

# Disability Data Strategies: An international scan

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## Executive Summary

The proposed new data strategy brings the situation of people with disabilities into the mainstream as the department undertakes an initiative to modernize the socio-economic data system for all Canadians.

The new strategy is composed of three components (pillars): data from surveys, data derived from administrative files and an integrated information platform. The first pillar consists of obtaining information using existing surveys, and when necessary, supplements to existing surveys. The second pillar is aimed at making better use of program and tax data to collect information on persons with disabilities who are eligible for programs thus enhancing the understanding of programs' beneficiaries and their characteristics. The third pillar will provide accessible, flexible, easily updatable and user friendly information on a web platform that will result in better knowledge sharing, communication and exchange to continuously meet the evolving information needs of people with disabilities.

The objectives of this research are to conduct an environmental scan of like-minded countries to develop an understanding of their system to collect and disseminate data concerning their adult population with disabilities, and to provide an inventory of the questions being used by these countries to identify their adult population with disabilities.

The International Classification of Functioning, Disability and Health (ICF) provides the framework for the development of questions to identify the population with disabilities in many of the countries and is the basis for the development of questions by international initiatives.

The Survey of Disability, Ageing and Carers (SDAC) is part of the ongoing survey program in Australia. The post-censal disability survey has been part of the ongoing survey program in New Zealand since 1996 with surveys conducted in 2001 and 2006. The 2011 survey was cancelled because of the earthquake in Christchurch. Both Ireland (2006) and the United States (1994-95) have conducted only one disability-specific survey.

Australia, Ireland and the U.S. have disability modules that they include in their ongoing survey. New Zealand is considering the development of a module given the cancellation of their 2011 post-censal survey. The European Union has developed a module for Member States to identify working age people with disabilities. They are also developing a module for inclusion in their health survey.

Use of administrative data is being considered by most countries surveyed. The U.S. has legislation that allows for the linkage of survey and administrative data. Ireland, through their StatCentral portal provide one-stop access to all statistical data (surveys and administrative data).

Most surveys include a derived severity of disability variable.

## 1. Background

In April 2010, the Minister responsible for Human Resources and Skills Development Canada (HRSDC) announced a new strategy for the collection and dissemination of data concerning people with disabilities. This new data strategy brings the situation of people with disabilities into the mainstream as the department undertakes an initiative to modernize the socio-economic data system for all Canadians.

Updated more often, from different sources and more easily usable, the information will enable policy-makers and researchers to be more responsive when addressing targeted disability issues in terms of education, income, labour market participation and health. Canadians will have access to the information through a citizen-centered portal. The “People with Disabilities” portal will structure the information through analytical tools and products, such as reports and indicators, synthesis, micro-simulation models, analyses, report cards, dynamic data charts, and discussion forums. It is anticipated that the implementation of the “People with Disabilities” portal will also include provincial and community-based information systems.

The new strategy is composed of three components (pillars): data from surveys, data derived from administrative files and an integrated information platform.

The first pillar consists of obtaining information using existing surveys, and when necessary, supplements to existing surveys. In the past, Pillar 1 included data derived primarily from the disability-specific surveys – the 1983/84 Canadian Health and Disability Survey (CHDS), the 1986 and 1991 Health and Activity Limitation Surveys (HALS) and the 2001 and 2006 Participation and Activity Limitation Surveys (PALS). This new approach maximizes the use of information in existing surveys by including a standard set of questions to identify people with disabilities that will be used in all surveys. This will enable the analysis and dissemination of the information in existing surveys for persons with disabilities and persons without disabilities – subject, of course, to sufficient sample size and other methodological considerations. Supplements to existing surveys may be required to quantify specific issues concerning people with disabilities such as supports needed to fully participate in chosen daily activities, barriers encountered that prevent or impede full participation, etc. When fully implemented, this strategy is anticipated to provide more timely information on labour market, health, education and social outcomes for people with disabilities.

The second pillar is aimed at making better use of program and tax data to collect information on persons with disabilities who are eligible for programs. Two sources are currently being explored: federal tax data (disability tax credit) and the Canada Pension Plan’s disability benefits. This pillar will provide useful complementary data for enhancing the understanding of programs’ beneficiaries and their characteristics.

The new “People with Disabilities” information Portal (Pillar 3) is part of a larger social, learning and labour market information system that HRSDC is developing. The “People with Disabilities” Portal will provide for accessible, flexible, easily updatable and user friendly

information on a web platform for better knowledge sharing, communication and exchange to continuously meet the evolving information needs of people with disabilities.

## **2. Objectives of the research**

The objectives of this research are:

1. to conduct an environmental scan of like-minded countries to develop an understanding of their system to collect and disseminate data concerning their adult population with disabilities, and
2. to provide an inventory of the questions being used by these countries to identify their adult population with disabilities.

To meet the first objective, we have included Australia, New Zealand, Ireland, the U.S.A. and the European Union. Because the second objective of the work deals with questions to identify the population with disabilities, the work of four groups is also included – the United Nations Washington Group on Disability, the Budapest Group, the World Health Organization and HUI Inc.

This research builds on a similar project undertaken by Adele Furrrie Consulting Inc. for HRSDC in 2005.

### 3. Australia

- The Australian Disability Data Strategy addresses the issues of different data collection methodologies and different sample sizes by using one data source – the Survey of Disability, Ageing and Caring (SDAC) – to establish prevalence of disability and all other data sources (social surveys and administrative) to measure differences and similarities between the population with disabilities and the population without disabilities. Users are encouraged not to use the results from the social surveys to update the SDAC prevalence rates.
- SDAC is conducted every 5/6 years and uses 75 questions to identify nature and severity of disability. It is the only recommended data source for prevalence of disability for all ages.
- The Disability Module (DM) is used in many social surveys to obtain social and economic data that enables disabled/non-disabled comparisons. It includes 10 questions and uses prompt cards to obtain detailed data on type of disability. The concepts and questions are similar to SDAC. It is not recommended to use these data to update prevalence of disability estimates because of different collection methodologies and smaller sample sizes nor is it recommended to use data across surveys, for the same reasons.
- Questions were added to the 2006 and again to the 2011 Census of Population to identify the population with disabilities.
- The Australian Bureau of Statistics (ABS) is working with program officials in other departments to develop a set of indicators that are consistent with SDAC data. These indicators provide a useful mechanism for mining the administrative data, allowing for measures of change over time.
- The “severity of disability” measure is SDAC is defined based on the core activity limitations, and whether or not people need personal assistance to overcome the activity limitations. The “severity of disability” measure generated using the DM is broadly comparable to the SDAC measure.

#### 3.1 Background

As in Canada, the setting of 1981 as the first International Year of Disabled Persons by the United Nations General Assembly highlighted the need for comprehensive national data on people with a disability. In response, the Australian Bureau of Statistics (ABS) conducted its first disability-specific survey within its household survey program in 1981 titled “Handicapped Persons Survey”. This initial survey was followed by revised and enhanced disability surveys in 1988 (Survey of Disability and Aged Persons), and the 1993, 1998 and 2003 and 2009 surveys (Survey of Disability Ageing and Carers (SDAC)).

Development of the content of these disability-specific surveys were progressively made based on evaluations of the previous surveys, user consultations involving community organizations and the public sector, and emerging policy issues. Questions used to identify the population with disabilities also evolved over time with questions as did the terminology used to reflect a changing community awareness and perception.

The large number of questions in the SDAC to identify the population with disabilities and needs (both met and unmet) for supports within the community limits the time on the survey in which to ask respondents additional questions about the social and economic context of their lives. To meet these needs, ABS developed a short disability module in the early 1990s for use in household surveys to investigate disability in relation to the social and economic circumstance of persons with disabilities vis-à-vis persons without disabilities. Various forms of this module have been used from 1992 onwards, with the current standard form of the Disability Module, as it has come to be known, first being used in the 2002 General Social Survey.

### 3.2 *Definition of disability*

Australia's *Disability Discrimination Act 1992* (DDA) defines disability very broadly<sup>1</sup>. The definition includes persons with physical, intellectual, psychiatric, sensory, neurological, and learning disabilities, as well as physical disfigurement, and the presence in the body of disease-causing organisms. The DDA includes people with a disability who now have the disability, who had in the past (for example: a past episode of mental illness), who may have in the future (eg: a family history of a disability that a person may inherit) and who are believed to have (for example: if people think someone has AIDS). The DDA also covers people with a disability who may be discriminated against because they are accompanied by an assistant, interpreter or reader, a trained animal, such as a guide or hearing dog, or they use equipment or an aid, such as a wheelchair or a hearing aid.

There are 75 questions used in SDAC to identify the population with disabilities. These questions have evolved over time using the frameworks of the International Classification of Impairments, Disabilities and Handicaps (ICIDH) and the International Classification of Functioning, Disability and Health (ICF). A person with a disability is an individual who ***has a limitation, a restriction or an impairment*** that has lasted or is likely to last for ***at least six months*** and ***restricts everyday activities***. The specified limitations, restrictions or impairments are:

- loss of sight (not corrected by wearing glasses or contact lenses)
- loss of hearing, that restricts communication or results in the use of an aid
- speech difficulties
- chronic or recurring pain or discomfort causing restriction

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<sup>1</sup> The DDA also protects people who have some form of personal connection with a person with a disability like relatives, friends, carers and co-workers if they are discriminated against because of that connection or relationship.

- shortness of breath or breathing difficulties causing restriction
- blackouts, fits, or loss of consciousness
- difficulty learning or understanding
- incomplete use of arms or fingers
- difficulty gripping or holding things
- incomplete use of feet or legs
- a nervous or emotional condition causing restriction
- a restriction in physical activities or in doing physical work
- a disfigurement or deformity
- mental illness or condition requiring help or supervision
- long-term effects of head injury, stroke or other brain damage causing restriction
- receiving treatment or medication for another long-term condition or ailment, and still
- restricted in everyday activities
- any other long-term condition resulting in a restriction.

The Disability Module (DM) is designed to identify the population with disability within any of the social surveys in which the module has been included. For example, the inclusion of the Disability Module in the 2006 General Social Survey, allows for analysis of the social characteristics of people with a disability compared to those without disability. The DM applies the same criteria as the SDAC to identify people with a disability and determine their severity of restriction, but uses only 10 questions and a series of prompt cards. The questions used are compatible with the Activities and Participation component of the ICF and are based directly on the questions used in the SDAC.

Data collection activities not undertaken by the ABS, in particular data collected from administrative sources, has in the past somewhat conformed to ABS standards because of a need to be able to relate data to the national population data collected by the ABS. There were however significant deviations that resulted in an inability to compare across data sets. In an effort to overcome the problem of incompatibility in data obtained from surveys and from administrative data, the National Community Services Information Agreement (NCSIA) was reached in 1997 by community and disability services ministers. The intent of the NCSIA was to establish a core set of data items, response categories and definitions which could be consistently applied. It was also agreed that a Data Dictionary (NCSDD) would be produced that would be the authoritative source for nationally endorsed definitions of data elements of relevance to community services. For the purposes of the Agreement, the scope of community service includes: aged care (including residential and community care), disability services, child care (including preschools), family support services, child welfare (including juvenile justice), supported accommodation assistance and emergency relief and crisis services. The ICF concepts have now been included in the NCSDD as either new data items or concepts, depending on the stage of practical implementation.

### **3.3 *Disability data strategy***

The Australian disability data strategy reflects the important position that data on people with disability play in the overall statistical system for Australia. Disability data are used by both

government and private agencies to determine how many people have a disability, where they live, whether they require supports and the nature and extent of the supports that they need. Data are also required for assessing the effectiveness of government policy and practice. Australia is a signatory to the UN Convention on the Rights of People with Disabilities and has obligations to ensure its people with disabilities receive every opportunity and assistance to be able to fully participate in society. The Council of Australian Governments (COAG) uses disability data to monitor and assess whether the needs of people with a disability are being met in accordance with these obligations.

ABS has used all of the opportunities available to them and, as a result, has developed a comprehensive strategy that they are consistently evaluating and updating. Their strategy includes:

- a disability-specific survey (SDAC) conducted every six years;
- a Disability Module that is included in all social surveys;
- a question on their 2006 and 2011 Census of Population;
- a set of indicators that are consistent with SDAC for use in administrative data collection and dissemination; and
- the guidelines on how the data from these data collection activities should be used.

### 3.3.1 Disability-specific survey

The most detailed and comprehensive source of disability data in the ABS is the Survey of Disability, Ageing and Carers (SDAC). This survey was first introduced in 1981 as the Survey of Handicapped Persons, reflecting in its title, the words used to describe persons with disabilities at that time. It has been conducted five times in the intervening years; in 1993, it was renamed the Survey of Disability, Ageing and Carers. The SDAC was last conducted in 2009. The next survey is due to be run in 2015.<sup>2</sup>

One of the main purposes of the SDAC is to collect extensive national and state level data on disability. It is the ***only source recommended by ABS to provide prevalence rates of disability*** for all ages including persons living in non-private dwelling and health establishments.

The SDAC provides information about the presence of long term health conditions leading to impairment, limitation or restriction in the context of the person's environment. It uses, as its conceptual base, the definition of disability used by the World Health Organisation (WHO) in the International Classification of Functioning, Disability and Health 2001 (ICF).

The survey questionnaire contains 149 questions designed to provide a detail on the identification of disability and the underlying conditions causing disability - 75 of these questions are used to establish if a person is restricted by disability and is in need of assistance. Based on the responses provided by one household member, persons were then selected to participate in a face-to-face interview. The average household interview time was 44 minutes in

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<sup>2</sup> A copy of the 2009 SDAC questionnaire is attached as Annex A. It was obtained from ABS (personal correspondence with the author.) Use of any part of the questionnaire must be approved by ABS.

2003.<sup>3</sup> Personal interviews are then conducted with seniors, persons with a disability and persons with long-term health conditions. Proxy interviews are conducted with the parent for children under 15 years of age, those aged 15–17 years whose parents would not permit them to be personally interviewed and those individuals with a disability that prevents them from having a personal interview.

The survey also provides a measure of a person's ability to perform Activities of Daily Living (ADLs) of self-care, mobility and communication, plus health care. The instrumental activities of daily living (IADLs) provide data on need for home help, home maintenance, meal preparation, transport, self management and personal business affairs. Education and employment limitations are also included. In 2003, information was collected on cognitive and emotional support.

For those identified as having a disability, the survey measures need for assistance and severity of specific limitations or restrictions (profound, severe, moderate, or mild core activity restrictions, or restricted participation in schooling and employment with or without core activity restriction or limitation). Assessment of need for assistance (because of disability) in the above activities, and the level to which this need is met, allows for a measure of unmet need.

### 3.3.2 Disability module

There are many social and economic dimensions to the experience of living with a disability – both for the individual him/herself and for the family and friends of the individual with the disability. SDAC uses 75 questions to establish both disability and severity of core activity limitation. As a result, the time in which to ask respondents additional questions about their social and economic status is limited. Since this is an area of particular interest for most users of data concerning persons with disabilities, it was determined that a less time-consuming approach was needed to be able to include 'disability' as a component of surveys focussed on these specific issues.

In response, the ABS designed a disability module to provide an efficient means of identifying all people with a disability in ABS non disability-related social surveys. The module evolved from 1992 with the current form of the Disability Module (DM) being used, for the first time, in the 2002 General Social Survey.<sup>4</sup>

The DM applies the same criteria as the SDAC to identify people with a disability and to determine their severity of restriction, but uses only 10 questions and a series of prompt cards rather than asking each screen as a separate question. The questions are based directly on the questions used in the SDAC. The module typically takes less than two minutes for an interviewer

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<sup>3</sup>Basic information was collected from a responsible adult about all persons in the selected household; this information included age, sex, marital status, country of birth, and information to identify people with a disability or long-term health condition and potential primary care givers.

<sup>4</sup> A copy of the disability module and the prompt cards can be found at [http://www.ausstats.abs.gov.au/Ausstats/subscriber.nsf/0/69F4AB340D15511ACA25778900119EC6/\\$File/attqvre7.pdf](http://www.ausstats.abs.gov.au/Ausstats/subscriber.nsf/0/69F4AB340D15511ACA25778900119EC6/$File/attqvre7.pdf), pages 32 - 36.

to administer. The responses to the questions can then be used to classify the person to one of the categories of 'Severity of Disability'.

Questions 1-4 determine the presence or absence of various health conditions, impairments, limitations or restrictions. The next four questions determine whether the person has a core-activity (the activities of self-care, mobility and communication) limitation and the severity of that limitation. Questions 5-7 are on the person's need for assistance and Question 8 is about the person's possible use of aids. The final two questions (Questions 9-10) determine whether the person has an education or employment restriction and are only asked of people aged less than 65 years.

Data from the social surveys that include the DM increases the range of data available for the population with disability, as long as users are aware of the limitations of the measure. If the measure is cross-classified with other data items within the same survey, it will produce results that broadly describe the differences and similarities between people with disability and those without disability for that particular characteristic. If the results are compared to a previous version of the same survey, one can measure change over time.

Work is currently underway to modify the DM to improve the correspondence between the populations identified in social surveys using the DM and the populations identified in SDAC. It will involve wide consultation with stakeholders and then testing of the revised module to measure its quality and comparability with the gold standard collection – SDAC.

### 3.3.3 Census of Population

<p><b>20 Does the person ever need someone to help with, or be with them for, self care activities?</b></p> <ul style="list-style-type: none"> <li>For example: doing everyday activities such as eating, showering, dressing or toileting.</li> <li>See page 9 of the Census Guide for more information.</li> <li>Remember to mark box like this: <input type="checkbox"/></li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Yes, always</li> <li><input type="checkbox"/> Yes, sometimes</li> <li><input type="checkbox"/> No</li> </ul>
<p><b>21 Does the person ever need someone to help with, or be with them for, body movement activities?</b></p> <ul style="list-style-type: none"> <li>For example: getting out of bed, moving around at home or at places away from home.</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Yes, always</li> <li><input type="checkbox"/> Yes, sometimes</li> <li><input type="checkbox"/> No</li> </ul>
<p><b>22 Does the person ever need someone to help with, or be with them for, communication activities?</b></p> <ul style="list-style-type: none"> <li>For example: understanding, or being understood by, others.</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Yes, always</li> <li><input type="checkbox"/> Yes, sometimes</li> <li><input type="checkbox"/> No</li> </ul>
<p><b>23 What are the reasons for the need for assistance or supervision shown in questions 20, 21 and 22?</b></p> <ul style="list-style-type: none"> <li>Mark all applicable reasons.</li> <li>Remember to mark boxes like this: <input type="checkbox"/></li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> No need for help or supervision</li> <li><input type="checkbox"/> Short-term health condition (lasting less than six months)</li> <li><input type="checkbox"/> Long-term health condition (lasting six months or more)</li> <li><input type="checkbox"/> Disability (lasting six months or more)</li> <li><input type="checkbox"/> Old or young age</li> <li><input type="checkbox"/> Difficulty with English language</li> <li><input type="checkbox"/> Other cause</li> </ul>

Questions relating to disabilities of respondents had not been included in the Census since 1931. A general question on the effect of disabilities was asked in 1976 but the quality of data obtained from this question was poor and no results were released.

A Census Consultative Group on Disability was established in 1995 to seek user input and to identify user requirements for these data. The Group also reviewed international practices including the development and testing of questions that might provide acceptable and accurate. However, disability questions were not included in the 1996

and 2001 Censuses as the questions developed proved unsuitable for a self-enumerated form. An Advisory Group on Disability was again established in 2003 to develop a suitable question for the 2006 Census and review the concepts these questions were attempting to measure. The Advisory Group agreed that for the 2006 Census the questions on disability should be based around the concept of 'profound or severe core activity limitation' using similar criteria to SDAC. Testing of the new questions indicated that the data would be of an acceptable quality for use as an indicator of the target population. It was included in the 2006 Census and will be included again in the 2011 Census.

While this topic is based on the criteria used in SDAC, the population measured is different as a result of the collapsed question format and different collection methodology. Because of this, ABS recommends that data generated from these questions should be taken as an indication of the characteristics of people who report a need for assistance, due to a disability, long-term health condition or old age, not as the total population prevalence of people with a 'profound or severe core activity limitation' as represented in the survey data.

### 3.3.4 Administrative data

In an effort to overcome the problem of incompatibility in data collected in ABS surveys and those collected from administrative sources, the National Community Services Information Agreement (NCSIA) was reached in 1997 by community and disability services ministers with intent to establish a core set of data items, response categories and definitions that could be

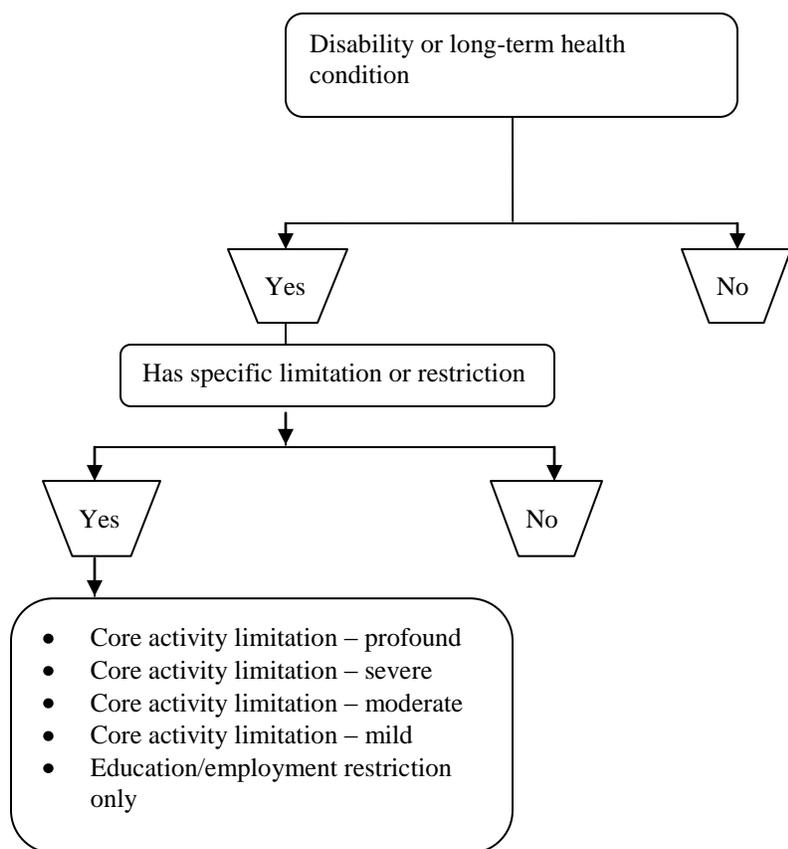
consistently applied across administrative data sources. It was further agreed that a Data Dictionary would be produced that would be the authoritative source for nationally endorsed definitions of data elements of relevance to community services. These data elements, or standards, would be used by all parties who had signed up to the community services agreement.

The National Community Services Data Committee (NCSDC) is responsible for developing and maintaining the National Community Services Data Dictionary (NCSDD) and promoting national data consistency in the community services field. It is a standing committee of the National Community Services Information Management Group (NCSIMG), a body established under the National Community Services Information Agreement to oversee implementation of the Agreement. For the purposes of this Agreement, the scope of community service includes aged care (including residential and community care), disability services, child care (including pre-schools), family support services, child welfare (including juvenile justice), supported accommodation assistance and emergency relief and crisis services.

The ICF concepts have now been included in the NCSDD as either new data items or concepts, depending on the stage of practical implementation. This allows for the generation of indicators from these data sources that are consistent with those generated by ABS surveys.

### 3.4 Severity of disability

Severity of disability is defined by ABS as a 4-level hierarchical classification that includes seven categories. It is based on the presence or absence of a disability or long-term health condition, limitation in core activities and/or specific limitation or restriction. The following diagram illustrates how the classification is derived.



Core activity limitation is if a person had a limitation in performing certain specific tasks associated with the activities of daily living listed below, because of their disability.

- Self-care: showering, bathing, dressing, eating, toileting, bladder or bowel control.
- Mobility: moving around away from the home/establishment, moving around at home/establishment, getting into or out of a bed/chair, walking 200 metres, walking up or down stairs without a handrail, using public transport, or bending to pick up something from the floor.
- Communication: understanding or being understood by strangers/family/friends in the person's native language.

Specific limitation or restriction corresponds with the concept of 'handicap' used in previous disability surveys and includes core activity limitations and:

- **Schooling:** unable to attend school, attended a special school, attended special classes at an ordinary school, needed time off school or had difficulty at school because of a disability.
- **Employment:** permanently unable to work, restricted in the type of work could do, often needed time off work, restricted in the number or hours could work, would require an employer to make special arrangements, or limited in prospects of obtaining/keeping/changing jobs.

Four levels of severity (profound, severe, moderate and mild) were determined in the survey for each of the three areas of core activity limitation: self-care, mobility and communication. These levels are based on the person's ability to perform tasks relevant to these three areas and on the amount of help required. For each area of core activity limitation, the levels of severity are as follows:

- **Profound** - personal help or supervision always required (households) or occupant cannot perform tasks without help or supervision (establishments)
- **Severe** - personal help or supervision sometimes required. In establishments, severe is only determined for verbal communication.
- **Moderate** - no personal help or supervision required but the person has difficulty in performing one or more of the tasks
- **Mild** - no personal help or supervision required and no difficulty in performing any of the specified tasks but the person uses an aid. In addition (for the household component only) any person having difficulty with walking 200 metres, walking up and down stairs without a handrail, or picking up an object from the floor was determined to have a mild handicap.

People with a schooling or employment restriction may also have a core limitation but the level of severity is not determined. The highest level of severity in any one of the areas of self-care, mobility or communication determines the severity of total limitation.

## 4. New Zealand

- The 2011 Census and 2011 post-censal disability survey will not be held because of the earthquake.
- The 2011 Census questionnaire included revised disability questions and it was anticipated that, using the post-censal results, it could be determined if the new questions worked better than the old.
- The screening questions used to identify the population with disabilities for children aged from birth to 14 years were revised for the 2011 post-censal survey to bring them more in line with the approach used to identify the adult population with disabilities.
- Because of the cancellation of the 2011 Census and post-censal survey, consideration is being given to including a module on ongoing social surveys including the New Zealand Health Survey that is conducted by the Ministry of Health.
- An initial review has been conducted to determine the nature and extent of disability data available through administrative sources.

### 4.1 Background

The need to collect disability data is part of the 2001 New Zealand Disability Strategy (NZDS) that is a long-term plan for changing New Zealand from a disabling to an inclusive society. Statistics New Zealand contributes to the fulfillment of Objective 10 of the NZDS, namely to “collect and use relevant information about disabled people and disability issues.”

The methodology used for the three disability-specific surveys (1996, 2001 and 2006) is the post-censal methodology developed by Statistics Canada

### 4.2 Definition of disability

The NZDS defines disability as “Disability is not something individuals have. What individuals have are impairments. They may be physical, sensory, neurological, psychiatric, intellectual or other impairments. Disability is the process that happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have.”<sup>5</sup>

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<sup>5</sup> <http://www.odi.govt.nz/publications/nzds/index.html>

The functional concept of disability is used in the disability-specific surveys and is based on the World Health Organization definition: "...any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being." Using this concept, disability was defined as any "self-perceived limitation in activity resulting from a long-term condition or health problem." People were not considered as having a disability if they use an assistive device (such as glasses or a hearing aid) that completely eliminated the impairment. In addition, the limiting condition must have lasted, or be expected to last, for at least six months.

### **4.3 Disability data strategy**

New Zealand's disability data strategy was the conduct of a post-censal survey every five years beginning in 1996. With the cancellation of the 2001 Census, New Zealand is now considering the use of a disability module to be included in their ongoing social surveys.

Statistics New Zealand has undertaken a review of administrative data to gain a better understanding of what data are available.<sup>6</sup> This Disability Stocktake is an initial step towards investigating the potential statistical uses of administrative data on disability and also assisted in the redevelopment of the 2011 Disability Survey.

#### **4.3.1 Disability-specific survey**

New Zealand has conducted three post-censal disability surveys (1996, 2001 and 2006). The sample design for the 1996, 2001 and 2006 post-censal surveys and the proposed 2011 survey included a sample of respondents who were living in private households at the time of the census and a sample from residents in long-term care facilities. The household-based survey included two samples – a sample of individuals who responded positively to at least one of the Census disability questions and a sample of persons who answered "No" to both Census disability questions.

The 2006 Household Disability Survey used four questionnaires. Each selected adult respondent completed a screening module to establish whether or not he/she had a disability – a "Yes" response to any of the screening questions. Adults who were identified as having a disability then completed a series of content modules with questions relating to services and assistance, employment, education, transport, accommodation, special equipment and economic characteristics. A copy of the screening module for the 2001 survey (identical questions used in 2006) can be found at

<http://www2.stats.govt.nz/domino/external/quest/sddquest.nsf/12df43879eb9b25e4c256809001e>

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<sup>6</sup> part of the Programme of Official Social Statistics (POSS) led by Statistics New Zealand to provide a robust foundation for the development and evaluation of evidence-based social policy through improved measurement of New Zealand's social well-being. This includes the investigation of the potential to use administrative sources of data to produce official statistics.

[e0fe/f8a5c5838da06086cc256ad8001d4a13?OpenDocument](#). Minor changes were proposed to the adult screening module for the 2011 survey and they are attached as Annex B – Part 1.

The parent or guardian of selected children aged from birth to 14 years completed a screening module. For those children who were identified as having a disability, the parent or guardian completed a series of content modules with questions relating to services and assistance, education, transport, accommodation and economic characteristics. A copy of the screening module for the 2001 survey (identical questions used in 2006) can be found at <http://www2.stats.govt.nz/domino/external/quest/sddquest.nsf/12df43879eb9b25e4c256809001e0fe/afe0296c8e1fa069cc256ad8001d99f7?OpenDocument>. Major changes were proposed for 2011 survey and a copy of the proposed screening module is provided in Annex B – Part 2.

The survey population for the 2006 Disability Survey of Residential Facilities was defined as all people aged 15 years and over who, at the time of the 2006 survey, were living in rest homes; occupying long-stay beds in continuing care hospitals; or living in long-stay residential units (with 10 or more people) for people with an intellectual or physical disability, or with multiple disabilities. This survey used two questionnaires. Each selected resident completed a screening module (similar to the adult household screening module) to establish whether or not he/she had a disability. Those adults who were identified as having a disability then completed a short content module that contained questions about assistance and equipment used.

### 4.3.2 Disability module

No disability module has been developed as yet. The social survey programme is under review and consideration is being given to the development of three integrated surveys.<sup>7</sup> According to personal correspondence with Shari Mason of Statistics New Zealand, any disability module would have to be considerably shorter than the screening module developed for the 2011 post-censal survey.

A similar approach is being considered by the Ministry of Health who is responsible for the ongoing health survey.<sup>8</sup>

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<sup>7</sup> [http://www.stats.govt.nz/surveys\\_and\\_methods/methods/research-papers/topss/integrated-household-surveys.aspx](http://www.stats.govt.nz/surveys_and_methods/methods/research-papers/topss/integrated-household-surveys.aspx)

<sup>8</sup> <http://www.moh.govt.nz/moh.nsf/indexmh/dataandstatistics-survey-nzhealth>

### 4.3.3 Census of Population

**16** Mark as many spaces as you need to answer this question. Does a health problem or a condition you have (lasting 6 months or more) cause you difficulty with, or stop you doing:

- everyday activities that people your age can usually do
- communicating, mixing with others or socialising
- any other activity that people your age can usually do

or

- no difficulty with any of these

**17** Do you have any disability or handicap that is long-term (lasting 6 months or more)?

- yes
- no

New Zealand used these two questions in their 1996, 2001 and 2006 Census of Population. Data from these two questions were not disseminated as part of the Census products. They are included in the Census for the sole use as the sampling frame for the post-censal

survey on disability.

**16** Mark as many spaces as you need to answer this question. Does a health problem or a condition you have (lasting 6 months or more) cause you difficulty with, or stop you from:

- seeing, even when wearing glasses or contact lenses
- hearing, even when using a hearing aid
- walking, lifting or bending
- using your hands to hold, grasp or use objects
- learning, concentrating or remembering
- communicating, mixing with others or socialising

or

- no difficulty with any of these

**17** Do you have a long-term disability (lasting 6 months or more) that stops you from doing everyday things other people can do?

- yes
- no

The disability questions were reviewed prior to the design of the 2011 Census. Question 16 was expanded to include six types of health problems or conditions that result in limitations. The wording on Question 17 was revised to be more in line with the ICF.

### 4.3.4 Administrative data

Obtaining an overview of the availability of disability data from administrative sources is part of the Programme of Official Social Statistics (POSS) led by Statistics New Zealand to provide a robust foundation for the development and evaluation of evidence-based social policy through improved measurement of New Zealand's social well-being. One important element of POSS involves investigating the potential for using administrative sources of data to produce official statistics. This was an initial step towards investigating the potential statistical uses of administrative data on disability and also assisted in the redevelopment of the 2011 Disability Survey. This process led to the identification of collections held by Veterans Affairs (VA), Housing New Zealand Corporation (HNZC), Ministry of Health (MoH), New Zealand Birth Defects Monitoring Programme (NZBDMP), Ministry of Education (Special Education) and the Ministry of Social Development (MSD). A total of 19 datasets from these six source agencies have been identified as containing information about people with disabilities.

## 4.4 *Severity of disability*

Statistics New Zealand uses a three-level definition to classify how severely people were affected by disability:

- People with *severe* disabilities received or needed daily help with activities such as preparing meals, shopping, everyday housework, bathing or dressing.
- People with *moderate* disabilities used or needed 'some type of assistive device, aid or equipment' and/or help with certain heavier or more difficult household tasks.
- People with *mild* disabilities had some kind of disability, but did not require regular help from other people or technical aids.

The classification of severity is derived from a slightly different set of questions for adults and children, because adults and children were not asked identical questions about the assistance they received or the equipment they used.

## 5. Ireland

- Ireland conducted its first disability-specific survey - the National Disability Study – following their 2006 Census and used the post-censal methodology developed in Canada for the sample design. There will not be a post-censal survey following the 2011 Census.
- Disability questions were included on the 2002 and 2006 Censuses of Population and a slightly different version on the 2011 Census.
- Two disability questions are included in the ongoing Quarterly National Household Survey (QNHS). To date, the results have not been generally disseminated, except as special requests and two cycles (2002 – Cycle 2 and 2004 – Cycle 2). However, given the demise of the post-censal survey, this decision will be revisited.
- A disability module developed by Eurostat has been included in the 2<sup>nd</sup> quarter data collection of 2011. It is possible that the module will be repeated in a 4-5 year cycle.
- StatCentral, maintained by the CSO is the portal to Ireland's Official Statistics and it provides information about statistics produced by government departments and state organizations.
- The National Disability Survey developed a severity index based on the respondent's perception of the degree of limitation for each screening question.

### 5.1 *Background*

The *National Disability Authority Act* was proclaimed in 1999 to secure the rights of people with disabilities by influencing public policy and legislation and by working to ensure that services

are of the highest quality. The National Disability Authority (NDA) was established in 2000 and is committed to two core principles: a social model of disability and empowerment of persons with disabilities. The key focus is on society and its disabling structure rather than on the person with the impairments.

## 5.2 *Definition of disability*

Disability, in the *National Disability Authority Act*, is defined as “in relation to a person, means a substantial restriction in the capacity of a person to participate in economic, social or cultural life on account of an enduring physical, sensory, learning, mental health or emotional impairment.”<sup>9</sup> The NDA, working with the Central Statistics Office (CSO) staff, has used the World Health Organization’s International Classification of Functioning, Disability and Health (ICF) to operationalize the definition.

## 5.3 *Disability data strategy*

Ireland began the collection of data concerning persons with disabilities in the new millennium. Their program includes questions on the 2002, 2006 and 2011 Censuses of Population, their first post-censal survey following the 2006 Census and a module in their Quarterly National Household Survey (QNHS). As part of their commitment to the European Union (EU), the EU disability module has been added to the Q2 2011 cycle of the QNHS. The StatCentral portal, housed and managed by the CSO, includes data sources from both the CSO (statistical surveys) and departments/agencies (administrative data).

### 5.3.1 *Disability-specific survey*

In 2006, Ireland conducted their first disability-specific survey – The National Disability Study (NDS). The development of the study followed a path similar to the one used in Canada. Experts from Statistics Canada, Statistics New Zealand and the Australian Bureau of Statistics were consulted as well as key stakeholders to determine what data were needed and how those data would be disseminated. The questionnaires included questions that covered the four domains of the ICF. Questions on vision, hearing, speech, breathing and pain were included to cover the “Body functions and structure” domain of the ICF. The “activities and participation” domain was included through questions covering communication, agility, mobility and self-care. “Major life areas” include education, employment, leisure and social activities. Finally, “environmental factors” covered include products and technology, support and relationships, attitudes and services, systems and policies.

Persons responding positively to the two Census questions on disability formed the population from which the “Census Disability Sample” of 14,518 was selected – 13,868 were residents in private households and 650 were residents in communal establishments such as a nursing home,

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<sup>9</sup> <http://www.irishstatutebook.ie/pdf/1999/en.act.1999.0014.pdf> - Part I, Section 2.

‘hospital or children’s home. This sample was supplemented with a “General population sample” of 1,551 persons drawn from all persons living in private households who did not answer “Yes” to the Census disability questions. The purpose of this second sample was to explore the extent to which the more detailed questions on the NDS would identify disability not picked up in the Census.

Copies of the four questionnaires are available on <http://www.cso.ie/nds/default.htm>.

### 5.3.2 Disability module

Ireland conducts two ongoing surveys that include questions to identify the population with disabilities – the Survey on Income and Living Conditions (SILC) and the Quarterly National Household Survey.

- **Survey on Income and Living Conditions (SILC)**

Each person aged 16 years and older living in a selected household completes a personal interview with a CSO interviewer. The disability questions include:

1. Do you suffer from long-standing (chronic) illness or condition (health problem)?
2. Which of the following long-standing conditions do you suffer from?
  - Deafness, or a severe hearing impairment
  - A condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting or carrying
  - A learning or intellectual disability
  - A psychological or emotional condition
  - Other, including any chronic illness
3. Do you have any difficulty in doing any of the following activities?
  - Learning, remembering or concentrating
  - Dressing, bathing or getting around inside the home
  - Going outside the home alone to shop or visit a doctor’s surgery
  - Working at a job or business or attending school or college
  - Participating in other activities, for example leisure or using transport
  - None of the above
4. For at least the last 6 months have you been limited in activities people usually do, because of a health problem? (If limited, specify whether strongly limited or limited).
  - Yes, strongly limited
  - Yes, limited
  - Not limited
5. Please describe the nature of your illness?

- **Quarterly National Household Survey**

Two questions on disability are included on the core questionnaire in each cycle of the Quarterly National Household Survey.<sup>10</sup> These questions are not routinely disseminated but are available to users through a special request. However, CSO is planning a review of all household-based data with the intention to fully exploit its potential.<sup>11</sup>

The two questions on disability are:

1. Do you have any of the following long-lasting conditions or difficulties?

- Blindness or a serious vision impairment
- Deafness or a serious hearing impairment
- A difficulty with basic physical activities such as walking, climbing stairs, reaching, lifting or carrying
- An intellectual disability
- A difficulty with learning, remembering or concentrating
- A psychological or emotional condition
- A difficulty with pain, breathing, or any other chronic illness or condition
- None

*If at least one “Yes” to Question , ask:*

2. Do you have difficulty in doing any of the following?

- Dressing, bathing or getting around inside the home
- Going outside the home alone to shop or visit a doctor’s surgery
- Working at a job or business or attending school or college
- Participating in other activities, for example leisure or using transport
- None

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<sup>10</sup> Personal correspondence with Pdraig Dalton, Central Statistics Office

<sup>11</sup> Ibid.

### 5.3.3 Census of Population

**14 Do you have any of the following long-lasting conditions:**

(a) Blindness, deafness or a severe vision or hearing impairment? Yes No  
1  2

(b) A condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting or carrying? Yes No  
1  2

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**15 Because of a physical, mental or emotional condition lasting 6 months or more, do you have any difficulty in doing any of the following activities:**

*Answer (a) and (b) if aged 5 years or over.*

(a) Learning, remembering or concentrating? Yes No  
1  2

(b) Dressing, bathing or getting around inside the home? Yes No  
1  2

*Answer (c) and (d) if aged 15 years or over.*

(c) Going outside the home alone to shop or visit a doctor's surgery? Yes No  
1  2

(d) Working at a job or business? Yes No  
1  2

Ireland used their 2002 Census, for the first time, as a source for disability data. Their two questions mirrored the questions used in the US with small changes to reflect the culture in Ireland namely changing “doctor’s office” to “doctor’s surgery” and having the questions on “going outside” and “working ...” completed by persons 15 and older rather than 16 and older.

Data from these two questions were disseminated in the census products.

**15 Do you have any of the following long-lasting conditions?**

(a) Blindness, deafness or a severe vision or hearing impairment? Yes No  
1  2

(b) A condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting or carrying? Yes No  
1  2

(c) A learning or intellectual disability? Yes No  
1  2

(d) A psychological or emotional condition? Yes No  
1  2

(e) Other, including any chronic illness? Yes No  
1  2

**16 IF 'Yes', to any of the conditions specified in Question 15, do you have any difficulty in doing any of the following activities?**

(a) Learning, remembering or concentrating? Yes No  
1  2

(b) Dressing, bathing or getting around inside the home? Yes No  
1  2

(c) Going outside the home alone to shop or visit a doctor's surgery? Yes No  
1  2

(d) Working at a job or business or attending school or college? Yes No  
1  2

(e) Participating in other activities, for example leisure or using transport? Yes No  
1  2

Both the structure and the content changed slightly in the 2006 Census of Population. More categories to identify type of disability were added and Question 16 was completed by only those respondents who had one or more “Yes” responses in Question 15.

The results from these two questions were disseminated as part of the

Census dissemination program. As well, these questions were used to identify the sample for the disability post-censal survey.

The first question was further refined for the 2011 Census of Population enabling the identification of seven types of disabilities.

<b>16 Do you have any of the following long-lasting conditions or difficulties?</b>		
(a) Blindness or a serious vision impairment	Yes	No
(b) Deafness or a serious hearing impairment	Yes	No
(c) A difficulty with basic physical activities such as walking, climbing stairs, reaching, lifting or carrying	Yes	No
(d) An intellectual disability	Yes	No
(e) A difficulty with learning, remembering or concentrating	Yes	No
(f) A psychological or emotional condition	Yes	No
(g) A difficulty with pain, breathing, or any other chronic illness or condition	Yes	No

<b>17 If 'Yes' to any of the categories specified in Question 16, do you have any difficulty in doing any of the following?</b>		
(a) Dressing, bathing or getting around inside the home	Yes	No
(b) Going outside the home alone to shop or visit a doctor's surgery	Yes	No
(c) Working at a job or business or attending school or college	Yes	No
(d) Participating in other activities, for example leisure or using transport	Yes	No

### 5.3.4 Administrative data

StatCentral is the portal to Ireland's Official Statistics. It provides information about statistics produced by government departments and state organizations. The site is maintained by the Central Statistics Office (CSO). The objective of StatCentral is to strengthen and coordinate statistics across the public service. To achieve this, the portal provides standard documentation on recurring official statistics and links to where they can be found.

The portal supports the National Statistics Board's (NSB) strategy of developing a whole-system approach for the Irish statistical system, involving all areas of the public sector where official statistics are produced. StatCentral was launched in 2008 with a range of official statistics from the CSO and other departments and agencies. The NSB has recommended that CSO consider the possibility of extending the StatCentral portal to include links to data held by regional bodies and local authorities.

Filed under the “People and Society/Health” (theme), there are currently descriptions for 29 data sources for disability<sup>12</sup>. These descriptions include:

- the department/agency that has the data,
- summary of the information contained in the data,
- links to the web pages that contain the data,
- a contact person/e-mail address where more details can be obtained,
- the source of the data,
- the coverage with respect to type of disabilities included and extent of coverage for each type of disability,
- reference period,
- start date,
- timeliness,
- standard classifications covered,
- date that page was created,
- date that page was modified, and
- keywords.

#### **5.4 *Severity of disability***

The NDS covered nine specific disability types including:

- Seeing
- Hearing
- Speech
- Mobility and dexterity
- Remembering and concentrating
- Intellectual and learning
- Emotional, psychological and mental health
- Pain
- Breathing

For each disability type, one or more filter questions were used to determine whether a respondent experienced this type of disability. All filter questions asked the extent to which the respondent experienced difficulty in everyday activities due to that particular disability type. Responses were coded on a five-point scale, where 1 = No difficulty and 5 = Cannot do at all (see example on the following page).

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<sup>12</sup> <http://www.statcentral.ie/search.asp?cx=007477919376516988184%3Aliry-v7jrlu&cof=FORID%3A11&ie=UTF-8&q=disability&siteurl=www.statcentral.ie%2Fviewstats.asp%3Ftype%3DHealth#926>

For seven of the nine disabilities, persons were coded as having a particular disability if they responded “3” (Moderate) or higher to the relevant filter question. For the other two disability types (F - Intellectual and learning and G - Emotional, psychological and mental health) persons answering “2” (Just a little) or higher were coded as having that disability.

To obtain an overall severity score for each disability type, persons were coded to the highest level of difficulty recorded in the filter questions relating to that disability. For example, if a respondent reported “just a little” for D1, D2 and D3 and “cannot do at all” for D4, the overall severity score for Mobility and Dexterity would be “cannot do at all”.

**NDS filter questions – Section D, Mobility and dexterity**

Do you have difficulty ...	No difficulty	Some difficulty		A lot of difficulty	Cannot do at all
		Just a little	A moderate level		
D1 Moving around inside your home (d4600)	1	2	3	4	5
D2 Going outside of your home (d4601 + d4602)	1	2	3	4	5
D3 Walking a longer distance, eg walking for about 15 minutes (d4501)	1	2	3	4	5
D4 Using your hands and fingers, eg picking up small objects or opening and closing containers (d4400 + d4402)	1	2	3	4	5

To obtain an overall severity score, the disability that had the highest score would be assigned. For example, if the individual had a severity of “cannot do at all” for mobility and dexterity and “a lot of difficulty” for three other types of disabilities, his/her overall severity score would be “cannot do at all”.

## 6. United States of America

- The US does not have a disability data strategy.
- The only disability-specific survey was conducted in 1994-95 – the National Health Interview Survey – Disability Supplement (NHIS-D). It included questions that operationalized different definitions of disability thus enabling analysts from various government programs to combine data items that would enable them to identify the population with disabilities included in their program.
- The US Census Bureau conducts the American Community Survey (ACS) and the Current Population Survey (CPS), both of which include questions to identify the population with disabilities.
- Other national surveys have, over the past 20 years, included questions to identify population with disabilities. These surveys are not covered in this report but a link to the list of surveys is provided in Section 6.3.2.
- The Census of Population long form was discontinued and the ACS was the replacement.
- Linking survey data to administrative data
- Severity of disability is not derived in the ACS or the CPS. The Kessler/NOD survey of Americans conducted by Harris Interactive asked respondents to classify their disability by level of severity.

### 6.1 Background

The collection of data concerning the impact of living with a disability in America has involved a patchwork of surveys that began in the 1960's. The Social Security Administration (SSA) conducted the Survey of Disability and Work every few years beginning in the early 1960s in order to measure the extent of disability in the working age population and to examine the experience of disabled workers on social security disability insurance (SSDI) and their families. The 1994-95 National Health Interview Survey – Disability Supplement (NHIS-D) was the only other disability-specific survey conducted in the US. Today, disability data are collected in a variety of surveys with the primary sources being the Current Population Survey (CPS) and the American Community Survey (ACS) that replaced the long form of the Census of Population. The Survey of Income and Program Participation (SIPP) that was one of the primary sources of disability data was cancelled in 2007 and a re-engineered version titled the SIPP-EHC (event history calendar) is scheduled to begin in 2014.

## **6.2 *Disability definition***

In the US, there is no single, universally accepted definition of disability. The most frequently applied framework of disability comes from Nagi. This conceptualization views disability as difficulty performing socially expected activities such as work for pay, and explicitly recognizes the interaction of the environment and pathologies/impairments to cause disabilities. The Americans with Disabilities Act (ADA) rests upon the Nagi framework and recognizes that improvements in the environment (access to public transportation, workplace accommodations, etc.) can reduce disability and thus improve the inclusion of all people. The World Health Organization's International Classification of Functioning, Disability and Health (ICF) classification system is conceptually similar to the Nagi framework. The key to both these approaches is the recognition that individuals move from the presence of a health condition to a point at which the condition begins to impinge on activities that are socially expected of them, and that this movement is related to the environment in which individuals live.

The incorporation of the measurements of disability process within surveys and administrative records is a very difficult task and there is no consensus as to the best approach. Developing such a consensus among government agencies is a goal of the Center for Disease Control's HealthyPeople 2010 benchmarking system and the efforts of the Interagency Subcommittee on Disability Statistics. An example of the benefits of interagency connections is the use of the Census2000 Long Form/American Community Survey (ACS) disability-related questions by a recent Department of Transportation (DOT) survey on transportation barriers for people with disabilities. This allows the DOT to draw inferences between their survey and the Census2000 and the ACS.

## **6.3 *Disability data strategy***

There does not appear to be an overall disability data strategy in the US. The collection of disability statistics depends on the purpose for which it is being used and the survey collecting the information. The Census Bureau collects disability data from four surveys, however, other agencies also collect disability data. Depending on the need, one survey may be more suitable than another.

### **6.3.1 *Disability-specific survey***

The only disability-specific survey conducted in the United States was the 1994-95 National Health Interview Survey – Disability Supplement (NHIS-D). It is the most comprehensive data

source regarding people with disabilities in the United States. In addition to the broader disability questions used in the NHIS, the supplement contained additional questions that identified various types of disability including questions about health conditions (both physical and mental), service receipt and program participation (e.g. SSI), activity limitations, and participation restrictions. The supplement also contained extensive information about the different facets of the lives of people with disabilities including the types of services people with disabilities receive, transportation issues facing working age adults with disabilities, social activities of people with disabilities, vocational rehabilitation services, and disability accommodations.

The highlight of the NHIS-D is its breadth of information about disability. All individuals in the NHIS were asked many detailed questions that proved useful in defining various populations of people with disabilities. Questions included those that identify activity limitations, mental health issues, and particular conditions. Data from the two years the supplement was fielded can be combined in order to produce larger sample sizes of people with disabilities. This approach facilitated the studying of subpopulations of interest or typically low-prevalence populations. The data were also linked to data in the Core NHIS for the respective years and to other supplements – for example, the Family Resource Supplement that collected information about a family's access to care, health insurance and detailed income information.

The primary limitation of the NHIS-D is that it is now over 10 years old. Many potentially significant policy changes have occurred since this time, responses of which obviously cannot be studied using these data. For example, data in the NHIS-D do not indicate how people with disabilities responded to the Social Security Administration's (SSA) Ticket to Work and Work Incentives Improvement Act enacted in 1999.

Another limitation to the NHIS-D is that it only included a sample from the non-institutionalized population of the United States. Members of the active duty military service, people living in prison, and those in nursing homes or long-term care facilities are the primary groups of people not included in the survey. The latter may be of particular importance to some disability related questions.

The website ([http://www.cdc.gov/nchs/about/major/nhis\\_dis/nhis\\_dis.htm](http://www.cdc.gov/nchs/about/major/nhis_dis/nhis_dis.htm).) includes a description of the survey, bibliography, downloadable copies of questionnaires, and downloadable public use micro-data files.

### **6.3.2 Disability module**

The U.S. Census Bureau provides a listing of surveys conducted by the Bureau and other agencies and organizations that include questions to identify the population with disabilities.<sup>13</sup> This link provides linkages to the other active and inactive surveys. For the purpose of this report, only the two main surveys conducted by the Bureau at this point in time – the American Community Survey and the Current Population Survey – are reviewed.

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<sup>13</sup> <http://www.census.gov/hhes/www/disability/datacollection.html>

- **American Community Survey**

The ACS is a continuous data collection that is used to produce annual estimates at the national, state and local level on the characteristics of the United States population. It replaces the decennial Census long form. The ACS collects information on an annual basis from approximately 3 million addresses in the United States, a 2.5 percent of the population living in group quarters and 36,000 addresses in Puerto Rico.

The ACS now includes six questions that are used to identify the population with disabilities and through these questions, identifies six types of “difficulties”. This set of disability questions was implemented in the 2008 ACS following the content test that determined the content for the 2008 cycle of the ACS<sup>14</sup>.

The six questions as asked in the 2008 ACS surveys are as follows:

**Hearing** (asked of all ages): Is this person deaf or does he/she have serious difficulty hearing?

**Visual** (asked of all ages): Is this person blind or does he/she have serious difficulty seeing even when wearing glasses?

**Cognitive** (asked of persons ages 5 or older): Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions?

**Ambulatory** (asked of persons ages 5 or older): Does this person have serious difficulty walking or climbing stairs?

**Self-Care** (asked of persons ages 5 or older): Does this person have difficulty dressing or bathing?

**Independent Living** (asked of persons ages 15 or older): Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor's office or shopping?

- **Current Population Survey**

The Current Population Survey (CPS) is a monthly survey of households conducted by the U.S. Census Bureau for the Bureau of Labor Statistics. The objective of the survey is to provide detailed employment data. The CPS uses six questions to identify the population with disabilities aged 16 and older. The questions are a variant of those used in the ACS. They appear on the CPS questionnaire as follows:

1. Because of a physical, mental, or emotional condition, does anyone have difficulty doing errands alone such as visiting a doctor's office or shopping?
2. Because of a physical, mental, or emotional condition, does anyone have serious difficulty concentrating, remembering, or making decisions?
3. Does anyone have difficulty dressing or bathing?
4. Does anyone have serious difficulty walking or climbing stairs?

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<sup>14</sup> [http://www.census.gov/acs/www/Downloads/methodology/content\\_test/P4\\_Disability.pdf](http://www.census.gov/acs/www/Downloads/methodology/content_test/P4_Disability.pdf)

5. Is anyone blind or does anyone have serious difficulty seeing even when wearing glasses?
6. Is anyone deaf or does anyone have serious difficulty hearing?

This set of six questions was added to the CPS to measure the employment status of persons with disabilities. There is not a requirement to identify or measure specific types of disabilities.

### **6.3.3 Census of Population**

For their 2010 Census of Population, the U.S. eliminated the long form. The ACS is now the source for the detailed socio-economic data.

### **6.3.4 Administrative data**

Administrative data collected and maintained by administrative agencies and commercial entities for the purpose of administering programs and providing services are accessible to the U.S. Census Bureau through the guiding statute, Title 13 U.S.C., Section 6. This statute directs the agency to use data from administrative records as extensively as possible in lieu of conducting direct inquiries of the public. Several National Academy of Science panels have encouraged the expansion of administrative records to support and enhance statistical programs. Furthermore, the Census Bureau's strategic plan emphasizes use of administrative records data to produce new information using existing data sources to meet emerging customer product needs, to minimize cost to taxpayers, and alleviate respondent burden.

Extensive use has been made data from the Social Security Administration (SSA) files including Old-Age, Survivors, and Disability Insurance (OASDI), commonly referred to as Social Security and Supplemental Security Income (SSI), a needs-based program that provides financial support for aged, blind, and disabled adults and children with limited income and resources.

The Office of Management and Budget, which oversees policies and procedures for all U.S. statistical programs, includes one component of SSA under its statistical purview: the Office of Research, Evaluation, and Statistics (ORES) within the Office of Retirement and Disability Policy (ORDP). ORES uses the Agency's administrative data to produce a wide range of research and statistical publications, as well as other products that inform the public about the beneficiary population and the operation of Social Security programs. ORDP develops and maintains a series of detailed statistical databases for research, evaluation, and analysis.

SSA has been linking its administrative data with survey results for over 40 years. SSA's biggest data-linkage partner is the U. S. Census Bureau. Linkages have been done with the CPS, ACS and the Survey of Income and Program Participation (SIPP).

## 6.4 *Severity of Disability*

Neither the CPS nor the ACS includes a severity of disability index. However, working with the Kessler Foundation and the National Organization on Disability, Harris Interactive conducted a telephone survey using questions to identify the population with disabilities that operationalized the definition of disability<sup>15</sup> as articulated in the *Americans with Disabilities Act*. Each respondent who answered “Yes” to one of the disability questions was asked to provide his/her assessment of the severity of their disability with the question “Would you describe your disability or health problem as slight, moderate, somewhat severe, or very severe?”

## 7. International Initiatives – Countries of the European Union

Eurostat is the statistical office of the European Union. It is tasked to provide the European Union with statistics at the European level that enable comparisons between countries and regions. Eurostat plays an integral role in ensuring that consistent statistics for people with disabilities are available across Member States. Consistent statistics are a necessary component to monitor and evaluate the European Disability Strategy 2010-2020 that was launched in November 2010 and the UN Convention. To that end, Eurostat has and is developing a comprehensive and coordinated set of surveys under the umbrella name of “European Core Health Interview Survey” (ECHIS). These surveys are and will be performed within the European Statistical System.

The ECHIS includes three pillars – The European Health Interview Survey (EHIS), Community Statistics on Income and Living Conditions (EU-SILC), and New modules on disability that include the 2011 LFS module on the employment of disabled persons and the European Disability and Social Integration Module (EDSIM) .

The EHIS, managed by Eurostat under the Community Statistical Programme, is planned to be held every five years with the first round taking place between 2007 and 2009. It will include the Mini European Health Module that is also included in the second pillar – EU-SILC.

### **Minimum European Health Module**

1. How is your health in general? *Very good / good / fair/ bad / very bad.*
2. Do you suffer from (have) any chronic (long-standing) illness or condition (health problem)? *Yes/ No.*
3. For the past 6 months or more have you been limited in activities people usually do because of a health problem? *Yes, strongly limited / Yes, limited / No, not limited.*

The third pillar of the ECHIS is comprised of two initiatives – the 2011 LFS module on the employment of disabled persons and the EDSIM. The 2011 LFS module includes 30 questions and is asked of persons aged 15 to 64 years inclusive. It is attached to this report as Annex C.

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<sup>15</sup> <http://www.2010disabilitysurveys.org/pdfs/surveyresults.pdf> - page 33.

The EDSIM was originally planned to be a module in the EHIS. The module has been tested with the latest revision completed in October 2010. In a presentation made to the Washington Group's meeting in Luxembourg in 2010, the EDSIM was described as having 12 sections based on the ICF with the questionnaire focussing on barriers to participation. To that end, the questionnaire begins with questions on participation and limitation in activities in areas such as learning opportunities, work, social activities, transport, mobility and accessibility to buildings. For those individuals who are not participating or with limited participation, the questions would then address personal barriers (health conditions and impairments) and environmental barriers (finances, lack of assistive devices, personal help)<sup>16</sup>. The EDSIM has evolved into a disability-specific survey – the European survey on health and social integration (ESHSI). It is currently planned to be implemented in 2012 in all Member States.

The Hungarian Presidency organized a conference on the New Challenges in the European Disability Strategy 2010-2020 that took place in Budapest on 19 and 20 April, 2011. The Conference had, as its focus, the areas for actions linked to the implementation and monitoring of the UN Convention.

## **8. International Initiatives – United Nations Washington Group on Disability Statistics**

The Washington Group (WG) is a City Group that has been operating under the aegis of the United Nations Statistical Commission since February 2002. The main focus of the WG is the development of a set of questions to identify the population with disabilities that are suitable for inclusion in country censuses. Ten meetings have taken place since 2002 with the latest being held in Luxembourg in November 2010. The next meeting is scheduled for November 2011 in Bermuda.

The following objectives were accepted by the participants at the first meeting and have been used to guide the ongoing work of the Group. The objectives are:

- to develop of a small set(s) of general disability measures, suitable for use in censuses, sample based national surveys, or other statistical formats, which will provide basic necessary information on disability throughout the world.
- to recommend one or more extended sets of survey items to measure disability or principles for their design, to be used as components of population surveys or as supplements to specialty surveys. These extended sets of survey items will be related to the general measures.

It was further accepted that the measures identified in Objectives 1 and 2 would be culturally comparable to the extent possible and that the ICF model would be utilized in developing the measures. It was also agreed that the Group would address the most pressing methodological issues associated with the measurement of disability.

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<sup>16</sup> [http://www.cdc.gov/nchs/ppt/citygroup/meeting10/WG10\\_Session1\\_3\\_Agafitei.pdf](http://www.cdc.gov/nchs/ppt/citygroup/meeting10/WG10_Session1_3_Agafitei.pdf)

The outcome of this international work has been the development of:

- a short set of questions that have been tested in numerous countries and implemented by countries in their most recent censuses,
- a proposal for an extended set of questions,
- an examination of the current state of the art and the issues for developing questions to identify children with disabilities, and
- an examination of the current state of the art and the issues for developing questions to identify environmental barriers and facilitators.

### **8.1 *The short set of questions***

The WG agreed that measurement of disability in countries is associated with a variety of purposes which relate to different dimensions of disability and/or different conceptual components of disability models. It was further agreed that there needed to be a clear link between the purpose of measurement and the operationalization of indicators of disability. Equalization of opportunities was agreed upon and selected as the purpose for the development of an internationally comparable general disability measure. In order to address this purpose, the starting point was the identification of persons who are at greater risk than the general population of experiencing restrictions in performing tasks such as activities of daily living or participating in roles such as working or going to school.

Based on these decisions, the WG developed a short set of questions designed to provide comparable data cross-nationally for populations living in a great variety of cultures with varying economic resources. The objective was to identify persons with similar types and levels of limitations in basic activity functioning regardless of nationality or culture. It was recognized that this short set may not meet all the needs for disability data, nor would it replicate a population identified through a larger set of questions.

The following is the set of questions on disability endorsed by the WG on July 8, 2009 identify six types of difficulties related to a health problem.

**Introductory Phrase:** The next questions ask about difficulties you may have doing certain activities because of a **HEALTH PROBLEM**.

#### **Set of 6 Questions**

1. Do you have difficulty seeing, even if wearing glasses?
  - a. No - no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all
2. Do you have difficulty hearing, even if using a hearing aid?
  - a. No- no difficulty
  - b. Yes – some difficulty

- c. Yes – a lot of difficulty
  - d. Cannot do at all
3. Do you have difficulty walking or climbing steps?
- a. No- no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all
4. Do you have difficulty remembering or concentrating?
- a. No – no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all
5. Do you have difficulty (with self-care such as) washing all over or dressing?
- a. No – no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all
6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?
- a. No – no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all

The WG has prepared a document that provides the rationale for each question and the definitions for various words that are imbedded in each question.<sup>17</sup>

According to the WG, the four sub-categories within each of the six questions afford countries the flexibility to decide who, within their country, would be considered as having a disability. For example, Country X may decide that only persons who respond “Cannot do at all” to at least one of the six questions while country Y may decide that any person who answers at least one “Yes – some disability” would be considered as having a disability.

## **8.2 *The extended set of questions***

The WG, in partnership with the United Nations Economic Commission for Asia and the Pacific (UNESCAP), have been working on an extended set of questions to identify people with disabilities. The version provided for the 10<sup>th</sup> meeting of the WG is attached as Annex D. This

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<sup>17</sup> [http://www.cdc.gov/nchs/data/washington\\_group/meeting6/appendix1\\_QxQ.pdf](http://www.cdc.gov/nchs/data/washington_group/meeting6/appendix1_QxQ.pdf)

set of questions is by no means final and this work overlaps with the work being done under the aegis of the Budapest Initiative.

### **8.3 Continuing work of the WG**

The focus for work over the next 12 months – leading up to the next meeting in Bermuda in November 2011 will include:

- additional development of the extended set of questions including the expansion of the cognitive testing in the Middle East, Africa and South America;
- continuation of the work of the children’s Working Group on the development of questions to identify children with disabilities; and
- continuation of the work to develop a set of questions to identify environmental barriers and facilitators.

## **9. The Budapest Initiative**

Members from the UN Economic Commission for Europe (UNECE), the World Health Organization (WHO) and Eurostat met in May 2004 to discuss the measurement of health status under the auspices of the Conference of European Statisticians (CES). The meeting focussed on the need for internationally comparable measurement of population health status within the framework of official statistics. During the meeting of this same group in November 2005, it was recommended, both for easy reference and identity purposes, to label the current UNECE/WHO/Eurostat work on health as the Budapest Initiative (BI).

The main purpose of the BI is to develop a new common instrument to measure health status in its multiple dimensions which would be included in population surveys as a recommended set of questions. Included in this instrument would be questions to identify activity limitation.

It is acknowledged that there is overlap between the work of the BI and the WG. The WG meeting held in Luxembourg in 2010 was a joint meeting of the two groups.

A version of the questionnaire was submitted for approval in February 2007. The questionnaire has evolved since then through cognitive testing and Version 13 of the questionnaire used in the 2010 cognitive testing phase is included in the report as Annex E.

In January 2010, the BI Steering Group’s Terms of Reference were extended to October 2013 and modified to include:

- to evaluate the results of BI-M1 data collection and work toward the refinement and finalisation of the agreed on question set;
- to conduct further development and testing of BI-M2 for finalization and approval in collaboration with the WG, health-related Eurostat projects and UNESCAP Disability Project;

- to provide Eurostat with a final BI-M2 question set and evidence from cognitive/field testing to justify changes between the BI-M1 and BI-M2 questionnaire versions;
- to document the work of the BI for future reference, such as lessons learned and testing methodology; and
- to disseminate BI materials through a website, including the results of testing and guidelines for the translation protocol.

## **10. World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0)**

The WHODAS 2.0 is grounded in the conceptual framework of the ICF and captures an individual's level of functioning in six major life domains: (i) cognition (understanding and communication); (ii) mobility (ability to move and get around); (iii) self-care (ability to attend to personal hygiene, dressing and eating, and to live alone); (iv) getting along (ability to interact with other people); (v) life activities (ability to carry out responsibilities at home, work and school); (vi) participation in society (ability to engage in community, civil and recreational activities). All domains were developed from a comprehensive set of ICF items and made to correspond directly with ICF's "activity and participation" dimension. For all six domains, the WHODAS 2.0 provides a profile and a summary measure of functioning and disability that is reliable and applicable across cultures in adult populations.

The WHODAS 2.0 can be used for many purposes. It can be used for conducting population surveys, for registers and for monitoring individual patient outcomes in clinical practice and in clinical trials of treatment effects.

The WHODAS 2.0 is comprised of a series of instruments that have been tested in 19 countries. These instruments include a self-completion version, an interviewer administered version and a version for proxy administration. Each of the three versions includes two sets of questions – a 12-question set and a 36-question set. All versions and sets require a signed User Agreement. The various questionnaires and the User Agreement are available at <http://www.who.int/classifications/icf/whodasii/en/index.html>.

## **11. Health Utility Index (HUI)**

The Health Utilities Index (HUI) is a generic, preference-scored, comprehensive system for measuring health status, health-related quality of life, and producing utility scores. The family of measures includes the Health Utilities Index Mark 1 (HUI1), Mark 2 (HUI2), and Mark 3 (HUI3) systems. Each HUI measure includes a health-status classification system and a preference-based scoring formula. Although HUI1 is still used, HUI2 and HUI3 are much more frequently used both in clinical and population health studies.

Applications of HUI require that data be collected to classify the health status of each subject at a point in time. A variety of health status questionnaires and related procedure manuals are available to facilitate the application of HUI systems.

The 2006 PALS included the HU13 on the adult questionnaire.

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NOTE: Some references are imbedded with the report in the form of footnotes or with the text. These references are not repeated here.

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***The Health Utility Index (HUI)***

<http://fhs.mcmaster.ca/hug/>

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## **Annex A**

The 2009 SDAC questionnaire consists of 449 pages and is available from HRSDC as a separate document. Information on the 2009 SDAC, including a full list of data items, will be available in Disability, Ageing and Carers, Australia: User Guide, 2009 (cat. 4431.0.55.001), to be released in June.

## Annex B

This document was provided by Shari Mason, Senior Analyst, Disability, Statistics New Zealand.

### 2011 Disability Survey screening questions

#### 1. ADULTS

Respondents are considered to be disabled if they select at least one of the response categories marked with a cross in red font. Questions are shown for a non-proxy respondent. Text in square brackets refers to inserts that may be added to the question depending on responses to previous questions. Text in blue is interviewer notes which are not read out.

Question	Response categories
<p>Can you hear what is said in a conversation with one other person: easily, with difficulty, or not at all?</p>	<p>11 <input type="checkbox"/> easily 12 <input checked="" type="checkbox"/> with difficulty 13 <input checked="" type="checkbox"/> not at all</p>
<p>Not counting noisy places such as a cafe, can you hear what is said in a group conversation with three other people: easily, with difficulty, or not at all?</p> <p><i>Count situations where more than one conversation is going on.</i></p>	<p>11 <input type="checkbox"/> easily 12 <input checked="" type="checkbox"/> with difficulty 13 <input checked="" type="checkbox"/> not at all</p>
<p>Because of a long-term condition or health problem do you have any difficulty speaking and being understood?</p> <p><i>IF NECESSARY:</i> Some of these questions may not apply but I do need to ask them all.</p> <p><i>If other people have difficulty understanding the person, select 'yes'.</i></p>	<p>1 <input checked="" type="checkbox"/> yes 2 <input type="checkbox"/> no</p>
<p>Can you see ordinary newspaper print [with glasses or contact lenses if you usually wear them]: easily, with difficulty, or not at all?</p> <p><i>This question is about seeing, NOT about reading.</i></p> <p><i>If the person can see easily but is not good at reading, select 'easily.'</i></p>	<p>11 <input type="checkbox"/> easily 12 <input checked="" type="checkbox"/> with difficulty 13 <input checked="" type="checkbox"/> not at all</p>

<p>Can you clearly see the face of someone across a room, that is from four metres away [with glasses or contact lenses if you usually wear them]:</p> <p>easily, with difficulty, or not at all?</p> <p><i>Four metres is the same as 12 feet.</i></p>	<p>11 <input type="checkbox"/> easily 12 <input checked="" type="checkbox"/> with difficulty 13 <input checked="" type="checkbox"/> not at all</p>
<p>Can you walk the distance around a rugby field, without resting, that is about 350 metres:</p> <p>easily, with difficulty, or not at all?</p> <p><i>350 metres is about a quarter of a mile.</i></p> <p><i>If the person can walk 350 metres easily using a walking stick or some other aid, select 'easily'.</i></p>	<p>11 <input type="checkbox"/> easily 12 <input checked="" type="checkbox"/> with difficulty 13 <input checked="" type="checkbox"/> not at all</p>
<p>Can you walk up and down a flight of stairs, that is about 12 steps:</p> <p>easily, with difficulty, or not at all?</p> <p><i>The person must be able to do both (up and down), but not necessarily one after the other.</i></p>	<p>11 <input type="checkbox"/> easily 12 <input checked="" type="checkbox"/> with difficulty 13 <input checked="" type="checkbox"/> not at all</p>
<p>Can you carry something as heavy as a 5 kilogram bag of potatoes, while walking, for 10 metres. That is about the length of three cars parked alongside the footpath:</p> <p>easily, with difficulty, or not at all?</p> <p><i>5 kilograms is about 10 pounds.</i> <i>10 metres is about 30 feet.</i></p>	<p>11 <input type="checkbox"/> easily 12 <input checked="" type="checkbox"/> with difficulty 13 <input checked="" type="checkbox"/> not at all</p>
<p>Can you move from one room to another:</p> <p>easily, with difficulty, or not at all?</p> <p><i>If the person can move from room to room easily in a wheelchair or using some other aid, select 'easily'.</i></p>	<p>11 <input type="checkbox"/> easily 12 <input checked="" type="checkbox"/> with difficulty 13 <input checked="" type="checkbox"/> not at all</p>
<p>Can you stand for 20 minutes:</p> <p>easily, with difficulty, or not at all?</p> <p><i>If the person can stand easily using crutches or another aid, select 'easily'.</i></p>	<p>11 <input type="checkbox"/> easily 12 <input checked="" type="checkbox"/> with difficulty 13 <input checked="" type="checkbox"/> not at all</p>

<p>Can you bend down and pick something up off the floor: easily, with difficulty, or not at all?</p>	<p>11 <input type="checkbox"/> easily 12 <input checked="" type="checkbox"/> with difficulty 13 <input checked="" type="checkbox"/> not at all</p>
<p>Can you get in and out of bed by yourself: easily, with difficulty, or not at all?</p>	<p>11 <input type="checkbox"/> easily 12 <input type="checkbox"/> with difficulty 13 <input type="checkbox"/> not at all</p> <p>Note this is not a screening question. If people answer '12' or '13', they are asked the next question.</p>
<p>Is that because of a long-term condition or health problem?</p>	<p>1 <input checked="" type="checkbox"/> yes 2 <input type="checkbox"/> no</p>
<p>Can you reach in any direction, for example above your head: easily, with difficulty, or not at all?</p>	<p>11 <input type="checkbox"/> easily 12 <input checked="" type="checkbox"/> with difficulty 13 <input checked="" type="checkbox"/> not at all</p>
<p>Can you dress and undress yourself: easily, with difficulty, or not at all?</p>	<p>11 <input type="checkbox"/> easily 12 <input checked="" type="checkbox"/> with difficulty 13 <input checked="" type="checkbox"/> not at all</p>
<p>Can you cut your own fingernails or toenails: easily, with difficulty, or not at all?</p> <p><i>This question is about agility and strength of hands and fingers.</i></p> <p><i>If the person has difficulty ONLY because nails are very tough, select 'easily'.</i> <i>If the person can cut fingernails easily but cannot reach toenails, select 'easily'.</i></p>	<p>11 <input type="checkbox"/> easily 12 <input checked="" type="checkbox"/> with difficulty 13 <input checked="" type="checkbox"/> not at all</p>
<p>Can you use your fingers to grasp or handle things like scissors or pliers: easily, with difficulty, or not at all?</p>	<p>11 <input type="checkbox"/> easily 12 <input checked="" type="checkbox"/> with difficulty 13 <input checked="" type="checkbox"/> not at all</p>
<p>Can you cut your own food, for example, meat or fruit: easily, with difficulty, or not at all?</p>	<p>11 <input type="checkbox"/> easily 12 <input checked="" type="checkbox"/> with difficulty 13 <input checked="" type="checkbox"/> not at all</p>

<p>Do you have a long-term condition or health problem that makes it hard in general for you to learn?</p> <p><i>IF NECESSARY:</i> Some of these questions may be repetitive, and some may not apply, but I do need to ask them all.</p> <p><i>This question is about the capacity to learn new things.</i></p> <p><i>If the person has difficulty ONLY because of physical barriers or physical limitations, select 'no'.</i></p>	<p>1 <input checked="" type="checkbox"/> yes</p> <p>2 <input type="checkbox"/> no</p>
<p>Do you have a long-term condition or health problem that causes you on-going difficulty with your ability to remember?</p> <p><i>Do NOT count occasional memory lapses.</i></p>	<p>1 <input checked="" type="checkbox"/> yes</p> <p>2 <input type="checkbox"/> no</p>
<p>Do you need support or help from other people or organisations because of an intellectual disability?</p> <p><i>If the person gets support from an individual, or an organisation/group such as IHC or People First, select 'yes'.</i></p>	<p>1 <input checked="" type="checkbox"/> yes</p> <p>2 <input type="checkbox"/> no</p>
<p>Did you go to a special school or receive special education because of an intellectual disability?</p>	<p>1 <input checked="" type="checkbox"/> yes</p> <p>2 <input type="checkbox"/> no</p>
<p>Does a long-term emotional, psychological, or psychiatric condition cause you difficulty doing everyday activities that people your age can usually do?</p> <p>Common conditions include depression, anxiety or bipolar disorder.</p>	<p>1 <input checked="" type="checkbox"/> yes</p> <p>2 <input type="checkbox"/> no</p>
<p>Does a long-term emotional, psychological or psychiatric condition cause you difficulty communicating, mixing with others, or socialising?</p>	<p>1 <input checked="" type="checkbox"/> yes</p> <p>2 <input type="checkbox"/> no</p>

## 2. CHILDREN

Children are considered to be disabled if at least one of the response categories marked with a cross (in red font) are selected. Questions may only be asked if children are in a certain age group. Text in square brackets refers to inserts that may be added to the question depending on responses to previous questions. Text in blue is interviewer notes which are not read out.

Question	Response categories	Age group answering this question
<p><i>[iUsingAid]</i> Can <i>[iName]</i> hear: easily, with difficulty, or not at all?</p> <p><i>This question is only about hearing NOT listening.</i></p>	<p>11 <input type="checkbox"/> easily</p> <p>12 <input checked="" type="checkbox"/> with difficulty</p> <p>13 <input checked="" type="checkbox"/> not at all</p>	0-14 years

<p>Because of a long-term condition or health problem, does [iName] have any difficulty speaking and being understood [iByFamilyMembers] ?</p> <p><i>IF NECESSARY:</i> Some of these questions may not apply but I do need to ask them all.</p>	<p>1 <input checked="" type="checkbox"/> yes 2 <input type="checkbox"/> no</p>	<p>2-14 years</p>
<p>[iWithGlasses] Can [iName] see: easily, with difficulty, or not at all?</p>	<p>11 <input type="checkbox"/> easily 12 <input checked="" type="checkbox"/> with difficulty 13 <input checked="" type="checkbox"/> not at all</p>	<p>0-14 years</p>
<p>Can [iName] stand: easily, with difficulty, or not at all?</p> <p><i>If the child can stand easily with braces or crutches, select 'easily'.</i></p>	<p>11 <input type="checkbox"/> easily 12 <input checked="" type="checkbox"/> with difficulty 13 <input checked="" type="checkbox"/> not at all</p>	<p>2-14 years</p>
<p>Compared with other children [iHisHer] age, can [iName] bend down: easily, with difficulty, or not at all?</p>	<p>11 <input type="checkbox"/> easily 12 <input checked="" type="checkbox"/> with difficulty 13 <input checked="" type="checkbox"/> not at all</p>	<p>2-14 years</p>
<p>Can [iName] move from one room to another at home: easily, with difficulty, or not at all?</p> <p><i>This question is about the child's ability to move NOT about difficulties with the home such as narrow doorways. If the child can move easily using a wheelchair, crutches, or a walker, select 'easily'.</i></p>	<p>11 <input type="checkbox"/> easily 12 <input checked="" type="checkbox"/> with difficulty 13 <input checked="" type="checkbox"/> not at all</p>	<p>2-14 years</p>
<p>Compared with other children [iHisHer] age, can [iName] walk on a flat footpath: easily, with difficulty, or not at all?</p>	<p>11 <input type="checkbox"/> easily 12 <input checked="" type="checkbox"/> with difficulty 13 <input checked="" type="checkbox"/> not at all</p>	<p>2-14 years</p>

<p><i>[iComparedWithOtherChildren]Can [iName] use [iHisHer] hands to grasp an object such as a spoon or a [iCrayonPencil]:</i></p> <p>easily, with difficulty, or not at all?</p> <p><i>This question is about grasping NOT about using the object.</i></p>	<p>11 <input type="checkbox"/> easily</p> <p>12 <input checked="" type="checkbox"/> with difficulty</p> <p>13 <input checked="" type="checkbox"/> not at all</p>	<p>2-14 years</p>
<p>Compared with other children <i>[iHisHer]</i> age, can <i>[iName]</i> take off <i>[iHisHer]</i> T-shirt:</p> <p>easily, with difficulty, or not at all?</p>	<p>11 <input type="checkbox"/> easily</p> <p>12 <input type="checkbox"/> with difficulty</p> <p>13 <input type="checkbox"/> not at all</p> <p>Note this is not a screening question. If people answer '12' or '13', they are asked the next question.</p>	<p>5-14 years</p>
<p>Is that because <i>[iHeShe]</i> has difficulty raising <i>[iHisHer]</i> arms?</p>	<p>1 <input checked="" type="checkbox"/> yes</p> <p>2 <input type="checkbox"/> no</p>	<p>5-14 years</p>
<p>Does <i>[iName]</i> have a condition or health problem that makes it hard in general for <i>[iHimHer]</i> to learn?</p> <p><i>IF NECESSARY:</i> Some of these questions may be repetitive, and some may not apply, but I do need to ask them all.</p> <p><i>This question is about the capacity to learn new things.</i></p> <p><i>If the child has difficulty ONLY because of physical barriers to learning a task, or physical limitations on attending a place of learning, select 'no'.</i></p>	<p>1 <input checked="" type="checkbox"/> yes</p> <p>2 <input type="checkbox"/> no</p>	<p>5-14 years</p>
<p>Does <i>[iName]</i> have a recognised intellectual disability?</p>	<p>1 <input checked="" type="checkbox"/> yes</p> <p>2 <input type="checkbox"/> no</p>	<p>5-14 years</p>

<p>Most children have occasional emotional, nervous, or behavioural problems.</p> <p>Does <i>[iName]</i> have any of these problems long-term, that limits the type or amount of activity that <i>[iHeShe]</i> can do?</p> <p><i>These problems can include excessive worrying, intense fear, or aggressive behaviours.</i></p>	<p>1 <input checked="" type="checkbox"/> yes 2 <input type="checkbox"/> no</p>	<p>5-14 years</p>
<p>Does a long-term psychological or mental health condition make it difficult for <i>[iName]</i> to do everyday activities?</p>	<p>1 <input checked="" type="checkbox"/> yes 2 <input type="checkbox"/> no</p>	<p>5-14 years</p>
<p>Has <i>[iName]</i> been diagnosed with a disorder or impairment that significantly delays <i>[iHisHer]</i> development?</p>	<p>1 <input checked="" type="checkbox"/> yes 2 <input type="checkbox"/> no</p>	<p>0-4 years</p>

## Annex C

This set of questions was provided by Padraig Dalton, Central Statistics Office, Cork, Ireland.



Directorate F: Social and Information Society statistics  
Unit F-5: Health and food safety; Crime

### 2011 Labour Force Survey ad hoc module on Employment of Disabled People

#### EU-LFS 2011 AD-HOC MODULE ON EMPLOYMENT OF DISABLED PEOPLE

Opening filter if  $15 \leq \text{age} \leq 64$

*All persons aged 15 to 64 inclusive*

*INTERVIEWER: READ "The following questions aim at identifying the extent to which people are limited in their work and the nature or type of this limitation."*

Press '1' to continue

#### 1. HEAL\_CON

Do you have any of the following types of longstanding health conditions or disease that are on this list?

**Show card**

01. Problems with arms or hands (which includes arthritis or rheumatism)
02. Problems with legs or feet (which includes arthritis or rheumatism)

03. Problems with back or neck (which includes arthritis or rheumatism)
04. Cancer
05. Skin conditions, including allergic reactions and severe disfigurement
06. Heart, blood pressure or circulation problems
07. Chest or breathing problems, including asthma and bronchitis
08. Stomach, liver, kidney or digestive problems
09. Diabetes
10. Epilepsy (include fits)
11. Severe headache such as migraine
12. Learning difficulties (reading, spelling or math disability)
13. Chronic anxiety
14. Depression
15. Other mental, nervous or emotional problems
16. Other progressive illnesses (which include multiple sclerosis, HIV, Alzheimer's disease, Parkinson's disease)
17. Other longstanding health problems

Interviewer to code

1. Yes
2. No

**2. CON\_TYP1**

**If HEAL\_CON = 1**

***The respondent has one of the longstanding health conditions***

Please point out what you consider your most severe condition

Interviewer to put in corresponding code

code of the 1<sup>st</sup> type of longstanding health condition or disease

**3. CON\_TYP2**

**If HEAL\_CON = 1**

***The respondent has one of the longstanding health conditions***

... and your next most severe condition?

Interviewer to put in corresponding code 00 if they do not have a second condition

□□ code of the 2<sup>nd</sup> type of longstanding health condition or disease

**[ON SCREEN] Note to interviewer if respondent does not have a second condition code 00**

**4. LMHRSHC**

**If HEAL\_CON = 1**

**If the respondent has a health condition**

Does your health condition limit the number of hours that you can work in a week?

1. Yes
2. No

**5. LMTYPHC**

**If HEAL\_CON = 1**

**If the respondent has a health condition**

Does it limit the type of work that you can do (for instance, having problems in carrying heavy loads, working outdoors or sitting for a long time)?

1. Yes
2. No

**6. LMFRMHC**

**If HEAL\_CON = 1 and ilostat2 in (1,2,3,4,5) If the respondent has a health condition**

Does it make it difficult getting to and from work?

1. Yes
2. No

**7. HPWKHC**

**If HEAL\_CON = 1 and ilostat2 in (1,2,3,4,5)**

**If the respondent has a health condition and is working**

Do you use personal assistance at work due to your health condition?

1. Yes
2. No

**8. ADWKHC**

**If HEAL\_CON = 1 and ilostat2 in (1,2,3,4,5)**

**If the respondent has a health condition and is working**

Do you use special equipment or have adaptations at work due to your health condition?

1. Yes
2. No

**9. ORGWKHC**

**If HEAL\_CON = 1 and ilostat2 in (1,2,3,4,5)**

**If the respondent has a health condition and is working**

Do you have special working arrangements due to your health condition?

1. Yes

2. No

**10. HPUHC**

**If HEAL\_CON = 1 and ilostat2 not in (1,2,3,4,5)**

**If the respondent has a health condition and is not working**

Would you need personal assistance to be able to work due to your health condition?

1. Yes
2. No

**11. ADUHC**

**If HEAL\_CON = 1 and ilostat2 not in (1,2,3,4,5)**

**If the respondent has a health condition and is not working**

Would you need special equipment or need adaptations at work due to your health condition to be able to work?

1. Yes
2. No

**12. ORGUHC**

**If HEAL\_CON = 1 and ilostat2 not in (1,2,3,4,5)**

**If the respondent has a health condition and is not working**

Would you need special working arrangements due to your health condition to be able to work?

1. Yes
2. No

**13. ACT\_DIFF**

***All persons aged 15 to 64 inclusive***

Do you have difficulties with any of the following basic activities?

**Interviewer show the respondent the 2<sup>nd</sup> show card**

- 01 Seeing, even if wearing glasses
- 02 Hearing, even if using a hearing aid
- 03 Walking, climbing steps
- 04 Sitting or standing
- 05 Remembering, concentrating
- 06 Communicating, for example understanding or being understood
- 07 Reaching or stretching
- 08 Lifting and carrying
- 09 Bending
- 10 Holding, gripping, or turning

- 1. Yes
- 2. No

**14. DIFF\_TYP1**

**If ACT\_DIF = 1**

**If the respondent has a difficulty**

Which do you consider causes you the most difficulty?

□□ code of the 1<sup>st</sup> basic activity

**15. DIFF\_TYP2**

**If ACT\_DIF = 1 If the respondent has a difficulty**

And the next most difficult

□□ code of the 2<sup>nd</sup> basic activity

**16. SORRY**

If HEAL\_CON = 1 and ACT\_DIF = 1

If the respondent has a health condition and an activity difficulty

I'm now going to ask a couple of similar questions but in relation to your activity difficulty

**17. LMHRSAD**

If ACT\_DIF = 1 If the respondent has an activity difficulty

Does your activity difficulty limit the number of hours that you can work in a week?

1. Yes
2. No

**18. LMTYPAD**

If ACT\_DIF = 1

If the respondent has an activity difficulty

Does your activity difficulty limit the type of work that you can do (for instance, having problems in carrying heavy loads, working outdoors or sitting for a long time)?

1. Yes
2. No

**19. LMFRMAD**

If ACT\_DIF = 1 If the respondent has an activity difficulty

Does your activity difficulty it make it difficult getting to and from work?

1. Yes
2. No

**20. HPWKAD**

**If ACT\_DIF = 1 and ilostat2 in (1,2,3,4,5)**

**If the respondent has an activity difficulty and is working**

Do you use personal assistance at work due to your activity difficulty?

1. Yes
2. No

**21. ADWKAD**

**If ACT\_DIF = 1 and ilostat2 in (1,2,3,4,5) If the respondent has an activity difficulty and is working**

Do you use special equipment or have adaptations at work due to your activity difficulty?

1. Yes
2. No

**22. ORGWKAD**

**If ACT\_DIF = 1 and ilostat2 in (1,2,3,4,5) If the respondent has an activity difficulty and is working**

Do you have special working arrangements due to your activity difficulty?

1. Yes
2. No

**23. HPUAD**

**If ACT\_DIF = 1 and ilostat2 not in (1,2,3,4,5)**

**If the respondent has an activity difficulty and is not working**

Would you need personal assistance to be able to work due to your activity difficulty?

1. Yes
2. No

**24. ADUAD**

**If ACT\_DIF = 1 and ilostat2 not in (1,2,3,4,5) If the respondent has an activity difficulty and is not working**

Would you need special equipment or need at work due to your activity difficulty to be able to work?

1. Yes
2. No

**25. ORGUAD**

**If ACT\_DIF = 1 and ilostat2 not in (1,2,3,4,5)**

**If the respondent has an activity difficulty and is not working**

Would you need special working arrangements due to your activity difficulty to be able to work?

1. Yes
2. No

**26. LIMWORK**

If 15 <= age =< 64 and HEAL\_CON ne 1 and ACT\_DIF ne 1

***All persons aged 15 to 64 inclusive and have no health condition or activity difficulty***

Is there any reason that restricts the work you can do? (number of hours, type, transport, etc.)

1. Yes
2. No

**27. LMWRKHC**

If 15 <= age =< 64 and HEAL\_CON = 1 and ACT\_DIF ne 1 ***All persons aged 15 to 64 inclusive and have a health condition but no activity difficulty***

Is there any reason other than your health condition that restricts the work you can do? (number of hours, type, transport, etc.)

1. Yes
2. No

**28. LMWRKAD**

If 15 <= age =< 64 and HEAL\_CON ne 1 and ACT\_DIF = 1 ***All persons aged 15 to 64 inclusive and do not have a health condition but due have an activity difficulty***

Is there any reason other than your activity difficulty that restricts the work you can do? (number of hours, type, transport, etc.)

1. Yes
2. No

**29. LMWHCAD**

If 15 <= age =< 64 and HEAL\_CON = 1 and ACT\_DIF = 1

***All persons aged 15 to 64 inclusive and have a health condition and an activity difficulty***

Is there any reason other than your health condition or activity difficulty that restricts the work you can do? (number of hours, type, transport, etc.)

1. Yes
2. No

**30. MAINREAS**

**If LIMWORK = 1 or LMWRKHC = 1 or LMWRKAD = 1 or LMWHCAD**

**If the respondent has a restriction in the type of work they can do**

What is the main reason?

1. Lack of qualifications/experience
2. Lack of appropriate job opportunities
3. Lack or poor transportation to and from workplace
4. Employers' lack of flexibility
5. Affects receipt of benefits
6. Family/caring responsibilities
7. Personal reasons
8. Other reason

## Annex D

### The Joint Washington Group/ ESCAP FIELD TEST QUESTIONNAIRE

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#### SECTION A. INTERVIEW AND SOCIODEMOGRAPHIC INFORMATION

*Interviewer record:*

A\_1 Date of interview: \_\_\_\_\_

A\_2 Interviewer ID: \_\_\_\_\_

A\_3 Country: \_\_\_\_\_

A\_4 Place of interview: \_\_\_\_\_

A\_5 Language of interview: \_\_\_\_\_

A\_6 Respondent number: \_\_\_\_\_

A\_7 Respondent's sex: 1. Male 2. Female

A\_8 Proxy Respondent: 1. Yes 2. No

*If "No" to A\_8, skip to A\_10.*

A\_9 Relationship of proxy to respondent: \_\_\_\_\_

*Interviewer read:* I will begin with some background questions.

A\_10 How old are you now?  
\_\_\_\_ Number of years  
777. Refused  
999. Don't know

A\_11 How many years in all did you spend studying in school? Include any kind of school.  
\_\_\_\_ Number of years

777. *Refused*  
999. *Don't know*

A\_12 What is the highest level of schooling or post-schooling that you have completed?

*Interviewer: Record country-specific level of education.*

\_\_\_ Level of education

777. *Refused*  
999. *Don't know*

A\_13 What is your current marital status?

*Interviewer: Mark only one.*

1. Never married
2. Currently married
3. Separated
4. Divorced
5. Widowed
6. Cohabiting
7. *Refused*
9. *Don't know*

A\_14 Which describes your main activity?

*Interviewer: Mark only one.*

01. Paid work
02. Self-employed, such as own your business or farming
03. Non-paid work, such as volunteer or charity
04. Student / attending school
05. Keeping house / homemaker
06. Unemployed and looking for work
07. Unemployed and not looking for work
08. Retired
09. Other (please specify:)
77. *Refused*
99. *Don't know*

A\_15 Using this card, please tell me which letter describes your household's total income. If you don't know the exact figure, please give an estimate. Use the part of the card that you know best: weekly, monthly or annual income.

*Interviewer: Show Card A to respondent. Record the appropriate response category.*

## A\_15 INCOME DECILES CARD

<b>YOUR <u>HOUSEHOLD</u> INCOME</b>				
	<b>Approximate WEEKLY</b>	<b>Approximate MONTHLY</b>	<b>Approximate ANNUAL</b>	
<b>J</b>	Weekly equivalent	Monthly equivalent	Income corresponding to that held by 10% of households with lowest income (0-10%)	<b>J</b>
<b>R</b>	Weekly equivalent	Monthly equivalent	Income corresponding to that held by next 10% of households (11-20%)	<b>R</b>
<b>C</b>	Weekly equivalent	Monthly equivalent	Income corresponding to that held by next 10% of households (21-30%)	<b>C</b>
<b>M</b>	Weekly equivalent	Monthly equivalent	Income corresponding to that held by next 10% of households (31-40%)	<b>M</b>
<b>F</b>	Weekly equivalent	Monthly equivalent	Income corresponding to that held by 10% of households (41-50%)	<b>F</b>
<b>S</b>	Weekly equivalent	Monthly equivalent	Income corresponding to that held by 10% of households (51-60%)	<b>S</b>
<b>K</b>	Weekly equivalent	Monthly equivalent	Income corresponding to that held by 10% of households (61-70%)	<b>K</b>
<b>P</b>	Weekly equivalent	Monthly equivalent	Income corresponding to that held by 10% of households (71-80%)	<b>P</b>
<b>D</b>	Weekly equivalent	Monthly equivalent	Income corresponding to that held by 10% of households (81-90%)	<b>D</b>
<b>H</b>	Weekly equivalent	Monthly equivalent	Income corresponding to that held by 10% of households (91-100%)	<b>H</b>

## SECTION B. VISION

VIS\_SS Do you have difficulty seeing, even when wearing glasses?

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do
7. *Refused*
9. *Don't know*

*If "Cannot do at all / Unable to do" to VIS\_SS, skip to VIS\_5.*

VIS\_1 Do you wear glasses to see far away?

1. Yes
2. No
7. *Refused*
9. *Don't know*

*If "Yes" to VIS\_1, include [glasses clause] in VIS\_2.*

VIS\_2 Do you have difficulty clearly seeing someone's face across a room [even when wearing these glasses]?

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do
7. *Refused*
9. *Don't know*

VIS\_3 Do you wear glasses for reading or to see up close?

1. Yes
2. No
7. *Refused*
9. *Don't know*

*If "Yes" to VIS\_3, include [glasses clause] in VIS\_4.*

VIS\_4 Do you have difficulty clearly seeing the picture on a coin [even when wearing these glasses]?

1. No difficulty
2. Some difficulty
3. A lot of difficulty

- 4. Cannot do at all / Unable to do
- 7. *Refused*
- 9. *Don't know*

If "No difficulty" to VIS\_SS and "No difficulty" to VIS\_2 and "No difficulty" to VIS\_4, skip to Section C Hearing.

VIS\_5 How old were you when the difficulty seeing began?

\_\_\_\_\_ Age in years

777. *Refused*

999. *Don't know*

VIS\_6 How much does your difficulty seeing limit your ability to carry out daily activities?

- 1. Not at all
- 2. A little
- 3. A lot
- 4. Completely
- 7. *Refused*
- 9. *Don't know*

P\_VIS\_6 Which of the following activities, if any, are you unable to do, or find it hard to do, because of your difficulty seeing?

		1. Yes	2. No	7. <i>Refused</i>	8. <i>Not applicable</i>	9. <i>Don't know</i>
A.	Working to support you or your family?					
B.	Working outside the home to earn an income?					
C.	Going to school or achieving your education goals?					
D.	Participating in leisure or social activities?					
E.	Getting out with friends or family?					
F.	Doing household chores such as cooking and cleaning?					
G.	Using transportation to get to places you want to go?					
H.	Participating in religious activities?					
I.	Participating in community gatherings?					

## SECTION C. HEARING

- HEAR\_SS      Do you have difficulty hearing, even when using a hearing aid?
1. No difficulty
  2. Some difficulty
  3. A lot of difficulty
  4. Cannot do at all / Unable to do
  7. *Refused*
  9. *Don't know*

*If "Cannot do at all / Unable to do" to HEAR\_SS, skip to HEAR\_5.*

- HEAR\_1      Do you use a hearing aid?
1. Yes
  2. No
  7. *Refused*
  9. *Don't know*

*If "No" to HEAR\_1, skip to HEAR\_3 and omit [hearing aid clause] in HEAR\_3 and HEAR\_4.*

*If "Yes" to HEAR\_1, continue with HEAR\_2 and include [hearing aid clause] in HEAR\_3 and HEAR\_4.*

- HEAR\_2      How often do you use your hearing aid(s)?
1. All of the time
  2. Some of the time
  3. Rarely
  4. Never
  7. *Refused*
  9. *Don't know*

- HEAR\_3      Do you have difficulty hearing what is said in a conversation with one other person in a quiet room [even when wearing your hearing aid(s)]?
1. No difficulty
  2. Some difficulty
  3. A lot of difficulty
  4. Cannot do at all / Unable to do
  7. *Refused*
  9. *Don't know*

*Interviewer: Complete BC\_1a, BC\_1b and BC\_1c by yourself and then continue with respondent question HEAR\_4.*

- BC\_1a      *Did the respondent need you to repeat any part of question HEAR\_3?*
1. Yes
  2. No
- BC\_1b      *Did the respondent have any difficulty using the response options?*
1. Yes
  2. No
- BC\_1c      *Did the respondent ask for clarification or qualify their answer?*
1. Yes
  2. No

*If “Cannot do at all / Unable to do” to HEAR\_3, skip to HEAR\_5.*

- HEAR\_4      Do you have difficulty hearing what is said in a conversation with one other person in a noisier room [even when wearing your hearing aid(s)]?
1. No difficulty
  2. Some difficulty
  3. A lot of difficulty
  4. Cannot do at all / Unable to do
  7. Refused
  9. Don't know

*Interviewer: Complete BC\_2a, BC\_2b and BC\_2c by yourself and then continue with respondent question HEAR\_5.*

- BC\_2a      *Did the respondent need you to repeat any part of question HEAR\_4?*
1. Yes
  2. No
- BC\_2b      *Did the respondent have any difficulty using the response options?*
1. Yes
  2. No
- BC\_2c      *Did the respondent ask for clarification or qualify their answer?*
1. Yes
  2. No

If “No difficulty” to HEAR\_SS and “No difficulty” to HEAR\_3 and “No difficulty” to HEAR\_4, skip to Section D Mobility.

HEAR\_5 How old were you when the difficulty hearing began?

\_\_\_\_\_ Age in years

777. *Refused*

999. *Don't know*

HEAR\_6 How much does your difficulty hearing limit your ability to carry out daily activities?

- 1. Not at all
- 2. A little
- 3. A lot
- 4. Completely
- 7. *Refused*
- 9. *Don't know*

P\_HEAR\_6 Which of the following activities, if any, are you unable to do, or find it hard to do, because of your difficulty hearing?

		1. Yes	2. No	7. <i>Refused</i>	8. <i>Not applicable</i>	9. <i>Don't know</i>
A.	Working to support you or your family?					
B.	Working outside the home to earn an income?					
C.	Going to school or achieving your education goals?					
D.	Participating in leisure or social activities?					
E.	Getting out with friends or family?					
F.	Doing household chores such as cooking and cleaning?					
G.	Using transportation to get to places you want to go?					
H.	Participating in religious activities?					
I.	Participating in community gatherings?					

## SECTION D. MOBILITY

MOB\_SS Do you have difficulty walking or climbing steps?

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do
7. *Refused*
9. *Don't know*

MOB\_1 Do you have difficulty moving around inside your home?

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do
7. *Refused*
9. *Don't know*

MOB\_2 Do you use any equipment or receive help for getting around?

1. Yes
2. No
7. *Refused*
9. *Don't know*

*"If "Yes" to MOB\_2, continue with MOB\_3 and include [aid clause] in MOB\_4, MOB\_5 and MOB\_6."*

*If "No" to MOB\_2, skip to MOB\_4 and omit [aid clause] in MOB\_4, MOB\_5 and MOB\_6.*

MOB\_3 Do you use any of the following?

		1. Yes	2. No	7. <i>Refused</i>	9 <i>Don't Know</i>
A.	Cane or walking stick?				
B.	Walker or Zimmer frame?				
C.	Crutches?				
D.	Wheelchair?				
E.	Artificial limb (leg/foot)?				
F.	Someone's assistance?				
G.	Other (please specify):				

*If respondent only answers "Wheelchair" to MOB\_3, skip to MOB\_10.*

- MOB\_4 Do you have difficulty walking 100 meters on level ground, that would be about the length of one football field or one city block [without the use of your aid]?
1. No difficulty
  2. Some difficulty
  3. A lot of difficulty
  4. Cannot do at all / Unable to do
  7. *Refused*
  9. *Don't know*

*If "Cannot do at all / Unable to do" at MOB\_4, skip to MOB\_6.*

- MOB\_5 Do you have difficulty walking half a km on level ground, that would be the length of five football fields or five city blocks [without the use of your aid]?
1. No difficulty
  2. Some difficulty
  3. A lot of difficulty
  4. Cannot do at all / Unable to do
  7. *Refused*
  9. *Don't know*

- MOB\_6 Do you have difficulty walking up or down 12 steps [without the use of your aid]?
1. No difficulty
  2. Some difficulty
  3. A lot of difficulty
  4. Cannot do at all / Unable to do
  7. *Refused*
  9. *Don't know*

- P\_MOB\_6 How much difficulty would you have walking up or down those steps without using a handrail [without the use of your aid]?
1. No difficulty
  2. Some difficulty
  3. A lot of difficulty
  4. Cannot do at all / Unable to do
  7. *Refused*
  9. *Don't know*

*If "Some difficulty", "A lot of difficulty" or "Cannot do at all" to any of MOB\_SS, MOB\_1, MOB\_4, MOB\_5, MOB\_6 and "No" to MOB\_2 skip to MOB\_10.*

*If "No difficulty" to MOB\_SS, MOB\_1, MOB\_4, MOB\_5, MOB\_6 and "No" to MOB\_2 then skip to Section E Communication. Otherwise, continue with MOB\_7*

- MOB\_7 Do you have difficulty walking 100 meters on level ground, that would be about the length of one football field or one city block, when using your aid?
1. No difficulty
  2. Some difficulty
  3. A lot of difficulty
  4. Cannot do at all / Unable to do
  7. *Refused*
  9. *Don't know*

*If "Cannot do at all / Unable to do" to MOB\_7, skip to MOB\_9.*

- MOB\_8 Do you have difficulty walking half a km on level ground, that would be the length of five football fields or five city blocks, when using your aid?
1. No difficulty
  2. Some difficulty
  3. A lot of difficulty
  4. Cannot do at all / Unable to do
  7. *Refused*
  9. *Don't know*

- MOB\_9 Do you have difficulty walking up or down 12 steps, even when using your aid?
1. No difficulty
  2. Some difficulty
  3. A lot of difficulty
  4. Cannot do at all / Unable to do
  7. *Refused*
  9. *Don't know*

*If "No difficulty" to MOB\_SS and MOB\_1 and MOB\_4 and MOB\_5 and MOB\_6 and MOB\_7 and MOB\_8 and MOB\_9, skip to Section E Communication.*

- MOB\_10 How old were you when the difficulty walking or climbing began?
- \_\_\_\_\_ Age in years
777. *Refused*
999. *Don't know*

- MOB\_11 How much does your difficulty walking or climbing limit your ability to carry out daily activities?
1. Not at all
  2. A little
  3. A lot
  4. Completely

7. *Refused*  
 9. *Don't know*

P\_MOB\_11 Which of the following activities, if any, are you unable to do, or find it hard to do, because of your difficulty walking or climbing stairs?

		1. Yes	2. No	7. <i>Refused</i>	8. <i>Not applicable</i>	9. <i>Don't know</i>
A.	Working to support you or your family?					
B.	Working outside the home to earn an income?					
C.	Going to school or achieving your education goals?					
D.	Participating in leisure or social activities?					
E.	Getting out with friends or family?					
F.	Doing household chores such as cooking and cleaning?					
G.	Using transportation to get to places you want to go?					
H.	Participating in religious activities?					
I.	Participating in community gatherings?					

## SECTION E. COMMUNICATION

COM\_SS Using your usual language, do you have difficulty communicating, for example understanding or being understood?

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do
7. *Refused*
9. *Don't know*

COM\_1 Do people have difficulty understanding you when you speak?

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do
7. *Refused*
9. *Don't know*

*If "No difficulty" or "Don't know" to COM\_SS and COM\_1 then skip to next section*

P\_COM\_1 Is this difficulty:

		1. Yes	2. No	7. <i>Refused</i>	9 <i>Don't Know</i>
A.	Because you sometimes feel shy or have trouble expressing yourself?				
B.	Because of a physical problem with your mouth or tongue?				
C.	Because you need to understand other languages or different ways of speaking?				
D.	Because you sometimes talk too fast?				
E.	Because you have trouble hearing?				

*If "No" to all P\_COM\_1, continue with P\_COM\_2. Otherwise, skip to COM\_2.*

P\_COM\_2 What is your difficulty related to?  
*Interviewer: Record answer* \_\_\_\_\_

COM\_2 Do you use sign language?

1. Yes
2. No
7. *Refused*

9. Don't know

If "No difficulty" to COM\_SS and "No difficulty" to COM\_1, skip to Section F Cognition.

COM\_3 How old were you when the difficulty communicating began?  
 \_\_\_\_\_ Age in years  
 777. Refused  
 999. Don't know

COM\_4 How much does your difficulty communicating limit your ability to carry out daily activities?  
 1. Not at all  
 2. A little  
 3. A lot  
 4. Completely  
 7. Refused  
 9. Don't know

P\_COM\_4 Which of the following activities, if any, are you unable to do, or find it hard to do, because of your difficulty communicating?

		1. Yes	2. No	7. Refused	8. Not applicable	9. Don't know
A.	Working to support you or your family?					
B.	Working outside the home to earn an income?					
C.	Going to school or achieving your education goals?					
D.	Participating in leisure or social activities?					
E.	Getting out with friends or family?					
F.	Doing household chores such as cooking and cleaning?					
G.	Using transportation to get to places you want to go?					
H.	Participating in religious activities?					
I.	Participating in community gatherings?					

## SECTION F. COGNITION (REMEMBERING)

- COG\_SS      Do you have difficulty remembering or concentrating?
1. No difficulty
  2. Some difficulty
  3. A lot of difficulty
  4. Cannot do at all / Unable to do
  7. *Refused*
  9. *Don't know*

*If "No difficulty" to COG\_SS, skip to Section G Upper Body.*

- COG\_1      Do you have difficulty remembering, concentrating, or both?
1. Difficulty remembering only
  2. Difficulty concentrating only
  3. Difficulty with both remembering and concentrating
  7. *Refused*
  9. *Don't know*

*If "Difficulty concentrating only" to COG\_1, skip to COG\_4.*

- COG\_2      How often do you have difficulty remembering?
1. Sometimes
  2. Often
  3. All of the time
  7. *Refused*
  9. *Don't know*

- COG\_3      Do you have difficulty remembering a few things, a lot of things, or almost everything?
1. A few things
  2. A lot of things
  3. Almost everything
  7. *Refused*
  9. *Don't know*

P\_COG\_3      Please tell me which of the following statements, if any, describe your difficulty remembering:

*Interviewer: please tick all that apply.*

		1. Yes	2. No	7. <i>Refused</i>	9 <i>Don't</i> <i>Know</i>
--	--	-----------	----------	----------------------	-------------------------------

A.	I forget things because I am busy and have too much to remember.				
B.	My difficulty is getting worse.				
C.	My difficulty has put me or my family in danger.				
D.	I only forget little or inconsequential things.				
E.	I must write down important things, such as my address or when to take medicine, so that I do not forget.				
F.	My family members or friends are worried about my difficulty remembering.				
G.	My difficulty is normal for someone my age.				

*If “Difficulty remembering only” to COG\_1, skip to COG\_6.*

COG\_4      How much difficulty do you have concentrating for ten minutes?

1. A little
2. A lot
3. Somewhere in between a little and a lot
7. *Refused*
9. *Don't know*

*Interviewer: Complete BC\_3a, BC\_3b and BC\_3c by yourself and then continue with respondent question COG\_5.*

*BC\_3a      Did the respondent need you to repeat any part of question COG\_4?*

1. *Yes*
2. *No*

*BC\_3b      Did the respondent have any difficulty using the response options?*

1. *Yes*
2. *No*

*BC\_3c      Did the respondent ask for clarification or qualify their answer?*

1. *Yes*
2. *No*

*If “Somewhere in between a little and a lot” to COG\_4, continue with COG\_5. Otherwise, skip to COG\_6.*

COG\_5      Would you say this is closer to a little, closer to a lot, or exactly in the middle?

1. Closer to a little
2. Closer to a lot

- 3. Exactly in the middle
- 7. *Refused*
- 9. *Don't know*

COG\_6      How old were you when the difficulty remembering or concentrating began?  
 \_\_\_\_\_ Age in years  
 777. *Refused*  
 999. *Don't know*

COG\_7      How much does your difficulty remembering or concentrating limit your ability to carry out daily activities?  
 1. Not at all  
 2. A little  
 3. A lot  
 4. Completely  
 7. *Refused*  
 9. *Don't know*

P\_COG\_7      Which of the following activities, if any, are you unable to do, or find it hard to do, because of your difficulty remembering or concentrating?

		1. Yes	2. No	7. <i>Refused</i>	8. <i>Not applicable</i>	9. <i>Don't know</i>
A.	Working to support you or your family?					
B.	Working outside the home to earn an income?					
C.	Going to school or achieving your education goals?					
D.	Participating in leisure or social activities?					
E.	Getting out with friends or family?					
F.	Doing household chores such as cooking and cleaning?					
G.	Using transportation to get to places you want to go?					
H.	Participating in religious activities?					
I.	Participating in community gatherings?					

## SECTION G. UPPER BODY

- UB\_SS Do you have difficulty with self care, such as washing all over or dressing?
1. No difficulty
  2. Some difficulty
  3. A lot of difficulty
  4. Cannot do at all / Unable to do
  7. *Refused*
  9. *Don't know*
- UB\_1 Do you have difficulty raising a 2 liter bottle of water or soda from waist to eye level?
1. No difficulty
  2. Some difficulty
  3. A lot of difficulty
  4. Cannot do at all / Unable to do
  7. *Refused*
  9. *Don't know*
- P\_UB\_1 Can you tell me how you arrived at your answer? Why did you answer  
[Interviewer: fill in respondent's answer to UB\_1]?  
Interviewer: Record answer \_\_\_\_\_  
\_\_\_\_\_
- UB\_2 Do you have difficulty using your hands and fingers, such as picking up small objects, for example, a button or pencil, or opening or closing containers or bottles?
1. No difficulty
  2. Some difficulty
  3. A lot of difficulty
  4. Cannot do at all / Unable to do
  7. *Refused*
  9. *Don't know*
- P\_UB\_2 In answering this last question, were you thinking about bending down to pick up an object from the floor, picking up an object from a table, or something else?
1. From the floor
  2. From a table
  3. Something else (please specify):
  7. *Refused*
  9. *Don't know*

If “No difficulty” to UB\_SS and “No difficulty” to UB\_1 and “No difficulty” to UB\_2, skip to Section H Learning.

UB\_3            How old were you when the difficulty lifting or using your hands and fingers began?  
                               \_\_\_\_\_ Age in years  
                               777. *Refused*  
                               999. *Don't know*

UB\_4            How much does your difficulty lifting or using your hands and fingers limit your ability to carry out daily activities?  
                               1. Not at all  
                               2. A little  
                               3. A lot  
                               4. Completely  
                               7. *Refused*  
                               9. *Don't know*

P\_UB\_4        Which of the following activities, if any, are you unable to do, or find it hard to do, because of your difficulty lifting or using your hands and fingers?

		1. Yes	2. No	7. <i>Refused</i>	8. <i>Not applicable</i>	9. <i>Don't know</i>
A.	Working to support you or your family?					
B.	Working outside the home to earn an income?					
C.	Going to school or achieving your education goals?					
D.	Participating in leisure or social activities?					
E.	Getting out with friends or family?					
F.	Doing household chores such as cooking and cleaning?					
G.	Using transportation to get to places you want to go?					
H.	Participating in religious activities?					
I.	Participating in community gatherings?					

## SECTION H. LEARNING

- LEARN\_1 Do you have difficulty learning the rules for a new game?
1. No difficulty
  2. Some difficulty
  3. A lot of difficulty
  4. Cannot do at all / Unable to do
  7. *Refused*
  9. *Don't know*

*Interviewer: Only for respondents 17 years of age or over, continue with LEARN\_2. Otherwise, skip to LEARN\_3.*

- LEARN\_2 Do you have difficulty understanding and following instructions for example, to use a new cell phone or to get to a new place?
1. No difficulty
  2. Some difficulty
  3. A lot of difficulty
  4. Cannot do at all / Unable to do
  7. *Refused*
  9. *Don't know*

- P\_LEARN\_2 Can you tell me how you arrived at your answer? Why did you answer  
[Interviewer: fill in respondent's answer to LEARN\_2]?  
Interviewer: Record answer \_\_\_\_\_  
\_\_\_\_\_

*If "No difficulty" to LEARN\_1(a) or LEARN\_2, skip to Section I Affect.*

- LEARN\_3 How old were you when the difficulty understanding and using information began?
- \_\_\_\_\_ Age in years
777. *Refused*
  999. *Don't know*

- LEARN\_4 How much does your difficulty [learning / understanding and using information] limit your ability to carry out daily activities?
1. Not at all
  2. A little
  3. A lot
  4. Completely
  7. *Refused*
  9. *Don't know*

P\_LEARN\_4 Which of the following activities, if any, are you unable to do, or find it hard to do, because of your difficulty [learning / understanding and using information]?

		1. Yes	2. No	7. <i>Refu sed</i>	8. <i>Not applic able</i>	9. <i>Don't know</i>
A.	Working to support you or your family?					
B.	Working outside the home to earn an income?					
C.	Going to school or achieving your education goals?					
D.	Participating in leisure or social activities?					
E.	Getting out with friends or family?					
F.	Doing household chores such as cooking and cleaning?					
G.	Using transportation to get to places you want to go?					
H.	Participating in religious activities?					
I.	Participating in community gatherings?					

## SECTION I. AFFECT (ANXIETY AND DEPRESSION)

ANX\_1 How often do you feel worried, nervous or anxious?

1. Daily
2. Weekly
3. Monthly
4. A few times a year
5. Never
7. *Refused*
9. *Don't know*

ANX\_2 Do you take medication for these feelings?

1. Yes
2. No
7. *Refused*
9. *Don't know*

*If "never" to ANX\_1 and "No" to ANX\_2, skip to DEP\_1.*

ANX\_3 Thinking about the last time you felt worried, nervous or anxious, how would you describe the level of these feelings?

1. A little
2. A lot
3. Somewhere in between a little and a lot
7. *Refused*
9. *Don't know*

*If "Somewhere in between a little and a lot" to ANX\_3, continue with ANX\_4. Otherwise, skip to P\_ANX\_4.*

ANX\_4 Would you say this was closer to a little, closer to a lot, or exactly in the middle?

1. Closer to a little
2. Closer to a lot
3. Exactly in the middle
7. *Refused*
9. *Don't know*

P\_ANX\_4 Please tell me which of the following statements, if any, describe your feelings.

		1. Yes	2. No	7. <i>Refused</i>	9. <i>Don't know</i>
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A.	My feelings are caused by the type and amount of work I do.				
B.	Sometimes the feelings can be so intense that my chest hurts and I have trouble breathing.				
C.	These are positive feelings that help me to accomplish goals and be productive.				
D.	The feelings sometimes interfere with my life, and I wish that I did not have them.				
E.	If I had more money or a better job, I would not have these feelings.				
F.	Everybody has these feelings; they are a part of life and are normal.				
G.	I have been told by a medical professional that I have anxiety.				

ANX\_5 How old were you when these feelings began?

\_\_\_\_\_ Age in years  
 777. *Refused*  
 999. *Don't know*

ANX\_6 How much do these feelings limit your ability to carry out daily activities?

1. Not at all
2. A little
3. A lot
4. Completely
7. *Refused*
9. *Don't know*

P\_ANX\_6 Which of the following activities, if any, are you unable to do, or find it hard to do, because of these feelings?

		1. Yes	2. No	7. <i>Refused</i>	8. <i>Not applicable</i>	9. <i>Don't know</i>
A.	Working to support you or your family?					
B.	Working outside the home to earn an income?					
C.	Going to school or achieving your education goals?					
D.	Participating in leisure or social activities?					
E.	Getting out with friends or family?					
F.	Doing household chores such as cooking and cleaning?					
G.	Using transportation to get to places you want to go?					
H.	Participating in religious activities?					
I.	Participating in community gatherings?					

DEP\_1 How often do you feel depressed?

1. Daily
2. Weekly
3. Monthly
4. A few times a year
5. Never
7. *Refused*
9. *Don't know*

DEP\_2 Do you take medication for depression?

1. Yes
2. No
7. *Refused*
9. *Don't know*

*If "Never" to DEP\_1 and "No" to DEP\_2, skip to Section J Pain.*

DEP\_3 Thinking about the last time you felt depressed, how depressed did you feel?

1. A little
2. A lot
3. Somewhere in between a little and a lot
7. *Refused*
9. *Don't know*

*If "Somewhere in between a little and a lot" to DEP\_3, continue with DEP\_4. Otherwise, skip to P\_DEP\_4.*

DEP\_4 Would you say this was closer to a little, closer to a lot, or exactly in the middle?

1. Closer to a little
2. Closer to a lot
3. Exactly in the middle
7. *Refused*
9. *Don't know*

P\_DEP\_4 Please tell me which of the following statements, if any, describe your feelings.

		1. Yes	2. No	7. <i>Refu sed</i>	9. <i>Don't know</i>
A.	My feelings are caused by the death of a loved one.				
B.	Sometimes the feelings can be so intense that I cannot get out of bed.				

C.	The feelings sometimes interfere with my life, and I wish I did not have them.				
D.	If I had more money or a better job, I would not have these feelings.				
E.	Everybody has these feelings; they are part of life and normal.				
F.	I have been told by a medical professional that I have depression.				

DEP\_5 How old were you when the depression began?

\_\_\_\_\_ Age in years

777. *Refused*

999. *Don't know*

DEP\_6 How much does your depression limit your ability to carry out daily activities?

1. Not at all

2. A little

3. A lot

4. Completely

7. *Refused*

9. *Don't know*

P\_DEP\_6 Which of the following activities, if any, are you unable to do, or find it hard to do, because of these feelings?

		1. Yes	2. No	7. <i>Refused</i>	8. <i>Not applicable</i>	9. <i>Don't know</i>
A.	Working to support you or your family?					
B.	Working outside the home to earn an income?					
C.	Going to school or achieving your education goals?					
D.	Participating in leisure or social activities?					
E.	Getting out with friends or family?					
F.	Doing household chores such as cooking and cleaning?					
G.	Using transportation to get to places you want to go?					
H.	Participating in religious activities?					
I.	Participating in community gatherings?					

**SECTION J. PAIN**

PAIN\_1 Do you have frequent pain?  
1. Yes  
2. No  
7. *Refused*  
9. *Don't know*

PAIN\_2 In the past 3 months, how often did you have pain?  
1. Never  
2. Some days  
3. Most days  
4. Every day  
7. *Refused*  
9. *Don't know*

*If "No" to PAIN\_1 and "Never" to PAIN\_2, skip to Section K Fatigue.*

PAIN\_3 Thinking about the last time you had pain, how long did the pain last?  
1. Some of the day  
2. Most of the day  
3. All of the day  
7. *Refused*  
9. *Don't know*

PAIN\_4 Thinking about the last time you had pain, how much pain did you have?  
1. A little  
2. A lot  
3. Somewhere in between a little and a lot  
7. *Refused*  
9. *Don't know*

*If "Somewhere in between a little and a lot" to PAIN\_4, continue with PAIN\_5. Otherwise, skip to P\_PAIN\_5.*

PAIN\_5 Would you say the amount of pain was closer to a little, closer to a lot, or exactly in the middle?  
1. Closer to a little  
2. Closer to a lot  
3. Exactly in the middle  
7. *Refused*  
9. *Don't know*

P\_PAIN\_5 Please tell me which of the following statements, if any, describe your pain.

		1. Yes	2. No	7. <i>Refused</i>	9. <i>Don't know</i>
A.	It is constantly present.				
B.	Sometimes I'm in a lot of pain and sometimes it's not so bad.				
C.	Sometimes it is unbearable and excruciating.				
D.	When I get my mind on other things, I am not aware of the pain.				
E.	Medication can take my pain away completely.				
F.	My pain is because of work.				
G.	My pain is because of exercise.				

PAIN\_6 How old were you when the pain began?

\_\_\_\_\_ Age in years

777. *Refused*

999. *Don't know*

PAIN\_7 How much does your pain limit your ability to carry out daily activities?

1. Not at all

2. A little

3. A lot

4. Completely

7. *Refused*

9. *Don't know*

P\_PAIN\_7 Which of the following activities, if any, are you unable to do, or find it hard to do, because of the pain?

		1. Yes	2. No	7. <i>Refused</i>	8. <i>Not applicable</i>	9. <i>Don't know</i>
A.	Working to support you or your family?					
B.	Working outside the home to earn an income?					
C.	Going to school or achieving your education goals?					
D.	Participating in leisure or social activities?					
E.	Getting out with friends or family?					
F.	Doing household chores such as cooking and cleaning?					
G.	Using transportation to get to places you want to go?					

H.	Participating in religious activities?					
I.	Participating in community gatherings?					

## SECTION K. FATIGUE

TIRED\_1 In the past 3 months, how often did you feel very tired or exhausted?

1. Never
2. Some days
3. Most days
4. Every day
7. *Refused*
9. *Don't know*

*If "Never" to TIRED\_1, skip to Section L : Needs for Assistance, Health Conditions and Impairments.*

TIRED\_2 Thinking about the last time you felt very tired or exhausted, how long did it last?

1. Some of the day
2. Most of the day
3. All of the day
7. *Refused*
9. *Don't know*

TIRED\_3 Thinking about the last time you felt this way, how would you describe the level of tiredness?

1. A little
2. A lot
3. Somewhere in between a little and a lot
7. *Refused*
9. *Don't know*

*If "Somewhere in between a little and a lot" to TIRED\_3, continue with TIRED\_4. Otherwise, skip to P\_TIRED\_4.*

TIRED\_4 Would you say it was closer to a little, closer to a lot, or exactly in the middle?

1. Closer to a little
2. Closer to a lot
3. Exactly in the middle
7. *Refused*
9. *Don't know*

P\_TIRED\_4 Is your tiredness the result of any of the following?

		1. Yes	2. No	7. <i>Refused</i>	9 <i>Don't Know</i>
A.	Too much work or exercise?				

B.	Not getting enough sleep?				
C.	A physical or health-related problem?				
D.	Something else? (please specify):				

TIRED\_5 How old were you when the tiredness began?

\_\_\_\_\_ Age in years

777. *Refused*

999. *Don't know*

TIRED\_6 How much does your tiredness limit your ability to carry out daily activities?

1. Not at all

2. A little

3. A lot

4. Completely

7. *Refused*

9. *Don't know*

P\_TIRED\_6 Which of the following activities, if any, are you unable to do, or find it hard to do, because of the tiredness?

		1. Yes	2. No	7. <i>Refused</i>	8. <i>Not applicable</i>	9. <i>Don't know</i>
A.	Working to support you or your family?					
B.	Working outside the home to earn an income?					
C.	Going to school or achieving your education goals?					
D.	Participating in leisure or social activities?					
E.	Getting out with friends or family?					
F.	Doing household chores such as cooking and cleaning?					
G.	Using transportation to get to places you want to go?					
H.	Participating in religious activities?					
I.	Participating in community gatherings?					

## SECTION L. NEEDS FOR ASSISTANCE, HEALTH CONDITIONS AND IMPAIRMENTS

ASSIST1 Do you ever need someone to help you with, or be with you for, self care activities? For example: doing everyday activities such as eating, showering, dressing or toileting.

1. No
2. Yes, sometimes
3. Yes, always
7. *Refused*
9. *Don't know*

ASSIST2 Do you ever need someone to help you with, or be with you for, body movement activities? For example: getting out of bed, moving around at home or at places away from home.

1. No
2. Yes, sometimes
3. Yes, always
7. *Refused*
9. *Don't know*

ASSIST3 Do you ever need someone **to help you** with, or be with you for, communication activities? For example: understanding, or being understood by, others.

1. No
2. Yes, sometimes
3. Yes, always
7. *Refused*
9. *Don't know*

*If "No" to ASSIST\_1 and ASSIST\_2 and ASSIST\_3, skip to COND\_1.*

ASSIST4 What are the reasons for the need for assistance or supervision shown in the previous three questions?

		1. Yes	2. No	7. <i>Refused</i>	8. <i>Not applicable</i>	9. <i>Don't know</i>
A.	Short term health condition (lasting, or likely to last, for less than 6 months)					
B.	Long term health condition (lasting, or likely to last, for 6 months or more)					
C.	Disability					
D.	Old or young age					
E.	Lack of fluency with local language where living now					

F.	Other (please specify):					
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COND\_1 Are you now...  
Interviewer: Mark all that apply.

A. Deaf or hard of hearing?

- 1. Yes
- 2. No
- 7. Refused
- 9. Don't know

B. Blind or do you have low vision?

- 1. Yes
- 2. No
- 7. Refused
- 9. Don't know

COND\_2 Do you have any of the following?  
Interviewer: Mark all that apply.

		1. Yes	2. No	7. Refused	8. Not applicable	9 Don't Know
A.	Paralysis of one or more limbs					
B.	Amputation or loss of one or more limbs					
C.	Head injury/trauma					
D.	Encephalitis, meningitis, hydrocephalus, etc.					
E.	Cerebral palsy					
F.	Stroke					
G.	Epilepsy					
H.	Asthma or breathing problems					
I.	Diabetes					
J.	High blood pressure or heart problems					
K.	Arthritis					
L.	Tuberculosis					
M.	Psychiatric illness					
N.	Albinism					
O.	Other illness (please specify):					
P.	Other injury (please specify):					

## Annex E

### 2010 Cross-cultural Cognitive Testing Work Group (CCTWG) European Cognitive Test

#### Question Set (Version: 13 January 2010)

**1. In general, would you say your quality of life is:.....**

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor

**2. In general, how would you rate your physical health:....**

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor

**3. In general, how would you rate your mental health, including your mood and your ability to think?**

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor

**4. In general, how would you rate your satisfaction with your social activities and relationships?**

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor

#### COMMUNICATION

**5. Using your usual language, do you have difficulty communicating, for example understanding or being understood?**

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do

**6 Do people have difficulty understanding you when you speak?**

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do

## UPPER BODY

**7. Do you have difficulty raising a 2 liter bottle of water or soda from waist to eye level?**

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do

**8. Do you have difficulty using your hands and fingers, such as picking up small objects, for example, a button or pencil, or opening or closing containers or bottles?**

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do

## COGNITION (REMEMBERING)

**9. Do you have difficulty remembering or concentrating?**

1. No difficulty (Go to Q 13)
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do

**10. Do you have difficulty remembering, concentrating, or both?**

1. Difficulty remembering only (Ask 11a and 11b)
2. Difficulty concentrating only (Ask 12)
3. Difficulty with both remembering and concentrating (Ask 11a, 11b and 12)

**11a. How often do you have difficulty remembering?**

1. Sometimes
2. Often
3. All of the time

**11b. Do you have difficulty remembering a few things, a lot of things, or almost everything?**

1. A few things
2. A lot of things
3. Almost everything

**12. How much difficulty do you have concentrating for ten minutes?**

1. A little
2. A lot
3. Somewhere in between a little and a lot

## LEARNING

**13. Do you have difficulty understanding and following instructions for example, to use a new cell phone or to get to a new place?**

1. No difficulty
2. Some difficulty
3. A lot of difficulty

4. Cannot do at all / Unable to do

**AFFECT (ANXIETY AND DEPRESSION)**

**14. How often do you feel worried, nervous or anxious?**

1. Daily
2. Weekly
3. Monthly
4. A few times a year
5. Never

**14a . Do you take medication for these feelings?**

1. Yes
2. No

(If Never to 14, go to Q15)

**14b. Thinking about the last time you felt worried, nervous or anxious, how would you describe the level of these feelings?**

1. A little (Go to Q15)
2. A lot (Go to Q15)
3. Somewhere in between a little and a lot

**14c. Would you say this was closer to a little, closer to a lot, or exactly in the middle?**

1. Closer to a little
2. Closer to a lot
3. Exactly in the middle

**15. How often do you feel depressed?**

1. Daily
2. Weekly
3. Monthly
4. A few times a year
5. Never

**15a. Do you take medication for depression?**

1. Yes
2. No

(If Never to 15, go to Q16)

**15b. Thinking about the last time you felt depressed, how depressed did you feel?**

1. A little (Go to Q16)
2. A lot (Go to Q16)
3. Somewhere in between a little and a lot

**15c. Would you say this was closer to a little, closer to a lot, or exactly in the middle?**

1. Closer to a little
2. Closer to a lot
3. Exactly in the middle

**PAIN**

**16. Do you have frequent pain?**

1. Yes

2. No

**17. In the past 3 months, how often did you have pain?**

1. Never
2. Some days
3. Most days
4. Every day

*If "No" to PAIN\_16 and "Never" to PAIN\_17, skip to Fatigue.*

**18. Thinking about the last time you had pain, how long did the pain last?**

1. Some of the day
2. Most of the day
3. All of the day

**19a. Thinking about the last time you had pain, how much pain did you have?**

1. A little (Go to Q20)
2. A lot (Go to Q20)
3. Somewhere in between a little and a lot (Go to Q19b)

**19b. Would you say the amount of pain was closer to a little, closer to a lot, or exactly in the middle?**

1. Closer to a little
2. Closer to a lot
3. Exactly in the middle

**20. How old were you when the pain began?**

\_\_\_\_\_ Age in years

**21. How much does your pain limit your ability to carry out daily activities?**

1. Not at all
2. A little
3. A lot
4. Completely

**22. Which of the following activities, if any, are you unable to do, or find it hard to do, because of the pain?**

A. Working to support you or your family?

1. Yes
2. No

B. Working outside the home to earn an income?

1. Yes
2. No

C. Going to school or achieving your education goals?

1. Yes
2. No

D. Participating in leisure or social activities?

1. Yes
2. No

E. Getting out with friends or family?

1. Yes
2. No

F. Doing household chores such as cooking and cleaning?

1. Yes
  2. No
- G. Using transportation to get to places you want to go?
1. Yes
  2. No
- H. Participating in religious activities?
1. Yes
  2. No
- I. Participating in community events or gatherings?
1. Yes
  2. No

**FATIGUE**

**23. In the past 3 months, how often did you feel very tired or exhausted?**

1. Never
2. Some days
3. Most days
4. Every day