)

1 = main power
2 = generator/battery/invertor
3 = kerosene/petrol/gas
4 = candles
5 = other, specify_____
6 = no source of light

1. /___/
2. /___/
3. /___/
specify choices
by order of importance

11.5 What is mainly used in your household for cooking ? (3 answers possible)

1 = gas
2 = stove with kerosene/petrol
3 = firewood
4 = dung
5 = charcoal
6 = electricity
7 = other, specify_____

1. /___/
2. /___/
3. /___/
specify choices
by order of importance

11.6 What kind of toilet facility does your household have ?

1 = private flush inside
2 = private flush outside
3 = shared flush
4 = traditional pit
5 = open backed
6 = open defecation field outside the house
7 = other, specify_____

/___/
specify choice

11.7 How many rooms are there in your household ?

specify number of rooms
888 = don't know **999 = no response**

/___/___/___/
specify number

N.B.: Specify all the rooms, kitchen and bathroom included

11.8 Where does your household get the majority of your food? (over the last 3 months)

1 = market/bazar
2 = self provided/farm
3 = combination of market, farm
4 = food-aid
5 = from family, other relatives
6 = other, specify_____

/___/
specify choice

11.9 Does any member of your household own any of the following ? (read the statements to the interviewee)

I = radio, tape recorder	1 = YES	2 = NO	I. /___/
II = television	1 = YES	2 = NO	II. /___/
III = pressure cooker	1 = YES	2 = NO	III. /___/
IV = oven, hotplate	1 = YES	2 = NO	IV. /___/
V = refrigerator	1 = YES	2 = NO	V. /___/
VI = bukhari	1 = YES	2 = NO	VI. /___/
VII = bicycle	1 = YES	2 = NO	VII. /___/
VIII = motorbike	1 = YES	2 = NO	VIII. /___/
IX = car	1 = YES	2 = NO	IX. /___/
X = tractor	1 = YES	2 = NO	X. /___/
XI = generator	1 = YES	2 = NO	XI. /___/
XII = kerosene lamp	1 = YES	2 = NO	XII. /___/
XIII = sewing machine	1 = YES	2 = NO	XIII. /___/
XIV = house or apartment	1 = YES	2 = NO	XIV. /___/

specify choices by order of importance

11.10 Does any member of your household own any animals ?

1 =YES 2 = NO -----> **go to Q. 11.12**

/___/
specify choice

11.11 Which ones ? (read the statements to the interviewee)

I = sheep	I. /___/
II = cows/buffalos	II. /___/
III = goats	III. /___/
IV = horses	IV. /___/
V = donkeys	V. /___/
VI = birds: chicken/hen/ ducks/turkeys and fowls	VI. /___/
VII = roosters	VII. /___/
VIII = camels	VIII. /___/

N.B.: Enter the number of animals of each kind, if none, enter 00

specify number

11.12 Does any member of your household own land ?

1 =YES 2 = NO ----------> **go to unit 12 for men, unit 16 for women**

/___/
specify choice

11.13 If YES, how much land is owned by the household members ?

specify the size of land **jerib:** /___/___/___/ **biswa:** /___/___/___/
00 = no land **888 = don't know** **999= no response**
specify area

11.14 How much of this land is cultivable ?

specify the size of land **jerib:** /___/___/___/ **biswa:** /___/___/___/
888 = don't know **999= no response**
specify area

11.15 Do you personally own any part of this land ?

1 =YES 2 = NO

/___/
specify choice

For men go to unit 12. For women go to unit 16

12 Self Perception *(Units 12 to 16 to be asked to Men Only)*

12.1 Which of the following qualifies you best? (3 answers required, please read out the list) (classify according to what describes you best)

I = disappointed *(naumed)*
II = normal *(normal/hechis)*
III = happy *(razi/khush)*
IV = useless *(nalayaq/az kar aftada)*
V = brave:courageous *(dalir)*
VI = willing *(kosha)*
VII = proud *(moftakhar)*
VIII = oppressed *(mazlum)*
IX = poor *(gharib)*
X = deprived *(mahrum)*

1. /___/
2. /___/
3. /___/

specify choices by order of importance

N.B. : It will be important to repeat the list many times

12.2 What do you think your situation will be like in 5 years? Read the 3 possibilities

1 = the same as today----------> **go to unit 13**
2 = better than today ----------> **go to Q. 12.3**
3 = worse than today ----------> **go to Q. 12.4**

/___/ specify choice

12.3 In what way will your situation be better ? (2 answers possible)

1 = I will earn more money
2 = I will own property (land, house, livestock…)
3 = I will be married
4 = I will benefit from better health services
5 = I/my children will benefit from better education
6 = I will benefit from better security
7 = I will benefit from better economic situation
8 = I will get better help from the international community
9 = other, specify_____

-------> **go to unit 13**

1. /___/
2. /___/

specify choices by order of importance

12.4 In what way will your situation be worse ? (2 answers possible)

1 = I will earn less money/be indebted
2 = I don't know if I will still be alive
3 = I will be alone
4 = I will be in worse health
5 = I /my children will not be educated
6 = insecurity/violence will resume
7 = the economic situation will worsen
8 = other, specify_____

1. /___/
2. /___/

specify choices by order of importance

13 AWARENESS (*Men Only*)

13.1 What organisation do you feel does something useful for you ?

1 = none
2 = the government
3 = international NGOs, specify_____
4 = national NGOs, NPOs specify_____
5 = organisation of persons with disability
6 = United Nations agency
7 = people from other countries
8 = other, specify_____

1. /___/
2. /___/

specify choices by order of importance

13.2 Do you think Malulin should have the same rights as other Afghans ?

1 = YES 2 = NO---->**go to Q. 13.4** 3 = Depends on which rights

/___/ specify the choice

13.3 Which rights do you think should be the same?(read out the answers)

I	= right to vote	1 = YES	2 = NO	I. /___/
II	= right to education	1 = YES	2 = NO	II. /___/
III	= right to good health	1 = YES	2 = NO	III. /___/
IV	= right to work	1 = YES	2 = NO	IV. /___/
V	= right to express oneself/say what he/she wants	1 = YES	2 = NO	V. /___/
VI	= right to get married and have children	1 = YES	2 = NO	VI. /___/
VII	= right to move around freely	1 = YES	2 = NO	VII. /___/
VIII	= the right to inheritance	1 = YES	2 = NO	VIII. /___/

specify choice

13.4 Do you think Mayubin should have the same rights as other Afghans ?

1 = YES 2 = NO---> **go to Q.13.6** 3 = Depends on which rights

/___/ specify choice

13.5 Which rights do you think should be the same? (read out the answers)

I	= right to vote	1 = YES	2 = NO	I. /___/
II	= right to education	1 = YES	2 = NO	II. /___/
III	= right to good health	1 = YES	2 = NO	III. /___/
IV	= right to work	1 = YES	2 = NO	IV. /___/
V	= right to express oneself s/say what he/she wants	1 = YES	2 = NO	V. /___/
VI	= right to get married and have children	1 = YES	2 = NO	VI. /___/
VII	= right to move around freely	1 = YES	2 = NO	VII. /___/
VIII	= the right to inheritance	1 = YES	2 = NO	VIII. /___/

specify choice

13.6 Do you think that by law Dewana/Lewanae should have the same rights as other Afghans? (read out the answers)

1 =YES 2 = NO---->**go to unit 14** 3 = Depends on which rights

1. /___/
2. /___/

specify choice

13.7 Which rights do you think should be the same?

I	= right to vote	1 = YES	2 = NO	I. /___/
II	= right to education	1 = YES	2 = NO	II. /___/
III	= right to good health	1 = YES	2 = NO	III. /___/
IV	= right to work	1 = YES	2 = NO	IV. /___/
V	= right to express oneself/say what he/she wants	1 = YES	2 = NO	V. /___/
VI	= right to get married and have children	1 = YES	2 = NO	VI. /___/
VII	= right to move around freely	1 = YES	2 = NO	VII. /___/
VIII	= the right to inheritance	1 = YES	2 = NO	VIII. /___/

specify choice

14 Marriage *(Men Only)*

14.1 Are you currently married ?

1 =YES-------> **go to Q. 14.6** 2 = NO /___/

specify choice

14.2 Have you ever been married ?

1 =YES-------> **go to Q. 14.6** 2 = NO /___/

specify choice

14.3 Why are you single ?

1 = not yet married, I have still the time
2 = no one would marry me---->**go to 14.4**
3 = I don't have enough money
4 = I am engaged-->**go to unit 15**
5 = I prefer to be single-->**go to unit 15**
6 = it is a decision of my family
7 = other, specify_____

/___/

specify choice

For all other options except 2, 4 and 5 go to Q. 14.5

14.4 Why doesn't anyone want to marry you?

1 = I am disabled
2 = I am not educated
3 = I am not attractive to look at
4 = I lost my family
5 = I have bad habits/bad character
6 = other, specify_____

/___/

specify choice

14.5 What will you do now, concerning marriage?

1 = I will ask a disabled person to marry me
2 = I will try and educate myself
3 = I will move to another province/region/country
4 = I will continue to look for a bride--> **go to unit 15**
5 = I am too disappointed, I will just give up
6 = other, specify_____
_____

/___/

specify choice

14.6 How many times did you get married ?

specify number of times /___/ specify number of times

14.7 Have you ever got separated/divorced ?

1 =YES 2 = NO-------> **go to Q. 14.11** /___/ specify choice

14.8 Who wanted this separation/divorce?

1 = I myself 2 = my wife-------> **go to Q. 14.10** /___/ specify choice
3 = family dispute 4 = both of us------> **For both 3 and 4 go to Q. 14.11**

14.9 If you wanted the divorce, for what reason?

1 = we couldn't have children 5 = she worked out of the house /___/ specify choice
2 = she had bad character 6 = she was not educated
3 = she did not look after me 7 = my family didn't like her
4 = she did not work enough 8 = other, specify_____

14.10 If it was your wife, for what reason?

1 = we couldn't have children 5 = I was disabled /___/ specify choice
2 = I had bad character 6 = I did not earn enough
3 = I was not educated enough 7 = her family didn't like me
4 = she thought that I did not work enough 8 = other, specify_____

14.11 At what age did you (first) get married ?

/___/___/ specify age

14.12 Who chose your (first) wife ?

1 = parents 3 = friends 5 = myself 6 = Jirga (dispute settlement) /___/ specify choice
2 = relatives 4 = neighbours/community members 7 = other, specify_____

For those who have only one wife please go to unit 15

14.13 Who chose your subsequent wives ?

1 = parents 3 = friends 5 = myself 6 = my first wife 8 = other, specify_____ /___/ specify choice
2 = relatives 4 = neighbours/community members 7 = jirga (dispute settlement)

14.14 For what reason did you take a second wife?

1 = My first wife was disabled 4 = I did not choose my first wife /___/ specify choice
2 = I did not have a child with my first wife 5 = because my wife died
3 = I was not happy

15 Social Participation *(Men Only)*

15.1 Who takes care of you in everyday life? (2 answers possible) (classify according to preference)

1 = mother 8 = mollah 1. /___/ 2. /___/
2 = father 9 = other leader of community
3 = sister/brother 10 = other member of community, specify_____ specify 1st and 2nd choice
4 = spouse 11 = no one --------> **go to Q. 15.2** by order of importance
5 = your children 12 = I myself--------> **go to Q. 15.2**
6 = in laws 13 = other, specify_____
7 = other member of family, specify_____

Persons who answer anything except 11 go to Q.15.3

15.2 If no one takes care of you, why ? (2 answers possible) (classify according to the order given by the interviewee)

1 = nobody has the time 6 = I live with another family 1. /___/ 2. /___/
2 = nobody loves me 7 = I take drugs/alcohol
3 = it is difficult 8 = I don't need it specify 1st and 2nd choice
4 = it is a permanent constraint 9 = other, specify_____ by order of importance
5 = I live alone because I lost my family

15.3 Has anyone ever ill-treated you ?

1 =YES 2 = NO ----------> **go to Q. 15.7** /___/

15.4 If YES, who was/is it ? (2 answers possible) (classify according to the order given by the interviewee)

1 = member of family, specify_____
2 = children in the street
3 = adults in the street
4 = people in public places
5 = government persons
6 = gunmen
7 = other, specify_____

1. /___/
2. /___/

specify 1st and 2nd choice by order of importance

15.5 How did/do they ill-treat you?

1 = bad language
2 = they peer/stare
3 = they push me
4 = they throw stones
5 = they laugh at me
6 = they hit me
7 = they steal things from me
8 = other, specify_____

1. /___/
2. /___/

specify 1st and 2nd choice by order of importance

15.6 What did/do you do to prevent or avoid this ill-treatment ?

1 = nothing, I don't know what to do
2 = nothing, I am afraid of being abused more
3 = I abuse too/abuse back
4 = I try and talk to an important person of the community
5 = I try to stay away
6 = I complained to someone
7 = other, specify_____

/___/

specify choice

15.7 Are you ever left alone ?

1 =YES 2 = NO ----------> **go to Q. 15.9**

/___/

specify choice

15.8 At what time of the day are you left alone ?

1 = when I wake up
2 = during the morning till noon
3 = during lunch
4 = in the afternoon
5 = during dinner
6 = during the night
7 = all the time
8 = other, specify_____

/___/

specify choice

15.9 Did you take part in any ceremony during the past year ?

1 =YES 2 = NO ----------> **go to Q. 15.11**

/___/

specify choice

15.10 If YES, which of the following ceremonies did you take part in ?

1 = birth ceremony
2 = *Nam Guzari*
3 = *Arusi/Wadah*
4 = *Marg/Marina*
5 = village ceremonies
6 = *Eid Ramazan*
7 = *Eid Qurban*
8 = *Nazr/Khairat*
9 = *Khatme Quraan*
10 = official days (Mujahidin Day…)
11 = circumcision
12 = new year
13 = engagement
14 = birthday
15 = other, specify_____

1. /___/
2. /___/
3. /___/

specify 1st and 2nd choice by order of importance

go to unit 20 "Final Questions"

15.11 If NO, why ?

1 = I was not invited
2 =There was no transport
3 = I couldn't access transport
4 = I had difficulty to access the venue (stairs, no chairs…)
5 = I am too ashamed to participate
6 = the ceremony was boring
7 = Because it disappoints me
8 = nobody would take me
9 = other, specify_____

1. /___/
2. /___/
3. /___/

specify 1st and 2nd choice by order of importance

go to unit 20 "Final Questions"

16 Self Perception *(Units 16 to 19 for Women only)*

16.1 Which of the following qualifies you best? (3 answers required, Please read out the list) (classify according to what describes you best)

I = tactful *(bosilaka)*
II = independent *(khudafa)*
III = poor *(gharib)*
IV = normal *(normal/hechis)*
V = distrusting *(beetamat)*
VI = unworthy *(haquir)*
VII = hopeful *(umeedwar)*
VIII = excluded *(mahrumiat)*
IX = strong *(tawanmand)*
X = weak *(zafijsui)*

1. /___/
2. /___/
3. /___/

specify choices
by order of importance

16.2 What do you think your situation will be like in 5 years? (read out the answers)

1 = the same as today----------> **go to unit 17**
2 = better than today ----------> **go to Q. 16.3**
3 = worse than today ----------> **go to Q. 16.4**

/___/
specify choice

16.3 In what way will your situation be better ? (2 answers possible)

1 = I will earn more money
2 = I will own property (land, house, livestock…)
3 = I will be married
4 = I will benefit from better health services
5 = I/my children will benefit from better education
6 = I will benefit from better security ---> **go to unit 17**
7 = I will benefit from better economic situation
8 = I will get better help from the international community
9 = other, specify_____

1. /___/
2. /___/

specify choices
by order of importance

16.4 In what way will your situation be worse ? (2 answers possible)

1 = I will earn less money/be indebted
2 = I don't know if I will still be alive
3 = I will be alone
4 = I will be in worse health
5 = I /my children will not be educated
6 = insecurity/violence will resume
7 = the economic situation will worsen
8 = other, specify_____

1. /___/
2. /___/

specify choices
by order of importance

17 Awareness *(Women Only)*

17.1 What organisation do you feel does something useful for you ?

1 = none
2 = the government
3 = international NGOs, specify_____
4 = national NGOs, specify_____
5 = organisation of persons with disability
6 = United Nations agency
7 = people from other countries
8 = other, specify_____

1. /___/
2. /___/

specify choices
by order of importance

17.2 Do you think Mayubin should have the same rights as other Afghans ?

1 = YES 2 = NO---->**go to Q. 17.4** 3 = Depends on which rights

/___/
specify choice

17.3 Which rights do you think should be the same? (read the statements)

I	= right to vote	1 = YES	2 = NO	I. /___/
II	= right to education	1 = YES	2 = NO	II. /___/
III	= right to good health	1 = YES	2 = NO	III. /___/
IV	= right to work	1 = YES	2 = NO	IV. /___/
V	= right to express oneself/say what he/she wants	1 = YES	2 = NO	V. /___/
VI	= right to get married and have children	1 = YES	2 = NO	VI. /___/
VII	= right to move around freely	1 = YES	2 = NO	VII. /___/
VIII	= the right to inheritance	1 = YES	2 = NO	VIII. /___/

specify choice

17.4 Do you think that Malulin should have the same rights as other Afghans ?

1 =YES 2 = NO---->**go to Q. 17.6** 3 = Depends on which rights

/___/
specify choice

17.5 Which rights do you think should be the same?

I	= right to vote	1 = YES	2 = NO	I. /___/
II	= right to education	1 = YES	2 = NO	II. /___/
III	= right to good health	1 = YES	2 = NO	III. /___/
IV	= right to work	1 = YES	2 = NO	IV. /___/
V	= right to express oneself/say what he/she wants	1 = YES	2 = NO	V. /___/
VI	= right to get married and have children	1 = YES	2 = NO	VI. /___/
VII	= right to move around freely	1 = YES	2 = NO	VII. /___/
VIII	= the right to inheritance	1 = YES	2 = NO	VIII. /___/

specify choice

17.6 Do you think that by law Dewana/Lewanae should have the same rights as other Afghans ?

1 =YES 2 = NO----> **go to unit 18** 3 = Depends on which rights /___/

17.7 Which rights do you think should be the same?

I	= right to vote	1 = YES	2 = NO	I. /___/
II	= right to education	1 = YES	2 = NO	II. /___/
III	= right to good health	1 = YES	2 = NO	III. /___/
IV	= right to work	1 = YES	2 = NO	IV. /___/
V	= right to express oneself/say what he/she wants	1 = YES	2 = NO	V. /___/
VI	= right to get married and have children	1 = YES	2 = NO	VI. /___/
VII	= right to move around freely	1 = YES	2 = NO	VII. /___/
VIII	= the right to inheritance	1 = YES	2 = NO	VIII. /___/

specify choice

18. Marriage *(Women Only)*

18.1 Concerning marriage, what are you?

1 = single
2 = married, monogamous---> **go to Q. 18.6**
3 = married, polygamous-----> **go to Q. 18.5**
4 = divorced----------> **go to Q. 18.7**
5 = widow----------> **go to Q.18.10**
6 = I am engaged --------> **go to unit 19**
7 = separated----------> **go to Q. 18.7**
8 = other, specify_____

/___/ specify choice

18.2 Why are you single ?

1 = not yet married, I still have time
2 = I didn't find anyone to marry me--> **go to Q. 18.3**
3 = the man does not have enough money
4= I am engaged --------> **go to unit 19**
5 = I prefer to be single--> **go to unit 19**
6 = it is my parents decision
7 = other, specify_____

/___/ specify choice

For all answers except 2, 4, 5, go to Q. 18.4

18.3 Why didn't you find anyone to marry you?

1 = I am disabled
2 = I am not educated
3 = I am not attractive to look at
4 = I lost my family
5 = I have bad habits/bad character
6 = other, specify_____

/___/ specify choice

18.4 What will you do now concerning marriage?

1 = I will ask a disabled person to marry me
2 = I will try and educate myself
3 = I will move to another province/region/country
4 = I will continue to look for a groom
5 = I am too disappointed, I will just give up
6 = other, specify_____

/___/ specify choice

go to unit 19

18.5 Are you your husband's first wife ?

1 =YES 2 = NO /___/ specify choice

18.6 Have you ever got separated/divorced ?

1 =YES 2 = NO-------> **go to Q. 18.10** /___/ specify choice

18.7 Who wanted this separation/divorce?

1 = I myself 2 = my husband-------> **go to Q. 18.9** /___/ specify choice
3 = family dispute 4 = both of us----------> **For both 3 and 4 go to Q. 18.10**

18.8 If you wanted the divorce, for what reason?

1 = we couldn't have children 5 = he had bad habits/bad character /___/ specify choice
2 = he had bad character 6 = he was not educated
3 = he did not look after me 7 = my family didn't like him
4 = he did not work enough, was lazy 8 = other, specify_____

For all answers go to Q.18.10

18.9 If it was your husband who wanted the separation/divorce, for what reason?

1 = we couldn't have children 5 = I was disabled
2 = I had bad character 6 = his family didn't like me /___/ specify choice
3 = I was not educated enough 7 = other, specify_____
4 = he thought that I did not look after him

18.10 At what age did you (first) get married ?

specify the age /___/ specify age

18.11 Who chose your (first) husband ?

1 = parents 4 = neighbours/community members 7 = other, specify_____ /___/ specify choice
2 = relatives 5 = myself
3 = friends 6 = jirga (dispute settlement)

19 Social Participation *(Women Only)*

19.1 Who takes care of you ? (2 answers possible) (classify according to preference)

1 = mother 8 = mollah
2 = father 9 = other leader of community 1. /___/
3 = sister/brother 10 = other member of community, specify_____ 2. /___/
4 = spouse 11 = no one --------> **go to Q. 19.2** specify 1st and 2nd choice
5 = your children 12 = I myself--------> **go to Q. 19.2** by order of importance
6 = in laws 13 = other, specify_____
7 = other member of family, specify_____

For answers other than 11 and 12 go to Q.19.3

19.2 If no one takes care of you, Why ? (2 answers possible) (classify according to the order given by the interviewee)

1 = nobody has the time 5 = I live alone because I lost my family 1. /___/
2 = nobody loves me 6 = I live with another family 2. /___/
3 = it is difficult 7 = I take drug/alcohol specify 1st and 2nd choice
4 = it is a permanent constraint 8 = because I don't need it by order of importance

19.3 Has anyone ever ill-treated you, inside the house?

1 =YES 2 = NO ----------> **go to Q. 19.7** /___/ specify choice

19.4 If YES, Who was/is it ? (2 answers possible) (classify according to the order given by the interviewee)

1 = husband 5 = mother/sister-in-law 8 = younger family members 1. /___/
2 = mother 6 = other-in-laws 9 = co-wives 2. /___/
3 = father 7 = spouses of brother/sister 10 = other, specify_____ specify 1st and 2nd choice
4 = sister or brother by order of importance

19.5 How did/do they ill-treat you?

1 = bad language/abuses
2 = they laugh at me
3 = they push me
4 = they hit me
5 = other, specify_____

1. /___/
2. /___/

specify 1st and 2nd choice by order of importance

19.6 What do (did) you do to prevent or avoid this ill-treatment ?

1 = nothing, I don't know what to do
2 = nothing, I am afraid of being abused more
3 = I abuse too/abuse back
4 = I keep quiet all the time
5 = I try to stay away from the person
6 = I complain to another member of family, specify_____
7 = other, specify_____

/___/ specify choice

19.7 Has anyone ever ill-treated you outside, in the street, the bazar... ?

1 =YES
2 = NO ----------> **go to Q. 19.11**

/___/ specify choice

19.8 If YES, who was/is it ? (2 answers possible)

1 = men outside
2 = women outside
3 = government persons/police…
4 = children in the street
5 = gunmen
6 = people in public places
7 = people in school/university
8 = people in workplace
9 = other, specify_____

1. /___/
2. /___/

specify 1st and 2nd choice by order of importance

19.9 How did/do they ill-treat you?

1 = bad language
2 = they peer/stare
3 = they push me
4 = they throw stones
5 = they laugh at me
6 = they hit me
7 = other, specify_____

1. /___/
2. /___/

specify 1st and 2nd choice by order of importance

19.10 What do (did) you do to prevent or avoid this ill-treatment ?

1 = nothing, I don't know what to do
2 = nothing, I am afraid of being abused more
3 = I abuse too/abuse back
4 = I try and talk to an important person of the community
5 = I try to stay away
6 = I complained to someone
7 = other, specify_____

/___/ specify choice

19.11 Are you ever left alone?

1 =YES
2 = NO ----------> **go to Q. 19.13**

/___/ specify choice

19.12 At what time of the day are you left alone ?

1 = when I wake up
2 = during the morning till noon
3 = during lunch
4 = in the afternoon
5 = during dinner
6 = during night
7 = all the time
8 = other, specify_____

/___/ specify choice

19.13 Did you take part in any ceremony during the past years?

1 =YES
2 = NO ----------> **go to Q. 19.15**

/___/ specify choice

19.14 If YES, which of the following ceremonies did you take part in ?

1 = birth ceremony
2 = *Nam Guzari*
3 = *Arusi/Wadah*
4 = *Marg/Marina*
5 = village ceremonies
6 = *Eid Ramazan*
7 = *Eid Qurban*
8 = *Nazr/Khairat*
9 = *Khatme Quraan*
10 = official days
11 = circumcision
12 = new year
13 = engagement
14 = birthday
15 = other, specify_____

1. /___/
2. /___/
3. /___/

specify 1st and 2nd choice by order of importance

go to unit 20 "Final Questions"

19.15 If NO, why ?

1 = I was not invited
2 = there was no transport
3 = I couldn't access transport
4 = I had difficulty to access the venue (stairs, no chairs…)
5 = I am too ashamed to participate
6 = the ceremony was boring
7 = because it disappoints me
8 = nobody would take me
9 = other, specify_____

1. /___/
2. /___/
3. /___/

specify 1st and 2nd choice by order of importance

20. Final Questions *(For men and Women)*

20.1 How often does your household get enough to eat?

1 = always enough
2 = sometimes not enough
3 = frequently not enough
4 = always not enough
5 = always enough but with poor quality

/___/
specify choice

20.2 Who do you feel loves you ? (2 answers possible) (classify according to preference)

1 = mother
2 = father
3 = sister/brother
4 = spouse
5 = your children
6 = in-laws
7 = other member of family, specify_____
8 = mollah
9 = other leader of community
10 = other member of community, specify_____
11 = no one --------> **go to Q. 20.3**
12 = other, specify_____

1. /___/
2. /___/
specify 1st and 2nd choice by order of importance

For all answers except 11, go to Q. 20.4.

20.3 If no one loves you, why ? (2 answers possible) (classify according to the order given by the interviewee)

1 = because of my disability
2 = because I am jobless
3 = because I take drugs/alcohol
4 = because I am poor
5 = because I am illiterate
6 = because I am bad tempered
7 = other, specify_____

1. /___/
2. /___/
specify 1st and 2nd choice by order of importance

N.B.: ***For persons who do not have difficulties according to our screening questions the interview ends here, for those who have difficulties ask the next questions.***

20.4 Do you consider yourself to be disabled ?

1 =YES
2 = NO
88 = don't know
99 = no response

/___/
specify choice

20.5 What are the causes of your difficulty(ies) ? (2 possible answers)

1 = from birth or during the first year, (genetic, illness or accident at birth:_____)
2 = landmine or unexploded ordnance
3 = other war injury: bullet, grenade, bomb, booby trap…
4 = work accident, specify_____
5 = home accident, specify_____
6 = road accident, specify_____
7 = disease, specify_____
8 = victim of ill-treatment, if possible specify by whom_____
9 = victim of crime or violence other than ill-treatment, specify_____
_____
10 = my mother's health during pregnancy was bad
11 = my mother did not have good/enough blood
12 = it is my destiny
13 = it is a curse of god/djins/black magic
14 = after a tragic personal event, specify _____
15 = other, specify_____

1. /___/
2. /___/
specify choice

20.6 At what age did your difficulty start?

specify age

/___/___/
specify age

3 Livelihoods (Household File & Screening Questions same as Adults)

3.1 Where is the main source of drinking water located?

1 = within the compound/house ---------> **go to Q. 3.3** /___/

2 = outside the compound/house

specify your choice

3.2 If it is outside the compound, how long does it take to fetch drinking water? (time per return trip)

specify time per return trip (in minutes) /___/___/___/

888 = don't know **999= no response**

specify time

3.3 What are the main sources of drinking water for your household ? (multiple answers possible)

N.B.: ***The order of importance is determined by the number of times you go for water to each source. Need to prompt for a second source***

Piped Water

1 = piped into residence/compound/plot 1. /___/

2 = public tap 2. /___/

Ground water 3. /___/

3 = hand pump in residence/coumpound/ plot

specify choices

4 = public hand-pump

by order of importance

Well water

5 = well in residence/compound/ plot

6 = covered well

7 = open well and kariz

Surface water

8 = spring

9 = river/ stream

10 = pond / lake

11 = still water: dam

12 = rain water

13 = tanker/ truck

14 = other, specify_____

3.4 What is the main source of lighting for your household ?

1 = main power

2 = generator/battery/invertor

3 = kerosene/petrol

4 = candles

5 = other, specify_____

6 = no source of light

1. /___/
2. /___/
3. /___/

specify choice

3.5 What is mainly used in your household for cooking ?

1 = gas

2 = stove with kerosene/petrol/gas

3 = firewood

4 = dung

5 = charcoal

6 = electricity

7 = other, specify_____

1. /___/
2. /___/
3. /___/

specify choice

3.6 What kind of toilet facility does your household have ?

1 = private flush inside

2 = private flush outside

3 = shared flush

4 = traditional pit

5 = open backed

6 = open defecation field outside the house

7 = other, specify_____

/___/

specify choice

3.7 How many rooms are there in your household ?

specify number of rooms /___/___/___/

888 = don't know **999 = no response**

specify number

N.B.: Specify all rooms, kitchen and bathroom included

3.8 Where does your household get the majority of your food? (over the last 3 months)

1 = market/bazar
2 = self provided/farm
3 = combination of market, farm
4 = food-aid
5 = from family, other relatives
6 = other, specify_____

/___/
specify choice

3.9 Does any member of your household own any of the following ? (read the statements to the interviewee)

I = radio, tape recorder	1 = YES	2 = NO	I. /___/
II = television	1 = YES	2 = NO	II. /___/
III = pressure cooker	1 = YES	2 = NO	III. /___/
IV = oven, hotplate	1 = YES	2 = NO	IV. /___/
V = refrigerator	1 = YES	2 = NO	V. /___/
VI = bukhari	1 = YES	2 = NO	VI. /___/
VII = bicycle	1 = YES	2 = NO	VII. /___/
VIII = motorbike	1 = YES	2 = NO	VIII. /___/
IX = car	1 = YES	2 = NO	IX. /___/
X = tractor	1 = YES	2 = NO	X. /___/
XI = generator	1 = YES	2 = NO	XI. /___/
XII = kerosene lamp	1 = YES	2 = NO	XII. /___/
XIII = sewing machine	1 = YES	2 = NO	XIII. /___/
XIV = house or apartment	1 = YES	2 = NO	XIV. /___/

specify choices
by order of importance

3.10 Does any member of your household own any animals ?

1 =YES 2 = NO ----------> **go to Q. 3.12**

/___/
specify the choice

3.11 Which ones ? (read out the statements to the interviewee)

I = sheep
II = cows
III = goats
IV = horses
V = donkeys
VI = birds
VII = roosters
VIII = camels

I. /___/
II. /___/
III. /___/
IV. /___/
V. /___/
VI. /___/
VII. /___/
VIII. /___/
specify number

N.B.: Enter the number of animals of each kind, if none, enter 00

3.12 Does any member of your household own land ?

1 =YES 2 = NO ----------> **go to unit 4**

/___/
specify choice

3.13 If YES, how much land is owned by the household members ?

jerib: /___/___/___/ **biswa:** /___/___/___/
specify area

specify size of land

00 = no land **888 = don't know** **999= no response**

3.14 How much of this land is cultivable ?

specify size of land **jerib:** /___/___/___/ **biswa:** /___/___/___/

888 = don't know **999 = no response**
specify area

3.15 Does your child personally own any part of this land ?

1 =YES 2 = NO

/___/
specify choice

4 Health

N.B. : If the child is older than 12 years of age and is able to answer the questions 4.1 to 4.6 him/herself if possible. If not, answers should be given by the caregiver in the presence of the child

4.1 Is your child able to do the following ? (read out the statements)

N.B.: Ask this question if the child is over 8

I	= bathing/ablutions	1 =YES	2 = NO	3=YES, with difficulty	I. /___/
II	= getting dressed	1 =YES	2 = NO	3=YES, with difficulty	II. /___/
III	= preparing meals for yourself	1 =YES	2 = NO	3=YES, with difficulty	III. /___/
IV	= going to the toilet	1 =YES	2 = NO	3=YES, with difficulty	IV. /___/
V	= eating/drinking	1 =YES	2 = NO	3=YES, with difficulty	V. /___/
VI	= moving around	1 =YES	2 = NO	3=YES, with difficulty	VI. /___/

For boys go to Q.4.3. For girls ask all the questions

specify choices

4.2 Is your child able to do the following inside the house/compound ? (read out the statements)

N.B.: Ask this question if the child is a girl

I	= sweeping, cleaning the house	1 =YES	2 = NO	3=YES, with difficulty	I. /___/
II	= helping to cook meals for everyone	1 =YES	2 = NO	3=YES, with difficulty	II. /___/
III	= helping to wash dishes	1 =YES	2 = NO	3=YES, with difficulty	III. /___/
IV	= helping to look after younger children	1 =YES	2 = NO	3=YES, with difficulty	IV. /___/
V	= helping to look after elder members	1 =YES	2 = NO	3=YES, with difficulty	V. /___/
VI	= helping to do the laundry	1 =YES	2 = NO	3=YES, with difficulty	VI. /___/

specify choices

4.3 What is he/she able to do outside the house/compound ? (read out the statements)

N.B.: Ask this question if the child is over 8

I	= climbing stairs	1 =YES	2 = NO	3=YES, with difficulty	I. /___/
II	= going to the bazar/shop	1 =YES	2 = NO	3=YES, with difficulty	II. /___/
III	= carrying water	1 =YES	2 = NO	3=YES, with difficulty	III. /___/
IV	= working in the field	1 =YES	2 = NO	3=YES, with difficulty	IV. /___/
V	= riding a bicycle/or animal	1 =YES	2 = NO	3=YES, with difficulty	V. /___/

specify choices

4.4 Does your child have the following difficulties? (read out the statements)

I	= expressing what he/she needs	1 =YES	2 = NO	I. /___/
II	= being with people he/she doesn't know	1 =YES	2 = NO	II. /___/
III	= keeping still, staying in one place	1 =YES	2 = NO	III. /___/
IV	= feeling very sad/cry without a specific reason	1 =YES	2 = NO	IV. /___/
V	= going out of the house because it scares him/her	1 =YES	2 = NO	V. /___/
VI	= going out of the house because everyone looks	1 =YES	2 = NO	VI. /___/
VII	= having repetitive, body movements	1 =YES	2 = NO	VII. /___/

specify choices

4.5 In the past 6 months has your child experienced the following? (read out the statements)

I = fits/epilepsy	1 = YES	2 = NO	I. /___/
II = physically violent behaviour towards other person	1 = YES	2 = NO	II. /___/
III = verbally violent behaviour towards other person	1 = YES	2 = NO	III. /___/
IV = violent behaviour regarding him/herself	1 = YES	2 = NO	IV. /___/
V = fainting or passing out	1 = YES	2 = NO	V. /___/
VI = screaming/yelling	1 = YES	2 = NO	VI. /___/

specify choices

4.6 In general does your child have difficulties to… (read out the statements)

I = remember things	1 = YES	2 = NO	I. /___/
II = talk to others	1 = YES	2 = NO	II. /___/
III = understand what people say	1 = YES	2 = NO	III. /___/
IV = make him/herself understood	1 = YES	2 = NO	IV. /___/
V = hear someone clearly calling in the house	1 = YES	2 = NO	V. /___/
VI = see someone clearly in front of him/her	1 = YES	2 = NO	VI. /___/

specify choices

N.B.: Ask Questions 4.7 to 4.11 to the caregiver directly

4.7 What kind of cures/services are available for your child ? (multiple answers possible)

1 = health centre
2 = hospital
3 = physiotherapic and/or orthopedic centre
4 = private clinic/ doctor
5 = pharmacy/chemist
6 = other, specify_____

1. /___/
2. /___/

specify choices
by order of importance

4.8 What kind of cures/services would be more useful for your child ?

1 = health centre
2 = hospital
3 = physiotherapic and/or orthopedic centre
4 = private clinic/ doctor
5 = pharmacy/chemist
6 = other, specify_____

1. /___/
2. /___/

specify choices
by order of importance

4.9 How do you get to the closest available health care facility?

1 = by foot
2 = by motorised vehicle (car, tractor…)
3 = by bicycle
4 = on an animal (donkey…)
5 = other, specify_____

1. /___/
2. /___/

specify choices
by order of importance

4.10 How long does it take to get to the closest available health care facility?

specify the number of minutes

(in case of no answer 999, 0 times is 0)

/__/___/___/___/

specifiy number of minutes

4.11 During the past one year, how many times have you used health facilities for your child ?

specify the number of times

(in case of no answer 999, 0 times is 0)

/__/___/___/___/

specifiy number

4.12 Have you tried any traditional or religious cures for your child's problem during the last year?

1 = YES 2 = NO--------> **go to Q.4.15**

/___/

Specify choice

4.13 If Yes, what kind of cure did you try?

1 = bonesetter
2 = tabi unani
3 = mollah
4 = other spiritual leader/old woman
5 = pilgrimage/prayer
6 = traditional healer/doctor/witch doctor
7 = other, specify_____

1. /___/
2. /___/

specify choices
by order of importance

4.14 During the past one year, how many times have you tried the traditional cures, you mentioned for your child ?

specify the number of times /__ /___/___/

(in case of no answer 999, 0 times is 0) specifiy number

4.15 What types of cures have you tried for your child during the past one year? (traditional and modern cures)

How much did you pay for these ? **What kind of difficulty did you face ?**

col.1 Indicate the Type of Service

1 = health centre
2 = hospital
3 = physiotherapic and/or orthopedic centre
4 = private clinic/ doctor
5 = pharmacy/chemist
6 = bonesetter
7 = tabi unani
8 = mollah
9 = other spiritual leader/old woman
10 = pilgrimage/prayer
11 = traditional healer/doctor/witch doctor
12 = other, specify_____

col. 2 **In which month did you last go for treatment during last year (Indicate the number of the month)**

col. 3 / col. 5 / col. 7 Type of Expense(s)

1 = fees, donation
2 = medication (modern or traditional)
3 = medical tests
4 = food
5 = transportation
6 = amulates (taweez) other rituals
7 = care taker
8 = equipment (crutches, devices…)
9 = other, specify_____

col. 4, 6, 8 / col. 9 Total Cost **Cost of the service**

col. 10 What kind of Difficulties Faced ? (3 answers are possible)

Financial difficulties

1 = my child was refused because I had no money (or not enough)
2 = I had difficulty to get the food for myself during my stay
3 = I didn't have money for fees/donation
4 = I didn't have money for medication /amulates/ objects
5 = I had to go into debt

Transport, access difficulties

6 = there was no available transportation/it's very far away
7 = I had difficulty to find the money for transportation
8 = I didn't find anybody to go with me because nobody had time to take me
9 = I didn't ask anyone because I felt that it was a waste of time
10 = I didn't find anybody to go with me because nobody thought it was important

Difficulties at the hospital

11 = there was no available medication
12 = there was no doctor to take care of me
13 = my child was refused because I am disabled
14 = attitude of the medical staff was very negative
15 = the equipment that they gave my child is not very useful (heavy, difficult to use…)
16 = there is no female professional
17 = no difficulty
18 = other, specify_____

(in case of multiple answers, please state by order of importance)

1	2	3	4	5	6	7	8	9	10
Type of health service used	**Month of use/ visit**	**What was the first type of expense?**	**What was the cost of the 1st expense? (in Afghanis)**	**What was the second type of expense?**	**What was the cost of the second expense? (in Afghanis)**	**What was the third type of expense?**	**What was the cost of the 3rd expense? (in Afghanis)**	**What was the total cost per visit? (in Afghanis 4+6+8)**	**What difficulties were faced? (by order of importance)**
/___/	/___/	/___/	/__//__//__//__/	/___/	/__//__//__//__/	/___/	/__//__//__//__//__/	/__//__//__//__//__/	/___//___//___/
/___/	/___/	/___/	/__//__//__//__/	/___/	/__//__//__//__/	/___/	/__//__//__//__//__/	/__//__//__//__//__/	/___//___//___/
/___/	/___/	/___/	/__//__//__//__/	/___/	/__//__//__//__/	/___/	/__//__//__//__//__/	/__//__//__//__//__/	/___//___//___/
/___/	/___/	/___/	/__//__//__//__/	/___/	/__//__//__//__/	/___/	/__//__//__//__//__/	/__//__//__//__//__/	/___//___//___/
/___/	/___/	/___/	/__//__//__//__/	/___/	/__//__//__//__/	/___/	/__//__//__//__//__/	/__//__//__//__//__/	/___//___//___/
/___/	/___/	/___/	/__//__//__//__/	/___/	/__//__//__//__/	/___/	/__//__//__//__//__/	/__//__//__//__//__/	/___//___//___/
N.B.: The supervisor will calculate the total cost of health expenses						/___//___//___//___//___//___//___//___//___/			**(in Afghanis)**

5 Education

5.1 Does your child know how to read and write (for instance a little note) ?

1 =YES 2 = NO /___/

specify choice

My name is (specify). I am from (specify the village or town). I am (X) years old.

_____

_____

_____

N.B. : For children above 8. Code again in the box below 1=YES if the interviewee could write the entire text, and 2=NO if he/she could not write the entire text

/___/

specify choice

5.2 What kind of education did your child receive/is your child receiving ? (2 answers possible)

1 = government school 3 = training centre 5 = in the family

2 = private school 4 = religious school (Madrasa) 6 = no education /___/___/

For answer 2 <u>go to Q. 5.4</u>

specify choice

5.3 Why did your child receive no formal education ?

1 = being disabled, he/she was refused 8 = too much work in the house/field /___/

2 = absence of school 9 = useless for girls

specify choice

3 = lack of money 10 = family does not allow girls to be educated

5 = need to work 11 = no school for girls in the village

6 = education not very useful 12 = he/she is too young to go to school

7 = doesn't like school 13 = because of the political situation

----------><u>go to Q.5.10</u> 14 = because quality of school is not good.

5.4 Which class is your child in?

1 = class 1 4 = class 4 7 = class 7 /___/

2 = class 2 5 = class 5 8 = class 8

specify choice

3 = class 3 6 = class 6

5.5 Did you have to interrupt or stop your child's studies ?

/___/

1 =YES 2 = NO----------><u>go to Q. 5.8</u>

specify choice

5.6 From which year to which year ?

from /___/___/___/___/ to /___/___/

specify year specify year

N.B. :If studies were stopped for a few months put the same year in the boxes

5.7 For what reason ?

<u>Political reasons</u>

/___/

specify choice

1 = because of the political regime

2 = because the school was destroyed

3 = because the school was shut down

<u>Reasons linked to the school</u>

4 = because teachers were not paid and did not teach

5 = because he/she was not well treated by the teachers

6 = because he/she was ill-treated by other children

7 = because he/she was rejected by parents of other children

8 = because he/she was disabled, he/she was refused in school although he/she could continue

9 = because he/she was disabled and school was too difficult

<u>Family, personal reasons</u>

10 = because he/she helps to look after the family

11 = because of illness

12 = because too much work at home

13 = because there was no money to pay for his/her education

14 = because there was nobody to take him/her to school

15 = because he/she had to work to get money

16 = other, specify_____

5.8 At what age did you stop your child's education?

specify age /___/___/

specify age

N.B. : Code 77 if the interviewee is still going to school

5.9 Why did you stop your child's education? (2 answers possible)

1 = school was shut down
2 = lack of financial means of the family
3 = didn't have the right to go to school
4 = death or inactivity of earning member
5 = switched to apprenticeship
6 = I was satisfied with the level he/she reached
7 = failed at school
8 = didn't like school
9 = found a paid job
10 = didn't learn anything
11 = because he/she became disabled, he/she was refused by the school
12 = because there was to much work at home/in the field
13 = because of war and bad political situation
14 = other, specify_____

1. /___/
2. /___/

specify choice

5.10 Would you like your child to go(back) to school ?

1 =YES 2 = NO---------->**go to Q. 5.12** /___/

specify choice

5.11 If YES, what prevented or prevents you from sending him/her to school ?

1 = he/she has to work and help the family
2 = no one can take him/her to school
3 = there is no money for school at home
4 = there was too much work at home/in the field
5 = there is no school closeby
6 = school is not of good quality
7 = no one can help him/her in the school
8 = the school did not accept him/her
9 = there are no female teachers in the school
10 = other, specify_____

1. /___/
2. /___/

specify choice

5.12 Do you think education is useful ?

1 = YES 2 = NO---------->**go to Q. 5.14** /___/

specify choice

5.13 If YES, for what reason ? (2 answers possible)

1 = because it is useful for everyday life
2 = because it improves the prospects for finding a job
3 = because it helps you find a better paid job
4 = because I liked school myself
5 = because it helps you to have a better position in society
6 = because it makes you independent
7 = because it helps you to be someone
8 = because it improves his/her chances of getting married later
9 = other, specify_____

1. /___/
2. /___/

specify choice

-------->**go to unit 6**

5.14 If NO, for what reason ? (2 answers possible)

1 = because it is not useful for everyday life
2 = because it does not improve prospects for finding a job
3 = because it does not help you find a better paid job
4 = because school is boring
5 = because I am happy with the level my child has completed
6 = because my child was ill-treated by the teachers
7 = because my child was ill-treated by other children
8 = other, specify_____

1. /___/
2. /___/

specify choice

6 Activity and Inactivity

N.B. : If the person with difficulty is older than 12 years of age and is able to answer the questionnaire him/herself ask questions to him/her directly. If not, answers should be given by the caregiver in the presence of the interviewee

6.1 Does your child help you in the house ?

1 =YES
2 = NO----------> **go to Q 6.4.**

/___/
specify choice

6.2 How many hours per day does your child spend on household tasks ?

specify number of hours

/___/___/
specify number

6.3 Which tasks does your child mainly do? (in case of multiple answers, please state according to the time spent)

1 = cooking
2 = cleaning
3 = fetching water
4 = taking care of other members of the family including children
5 = laundry
6 = groceries/everyday shopping
7 = other, specify _____

1. /___/
2. /___/
3. /___/
4. /___/
5. /___/
6. /___/

specify choices

N.B.: You ask the interviewee to evaluate the most time consuming

by order of importance

6.4 Does your child help you in the field ? (ask only in rural areas)

1 =YES
2 = NO----------> **go to Q 6.8**

/___/
specify choice

6.5 How many hours per day does your child spend on fieldwork during the season of work ?

specify number of hours

/___/___/
specify number

6.6 How many months per year does your child mainly work in the field?

specify number of months

/___/___/
specify number

6.7 What work does your child mainly do in the field? (in case of multiple answers, please state according to the time spent)

1 = work the soil, harvest
2 = look after the animals
3 = fetch and carry things
4 = guarding the products
5 = other, specify _____

1. /___/
2. /___/
3. /___/
4. /___/
5. /___/

specify choices

N.B.: You ask the interviewee to evaluate the most time consuming

by order of importance

6.8 Does your child do any work outside the house and fieldwork ?

1 =YES
2 = NO----------> **go to Q. 6.11**

/___/
specify choice

6.9 How many hours per day does your child spend on work outside the house ?

specify number of hours /___/___/

specify number

6.10 What work does your child mainly do outside the house? (in case of multiple answers, please state according to the time spent)

1 = begging
2 = odd jobs (rag-picking, bottle collecting...)
3 = helps someone we know in his/her work
4 = employed in a fixed job
5 = employed in occasional work
6 = independent small job (shoe polish, newspaper vendor…)
7 = other, specify _____

1. /___/
2. /___/
3. /___/
4. /___/
5. /___/
6. /___/

specify choices

by order of importance

N.B.: You ask the interviewee to evaluate the most time consuming

6.11 What is your child's contribution to the running of the house ?

1 = essential, without it we could not survive
2 = quite important
3 = allows us to buy a few extra things
4 = not very important
5 = no contribution
6 = other, specify _____

/___/

specify choice

6.12 Do you think that your child can help the family more ?

/___/

specify choice

1 = YES
2 = NO----------> **go to Q. 6.14**

6.13 Why do you think that ? (in case of multiple answers, please state by order of importance)

1 = because he/she has a lot of free time
2 = because he/she is very lazy
3 = because my child is very smart
4 = because we need more money
5 = because he/she says he/she wants to work more
6 = because his/her employer says that he/she can work more
7 = because there are a lot of jobs he/she can do
8 = other, specify_____

1. /___/
2. /___/
3. /___/

specify choice

by order of importance

6.14 What is your child's monthly income ?

amount of income in Afghanis for a month /___/___/___/___/___/___/___/

specify amount in Afghanis

N.B. : If the person with difficulties is older than 12 years of age and is able to answer then questions must be asked directly to him/her. If not, answers should be given by the caregiver <u>in the presence of the interviewee</u>

7 FUTURE PROSPECTS

7.1 What do you think your child's situation will be like in 5 years ?

1 = the same as today----------> **<u>go to unit 8</u>**
2 = better than today ----------> **<u>go to Q. 7.2</u>**
3 = worse than today ----------> **<u>go to Q. 7.3</u>**

/___/
specify choice

7.2 In what way will your child's situation be better ? (2 answers possible)

1 = because he/she will earn money
2 = because he/she will own property (land, house, livestock…)
3 = because he/she will be married
4 = because he/she will benefit from better health services
5 = because he/she will benefit from better education
6 = because he/she will benefit from better security
7 = because he/she will have a good job
8 = other, specify_____

------- > **<u>go to unit 8</u>**

1. /___/
2. /___/
specify choices
by order of importance

7.3 In what way will your child's situation be worse ? (2 answers possible)

1 = because he/she will earn less money/be indebted
2 = I don't know if he/she will still be alive
3 = because he/she will be alone
4 = because he/she will be in worse health
5 = because he/she will not be educated
6 = because insecurity/violence will resume
7 = because the economic situation will worsen
8 = other, specify_____

1. /___/
2. /___/
specify choices
by order of importance

8 SOCIAL PARTICIPATION

8.1 Who takes care of your child besides yourself ? (2 answers possible) (classify according to preference)

1 = mother
2 = father
3 = sister/brother
4 = he/she herself or himself
5 = other children
6 = other member of the family, specify_____
7 = mollah
8 = other leader of the community
9 = other member of the community, specify_____
10 = no one --------> **<u>go to Q. 8.2</u>**
11 = other, specify_____

1. /___/
2. /___/
specify 1st and 2nd choice
by order of importance

Persons who answer anything except 11 <u>go to Q.8.3</u>

8.2 If no one helps take care of your child, why ? (2 answers possible) (classify according to the order given by the interviewee)

1 = nobody has the time
2 = nobody loves him/her
3 = it is difficult
4 = I live alone with my child
5 = I and my child live with another family
6 = my child is very violent
7 = because I lost my family
8 = other, specify_____

1. /___/
2. /___/
specify 1st and 2nd choice
by order of importance

8.3 Has anyone ever ill-treated your child ?

1 =YES 2 = NO ----------> **go to Q. 8.7** /___/

specify choice

8.4 If YES, who was/is it ? (2 answers possible) (classify according to the order given by the interviewee)

1 = member of family, specify_____
2 = children in the street
3 = adults in the street
4 = people in public places
5 = government persons
6 = other, specify_____

1. /___/
2. /___/

specify 1st and 2nd choice by order of importance

8.5 How did/do they ill-treat your child?

1 = bad language 5 = they laugh
2 = they peer/stare 6 = they hit
3 = they push him/her 7 = other, specify_____
4 = they throw stones

1. /___/
2. /___/

specify 1st and 2nd choice by order of importance

8.6 What did/do you do to prevent or avoid this ill-treatment ?

1 = nothing, I don't know what to do
2 = nothing, I am afraid they would abuse even more
3 = I abuse too/abuse back
4 = I try and talk to an important person of the community
5 = I try to stay away and keep my child away also
6 = I try and talk to the person (or the parents) who ill-treats my child
7 = other, specify_____

/___/

specify choice

8.7 Did you and your child take part in any ceremony during the past year ?

1 =YES 2 = NO ----------> **go to Q. 8.9** /___/

specify choice

8.8 If YES, which of the following ceremonies did your child take part in ?

1 = birth ceremony 5 = village ceremonies 9 = Khatme Quraan
2 = Nam Guzari 6 = Eid Ramazan 10 = other, specify_____
3 = Arusi/Wadah 7 = Eid Qurban
4 = Marg/Marina 8 = Nazr/Khairat **go to unit 9**

1. /___/
2. /___/
3. /___/

specify 1st and 2nd choice by order of importance

8.9 If NO, why ?

1 = he/she was not invited
2 = there was no transport
3 = my child couldn't access transport
4 = my child had difficulty to access the venue (stairs, no chairs…)
5 = I am too ashamed to participate with my child
6 = everyone looks at us when we go
7 = because people's attitudes make me angry
8 = other, specify_____

1. /___/
2. /___/
3. /___/

specify 1st and 2nd choice by order of importance

N.B.: If the child is under 10 then go to unit 9, if the child is between 10 and 15 ask the next question.

8.10 Is your child engaged or married ?

1 =YES 2 = NO ----------> **go to unit 9** /___/

specify choice

8.11 At what age was your child married ?

specify age /___/___/

specify age

9. Final Questions

9.1 How often does your household get enough to eat ?

1 = always enough
2 = sometimes not enough
3 = frequently not enough
4 = always not enough
5 = enough but with poor quality

/___/
specify choice

9.2 Who do you think loves your child ? (2 answers possible) (classify according to preference)

1 = mother
2 = father
3 = sister/brother
4 = other children
5 = other member of family, specify_____
6 = mollah
7 = other leader of community
8 = other member of community, specify_____
9 = no one --------> **go to Q. 9.3**
10 = other, specify_____

1. /___/
2. /___/
specify 1st and 2nd choice by order of importance

Persons who answer anything but 9, go to Q. 9.4

9.3 If no one loves your child, why ? (2 answers possible) (classify according to the order given by the interviewee)

1 = because of his/her disability
2 = he/she is considered useless
3 = he/she is very strange
4 = we are poor
5 = he/she is illiterate
6 = he/she is bad tempered/violent
7 = other, specify_____

1. /___/
2. /___/
specify 1st and 2nd choice by order of importance

N.B.: For children who do not have difficulties according to our screening questions the interview ends here, for those who have difficulties ask the next questions.

9.4 Do you consider your child to be disabled ?

1 = YES
2 = NO
88 = don't know
99= no response

/___/
specify choice

9.5 What are the causes of your child's difficulty ? (2 possible answers)

1 = from birth or during the first year, (genetic, illness or accident at birth:_____)
2 = landmine or unexploded ordnance
3 = other war injury: bullet, grenade, bomb, booby trap…
4 = work accident, specify_____
5 = home accident, specify_____
6 = road accident, specify_____
7 = disease, specify_____
8 = victim of ill-treatment, if possible specify by whom_____
9 = victim of crime or violence other than ill-treatment, specify_____
_____
10 = mother's health during pregnancy was bad
11 = mother did not have good/enough blood
12 = it is destiny
13 = it is a curse of god/djins/black magic
14 = after a tragic personal event, specify _____
15 = other, specify_____

1. /___/
2. /___/
specify choice

9.6 At what age did your child's difficulties start?

specify age

/___/___/
specify age

The National Disability Survey in Afghanistan was carried out in 2005. It is the first such study that covered the entire territory. Based on the International Classification of Functioning, Disability and Health of the World Health Organization, and the Capabilities Approach of Amartya Sen, the NDSA aims to provide insights into the living conditions, needs and hopes of Afghans with disability and their families.

The present toolkit is an attempt to answer questions regarding ways of implementing field survey research on disability. The approach adopted is less theoretical and conceptual than practical, putting into perspective theory and definitions with the help of a field experience in Afghanistan. For this reason, the toolkit is organised in fact files, each one covering a specific dimension of the survey process: conception of the project, survey methodology, elaboration of tools, training of teams, field organisation and analysis of data.

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