



## **Model Disability Survey (MDS)**

### **SURVEY MANUAL**

**World Health Organization 2017** 

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### **PART 1: INTRODUCTION**

### **OVERVIEW**

### Introduction

The World Health Organization's Model Disability Survey (MDS) Manual is a tool to help implement the MDS in countries and to improve the quality of the interview process. This manual is intended to provide practical information about the survey instruments and their use during interviews.

### **Purpose**

This manual is to be used as a training tool for interviewers when administering the questionnaire.

### Intended audience

The manual is intended for all parties responsible for implementing the Model Disability Survey and using the resulting data. The various parties include a wide range of people from interviewers, field staff, supervisors and principal investigator(s), laboratory and data entry technicians and statisticians, to public health officials in the Ministry of Health and/or any health institutions.

# Guide to using the manual

This manual has been written in eight parts. The first three parts cover background information about the Model Disability Survey, questionnaire conventions, specific roles and responsibilities including an editing guide and advice for interviewers.

Parts four, five and six are the specific question by question (QxQ) guides of the following two MDS questionnaires:

- 1. Household (Part 4);
- 2. Individual (Part 5);
- 3. Proxy Individual (Part 6)

Each part is introduced with an overview and a short table of contents to help readers find specific topics. This also enables individual parts to be easily removed from the manual and used as in-the-field reference.

### In this module

This module contains the following topics:

Topic	See Page
ABOUT MDS	4
MDS QUESTIONNAIRE	5
PROCESS OVERVIEW	6

### **ABOUT MDS**

#### Introduction

The WHO Multi-Country Surveys team and their external consultants developed the WHO Model Disability Survey (MDS) as a data collection platform to collect comprehensive, comparable and relevant disability information of adult populations to monitor the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

### **Basis of MDS**

The motivation for the Model Disability Survey project of the World Health Organisation and the World Bank arose from the recognition, clearly enunciated in the 2012 joint Report on Disability, that there is a worldwide need to collect comprehensive, comparable and relevant disability information that countries can use with confidence. In addition, the CRPD mandates that ratifying States Parties "collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention".

The development of the Model Disability Survey is grounded in the choice to evolve beyond the traditional disability data collection strategy of defining a population of individuals who are labelled as 'disabled' in terms of the health conditions or body dysfunctions they have, and then probe the difficulties they have as a consequence. The Model Disability Survey asks people – not previously identified in terms of the health conditions – what they do, or do not do, in their daily lives. These kinds of questions concern how people actually function in

multiple domains given the environmental barriers and facilitators that constitute their real life situation.

#### **Purpose**

The purpose of the MDS is to collect data about all dimensions of disability – information about impairments, activity limitations, participation restrictions, and the environmental factors that facilitate or hinder full participation – are essential to understand how disability plays out in people's lives. It is necessary to examine the entirety of the disability experience in order to understand the impact of disability on people's lives and determine the appropriate response. In the scope of the MDS a metric of disability will be developed to allow for:

- (i) the collection of comprehensive and relevant information that helps countries construct a complete picture of disability with particular relevance to disability policy
- (ii) direct and reliable international comparisons of disability data and
- (ii) national and global monitoring of the implementation of the CRPD.

### MDS and other studies

In developing the MDS WHO carried out following steps:

- An extensive search was used to identify disability and population health surveys from countries around the world and a subset of surveys for subsequent analysis were identified.
- A qualitative content analysis of the questions of those surveys was performed by mapping them to the International Classification of Functioning Disability and Health (ICF). The information from the two first steps is available at http://disabilitysurvey.checkdesign.de/
- Quantitative analysis of altogether 10 surveys, such as Health 2000 in Finland or ENDISC-CIF in Chile, was carried out to identify questions that address the entire spectrum of disability, distinguish capacity and performance, the impact of environmental factors, and are reliable and valid.

### **Pre-testing**

A series of cognitive testing and pilot implementation exercises of the MDS questionnaire were carried out in 2013 and 2014 with over 500 respondents in four countries. Summary results and data will be available for registered users at: http://www.who.int/disabilities/data/mds/en/

### MDS QUESTIONNAIRE

### Introduction

The MDS questionnaire consists of the following three main instruments. Each instrument contains multiple modules addressing different aspects of disability and health in general populations:

- Household Questionnaire
- Individual Questionnaire
- Proxy Questionnaire

In addition, there are consent forms for informants and/or respondents.

### Household Questionnaire

The table below lists each of the modules included in the Household Questionnaire.

Module	Title
0000	COVERSHEET
0100	SAMPLING INFORMATION
0200	CONTACT RECORD
1000	HOUSEHOLD ROSTER

### Individual Questionnaire

The table below lists each of the modules included in the Individual Questionnaire.

Module	Title
0000	CONTACT RECORD
0100	ELIGIBILITY
1000	SOCIO-DEMOGRAPHIC CHARACTERISTICS
2000	WORK HISTORY AND BENEFITS
3000A	ENVIRONMENTAL FACTORS
4000	FUNCTIONING

Module	Title
5000	HEALTH CONDITION
3000B	PERSONAL ASSISTANCE, ASSISTIVE DEVICES AND FACILITATORS
6000	HEALTH CARE UTILISATION
7000	WELL-BEING
8000	EMPOWERMENT
9000	INTERVIEWER OBSERVATIONS

### Proxy Questionnaire

The table below lists each of the modules included in the Proxy Questionnaire.

Module	Title	
0000	CONTACT RECORD	
0100	ELIGIBILITY	
0110	PROXY CONSENT FORM	
1000	SOCIO-DEMOGRAPHIC CHARACTERISTICS	
2000	WORK HISTORY AND BENEFITS	
3000A	ENVIRONMENTAL FACTORS	
4000	FUNCTIONING	
5000	HEALTH CONDITION	
3000B	PERSONAL ASSISTANCE, ASSISTIVE DEVICES AND FACILITATORS	
6000	HEALTH CARE UTILISATION	
7000	WELL-BEING	
8000	EMPOWERMENT	
9000	INTERVIEWER OBSERVATIONS	

#### **Target groups**

The Household and Individual Questionnaires are to be administered to adults aged 18 years and older from different educational and cultural backgrounds. Supervisors will instruct interviewers about the type of interview to be conducted in selected households and the targeted respondent.

### Literacy

Respondents do not need to be able to read and write. However, depending on their age, maturity, and cognition, as well as the place where they come from, some questions or concepts may be more difficult to understand than others. SHOWCARD (written prompts) will be provided to respondents as a memory aid.

### Duration of interviews

An interview is expected to last on average 120 to 150 minutes but may take longer depending on respondents' comprehension and literacy levels. Respondents with language difficulties, limited education, those who are very talkative or who suffer from poor health, may take longer to complete the interview.

### **Privacy**

The preferred condition for interviewing respondents is in private, with no other member of the household present. In some situations this may be difficult. If total privacy is not possible, the respondent may have to be interviewed outside the house or where the respondent feels comfortable discussing matters which may be sensitive.

If the respondent wishes to have someone with them during the interview, these requests should be considered and noted in module 9000.

### PROCESS OVERVIEW

### Introduction

For a MDS study to be effective, the whole process needs to be properly planned and organized.

### Key stages, tasks and timeframes

The total timeframe to conduct a MDS study, from training the trainers to releasing the study data into the public domain is approximately nine to ten months.

### **PART 2: ROLES AND RESPONSIBILITIES**

### **OVERVIEW**

### Introduction

There are a number of key roles involved in a MDS study; however, this manual focuses only on the roles required for administering the survey.

### In this part

This part covers the following roles.

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### **INTERVIEWERS**

### Introduction

The interviewers are all those who have been trained to administer the MDS survey in the field.

#### **Core roles**

The core roles and responsibilities of an interviewer include:

Role	Description
1	Physically locating and approaching sampled households in specified
	areas.
2	Introducing MDS to the sampled households and getting household
	member participation and informed consent.
3	Recording household member details
4	Asking the questions in the survey, clarifying any confusion and
	answering queries respondents may have.
5	Setting the pace of the interview, keeping the respondent focused and interested and making the interview atmosphere comfortable and
	pleasant at all times.
6	Recording respondents' answers and editing completed questionnaires.
7	Checking all forms before handing to supervisor.
8	Reporting any difficulties to supervisor.

### Skills and attributes

Interviewers should have the following general skills and attributes:

- good oral and written communication skills
- friendly manner and patience
- good attention to detail
- clean and tidy appearance.

# HOUSEHOLD INFORMANT, INDIVIDUAL RESPONDENT AND PROXY RESPONDENT

### Introduction

Households are randomly selected to participate in the MDS survey. Household informants are selected by the interviewer and individual respondents are the eligible persons selected through one of the survey methods. Proxy respondents are people identified to respond on behalf of selected individual respondents whom are unable to respond for themselves.

### **Roles**

The table below lists each of the roles and their desired characteristics.

Role	Attributes
Household informant	<ul> <li>Most knowledgeable person in the household about the household members and characteristics, household's health status, transfers and financial status, including income and expenditures.</li> <li>This person will often be the main income provider, the head of the household, who can be formally defined as "the individual in the family setting who provides actual support and maintenance to one or more individuals who are related to him or her through adoption, blood, or marriage".</li> <li>The household informant may be different from the</li> </ul>
	person selected to complete the Individual Questionnaire.
Individual respondent	Household member who is above the age of 18 and who was randomly selected during the Household Questionnaire (using the Kish Table method) to complete the Individual Questionnaire.
Proxy respondent	A person who knows the respondent very well and is able to accurately answer questions about the respondent's environment, functioning, health and well-being on their behalf.

### Requirements

The principle requirement of informants, respondents, and proxy respondents is to cooperate with the interviewer and follow instructions. They should also:

- Listen to questions attentively without interrupting;
- Think through the answers before answering, and try to give an accurate and complete responses as much as possible; and,
- Ask for clarifications whenever a question seems unclear to him and ask the interviewer to repeat or rephrase it.

### Voluntary role

Respondents can refuse to answer any question and can stop the interview at any time. Interviewers should attempt to continue but not force a person to continue.

### **SUPERVISOR**

### Introduction

The supervisor is responsible for monitoring the progress and quality of the data collection, and ensuring that interviewers are performed to a high and consistent standard.

Supervisors are the interface between data collection and the principal investigators. Supervisors may also be involved in monitoring the data entry process, laboratory analyses and quality control processes in every stage of the survey work.

### Core roles

The core roles of a Supervisor include:

Role	Description
1	Recruiting and training interviewers.
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