General Measure on People with Disabilities in the European Statistical System (E.S.S.)

FIRST DRAFT REPORT in progress

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General Introduction

In the framework of its activities on Health Statistics, EUROSTAT is assuring the coordination of the efforts of the European Statistical System (E.S.S.) in relation to the Washington Group on Disability Statistics (WG).

PG/TNO-NL has supported this work until 31 August 2002 through the European Disability Measurement (EDM) Project. A new subvention for the continuation of the coordination can come into force by March 2003 at the earliest.

ISTAT-Italy had offered to bridge the gap and to carry out activities required for the preparation of WG *interim* meeting which in Ottawa, Canada (January 9 -10, 2003), organized by the Statistical Institute of Canada (STATCANADA).

The second meeting of the Washington Group will be held in Europe in recognition of the "European year of persons with disabilities (2003)". It was decided to organize an *interim* meeting in order to make progress in WG work and be able to report this to the UN Statistical Commission in March 2003.

The main issues of this meeting are:

- the question matrix on the purposes of general disability measures
- results of methodological testing of general disability measures.

As result of the first WG meeting two Matrices were developed for approaching the "Global measure" issue and the term "Comparable general disability measure" was adopted to reduce confusion about multiple meanings of the term "global".

These two matrix are: a) <u>"Conceptual Matrix"</u> that cross-classifies the purpose that a general disability measure is supposed to address (i.e., the use that the data will be put to) with a typology of question characteristics which address concepts such as ICF domain, severity, etiology and duration; b) <u>"Empirical Questions Matrix"</u> for evaluating the characteristics of the general measures currently in use according to the dimensions of the matrix.

These two matrices are intended to be tools for identifying the gaps that exist in disability measurement and for directing future work in developing internationally comparable general measures of disability.

To full contribute on the Ottawa meeting topics and to enhance the European Countries experience on statistical disability, ISTAT has focused its activities on the "Empirical Questions Matrix" and furthermore on the Minimum European Health Module (MEHM) proposed to use in all European surveys as one of the results of the "European Disability Measurement Project". The MEHM, can be considered the EU contribution to the first priority of the Washington Group (to guide development of a small set of comparable general disability measures for censuses and national surveys).

This report presents the result of the activities carried out by ISTAT, in collaboration with M. De Smedt, J. Bonte, M. de Klein, as preparatory work at the European level for the meeting in Ottawa (9-10 January 2003).

The report is composed of two parts: the first one is focused on the "Empirical Questions Matrix" and the second one is focused on "MEHM".

Part 1

"Empirical Questions Matrix"

1. Identification of surveys available

For our purpose it was decided to focus only on population-based surveys (administrative data sources were not taken into account). The fully harmonized EU-wide surveys (European Community Household Panel -ECHP, European Labour Force Survey -LFS, Survey on Income and Living Conditions -SILC) were included and analyzed using the questions given as reference instruments to the MS.

To have an overview of all surveys carried out in Europe and related to health/disability issues it was necessary to collect information by using reference documents (HIS/HES database) and sending a letter to all Member States (MS) asking them to submit questions used as general measures to identify persons with disabilities.

Hungary, an EU Candidate Country, was also included because it is represented by Eva Gardos at the Ottawa meeting.

As result was an Inventory was done (see Appendix 1) with a total of n. 86 surveys.

As reference the following documents were used:

- "EUROSTAT Disability Project: Survey data on disability" (1999)¹
- "Inventory of survey data on disability in EU member state" $(2002)^2$
- European Commission's "European Health Interviews & Health Examination Surveys" (HIS/HES) database³ (version of July and of November2002).

Because of the large number of surveys available, it was decided to adopt the following criteria to select surveys for an analysis of the General Measure Questions on disability:

- *Survey typology*: all types of survey census, health interview, health examination with a selfcompleted questionnaire component, social surveys, designated disability surveys - were included if they were carried out at national level.
- *Period of time*: from 1998 to 2002. Some exceptions were made for countries that did not have surveys in the identified period such as Greece (EL01,1991) or Luxembourg (L01, 1996) or Portugal (P01, 1995; P02, 1994). Switzerland (Ch01,1997).

Following these criteria a total of 53 surveys were selected. Details on these surveys, when available, are included in *Appendix* 2

¹ "EUROSTAT Disability Project:: Survey Data on Disability", Final Project Report (15 October 1999), prepared by: Claire Gudex, Stine Hvitved Christensen, Niels Rasmussen, National Institute of Public Health, Copenhagen (DK)

² "Inventory of survey data on disability in EU member state" (2002), prepared by: Denise M. Sanderson, Niels Kr. Rasmussen, National Institute of Public Health, Copenhagen (DK)

³ INSERIRE RIFERIMENTI- The European Commission's "European Health Interviews & Health Examination Surveys (HIS/HES)database., Project carries out by...

2. Selection of the General Measure Questions

The term of General Measure refers to a general question, or a fort set of questions, used to identify persons with disabilities.

For the selected surveys (53), one o more questions considered as General Measure were identified through the HIS/HES Database (version of July 2002 and version November 2002) or, in a few cases, from documents that were sent directly by the Member States.

It was decided to refer to the most recent survey if the same one was carried out more than once in the defined period of time (1998-2002), (e.g. CH01-1997 and CH02- 2002, F08-1999 and F12-2002; I03-2000 and I04-2001; IRL01-1998 and IRL03-1998; IRL02-2000 and IRL04-2001).

For some surveys general measure questions were not identified for lack of information available or because it was clear that a "battery of questions" (such as ADL scale, IADL scale or similar scale) was used to identify persons with disability.

In other cases, the full wording was not available (e.g. The Austrian Survey on disability) or the English translation was not completed (e.g. N02).

Due to the above decisions/situations the number of surveys included in the "Empirical Matrix Questions" (see Appendix 3) is less than the total number of the surveys selected.

In fact, a total of *30 national surveys* and *6 census* containing general measure question(s) on disability were used for the analysis, plus the three fully harmonized EU-wide surveys ECHP, LFS, SILC.

Main criteria to be used in the "Empirical Matrix Questions" were then identified such as: number of questions used, reference to ICF domain, specification of duration of disability, response categories, attribution to health condition, use of neutral terminology, reference to norms, complexity of the question, age orientation, specific reference to mental health. (for more information see *Appendix 3b*).

To better represent the characteristic of the questions used in the European surveys the original version of the Empirical Questions Matrix was slightly modified by adding other criteria such as: mix of concepts, need of help, specific reference to work/job activities.

The wording of each question selected available was analysed by the above criteria.

3. Main Results

From the statistical point of view, the disability issue has a long tradition in surveys carried out in Europe. In fact, almost all surveys (1998-2002) have questions on health condition related to disability.

Table 1 shows the distribution of the selected surveys having a general measure by types of surveys. The majority of these are Health Interview Surveys (13) and General Social Surveys (10). There are also 6 Censuses.

Type Survey	Number	Code Survey
HIS	13	A01, B02, CH02, DK02, E02, EL02, F09,
		F1999, FIN06, I01, IS02, NL02, H01
General Social Survey*	10	B03, D02, F12, I04, IRL04, IS03, L02, N01,
		S02, UK11
Census	6	Bc02, EL01, IrlC02, P04, UK15, H02
HIS/HES	3	FIN03, IRL03, NL03
Disability	2	F02
Other	3	UK02, H03, H04
Total	36	

Table 1Breakdown by survey type

* Multipurpose Surveys and Standard of Living Surveys were included under this category.

The results of the analysis are presented according to the criteria previous mentioned.

Number of questions used to identify people with disabilities

In the surveys examinated this number ranges from 1 to 7 questions (Multiresponses questions have been counted as total number of items such as in IrlC02, IS02, IS03, NL03).

In the European context 17 out of 36 surveys use only 1 question and 13 surveys use 2 questions, as showed in the below table.

 Table 2 Distribution of surveys by the number of question used to identify people with disabilities

Number	Survey code	Number	
of		surveys	% of total
questions			
1	CH02, D02, E02, EL01, EL02, F02, F12, F1999, FIN03, I01,	17	47,1
	I04, IRL03, NL02, S02, UK15, H02, H03		
2	A01, B02, B03, Bc02, DK02, F09, FIN06, IRL04, L02, P04,	13	36,1
	UK02, UK11, H01		
3	IS03 – H04	2	5,6
4		0	0
5	NL03	1	2,8
6	IrlC02 - N01	2	5,6
7	IS02	1	2,8
Total		36	100
Number			

Survey Type N. of questions	His	General Social Survey	Census	HIS/HES	Disability	Other	Number of surveys
1 question	6	4	3	2	1	1	17
2	6	4	2			1	13
3		1				1	2
4							0
5				1			1
6		1	1				2
7 questions	1						1
Total	13	10	6	3	1	3	36

Table 3 Distribution of surveys by question(s) used as general measure and survey type

The above table shows that:

- 6 out of 13 *HIS* use only 1 question (CH02, E02, EL02, E1999, I01, NL02), 6 others use 2 questions (A01, B02, DK02, F09, FIN06, H01), and only 1 (IS02) uses 7 questions;
- 4 out of 10 *General Social Surveys* utilize 1 question (D02, F12, I04, S02) or 2 questions (B03, IRL04,L02,UK11), 1 (IS03) uses 3 questions and 1 (N01) uses 7 questions;
- 3 out of 6 *Censuses* use 1 question (EL01, H02, UK15), 2 (Bc02, P04) use 2 questions and 1 (IrlC02) uses 6 questions;
- 2 out of 3 *HIS/HES* use only 1 question (FIN03, IRL03) and 1 (NL03) uses 5 questions;
- the one Disability Survey (F02) uses 1 question;
- 3 surveys belonging to "other" categories use respectively 1 (H03), 2 (UK02) and 3 (H04) questions.

ICF Domain

The ICF domains most frequently covered in the European surveys are *Activities, Body Structures and Body Function*. In fact, these are investigated in all the surveys considered: *Activities* is included in 32 out of 36 surveys, and *Body Structures and Body Function* in 31 surveys.

The *Participation* domain has also been taken into consideration in several surveys (17 out of 36) generally by using 1 question (8 surveys) or two or more (9 surveys).

As an example among the surveys using more than one questions, Activities and Participation are investigated in more completed way, in NL03. It takes also into account the age of the respondent. In fact, if the respondent is under 12 years old (proxy is allowed) is asked if he/she is limited in activities in schools or in other activities which are normal for a child of his/her age; if over 12 years old to what degree he/she is limited in daily activities at home?; and to all respondents is asked to what degree he/she is limited at school, work, in leisure time activities, sports or traveling.

In Eleven of the 17 surveys using the Participation domain the wording also include specific reference to *work context* or to job activities. (e.g.: DK02, E02, FIN06, H01 (HIS); D02, N01 (General Social Survey); FIN03, NL03 (HIS/HES); IrlC02, UK15 (Census); H04 (other).

Table 4 shows the distribution of the surveys by ICF Domain and number of questions used to identify persons with disabilities.

Many surveys (15 out of 36) focus on *Body Structures, Body Function and Activities* (BS, BF, A) using: 1 question (6 surveys: CH02, EL01, EL02, F12, S02, H03) or 2 questions (9 surveys: A01, B02, B03, Bc02, F09, IRL04, P04, UK02, UK11).

While all four ICF domains (BS, BF, A, P) are used in 12 surveys with: 1 question (6 surveys: E02, FIN03, I01, I04, IRL03, UK15) or 2 questions (3 surveys : DK12, FIN06, H01) or two or more (3 surveys: H04, NL03, IrlC02).

Furthermore, four surveys focus on Activities and Participation (D02, F1999, IS03, IS02), three surveys focus on Body Structure and Body Functions (F02, H02, L02), one focuses on Body Structure, Body Functions and Participation (N01) and one only on Activities (NL02).

Table 4 Distribution of surveys by ICF Domain and number of questions used to identify persons with disabilities

Number	BS BF A	BS BF A P	AP	BS BF	BS BF P	Α	Total
of							
questions							
1	6	6	2	2		1	17
2	9	3		1			13
3		1	1				2
4							0
5		1					1
6		1			1		2
7			1				1
Total	15	12	4	3	1	1	36

Table 5 shows the distribution of surveys by ICF domain and type of survey, from what result that:

- Of the total 13 HIS, 5 surveys (A01, B02, CH02, EL02, F09) refer to BS, BF and A; 5 others (E02, I01, DK02, FIN06, H01) refer to all 4 ICF Domains; 2 surveys (F1999, IS02) refer to A and P, and 1 survey (NL02) only to Activity.
- Of the total 10 General Social Surveys, 5 (B03, F12, IRL04, S02, UK11) refer to BS, BF and A; 1 (I04) to all four ICF domains, 2 (D02, IS03) refer to A and P; 1 (L02) refers only to BF and BF, 1 (N01) only to Activity.
- Of the total 6 censuses, 3 (Bc02, EL01, P04) refer to BS, BF and A; 2 (IrlC02, UK15) to all 4 ICF domains and 1 (H02) to only BS and BF.
- All three HIS/HES (FIN03, IRL03, NL03) refer to all four ICF domains.
- The one Disability Survey refers to only BS and BF.
- Of the total 3 surveys belonging to "other" types of surveys, 2 (UK02, H03) refer to BS, BF and A, and 1 (H04) to all four ICF domains.

Type of Survey	BS BF A	BS BF A P	A P	BS BF	BS BF P	Α	Total of surveys
HIS	5	5	2			1	13
General Social Survey	5	1	2	1	1		10
Census	3	2		1			6
HIS/HES		3					3
Disability				1			1
Others	2	1					2
Total	15	12	4	3	1	1	36

Table 5 Distribution of surveys by ICF Domain and type of survey

Taking into consideration the number of questions and the type of ICF domains that they refer to, it seems that <u>when only 1 question</u> is used there is much of variability in the wording of the instrument. Despite of this variability 15 surveys out of 17 refer to Activity Limitations and only 2 (F02, H02) refer to BS and BF.

Generally the variability in the wording is due to the introduction of more specified information, e.g. on health conditions, cause of illness, etc. When activity and participation limitations are investigated, other concepts are added, such as need of help or limitation due to health conditions/disabilities/handicaps.

The following examples of wording give an idea of this variability.

- *Limitation of activities*, (A) e.g.:

"What about your day-to-day activities? - I have no difficulties in my day-to-day activities/ I have some difficulties in my day-to-day activities/I am unable to carry out my day-to-day activities." (NL02).

- Activities limitation and participation (A, P) e.g.:

"Is he/she restricted in the kind or amount of exercise he/she can do? (at home, work, or school or any other occupation of his/her age such as travelling, games, sports, leisure activities?" (F1999)

"Apart from short illness: does your state of health prevent you from carrying out your day to day activities, for example, in the home, at work or in your training? - Not at all/ A little/ Considerably." (D02);

Long standing illness/disability that limits Activities and Participation, (BS, BF, A, P). e.g:
 "Do you have some permanent or chronic illness or some defect, trouble or injury, which diminishes your working capacity or functional ability? – Yes/ No" (FIN03);

"Do you have any long-term illness, health problems or disability which limits your daily activities or work that you ca do? -Yes/ No" (UK15)

- Activities and participation limitations due to health condition/disability and needs for help, (BS,BF, A, P) e.g.:

"Does some of people of the household need some type of special dedication for the fact of suffering a handicap or some limitation to carry out with normality the activities of the family, social and labour life? – Yes/ No" (E02);

"Are you affected by longstanding illness or a permanent disability that reduces your personal freedom till requiring help from other people for daily needs inside and outside the home? - No/ Yes occasionally for some needs/ Yes continuously or for important needs" (I01, I04).

When <u>2 questions</u> are used to identify people with disability there is more homogeneity in fact the first enquires about chronic illness and the second one about activities or activities and participation limitations. Again the variability is due to the introduction of more specified information on health conditions (disability/handicap/mental health illness...), examples of activities and contexts or type of answer categories.

The following examples of wording give the general idea of this variability.

- The first question refers to "suffering of chronic disease/disability/handicaps" (BS/BF) and the second one refers to "activities limitation due to health condition" (A). e.g.:

(B02, B03, Bc02,)

1. "Do you suffer from one or more longstanding illnesses, chronic conditions or handicaps?-Yes/ No";

2. "Are you restricted in your daily activities due to this (these) illness(es), chronic condition(s) or handicaps? – Continually/ At intervals/ Not or seldom".

(IRL04)

- 1. "Do you have any chronic, physical or mental problem, illness or disability? -Yes/ No"
- 2. "Are you hampered in your daily activities by this physical or mental health problem, illness or disability?- Yes severely/ Yes to some extent/ No".

(UK02, UK11)

- 1. "Do you have any long-standing illness, disability or infirmity? Yes/ No"
- 2. "Does this illness or disability limit your activities in any way? Yes/ No"

(F09)

- 1. "Do you suffer from a chronic disease or health problems? Yes/ No"
- 2. "During at least six months, have you been limited in activities which people normally carry out due to a health problem? Yes/ No"
- the first question refers to suffering of chronic disease/disabilities/handicaps" (BS/BF) and the second one refers to A and P. e.g.:

(DK02)

- 1. "Do you suffer from any long standing illness, long standing after effect from injury, any disability or other long-standing condition? Yes/ No"
- 2. "Are you restricted by this illness in your work/usual activities? Yes, very much/ Yes a little/ No".

Duration specification on disability

11 surveys do not include a specific time reference in the wording. In these cases the verb is used in Present tense.

25 surveys refer to specific time as follows:

Long standing: 17 (B02, B03, Bc02, DK02, EL01, EL02, I01, I04, IRL03, IrlC02, N01, NL03, S02, UK02, UK11, UK15, H03); Apart from short/not short period: 2 (D02, H01); At least three months/or more: 2 (FIN03, H04); More than one year: 1 (Ch02); Past/6 months: 1 (F09); Specific date: 1 (L02); Future:1 (F12).

Reference Norms

In the European surveys a reference norm to compare with something or someone, such as "compared with persons of your own age..." is never used.

Attribution to health conditions

There are 25 (out of 36 survey) that include a specific reference to health problems or disability as the cause of restriction in activities and participation, while 6 surveys have no such reference (EL01, F12, F1999, IS02, NL02, S02). For 5 surveys the criterion is not applicable (EL02, L02, P04, H02, H03).

Answer categories

The answer categories as criteria were: dichotomous, multiple and their combination. As *Table 6* shows, the *Dichotomous* answer category is more used (16 surveys: Ch02, E02, EL01, EL02, F02, F12, F09, F1999, Fin03, IrlC02, IS03, S02, UK02, UK11, UK15,H03). Eleven out of 36 surveys use both categories (B02, B03,Bc02, Dk02, Fin06, IRL04, L02, N01, NL03, P04, H01), and only 9 surveys use *Multiple* answer category (A01, D02, I01, I04, IRL03, ISO2, NL02, H02, H02, H04).

If we analyse the types of answer category used by number of questions the result are as it follow. The surveys with one question (17) can be split up in:

- dichotomous answer category: 12 surveys (Ch02, E02 EL01, EL02, F02, F12, F1999, FIN03, IRL03, S02, UK15, H03) and
- multiple answer category: 5 surveys (D02, I01, I04, NL02, H02).

The surveys using two questions (13) are split up in:

- dichotomous answer category: 3 surveys (F09, UK02, UK11)
- multiple answer category: 1 survey (A01)
- both answer categories: 9 surveys (B02, B03, Bc02, DK02, FIN06, IRL04, L02, P04, H01).

Surveys using 3 questions (IS03 and H04) use respectively Dichotomous and Multiple category. Surveys using 5 questions (IrlC02 and NL03) use respectively Dichotomous and Dichotomous followed by Multiple answer category.

The survey N01, using 6 questions, utilizes Dichotomous for the first one and Multiple for the others.

The survey IS02, using 7 questions, utilizes Multiple answer category for all questions.

N. of	Dichotomous	Multiple	Dic and Multiple	Number of
questions				surveys
1	12	5		17
2	3	1	9	13
3	1	1		2
4				-
5	1		1	2
6			1	1
7		1		1
Total surveys	17	8	11	36

Table 6 Survey distribution by answer categories and by number of questions

Use of neutral terminology

The ICF as conceptual framework force to use a neutral terminology as result also to the cultural change in definition of people with disabilities. In the European context the word "handicap" and "disability" were considered with a negative connotation. As result of using this criteria only 12 out of 36 surveys use neutral terminology (1/3 of the total).

Complexity

A wording were considered "complex" not only for the syntax but also for the format used to submit the question(s). It was excluded, as criteria for complexity, the mix of concepts that was analysed separately. 19 out of 36 surveys use "no complex wording" while 17 use a complex one.

Mix of concepts

This stresses if in the wording there is a mix of concepts such as long-standing illness, disability, health problems or/and activities and participation with reference to environment too. The most common mix of concepts is related with longstanding illness/chronic conditions and disability or handicap.

Age oriented

The question(s) was considered age oriented when it refers to specific target population. In only 4 surveys it happens (A01, FIN06, IrlC02, NL03) by selecting a question on the age of the respondent (A01, NL03, IrlC02), or referring to example of activities or context that are related with specific age of the population surveys (e.g.: FIN06).

It must be underline that in almost all the other surveys when the question is related with activity limitation refers to activity in general (B02, B03, Bc02, CH02, F02, F09, F1999, I01, I04, IRL04, NL02, UK02, UK11) so that can be use for all type of population survey.

Need of Help

This concept is included in only 6 surveys. The breakdown for number of questions used is: one question (E02, I01, I04), two questions (A01, H01) and three questions (IS03).

Examples of wording:

IO1 "Are you affected by a longstanding illness or a permanent disability that reduces your personal freedom till requiring help from other people for daily needs inside and outside the home? NO

YES, intermittently, for some needs

YES, continuously, or for important needs";

E02 "Does some of people of the household need some type of special dedication for the fact of suffering a handicap or some limitation (not being able to be alone at nights, to need help to go out in the street, personal hygiene, etc.) to carry out with normality the activities of the family, social and labour life?

Yes No"

Specific reference to mental health functioning

Only 9 surveys refers to Mental Health: 8 refers to Psychological functioning (Ch02, IRL04, IrlC02, L02, P04, H01, H04) and 1 to Psychological and Cognitive functioning (F02).

Special Questions

In Four surveys, not included in the above presentation on results, a special general measure was found. These in fact, have a general question that aims only to identify people who have an official recognition of disability or who have a disability pension.

The surveys are:

D01 Germany - Microcensus, 1999 (HIS)

114. Is your handicap established by an official notice, or have you made an appropriate application?

D05 German National Health Examination and Interview Survey 1998 (HIS)

25. Do you have a disability which has been officially acknowledged by the appropriate body/pension office?

E04 Spain – Impairment, Disabilities and Health Status Survey, 1999 (Disability survey).

19. Does any person in the household have a handicap certificate issued by the National Social Services Institute or the respective Autonomous Community body as a result of suffering from a disability, problem or disease?

FIN07 Finland – The National FinRisk, 2002) (HIS/HES)

21. Do you receive disability pension for a disease or inability? no

yes, partial disability pension

yes, temporary disability pension

yes, permanent disability pension

Several others surveys include this kind of question but they have also questions as general measure (e.g. D02, FIN06, P04).

Fully harmonized EU-wide surveys and general measure

The three fully harmonized EU-wide surveys are: European Community Household Panel -ECHP, European Labour Force Survey -LFS, Survey on Income and Living Conditions –SILC.

In the ECHP (1994-2001) is used a general measure composed by two questions:

"Do you have any chronic physical or mental health problem, illness or disability?- Yes/No" followed by "Are you hampered in your daily activities by this physical or mental health problem, illness or disability?" – Yes severely/ Yes to some extent/ No".

The first one investigate the health/disability condition (BS, BF) and the second one the limitations of the activities. As we can see the main characteristics of this general measure are: to refer to BS, BF e A domains, no specification of duration of the chronic condition or disability, no age orientation, no use of neutral terminology (if "disability" is considered as no neutral), no complexity in the syntax but mix of concepts in the wording, specific reference to mental health problem (Psychological and Cognitive) is included.

The activity limitations are investigated by referring to health condition and without using reference norms ("in your daily activities) or to work contest/job activities. Need for help is not included. The answer categories are dichotomous (in the first one) and multiple (in the second one).

The two questions are introduced by a Self-perceived health question "How is your health in general?". All three questions are a first version of the Minimum European Health Module (MEHM).

This module, that will be describe in the second part of the report, will be used in the Survey on Income and Living Conditions –SILC (2004).

In the European Labour Force Survey 2002 it is used only one question as general measure for screening the respondents for the module on "employment of disable people". The question is "Do you have any longstanding health problem or disability? – Yes/ No". This question is also part of the MEHM.

The main characteristics of the question are: it refers to BS BF domains, with no neutral terminology (disability) and mix of concepts but not complex wording; there is not reference to mental health functioning or work/job activity, or to need for help. The question is not age oriented and not use any reference to norms. The duration of health problem is specified (longstanding).

Appendix 1 (file Annex1)

Inventory surveys available

Appendix 2 (cfr file Annex 2)

Information on selected surveys

Appendix 3a (cfr file Annex 3)

Empirical Questions Matrix

Appendix 3b

Legend of criteria for the Empirical Matrix

Survey-CodeNumber used in the HIS/HES database. When the survey is not in the database it is
underline but an unofficial code is given.CountryCountryYearYear in which the survey was doneTitle SurveyTitle of the Survey

General Measure: answer categories: Yes, No. General measure refers to questions (one or more) that are used to identify persons with disabilities.

ICF Domain: Description of ICF domain that are addressed by the general measure. Answer categories: BS (Body Structure), BF (Body Function), A (Activities), P (Participation). It refers to the type of ICF domain used to identify persons with disabilities. When the wording includes words like handicap/disability it is considered linked to BF - BS and A as ICF domain.

Mixture of concepts: This stresses if in the wording there is a mix of concepts such as longstanding illness, disability, health problems or/and activities and participation with reference to environment too. Answer categories: Yes, No.

Duration specified: Answer categories: It is reported the expression used in the wording or in the instruction, if not specified it is reported "Not specified".

Response categories: Description of the type of response categories used: Dichotomous, Multiple, Open

Attribution to a health condition: This address the issue of whether the general measure enclosed a specific reference to health problem or disability as cause of restriction in activities and participation.

Answer categories: Yes (when there is a specific reference to health problem, disability...in the wording), No.

Use of neutral terminology in question: It stresses the type of terminology used in the wording. Answer categories: Yes, No. Yes when neutral or biased words are used, and No when words such as handicaps or disability are used.

Reference/Norms: answer categories: Yes, No. Yes when there is a reference to something or someone ,such as "compared with persons of your own age...".

Complexity: It refers to cognitive complexity of the general measure such as syntax used. Answer categories: yes (if the wording is complex for the syntax used), no (if the syntax is simply).

Age-oriented: answer categories: Yes (if the wording refer to specific target population), No

Specific reference to Mental health functioning: It refers to if and how the general measure address mental functioning. Answer categories: Yes, (*cognitive*, if in the list there is specific

reference to intellectual or cognitive problems, *psychological*, when it used "mental health" or emotional problems), No.

Specific reference to work activities: Answer categories: Yes, when there is specific reference to work or working activities, No.

Need of help: This address the issue whether in the wording it is enclosed the concept of need of help in daily life. Answer categories: yes (if there is specific reference to need of help for carrying out activities)

Number of questions used to identify persons with disabilities: It refers with the number used for selected. The multiresponses have been counted as total number of items.

Appendix 4 (cfr file Annex 4)

List of general measure questions selected from the MS survey and census.