



Equality Impact Assessment for the
Office for National Statistics

Development of disability questions:
2011 Census for England and Wales
&
Integrated Household Survey

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ONS references

Published reports and latest information on question development for the 2011 Census in England and Wales are available on the Office for National Statistics website at:

<http://www.ons.gov.uk/census/2011-census/index.html>

Published reports and latest information on question development for the Integrated Household Survey are available on the Office for National Statistics website at:

<http://www.statistics.gov.uk/cci/nugget.asp?id=936>

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Executive summary

The Disability Discrimination Act 2005 gives ONS statutory general and specific equality duties to make sure its policies and practices do not result in unlawful discrimination against disabled people. Around 43,000 UK public bodies have similar duties. The Government reports¹ that, according to the widest definition of disability, there are around 11 million disabled adults in the UK – one in five of the adult population - and 770,000 disabled children.

“Many of these people would not define themselves as disabled. The majority of these people experience low level impairments – wheelchair users, blind people and Deaf people make up an important minority. The population of disabled people is distinct from and much larger than the three million people in receipt of disability related benefits.

The population of disabled people is highly diverse. It includes people from all age groups and across the income and education spectrum. There are large differences in impairment experienced by disabled people. Because of this, generalisations are often unhelpful. Disabled people with different impairments, from different socio-demographic backgrounds and facing different barriers will have very different day-to-day experiences.”²

Official disability statistics provided by the Office for National Statistics (ONS) and other government departments present a picture of structural inequality experienced by disabled people in all communities and age groups across England and Wales. The quality of official disability data available today may not be fully adequate. Even so, it is clear that inequalities faced by disabled people present real and significant barriers to social inclusion, work opportunities, services, facilities and products.

ONS is meeting the challenge to deliver high quality disability data by developing a disability question for the 2011 National Census and a suite of disability questions for inclusion on the

¹ *Improving the Life Chances of Disabled People*, Prime Minister’s Strategy Unit, 2005, page 9: <http://www.cabinetoffice.gov.uk/media/cabinetoffice/strategy/assets/disability.pdf>

² *ibid*, page 9

Integrated Household Survey core module. The Office for Disability Issues is also working with ONS to develop the Life Opportunities Survey, which will be the first major UK government survey to explore disability in terms of social barriers. Although it is not the subject of this assessment, the Life Opportunities Survey will produce longitudinal data on socially disabling barriers that limit life opportunities in comparison with data on a control group of people without a disability. The resulting data will complement the disability data outputs of the 2011 Census and the Integrated Household Survey.

Policy makers use official statistics, provided by ONS and other government agencies, to demonstrate the needs and requirements of disabled people; however, no single, coherent definition of disability is applied across government. For the UK's public policy makers, the definitions used are based generally on the social, medical and charity models of disability.

The lack of an agreed definition of disability and harmonised disability questions for use in official surveys has an adverse impact on the production of coherent estimates of the number of disabled people living in the UK. Consequently, this creates adverse equality impacts for the UK's population of disabled people. A key task accepted by ONS is, therefore, to achieve a harmonised definition of disability and operationalise it through a suite of questions that can be applied in key administrative and survey data sources for use by relevant UK government bodies.

The statutory duties to promote disability equality and the general requirements of disability law create considerable demand from the public sector and other business sectors for comprehensive disability data. Therefore, the disability questions that are designed, tested and implemented by ONS are likely to be replicated in social surveys and other data collection tools used by the public, commercial and third sectors, applied across a range of different modes of data capture. Sectors that adopt the questions will have the opportunity to benchmark the results of their own disability surveys against ONS disability data. The improvements in data quality across all sectors should result in positive equality impacts for disabled people.

The Government's Equalities Review³ reported that:

³ *Fairness and Freedom, the Final Report of the Equalities Review*, 2007, pages 10 and 111: Available online at <http://archive.cabinetoffice.gov.uk/equalitiesreview/>

“Poor measurement and a lack of transparency have contributed to society and governments being unable to tackle persistent inequalities and their causes. The data available on inequality are utterly inadequate in many ways, limiting people’s ability to understand problems and their causes, set priorities and track progress. And even where data do exist, they are not consistently used well or published in a way that makes sense....And the Office for National Statistics (ONS) should be responsible for ... ensuring data on equalities across government and the devolved administrations meet existing and future need, nationally and locally.”

In its formal response to the Review⁴, ONS recommended that

“the Office for Disability Issues and the Government Equalities Office in partnership with ONS and devolved governments, [should] urgently agree a consistent approach to collecting information on disability, and champion this widely across Government and the wider public sector.”

As part of meeting this recommendation, ONS is working with its partners, including the devolved governments, to develop a suite of disability questions that uses an agreed definition of disability for use in all surveys to ensure a consistent and coherent approach to collecting disability data across government.

This equality impact assessment summarises the development of disability questions for the 2011 Census in England and Wales and the Integrated Household Survey. The assessment is predictive. It uses the social model of disability to analyse the likely positive and adverse equality impacts of the proposed disability questions on disabled people. The assessment highlights the positive impacts identified at the testing stage to March 2009. The assessment recommends ways of eliminating or mitigating the potential for adverse equality impacts where such impacts are identified.

⁴ *Report from the review of equality data*, ONS 2007: Available online at <http://www.ons.gov.uk/about-statistics/measuring-equality/equality-data-review/index.html>

The development of a disability question for the 2011 Census is almost complete, with final testing in the Census rehearsal 2009. Question testing is underway for the Integrated Household Survey.

The assessment makes recommendations that assist ONS to develop and implement disability questions that should:

- identify and reduce the barriers to social inclusion and equal access to work opportunities and services faced by disabled people in all areas of life
- improve disability equality practice in the public, commercial and not-for-profit business sectors
- improve the wider community's understanding of definitions of impairment and disability
- enable more disabled people to feel confident about identifying as disabled

The recommendations reflect the outcomes of ONS research that has been informed by the views of internal and external experts, including the ONS Census Health Topic Group and the Office for Disability Issues (ODI).

The assessment is based on an analysis of ONS documents, consultation outputs available at February 2009, and interviews with lead officials of ONS and ODI. Key documents analysed include the Information Paper entitled *The 2011 Census: Statement of user requirements – Health & Care*, ONS 2007; *Summary of the ONS/ODI Workshop on Disability Definitions and Harmonisation*, ONS, June 2008; and *Health and Disability Questions Harmonisation Sub-Group: Road Map to Harmonisation*, ONS February 2009. Although it is not the subject of the assessment, information available on the development of the Life Opportunities Survey has also been taken into account.

Summary of positive impacts likely to result from the project

This section summarises the positive equality impacts that are likely to result from the development and implementation of a suite of acceptable disability questions.

1. The disability question proposed for the 2011 Census for England and Wales will provide benchmark data on disability and activity limitation.
2. A suite of disability questions in the Integrated Household Survey should result in improved disability data about the needs and requirements of disabled people in all diverse communities, across different age groups and at a sub-national geographical scale.
3. Raised awareness of the needs and requirements of disabled people should help to
 - eliminate barriers faced to social inclusion in all areas of life
 - improve community cohesion across and within all communities
 - enable disabled people to have equal access to work opportunities
 - improve the availability of accessible products, facilities and services provided by all business sectors
4. The availability of more reliable data about disabled people should enable improved monitoring of disability discrimination, which in turn should lead to reduced discrimination.
5. Training interviewers to ask questions about disability identity in appropriate and sensitive ways will help to eliminate any discomfort about asking such questions; and any unease felt by respondents when asked about disability identity.
6. Monitoring the equality outcomes of disability question development and their implementation will assist ONS to maintain accountability and transparency of the decision-making process related to developing the questions; and to eliminate or mitigate any unforeseen adverse equality impacts.

Recommendation to promote positive impacts

One recommendation is made with a view to promoting the positive equality impacts that may result from the design and implementation of the disability question suites for the 2011 Census and the Integrated Household Survey, as follows:

Recommendation 1: that ONS continues its work to achieve a harmonised definition of disability, including those related to learning disability and learning difficulty. The definition should be framed with due regard to the social model of disability.

Summary of adverse impacts likely to arise from the project

This section summarises the adverse equality impacts that may result from the design or implementation of disability questions in the 2011 Census and the Integrated Household Survey, together with recommendations for eliminating or mitigating the impact.

ONS acknowledges that a comprehensive disability question cannot be asked in the 2011 Census that satisfies the range of user requirements identified during the various consultation exercises conducted between 2005 and 2008. This is due to lack of space in the 2011 Census questionnaire form. The 2011 Census is not the only source of disability data outputs from ONS surveys. The harmonised suite of disability questions to be asked in the Integrated Household Survey mitigates the potential for adverse equality impacts from the limited question to be asked in the 2011 Census. In addition, the Office for Disability Issues is currently developing the Life Opportunities Survey in partnership with ONS. In due course, this survey will be added as a module to the Integrated Household Survey.

The guidance developed by ONS called “Equal chance for all” acknowledges that disabled people and non-English speakers need additional information and alternative interviewing practices to ensure they are included in ONS social surveys. The guidance “aims to provide best practice and practical guidance on how to meet and engage with these respondents.” The guidance is a reasonable adjustment by ONS, to ensure that disabled people and their experiences are not excluded from its survey interviews. However, guidance is not effective if employees are not properly trained to implement it. The interview implementation process is identified as the main risk area to ONS for the potential to result in unlawful discrimination. Disability and racial discrimination is identified as the highest potential risk area.

Adverse equality impacts may arise from differential survey implementation. Differential

implementation may occur if appropriate interview, translation and interpretation arrangements do not take account of people with different types of impairments and communication needs. It may also occur if ONS Interviewers fail to implement the survey without due justification with people who have different types of impairments and communication needs.

Recommendations to eliminate or mitigate adverse impact

Recommendations to eliminate or mitigate the potential for adverse equality impacts that may result from the design and implementation of the disability question suites for the 2011 Census and the Integrated Household Survey are as follows:

Recommendation 2: where informed consent is an issue, that clear procedures are in place that require all Interviewers to justify in writing their decisions to rely on family members, carers or professionals to answer questions by proxy on behalf of disabled people.

Recommendation 3: that all Interviewers, relevant managers and support staff receive appropriate, timely and proportionate training that equips them to understand how to deliver accessible interviews to people with different impairments and language needs; and that this training is refreshed at regular intervals.

Recommendation 4: that the 'Contact Us' section of the National Statistics website should include the facility to make comments and complaints, as well as enquiries; and that this facility is promoted at other appropriate points such as information cards left by Interviewers.

Recommendation 5: that this equality impact assessment is published by ONS to enable individuals and groups to comment on the assessment, which may not have considered every possible equality dimension or potential outcome.

Recommendation 6: that the equality outcomes of the suite of disability questions and survey implementation should be monitored at regular intervals

Recommendation 7: that an action plan is devised by ONS to implement the recommendations adopted from this assessment.

Recommendation 8: that the equality impact assessment is updated at regular intervals to take account of equality monitoring outcomes.

Introduction

In November 2009, Diversity Solutions was commissioned by the Office for National Statistics to conduct an equality impact assessment of the development of disability questions for the 2011 Census and the Integrated Household Survey.

ONS acknowledges that a comprehensive disability question cannot be asked in the 2011 Census that satisfies the range of user requirements identified during the various consultation exercises conducted between 2005 and 2008. This is due to lack of space in the 2011 Census questionnaire form. However, a suite of disability questions is being developed for use in the Integrated Household Survey and other surveys. These are being tested with support from the Office for Disability Issues. The final suite of questions agreed for the Integrated Household Survey should enable ONS to meet many of the user requirements identified during consultation.

The purpose of the equality impact assessment is to highlight the potential equality impacts of the disability questions currently being tested for implementation. It is anticipated that the questions will be asked in the Integrated Household Survey from April 2010. The assessment will enable ONS, during the development phase, to maximise the potential for positive equality impacts and eliminate or reduce the potential for adverse equality impacts.

The recommendations reflect the outcomes of ONS research that has been informed by the views of internal and external experts, including the ONS Census Health Topic Group, the Health and Disability Harmonisation Sub-Group, the Office for Disability Issues (ODI) and the devolved administrations.

The assessment is based on an analysis of ONS documents, consultation outputs available at February 2009, and interviews with lead officials of ONS and ODI.

What is an equality impact assessment?

An equality impact assessment is a systematic way of finding out whether a function, such as a policy or practice, has a differential impact on particular communities, or groups within communities. Equality impact assessments can be used to determine disadvantage for any one, or all, of the following:

- minority and majority ethnic communities
- women and men, including transsexual people
- disabled people
- lesbians, gay men, bisexual and heterosexual people
- people with different religious and non-religious beliefs
- people in different age groups

These groups are protected by equality legislation, and are sometimes called 'equality groups'.

An equality impact assessment provides evidence that 'due regard' is given to the impact of policies and practices on particular communities, or on groups within communities. Impact may be positive, adverse or neutral. Where adverse impact occurs, this must be justified. All reasonable attempts must be made to mitigate adverse impact and promote positive impact.

Applying the principle of 'due regard' is required by the Race Relations (Amendment) Act 2000, Disability Discrimination Act 2005 and the Gender Duty of the Sex Discrimination Act 1975, as amended by the Equality Act 2006.

'Due regard' comprises two linked elements: proportionality and relevance. This means that, in all their decisions and functions, ONS has a statutory duty to give due weight to the need to promote race, disability and gender equality. The Government has indicated that it will publish an Equality Bill in 2009 that proposes to extend the duty of public authorities to promote equality to include the grounds of sexual orientation, religious and non-religious belief, and age.

Detailed information about 'due regard' is available in the statutory codes of practice on the race, disability and gender equality duties. These codes are available on the website of the Equality and Human Rights Commission, as follows:

Models of disability

In developing acceptable disability questions that will benefit both data users and disabled people, ONS has considered the most common models of disability used in the UK to develop and implement policy and practice. These are the social model and the medical model.

The ONS sub-group responsible for harmonising health and disability questions⁵ points out that there is no harmonised definition of disability across government. This situation hampers the delivery of coherent national disability data. The sub-group states that:

“The word ‘disability’ is widely perceived as synonymous with impairment or general ill-health: a link which conforms to a medical model of disability... The medical model promotes the view of a disabled person as dependent and needing to be cured or cared for: it justifies the way in which disabled people have been systematically excluded from society. However, the Prime Minister’s strategy unit in 2005⁶ clarified the differences between the terms impairment and disability: impairment is defined as a loss of actual attributes of a person, whether in terms of limbs, organs or mechanisms, including psychological functioning; disability refers to the restrictions caused by society when it does not give equivalent attention and accommodation to the needs of individuals with impairments. These disadvantages experienced by an individual result from barriers to independent living, and access to education, employment and other opportunities. A ‘disabled person’, therefore, can be described as someone who is disadvantaged by the way in which the wider environment interacts with their impairment or ill-health...

“A fundamental prerequisite to achieving coherent national statistics on the subject of disability, which is capable of meeting the range of users needs, is for relevant

⁵ *Road Map to Harmonisation*, ONS, February 2009, page 9: Attached at Appendix 1.

⁶ *Improving the Life Chances of Disabled People*, Prime Minister’s Strategy Unit, 2005, <http://www.cabinetoffice.gov.uk/media/cabinetoffice/strategy/assets/disability.pdf>

government bodies across the United Kingdom to settle on a harmonised definition that can be applied in key administrative and survey data sources.”

Social model of disability

The social model of disability is promoted by many disabled people, including those who are members of the UK’s Disabled People’s Movement⁷. It is also promoted by the Office for Disability Issues (ODI)⁸, which works to the Minister for Disabled People and with a cross-government ministerial group.

The social model was developed by disabled people to describe their actual experience of disability discrimination and provides the means to campaign for equality and human rights. It emphasises the barriers that are put in the way of disabled people in a world that is run by and for non-disabled people. The barriers prevent disabled people from doing what they want to do, which results in discrimination.

ONS describes the social model of disability as follows⁹:

“Under the social model, disability is caused by society: the physical, organisational and attitudinal barriers created by society, either deliberately or accidentally, compromise the ability of a person with impairment or illness to live independently and have the opportunity to participate in educational, employment and leisure activities.”

ODI describes the social model of disability as follows¹⁰:

“**Impairment** is an injury, illness, or congenital condition that causes or is likely to cause a long-term effect on appearance and/or limitation of function of the individual.

⁷ UK Disabled People’s Movement website: <http://www.disabilityinformation.com/>

⁸ ODI website: <http://www.officefordisability.gov.uk/default.asp>

⁹ *Road Map to Harmonisation*, ONS, February 2009, page 9

¹⁰ ODI: <http://www.officefordisability.gov.uk/resources/models-of-disability.asp>

“Disability is the loss or limitation of opportunities to take part in society on an equal level with others due to social and environmental barriers.

“Impairments and chronic illness often pose real difficulties for disabled people but they are not the main problems. It is the 'barriers' which exist in society that create the main problems. The three main areas of barrier are:

- environment (including inaccessible buildings and services)
- attitudes (stereotyping, discrimination and prejudice)
- organisations which operate inflexible procedures and practices

“Disabling barriers experienced in the past can continue to have an adverse effect. For example, disabled people who attended segregated schools may have gained lower academic qualifications than their non-disabled peers, because their ‘special’ school failed to provide a proper mainstream curriculum.”

Medical model of disability

The medical model of disability is based on a concept of ‘normality’, where disabled people are unable to integrate into society because of their impairments. This model places the responsibility on disabled people for removing barriers to participation.

The policy impacts of the medical model included segregated, institutionalised ‘special’ services, for example in education and health. Because of the positive impacts of the social model, many previously segregated services are now part of mainstream provision.

ONS describes the medical model of disability as follows¹¹:

“Under the medical model, disabled people are defined by their impairment or health condition, which is perceived as causing dependence and a need for treatment or care. The consequence is constraints placed on independent living and special arrangements imposed to access benefits, housing, education, leisure and employment.”

¹¹ *Road Map to Harmonisation*, ONS, February 2009, page 9

ODI describes the medical model of disability as follows¹²:

“The medical model is sometimes also known as the ‘personal model’. This is the traditional view that the inability of disabled people to fully participate in society is a direct result of having a disability, not a result of physical features of society. The individual is ‘impaired’ and the impairment is the problem to be overcome. This model relies on a strong notion of what is ‘normal’, thereby emphasising the ‘abnormality’ of impaired people.

“This model is more likely to lead to the targeting of special welfare benefits, and the provision of segregated services for disabled people.

“The focus of the medical profession is to alleviate the effects of impairments, and disabled people need to be treated and rehabilitated to enable them to participate more fully. This model suggests that disabled people should try, wherever possible, to live in the norms and patterns of mainstream society.”

In their response to the first ONS consultation exercise for the 2011 Census topics, Mencap expressed the view¹³ that statistics on the prevalence of learning disability are confused because there is not a clear distinction between a learning disability and a learning difficulty. They provided definitions of both:

- *Learning disability* - A learning disability affects someone’s intellectual and social development throughout their life. This means that someone with a learning disability will always find it harder than other people to learn, understand and communicate. It’s what used to be called ‘mental handicap’, but this term isn’t used anymore because most people find it offensive. All learning disabilities are caused by the way the brain develops before, during or after birth.

¹² ODI: <http://www.officefordisability.gov.uk/resources/models-of-disability.asp>

¹³ *Summary of Consultation Responses Regarding Nature/Cause of Disability/Limiting Long-term Illness*, ONS, November 2005

- *Learning difficulties* - Learning difficulties also affect people's abilities and behaviour throughout their life, but do not affect intellectual capacity or social development. Common examples include dyslexia (affecting reading ability) and dyspraxia (affecting language, perception and thought).

Disability Discrimination Act definition of disability

The Disability Discrimination Act 1995 is the most comprehensive legislation introduced by the UK government to protect disabled people against unlawful discrimination. It protects people who are considered to be disabled according to the definition of disability set out in the Act; and protects disabled and non-disabled people against victimisation on grounds of disability. The Act has been amended substantially, including by the Disability Discrimination Act 2005.

The term 'disabled people' is used throughout the assessment to refer to people who have an impairment or long-term health condition that should meet the definition of disability in the amended Disability Discrimination Act. This includes people with sensory and visual impairments, learning disabilities, mental health problems and long-term health conditions such as diabetes, HIV, multiple sclerosis and cancer. Many individuals do not consider themselves to be disabled or know that they are entitled to the protection of the amended Disability Discrimination Act.

The Disability Discrimination Act 2005¹⁴ defines a disabled person as

“someone who has a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities.

For the purposes of the Act:

- Substantial means neither minor nor trivial
- Long term means that the effect of the impairment has lasted or is likely to last for at least 12 months (there are special rules covering recurring or fluctuating conditions)

¹⁴ DDA definition of 'disability', website of the UK Government:

www.direct.gov.uk/en/DisabledPeople/RightsAndObligations/DisabilityRights/DG_4001069

- Normal day-to-day activities include everyday things like eating, washing, walking and going shopping
- A normal day to day activity must affect one of the ‘capacities’ listed in the Act which include mobility, manual dexterity, speech, hearing, seeing and memory.

The DDA amended the definition of a disability. It removed the requirement that a mental illness should be ‘clinically well-recognised’.

It also ensured that people with HIV, cancer and multiple sclerosis are deemed to be covered by the DDA effectively from the point of diagnosis, rather than from the point when the condition has some adverse effect on their ability to carry out normal day-to-day activities.”

A disability can arise from a wide range of impairments, many of which are not obvious. Impairments that may give rise to disability can include¹⁵:

- “sensory impairments, such as those affecting sight or hearing;
- impairments with fluctuating or recurring effects such as rheumatoid arthritis, myalgic encephalitis (ME)/chronic fatigue syndrome (CFS), fibromyalgia, depression and epilepsy;
- progressive, such as motor neurone disease, muscular dystrophy, forms of dementia and lupus (SLE);
- organ specific, including respiratory conditions, such as asthma, and cardiovascular diseases, including thrombosis, stroke and heart disease;
- developmental, such as autistic spectrum disorders (ASD), dyslexia and dyspraxia;
- learning difficulties;
- mental health conditions and mental illnesses, such as depression, schizophrenia, eating disorders, bipolar affective disorders, obsessive compulsive disorders, as well as personality disorders and some self-harming behaviour;
- produced by injury to the body or brain.”

¹⁵ Disability Discrimination Act: Guidance on matters to be taken into account in determining questions relating to the definition of disability, Disability Rights Commission, May 2006, page 4.

A person who is no longer disabled, but who met the requirements of the definition in the past, is protected by the Disability Discrimination Act even if they have recovered.

“For example, a woman who, four years ago, experienced a mental illness that had a substantial and long-term adverse effect on her ability to carry out normal day-to-day activities, but who has experienced no recurrence of the condition, is still entitled to the protection afforded by the Act, as a person with a past disability.”¹⁶

The DDA 2005¹⁷ amended the Act to insert a general duty to promote disability equality, which applies to all public authorities. The general duty came into force at the end of December 2006, and

“.....requires all public authorities to actively look at ways of ensuring that disabled people are treated equally.

This equality impact assessment sets out some of the work undertaken by ONS as part of its general duty to promote disability equality.

Achieving a harmonised definition of disability

In its report to Government¹⁸, the Equalities Review said that:

“Poor measurement and a lack of transparency have contributed to society and governments being unable to tackle persistent inequalities and their causes. The data available on inequality are utterly inadequate in many ways, limiting people’s ability to

¹⁶ *Disability Discrimination Act: Guidance on matters to be taken into account in determining questions relating to the definition of disability*, Disability Rights Commission, May 2006, page 7:
<http://www.equalityhumanrights.com/en/publicationsandresources/Pages/Guidanceondefinitionofdisability.aspx>

¹⁷ *Duties of the Disability Equality Duty*, Disability Rights Commission:
http://83.137.212.42/sitearchive/DRC/employers_and_service_provider/disability_equality_duty/explaining_the_duty.html

¹⁸ *Fairness and Freedom, the Final Report of the Equalities Review*, 2007, pages 10 and 111:
<http://archive.cabinetoffice.gov.uk/equalitiesreview/>

understand problems and their causes, set priorities and track progress. And even where data do exist, they are not consistently used well or published in a way that makes sense....

“And the Office for National Statistics (ONS) should be responsible for ... ensuring data on equalities across government and the devolved administrations meet existing and future need, nationally and locally.”

In its response to the Equalities Review¹⁹, ONS recommended that

“the Office for Disability Issues and the Government Equalities Office in partnership with ONS and devolved governments, [should] urgently agree a consistent approach to collecting information on disability, and champion this widely across Government and the wider public sector.”

As part of meeting this recommendation, ONS is working with its partners, including the devolved governments, to develop disability questions based on a harmonised definition of disability. The aim of ONS is to ensure a coherent approach to collecting disability data across government.

The Equality Bill is due for publication in April 2009. The Bill, which promises to streamline complex equality law, may assist the efforts of ONS to gain agreement to a harmonised definition of disability.

Recommendation 1: that ONS continues its work to achieve a harmonised definition of disability, including those related to learning disability and learning difficulty. The definition should be framed with due regard to the social model of disability.

Background to question development

2009 Census Rehearsal

¹⁹ *Report from the review of equality data*, ONS 2007: Available online at <http://www.ons.gov.uk/about-statistics/measuring-equality/equality-data-review/index.html>

The disability question to be tested in the 2009 Census Rehearsal is shown below. The question was developed following detailed consultations by the ONS Census Health Topic Group with expert users of disability data, including central government departments, local government and third sector agencies. This included a general topics consultation in 2005 and a more detailed consultation specifically on long-term illness/disability in 2007. ONS has produced a paper detailing the consultation process, design history and testing programme of the questions²⁰. ONS plans to publish the paper in Summer 2009.

The question has been tested and refined and it is not expected that the question will be modified for the 2011 Census after the Rehearsal.

Disability question for Census Rehearsal in October 2009

Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months?

Include problems related to old age.

- Yes, limited a lot
- Yes, limited a little
- No

Data users are keen to have a dataset of Census 2011 disability outputs that will enhance the usability of other official datasets by providing a benchmark against which they can be measured. The proposed question will provide benchmark data on disability and activity limitation that fits with the Disability Discrimination Act definition of disability.

However, the 2009 Census Rehearsal question does not measure type of impairment, as in the 2007 Census test question. The question measures only current disability and does not ask about past disability as defined by the Disability Discrimination Act 1995. A person who has

²⁰ *The 2nd consultation on the inclusion of a disability question in the 2011 Census*, Appendix, ONS 2008

had a disability within the definition is protected from some forms of discrimination even if he or she has since recovered or the effects have become less than substantial.²¹

The omissions of impairment type and past disability should be mitigated by the data derived from the disability questions currently being tested for use in the Integrated Household Survey.

Question options considered for the 2011 Census

The 2001 Census included a single question on limiting long-term illness and disability, and there was some demand from users for continuity for this topic. However, the 2001 Census question was deemed unsuitable for the 2011 Census since it would not meet user need related to the policy monitoring requirements of the Disability Discrimination Act 2005.

For the 2007 Census Test, two new questions were developed for evaluation on a large scale. They distinguished between different types of disability and illness and asked whether any illness or disability limited day-to-day activities. The questions were designed to collect the additional detail required by users, while providing some continuity with the 2001 Census.

2007 Test Questionnaire: the disability questions tested

Test question 1:

Do you have any of the following long-standing conditions?

Include problems which are due to old age.

Tick all boxes that apply.

- Deafness or severe hearing impairment
- Blindness or severe visual impairment
- A condition that substantially limits one or more basic physical activities such as walking, climbing stairs, lifting or carrying
- A learning difficulty
- A long-standing psychological or emotional condition

²¹ *Disability Discrimination Act: Guidance on matters to be taken into account in determining questions relating to the definition of disability*, Disability Rights Commission, May 2006, page 20:

<http://www.equalityhumanrights.com/en/publicationsandresources/Pages/Guidanceondefinitionofdisability.aspx>

- Other, including any long-standing illness
- No, I do not have a long-standing condition

Test question 2:

Does a long-standing health problem or disability mean you have substantial difficulties doing day-to-day activities?

Include problems which are due to old age.

1 - Yes

2 - No

The Census Health Topic Group considered that the activity limitation question developed for the 2007 Census Test would still meet some of the user requirements for this information and it would still be possible to derive the definition of disability used in the Disability Discrimination Act. However, the information obtained would not be as detailed as that obtained from asking both questions.

Following the first 2007 Census Test, a decision was taken by ONS that there would only be one disability question in the 2011 Census due to the priority of other topics and space constraints on the questionnaire.

ONS conducted a detailed consultation exercise to help inform the design of the single question. Four question options were proposed. These are shown below, together with ONS commentary on the positive and negative implications for each question.

Question options considered for the 2011 Census

Each option below was considered for further testing. The question chosen for the 2009 Census Rehearsal is a modified form of Option 3.

Option 1: Census 2001 question unchanged

Do you have any long-term illness, health problem or disability which limits your daily activities or the work you can do?

(include problems which are due to old age)	
Yes No	
Positives	Negatives
<ul style="list-style-type: none"> Continuity Used for DH resource allocation/health poverty index 	<ul style="list-style-type: none"> Does not map on to the DDA definition as does not include a specified time period or severity of limitation

Option 2: Modified Census 2001 with severity

<p><i>Do you have any long-term illness, health problem or disability which limits your daily activities or the work you can do?</i> <i>(include problems which are due to old age)</i> 1 - Yes, limits severely 2 - Yes, limits but not severely 3 - No</p>	
Positives	Negatives
<ul style="list-style-type: none"> Continuity as the question remains unchanged and the response categories can be aggregated to map the previous yes/no categories Provides more information on level of severity of limitation, especially useful for local service planning 	<ul style="list-style-type: none"> Does not specify the duration of longstanding so does not agree with the DDA definition or provide a common reference period for respondents

Option 3: Modified Census 2001 with severity and duration of disability

<p><i>Do you have any long-standing illness, health problem or disability which has limited your daily activities or the work you can do over a period of at least 12 months or that is likely to affect you over a period of at least 12 months?</i> <i>(include problems which are due to old age)</i> 1 - Yes, limits severely 2 - Yes, limits but not severely 3 - No</p>	
Positives	Negatives
<ul style="list-style-type: none"> Maps into DDA definition of disability more 	<ul style="list-style-type: none"> Continuity is affected with the change in

<p>precisely</p> <ul style="list-style-type: none"> • Will get more consistent responses with defined reference period 	<p>the question asked. However, the impact of this change is likely to be small but needs to be tested</p>
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Option 4: Census 2007 Test Question

<p><i>Does a long-standing health problem or disability mean you have substantial difficulties doing day-to-day activities?</i> <i>Include problems which are due to old age.</i></p> <p>1 - Yes 2 - No</p>	
<p>Positives</p>	<p>Negatives</p>
<ul style="list-style-type: none"> • By including ‘substantial difficulties’ it maps onto the DDA concept of severity • Substitutes ‘day-to-day’ activities for the 2001 wording of ‘daily activities or the work you can do’. By removing reference to work the question wording becomes relevant to all ages. 	<ul style="list-style-type: none"> • Loss of continuity with the 2001 Census question • ‘Substantial difficulties’ is open to reporting biases as it is not defined

The first ONS consultation exercise for the 2011 Census topics ran from May to August 2005. The responses received from a variety of data users identified many positive impacts associated with the development of disability questions for the 2011 Census. They have also informed the disability questions developed for the Integrated Household Survey. Interested parties were invited to comment on the proposals outlined in the consultation document entitled, ‘The 2011 Census: Initial View on Content for England and Wales’. In total, more than 1400 responses were received from over 450 respondents.

ONS summarised the 65 responses received supporting the inclusion of a question on the nature and cause of disability and limiting long-term illness²². The responses were summarised according to six categories; user need, the requirement for data at small geographies or for small populations, alternative sources, multivariate analysis, UK comparability, and continuity with previous Censuses.

Central government respondents supported the inclusion of disability questions in the 2011 Census to inform formulas for:

- resource allocation
- planning service provision
- monitoring and developing policies
- monitoring equality

Central government respondents considered that information on the nature and cause of disability and limiting long-term illness would provide a more precise and accurate basis than simply knowing whether a person has a disability or limiting long-term illness. Whilst acknowledging the practical difficulties in collecting this information in the Census, DfES²³ said that “it is essential that any questions used distinguish broad categories such as learning disability, physical or sensory impairments”.

Local government respondents identified the uses below for collecting the information in the Census:

- *Resource allocation*: information on the nature and cause of a person’s disability or long-term limiting illness would provide more precise and valuable database upon which to target resources than the current limiting long-term illness data.

²² *Summary of Consultation Responses Regarding Nature/Cause of Disability/Limiting Long-term Illness*, ONS, November 2005

²³ Now the Department for Children, Schools and Families (DCSF)

- *Service provision:* reliable data on the types of disabilities prevalent in an area would enable authorities to improve their planning of service provision and access to services.
- *Statutory requirements:* reliable data would enable authorities to monitor compliance with their statutory equality duties
- *Identifying employment opportunities:* the information should help identify opportunities for disabled people to become employed if they are either inactive or unemployed.
- *Social exclusion:* this data needs capturing if inequality and social exclusion are to be taken seriously as different impairment groups experience differing social barriers.
- *Housing:* accurate data related to the number of disabled people and the severity of their disability will allow councils to budget correctly for the services they provide, including the provision of supported housing, housing aids and adaptations and employing staff to work with disabled people.
- *Medical complaints:* The data would provide the only fully comprehensive information source relating to the nature of disability and limiting long term illness for the whole population. As such it would provide the only holistic picture of the most serious medical complaints suffered by residents and would be valuable in identifying chronic conditions and underlying issues such as recurrent causes of disability in some areas. The data would also show pockets of under-exposed health problems.

Other respondents, for example from the charity sector, echoed the views of central and local government, making the additional points below:

- *Socio-economic status:* the data would give a better picture of the number of people with different types of disability and their socio-economic position.
- *Research:* the government could use the data to decide if there are enough people affected by one type of condition or impairment, and if so can then decide whether to fund relevant research or not.

Many respondents to the initial consultation exercise in 2005 thought that a Census 2011 dataset of disability outputs would enhance the usability of the sources below by providing a benchmark against which they can be measured:

- *DWP Benefits Data* - DWP have data that charts in some detail the causes of illness suffered by those claiming DWP health benefits. However, this is limited to those claiming benefits. Merseyside Local Authorities also state that “people claiming multiple benefits get ‘lost in the mix’ and therefore the data cannot provide an accurate representation of the real numbers of people suffering from different ailments”.
- *Department of Health/PCT Data* - Department of Health/Primary Care Trust data does contain information relating to residents suffering from various health complaints, but is often limited to the number of people receiving health treatment. Longer term, NHS records should be able to provide some of the information, but will not offer the multivariate analysis that the Census does.
- *GP Data* - GP data is able to provide a small amount of information in some areas but this varies widely and also access to the data is limited. This may however improve over time.
- *Voluntary Registers* - Currently there is a voluntary register held with local authorities for people with learning disabilities. However, this is not statutory and provides very incomplete data with much variation between local authorities. The data is inadequate for local planning and does not provide information at national or regional levels.
- *Welsh Health Survey* - The Welsh Health Survey includes detailed information on various illnesses but does not allow analysis below local authority level. Other survey research is also available, but this is based on small samples and the Census would be a much more comprehensive source.
- *Social Services Data* - Social services have lists of deaf people as they require a deaf person to register if they need their services. However, most do not make themselves known to social services for fear of exposure or interference into their personal circumstances.

Disability question development for the Integrated Household Survey

ONS, ODI and other government departments in England and the devolved administrations have considered in detail the options for harmonising questions on chronic health conditions and disability in national household surveys. Their partnership work is undertaken in response to weaknesses of disability data coordination, comparability and accessibility identified by the Equalities Data Review²⁴. ONS has summarised this work in the paper entitled *Road Map to Harmonisation*²⁵.

As part of its response to the review, ONS is working with ODI to develop a suite of disability questions for use in the Integrated Household Survey²⁶. The questions, which complement the 2011 Census disability question, should:

- help to establish consistency in the collection of disability data
- deliver harmonised disability data and coherent national statistics
- enhance and extend the disability data outputs from the 2011 Census, and other data sources

ONS plans to produce an authoritative guide for those who administer the disability questions and analyse the data. The guide should be a valuable tool for other organisations in the public, private and not-for-profit sectors that design and administer surveys that include disability questions.

Stakeholder workshop

In June 2008, ONS and ODI held a workshop with government departments and the devolved administrations to reach agreement on question content, scope and priorities for testing²⁷. This

²⁴ *Fairness and Freedom, the Final Report of the Equalities Review*, 2007: Available online at <http://archive.cabinetoffice.gov.uk/equalitiesreview/>

²⁵ *Road Map to Harmonisation*, ONS, February 2009, page 9: Attached at Appendix 1.

²⁶ *Report from the review of equality data*, ONS 2007: Available online at <http://www.ons.gov.uk/about-statistics/measuring-equality/equality-data-review/index.html>

²⁷ *Summary of the ONS/ODI Workshop on Disability Definitions and Harmonisation*, ONS, 17 June 2008: See Appendix 2

harmonisation process takes account of the equality monitoring and equality outcome requirements of the amended Disability Discrimination Act. It also takes account of the health monitoring requirements of the European Union, including the proposed European Health Interview Survey (EHIS) and the Minimum European Health Module component of their Statistics on Income and Living Conditions (EU-SILC) currently supplied from the IHS.

The question suite options developed for discussion and linked to the stakeholders' specific expressed data needs are presented below. These options were discussed at the workshop.

Option 1: aims to measure DDA defined disability

Q1a. Do you have any long-standing physical or mental illness or disability that has limited your day-to-day activities over a period of at least 12 months or is likely to over a period of at least 12 months? Please include limitations that are due to old age.

Would you say you are:

- a). Substantially limited
- b). Limited, but not substantially
- c). Not limited now, but was substantially limited for a period of at least 12 months in the past
- d). Not limited at all

If responds d above

Q1b. Do you receive any medication or other treatment without which your health conditions would substantially limit your day-to-day activities?

- a) Yes; b) No; c) Don't know

Q2. Do you have any of the following impairments or health conditions?

- a). a physical impairment such as difficulty using your arms or mobility difficulties which require you to use a wheelchair or other mobility aid

- b). a sensory impairment such as serious vision difficulties or blindness, or deafness
- c). a mental health condition, such as depression or schizophrenia that has lasted or is expected to last 12 months or more
- d). a learning difficulty or disability such as down's syndrome or dyslexia or a cognitive impairment such as autistic spectrum disorder
- e). Diagnosed as having HIV, Cancer or Multiple Sclerosis
- f). Other long-term illness or health condition that has lasted or is expected to last 12 months or more

Option 2: aims to measure current disability

Q1. Are your day-to-day activities limited because of a physical or mental health problem or disability which has lasted, or is expected to last at least 12 months?

Include limitations you would experience without medication or treatment and limitations that are due to old age.

- (1) Yes, limited substantially
- (2) Yes, limited but not substantially
- (3) No

If responds 1 or 2 above

Q2. Do you have any of the following impairments or health conditions?

- a). a physical impairment such as difficulty using your arms or mobility difficulties which require you to use a wheelchair or other mobility aid
- b). a sensory impairment such as serious vision difficulties or blindness, or deafness
- c). a mental health condition, such as depression or schizophrenia that has lasted or is expected to last 12 months or more
- d). a learning difficulty or disability such as down's syndrome or dyslexia or a cognitive impairment such as autistic spectrum disorder
- e). Diagnosed as having HIV, Cancer or Multiple Sclerosis
- f). Other long-term illness or health condition that has lasted or is expected to last 12 months or more

Option 3: aims to measure current disability to meet both UK and EU-SILC data requirements

Q1a. Over the past 6 months, to what extent have you been limited in activities that people usually do because of a health problem or disability? Would you say you have been...?

- a). Severely limited
- b). Limited, but not severely
- c). Not limited at all

If a or b

Q1b. If you are limited, have these limitations lasted for 12 months or more?

- a). Yes
- b). No

If b

Q1c. If you receive medication or treatment for a health problem or disability, would your day to day activities be severely limited without this medication or treatment?

- a). Yes
- b). No
- c). Don't have a health problem or disability

Q2. Have you ever been diagnosed with any of the following health conditions?

- a). HIV
- b). Cancer
- c). Multiple sclerosis
- d). None of these

Option 4: aims to measure current disability to meet UK data requirements - most condensed format

Q1. Are your day-to-day activities substantially limited because of any physical or mental health conditions or disabilities which have lasted or will last at least 12 months?

If on medication please consider the effects without.

- a). Yes
- b). No

Outcome of stakeholder workshop

Following the workshop, and taking into account all views expressed by the stakeholders, decisions on question suite content and format were reached by ONS in partnership with ODI.

ONS recommends that the priority for the question suite should be to:

- monitor people with potential rights under the Disability Discrimination Act (DDA)
- meet national user needs
- be able to meet EU requirements wherever possible

It was agreed that this suite should be composed of:

- **Two core questions** which are recommended for inclusion on all surveys and will measure the number of people with potential rights under the DDA i.e. people who currently have longstanding illnesses, impairments or health conditions which substantially constrains their ability to carry out normal daily activities . It will also provide a breakdown by type of impairment or condition.
- **Another optional question** which can be included on surveys, if required, to monitor disability by looking at the barriers faced by people with impairments.
- Additional people with potential rights under the DDA, such as those with past DDA disabilities, will be collected in an alternative source or module.
- A twelve month time period should be the standard for the question suite as it links to the Census 2011 question and the DDA definition. The differences in prevalence that arise with a six month time period should be evaluated using existing data where possible.

- Impairment types, if collected second, should not be routed from the question eliciting adverse effects. This will allow true prevalence of impairments to be collected and the proportion whose normal activities are unaffected by their impairment.
- The list of impairments is valued and should be included, but an expansion of the fifth category to differentiate DDA conditions and other long-standing conditions should be considered.

Revised question suite adopted for IHS testing

ONS and ODI compiled a revised question suite on the basis of decisions taken at the workshop which has the following specification (see questions in Table 1 below). The question testing process will be completed in time for the implementation of the question suite in the Integrated Household Survey that will be conducted in April 2010.

Question 1 versions aim to establish the presence of conditions, impairments and disabilities, with open and prescribed breakdowns elicited in version b and c respectively.

Question 2 aims to establish the presence of limitations in respondents' day-to-day activities: the questions differ in their strength of linkage of the condition or impairment with the limitation (i.e. 'mean' or 'because') and in routing; version b is routed from Q1, whereas version a is not.

Question 3 aims to place the duration of limitations in daily activities into a time frame that is consistent with DDA and European data needs. The timeframe for the DDA is 12 months or more; and for at least six months for EU-SILC.

Question 4 asks respondents if they are taking medication for their condition or impairment and, if they answered 'No' to question 2, whether their daily activities would be limited without medication.

Table 1

Q1a. Do you have any long-standing physical or mental health condition, impairment or disability that has lasted or is expected to last 12 months or more? Please

Q1b. Do you have any long-standing physical or mental health condition, impairment or disability that has lasted or is expected to last 12 months or

Q1c. Do you have any of the following long-standing physical or mental health conditions or impairments that have lasted or are expected to last 12 months or

include those that are due to old age

1. Yes
2. No

more? Please include those that are due to old age

1. Yes
2. No

IF 1:

What is the nature of your physical or mental health condition, impairment or disability?

0. Open text - code up to 6 replies

more? Select all that apply. Please include those that are due to old age

1. Blindness, deafness or other communication impairment
2. Mobility impairment, such as difficulty walking
3. Learning difficulty or disability, such as Down's syndrome
4. Mental health condition, such as depression
5. HIV, Multiple Sclerosis or cancer
6. Other long-standing health condition or disability
7. None

Q2a. Are your day-to-day activities limited because of any physical or mental health condition, impairment or disability? Please include those that are due to old age.

Would you say you are:

1. Severely limited
2. Limited but not severely
3. Not limited at all

IF Q2 = 1 or 2

Q2b. Do your physical or mental health condition(s), impairment(s) or disability(ies) mean that your day-to-day activities are limited? Please include those that are due to old age.

Would you say you are:

1. Limited a lot
2. Limited a little
3. Not limited at all

Q3. How long have your day-to-day activities been limited?

1. Less than 6 months
2. At least 6 months but less than 12 months
3. At least 12 months

IF 1 or 2:

Do you expect your day-to-day activities to be limited for 12 months or more altogether?

1. Yes
2. No

IF 1 to Q1b or 1 thru 6 to Q1c AND 2 or 3 to Q2:

Q4. Do you take any medication for your long-standing health condition(s) or disability(ies)?

1. Yes
2. No

IF 1:

If you did not have this medication, do you think your activities would be limited by your long-standing health condition(s) or disability(ies)?

1. Severely limited/limited a lot
2. Limited but not severely/limited a little
3. Not limited at all

Terminology issues

The changes to the revised question suite are needed so that data can be harmonised across surveys. However, ONS is not certain about how the questions will be understood by respondents. In addition, ONS is not clear whether the wording, routing and categorisation will define the target population in valid and reliable ways.

ONS is conducting cognitive testing of the question suite with 31 adults to identify if the terminology allows respondents to answer accurately. Issues of concern with the proposed suite that require testing of interpretability are:

- understanding of the relationship between impairment and disability;
- the merits of each alternative question formulation;
- the terms impairment and category of condition or impairment if asked to fit within specific response categories or open responses;
- the merits of separating out learning disability and learning difficulty;
- respondents' thought processes while formulating their answers;
- whether the answer categories at different questions correspond to the way in which respondents think about the issues concerned, and if the categories are complete and comprehensive;
- if and how the order in which the questions are asked affects the answers respondents give;
- the extent to which respondents feel able and willing to provide answers to the survey questions;
- the length of time daily activities have been limited (past and future);
- the linkage of medication with condition, impairment or disability asked about in question 1 and question 2;
- the requirement to speculate on whether and what level of severity daily activities would be limited without medication.

Social barriers questions

The Disability Discrimination Act requires public bodies to take actions that identify and remove barriers that encourage and support the participation of disabled people in all aspects of life. Organisations in the private and not-for-profit sectors also have legal duties related to providing equality of access for both disabled and non-disabled people to employment, goods, facilities and services. It is important for all business sectors to be able to identify and eliminate the social barriers that might otherwise result in unlawful disability discrimination.

A measurement of disability that identifies social barriers in particular areas of life will assist organisations in all business sectors to eliminate the barriers or find ways of minimising their impact on disabled people.

To take account of the measurement of disability in the context of the social barriers faced by people with health conditions and impairments, two variants of a social model based question suite have been developed for testing. These are shown in Table 2 below.

Table 2

Q5a. There are many reasons why people can't take part in activities as much as they would like to. Are you limited in the following areas of life for any reason...

Individual Prompt – Code all that apply

- (1) Education?
- (2) Work?
- (3) Transport?
- (4) Personal relationships?
- (5) Leisure?
- (6) None of these

If Q5a = 1 thru 5

Q5a. SHOWCARD

Q6a What limits you in these areas?

Code all that apply

- (1) Financial reasons
- (2) Too busy/not enough time
- (3) A health condition, illness or impairment
- (4) A disability
- (5) Poor services
- (6) Lack of assistance or equipment
- (7) Badly designed buildings
- (8) Attitudes of others
- (9) Lack of information
- (10) Other reasons

Q5b. There are many reasons why people can't take part in activities as much as they would like to. Do you have any difficulty taking part in the following areas of life for any reason...

Individual Prompt – Code all that apply

- (1) Education?
- (2) Work?
- (3) Transport?
- (4) Personal relationships?
- (5) Leisure?
- (6) None of these

If Q5b = 1 thru 5

Q5b. SHOWCARD

Q6b What causes you difficulty in these areas?

Code all that apply

- (1) Financial reasons
- (2) Too busy/not enough time
- (3) A health condition, illness or impairment
- (4) A disability
- (5) Poor services
- (6) Lack of assistance or equipment
- (7) Badly designed buildings
- (8) Attitudes of others
- (9) Lack of information
- (10) Other reasons

The aim of these questions is to collect a high-level indicator of the social model of disability. Under the social model, people may have health conditions or impairments that cause them to function differently, but they are not necessarily disabled by them. Instead, people with health conditions or impairments are disabled by the social and environmental barriers imposed on them by aspects of society that take little or no account of their needs; and which may result in less favourable treatment when compared to the lived experiences of non-disabled people.

The social barriers questions designed for testing attempt to recognise that there is not necessarily a direct link between impairment and disability. Rather than asking 'does your impairment limit you', they allow a respondent to choose what limits them from a range of social and environmental barriers.

The questions are based on the International Classification of Functioning (ICF)²⁸. The ICF partitions disability into the series of components below:

1. Body functions and structures, for example a defect in the structure of the ear.
This component is measured in questions relating to impairments and health conditions which are broadly captured in questions 1a, 1b and 1c.
2. Activity limitations, for example inability to work or shop.
This component is collected in questions 2a and 2b.
3. Participation restrictions, for example difficulty finding employment.
This component is measured by 5a and 5b.
4. Contextual factors, including environmental and personal factors.
This component is measured in 6a and 6b.

The questions recognise that it is a combination of these contextual factors, and the interactions between them, that creates disabling barriers for individuals. Questions 5a and 5b attempt to measure the ICF concept of 'participation restrictions'. Questions 6a and 6b attempt

²⁸ ICF checklist, World Health Organisation: <http://www.who.int/classifications/icf/icfaptraining/en/index.html>

to provide some of the most common contextual factors which influence participation restrictions. Contextual factors include social/environmental factors such as poor services, as well as individual factors such as health conditions.

During the cognitive testing process, ONS wishes to establish the following:

Question 5a and 5b

- 1 What does “activity” mean to the respondent?
- 2 What does “limited” mean to the respondent? (5a)
- 3 What does “difficulty” meant to the respondent? (5b)
- 4 What do respondents think each answer category means to them?
- 5 Are there any categories missing?
- 6 How did the respondent formulate their answer?
- 7 What kind of reasons for limitations/difficulties do respondents have in mind when answering the question?

Question 6a and 6b

- 1 What does “limit” mean to the respondent? (6a)
- 2 What does “difficulty” mean to the respondent? (6b)
- 3 How does the respondent distinguish answers 3 and 4?
- 4 How does the respondent allocate his/her answer to the categories?
- 5 How did the respondent formulate their answer?
- 6 Are respondents able to fit the reason for their limitation into these categories? If not, what other categories need to be added to the showcard?

Positive equality impacts

This section presents the positive equality impacts that are likely to result from the development by ONS of a suite of disability questions. Three major positive equality impacts are identified by this assessment of the development work:

1. A disability question will be asked on the 2011 Census, which is based on the Disability Discrimination Act definition of disability; and the outputs will enable benchmarking with other official disability datasets.
2. The development of the questions is assisting ONS, ODI and UK government departments to agree on a harmonised definition of disability that can be applied in key administrative and survey data sources.
3. Consultations with expert users of disability data are being used to inform the development of a suite of disability questions for use in the ONS Integrated Household Survey and other official surveys.
4. Disability data outputs that identify social barriers in particular areas of life will assist organisations in all business sectors to eliminate the barriers or find ways of minimising their impact on disabled people.

When the testing process is completed, the suite of approved disability questions should result in improved data about the needs and requirements of disabled people in all diverse communities and across different age groups.

The data outputs of the Integrated Household Survey and other surveys that use the questions should help to:

- increase awareness of the needs and requirements of disabled people
- eliminate barriers faced to social inclusion in all areas of life
- improve community cohesion across and within all communities
- enable disabled people to have equal access to work opportunities
- improve the availability of accessible products, facilities and services provided by all business sectors
- improve monitoring of disability equality outcomes at local area level
- reduce disability discrimination

Monitoring the equality outcomes of disability question development and their implementation will assist ONS to maintain accountability and transparency of the decision-making process related to developing the questions; and to eliminate or mitigate any unforeseen adverse equality impacts.

Adverse equality impacts

This section of the assessment considers the potential for adverse equality impacts that may arise as a result of the development and implementation of the suite of disability questions in the 2011 Census and the Integrated Household Survey. Recommendations are made to mitigate any identified potential adverse impacts. Any further adverse equality impacts that may be identified during the course of the question development and/or implementation must also be eliminated or mitigated.

The equality groups considered are as follows:

- minority and majority ethnic communities
- women and men, including transsexual people
- disabled people with physical, sensory and mental health impairments
- lesbians, gay men, bisexual and heterosexual people
- people with different religious and non-religious beliefs
- people in different age groups

Adverse equality impacts may arise from differential survey implementation. Differential implementation may occur if appropriate interview, translation and interpretation arrangements do not take account of people with different types of impairments and communication needs. It may also occur if interviewers fail to implement the survey with people who have different types of impairments and communication needs.

ONS is conducting cognitive testing of the disability question suite for the 2011 Census and the Integrated Household Survey with a limited cohort of adult respondents.

Cognitive testing determines if terminology used in the questions is clear and easily understood by respondents. If terminology used in questions is not understood, people will be unable to answer accurately. ONS has identified issues of concern with the proposed suite that require testing of interpretability. The issues are as follows:

- understanding of the relationship between impairment and disability;
- the merits of each alternative question formulation;
- the terms impairment and category of condition or impairment if asked to fit within specific response categories or open responses;
- the merits of separating out learning disability and learning difficulty;
- respondents' thought processes while formulating their answers;
- whether the answer categories at different questions correspond to the way in which respondents think about the issues concerned, and if the categories are complete and comprehensive;
- if and how the order in which the questions are asked affects the answers respondents give;
- the extent to which respondents feel able and willing to provide answers to the survey questions;
- the length of time daily activities have been limited (past and future);
- the linkage of medication with condition, impairment or disability asked about in question 1 and question 2;
- the requirement to speculate on whether and what level of severity daily activities would be limited without medication.

The cohort of adult respondents who participate in cognitive testing is not likely to be representative of all equality groups, including people with different types of impairments and communication needs. People with such needs are at risk of exclusion from social survey opportunities. Such exclusion may result in adverse equality impacts. Exclusion risks arise from inadequate training of managers, interviewers and support staff. Under-resourcing of access requirements is also an exclusion risk.

People at risk from exclusion are identified as follows:

- people with visual impairments
- people with hearing impairments
- people who use British Sign Language and other sign languages
- people who are not fluent speakers of English
- people with speech impairments
- people who do not read English
- people with learning difficulties such as dyslexia
- people with learning disabilities such as Down's Syndrome
- people with mental health impairments
- people with cognitive impairments such as dementia

It is important that ONS Interviewers are required to justify in writing all decisions to rely on family members, carers or professionals to answer questions by proxy on behalf of disabled people. Excluding people with particular impairments and communication needs from the opportunity to answer questions on their own behalf may result in adverse equality impacts since their direct experiences will not be recorded and analysed. This is inevitable where people cannot give informed consent to be interviewed due to cognitive or mental health impairments; and where they are too young to give informed consent. However, ONS Interviewers may fail to gain informed consent from disabled people who are capable of giving it, such as those with mild to moderate learning disabilities. They may fail also to understand how to deliver appropriate access facilities.

However, by delivering appropriate training, ensuring adequate resourcing and making reasonable adjustments to survey administration, ONS will offer most people with impairments and communication needs the same opportunity to participate in surveys as everyone else. For example, people with learning disabilities and sensory impairments will not be excluded if the questions that must be read to respondents, or by respondents, are available in accessible

media formats, such as Easy Read, Braille and British Sign Language.

Complaints and comments

One of the essential ways in which an organisation receives performance feedback from members of the public is through its system of complaints and comments. This interaction facility is a positive organisational learning tool used widely across all business sectors.

An invitation to make comments and complaints is not available on the National Statistics website. The 'Contact Us' section of the website at <http://www.statistics.gov.uk/email.asp> only invites enquiries. This may reflect other lost opportunities to offer members of the public the opportunity to make comments and complaints, such as the failure of an Interviewer to deliver an appropriately accessible interview and, conversely, to compliment an Interviewer for delivering an excellent interview.

Mitigation of adverse equality impacts

Few potential adverse equality impacts are identified as a result of this assessment. ONS is promoting disability equality by paying due regard to the development of a suite of disability questions for implementation in the 2011 Census and the Integrated Household Survey. This is further enhanced by partnership work with the Office for Disability Issues on the Life Opportunities Survey.

The disability question to be asked in the 2011 Census will provide essential baseline disability data for the whole population. The question will not produce output data on the complexities and impacts of disability that are prevalent within majority and minority communities and equality groups. However, the limitations of the 2011 Census question are mitigated by the development of a harmonised disability question suite for implementation within the Integrated Household Survey. In addition, the longitudinal Life Opportunity Survey, commissioned by the Office for Disability Issues (ODI) and administered by ONS, will "track the experiences of disabled people over time to assess transitions through key life stages, such as moving from

childhood to adulthood or in and out of work, and people's experience of receiving a range of benefits and services"²⁹ in comparison with a control group of non-disabled people.

The ONS Instruction Manual document called "An equal chance for all respondents", to be published in due course, is part of ONS's response to the risk of excluding people with different types of impairments and communication needs from survey opportunities.

The following is a summary provided by ONS of the current procedures used when Interviewers gain consent to interview respondents with impairments, or where English is not their first language.

- 1) The guidance "An Equal Chance for All Respondents" sets out the procedures that need to be followed by Interviewers and other ONS personnel.
- 2) Interviewers are required to establish whether they have received informed consent before interviewing an eligible sample member. Training is provided to help with this, and is applicable to all ONS surveys.
- 3) New Interviewers will receive training both in the classroom and in the field. They will observe experienced interviewers to see how to deal with such situations. They will also be accompanied by a manager or mentor when they first start working. They have access to their manager (via their office mobile phone) and to the Field Enquiry Line (HQ staff, based in Titchfield), with whom they can seek guidance on how to deal with the circumstances they are faced with on the doorstep.
- 4) Three times a year, Interviewers will attend regionally based support group meetings where they will have the opportunity to share their experiences with other colleagues and to develop their skills. There will also be other opportunities (e.g. briefings for new surveys).
- 5) Interviewers will not know whether they will need an interpreter (or other assistance) before making contact with a respondent. Section 1.13 of "An Equal Chance for All Respondents" sets out what the Interviewer needs to do.

²⁹ Life Opportunities Survey (LOS) Briefing Pack, ODI 2009 (see Appendix 2). For more information on the LOS, go to <http://www.odi.gov.uk/research/survey.php>

- 6) Interpreter services are provided through a number of sources. ONS has a contract with Language Line (for details see <http://www.languageline.co.uk/>). Language Line is used mainly for establishing initial contact and gaining consent. Their service is provided over the telephone, although in some situations, they can provide a face-to-face support.
- 7) Where interpreters are required for survey interviews, locally based interpreter services are normally used. Centrally, ONS maintains a list of approved interpreters which regionally based Field Managers can access, and arrange to be used. Most of these interpreters work for local authorities.
- 8) These procedures apply to the entire Integrated Household Survey.
- 9) ONS does not exclude questions from certain populations on the basis of a respondent's ability to communicate in English. The questionnaire is the same for all respondents. Detailed testing of the questionnaire occurs in order to ensure that it can be answered by everyone, regardless of whether they are English speakers, and regardless of any impairment. All surveys are piloted in the field before the start of the main data collection period.
- 10) All respondents have the right to refuse to answer a question.
- 11) Translators are required to follow the same set of rules as Interviewers for administering survey questionnaires. They are required to ask questions as they appear on screen (interviewing is done by Computer-Assisted-Interviewing (CAI)) and will be guided by our Interviewer on whether it is necessary to elaborate further on a question.
- 12) When requested, ONS allows for an adult family member to translate. This practice is currently being reviewed.

Potential adverse equality impacts

The "Equal chance for all" guidance is a reasonable adjustment by ONS, which aims to ensure that disabled people and their experiences are not excluded from its survey interviews. However, guidance is not effective if employees are not properly trained to implement it. The interview implementation process is identified as the main risk area to ONS for the potential to

result in unlawful discrimination. Disability and racial discrimination is identified as the highest potential risk area.

Interviewers, managers and support staff cannot deliver accessible interviews if they do not receive appropriate, timely and proportionate training that equips them to understand the access needs of groups with different impairment and communication needs. ONS expects these different needs to be met. However, inadequate resourcing and delivery of a quality training programme would leave ONS vulnerable to complaints of unlawful discrimination and vicarious liability.

ONS should ensure that its Interviewers are required to justify in writing all decisions to rely on family members, carers or professionals to answer questions by proxy on behalf of disabled people. Excluding people with particular impairments and communication needs from the opportunity to answer questions on their own behalf may result in adverse equality impacts since their direct experiences will not be recorded and analysed.

ONS should ensure that it has a reliable training programme in place that will eliminate the risk of unlawful direct and indirect disability and racial discrimination. ONS should also monitor the implementation of the training programme in accordance with the employment equality monitoring requirements of equality law, including the Race Relations (Amendment) Act 2000. Effective evaluation and monitoring will enable ONS to provide evidence that it is delivering appropriate, effective, timely and proportionate training to all relevant staff.

If the access needs of respondents are not met and the interview experience is negative, individuals need the facility to complain and make comments. If access needs are met and the interview experience is positive, individuals should have the facility to compliment ONS and its employees.

The recommendations below are made in order to eliminate and mitigate the potential for such risks.

Recommendation 2: where informed consent is an issue, that clear procedures are in place that require all Interviewers to justify in writing their decisions to rely on family members, carers or professionals to answer questions by proxy on behalf of disabled people.

Recommendation 3: that all Interviewers, relevant managers and support staff receive appropriate, timely and proportionate training that equips them to understand how to deliver accessible interviews to people with different impairments and language needs; and that this training is refreshed at regular intervals.

Recommendation 4: that the 'Contact Us' section of the National Statistics website should include the facility to make comments and complaints, as well as enquiries; and that this facility is promoted at other appropriate points such as information cards left by Interviewers.

Consultation with affected communities

The Race Relations (Amendment) Act 2000, Disability Discrimination Act 2005 and the Gender Duty of the amended Sex Discrimination Act 1975 require public bodies to consult on the likely impact of proposed policies on the promotion of race, disability and gender equality. This assessment is part of the process.

ONS is a model of good consultation practice and has considerable expertise in organising effective and inclusive consultations. Its good practice includes publishing information papers that give important progress information to all business sectors and the wider community.

To develop questions for the 2011 Census, ONS has conducted extensive public and expert user consultations since 2005. These consultations are documented and published by ONS³⁰.

To develop the suite of disability questions for the Integrated Household Survey and other surveys, ONS has consulted with expert users of disability data. In collaboration with ODI, ONS is conducting cognitive testing of the proposed survey questions with 31 members of the

³⁰ See 'Consultations' at <http://www.ons.gov.uk/census/2011-census/consultations/index.html>

public. The results of the testing should ensure that respondents understand the meaning of the questions. When the cognitive testing is completed in mid-2009, ONS plans to hold further consultation in Scotland with disability organisations and other interested parties. The consultation outputs will influence the final question suite, which may be adapted further in light of comments received from consultees.

Publishing the assessment

The Race Relations (Amendment) Act 2000, Disability Discrimination Act 2005 and the Gender Duty of the Sex Discrimination Act 1975 require ONS to make arrangements to publish the results of equality impact assessments. The assessments are a positive, valuable means by which ONS shows due regard and a robust approach to promoting race, disability and gender equality.

Publishing the assessment in full will enable individuals to comment on the assessment, which may not have considered every possible equality dimension or potential equality outcome.

Recommendation 5: that this equality impact assessment is published by ONS to enable individuals and groups to comment on the assessment, which may not have considered every possible equality dimension or potential outcome.

Monitoring equality outcomes

The Race Relations (Amendment) Act 2000, Disability Discrimination Act 2005 and the Gender Duty of the Sex Discrimination Act 1975 require ONS to make arrangements to monitor the impact of its policies on its duty to promote race, disability and gender equality. The equality outcomes of policy must be monitored, and any adverse equality impacts eliminated or mitigated.

Monitoring the outcomes will assist ONS to maintain accountability and transparency of the decision-making process related to the following:

- developing the suite of disability questions
- monitoring the potential for disability or racial discrimination that may arise from survey implementation
- eliminating or mitigating any adverse equality impacts that are not identified by this assessment.

Effective monitoring will be assisted by the development of an action plan to implement the recommendations of this equality impact assessment.

Recommendation 6: that the equality outcomes of the suite of disability questions and survey implementation should be monitored at regular intervals.

Recommendation 7: that an action plan is devised by ONS to implement the recommendations adopted from this assessment.

Recommendation 8: that the equality impact assessment is updated at regular intervals to take account of equality monitoring outcomes.

Appendices

Appendix 1: *Summary of the ONS/ODI Workshop on Disability Definitions and Harmonisation*, ONS, 17th June 2008

Appendix 2: *Life Opportunities Survey (LOS) Briefing Pack*, ODI 2009

Appendix 3: *Road Map to Harmonisation*, ONS, February 2009

Summary of the ONS/ODI Workshop on Disability Definitions and Harmonisation 17th June 2008

Attendees

Present were representatives from –
Welsh Assembly Government
The Scottish Government
Department for Children, Schools and Families
Department for Work and Pensions
Communities and Local Government
Equality and Human Rights Commission
Office for National Statistics
Office for Disability Issues

Absentees

Department of Health
Department for Innovation, Universities and Skills
Government Equalities Office
Department for Transport
Business, Enterprise and Regulatory Reform
Culture, Media and Sport
Northern Ireland Assembly

Aim of the Workshop

1. The aim of this workshop was to progress recommendation 4.3 of ONS's Equality Data Review- *'The Office for Disability Issues and the Government Equalities Office in partnership with ONS and devolved governments, urgently agree a consistent approach to collecting information on disability, and champion this widely across Government and the wider public sector.'*
2. In order to agree a consistent approach ONS, ODI, GEO and the devolved governments are developing an agreed **suite of questions** to be used on all surveys which will ensure there is a consistent approach to collecting disability data across government.
3. Prior to the workshop an initial suite was circulated which was the focus of discussions during the day. The rationale for this suite is set out in ODI's position paper which was circulated in early June 2008.

Summary

Agreed Approach for Question Suite

4. The consensus was that the priority for the suite should be –
 - To monitor people with potential rights under the Disability Discrimination Act (DDA)
 - To meet user needs
 - To be able to meet EU requirements wherever possible
5. It was agreed that this suite should be composed of:
 - **Two core questions** which are recommended for inclusion on all surveys and will measure the number of people potential rights under the DDA i.e. people who currently have longstanding illnesses, impairments or health conditions. It will also provide a breakdown by type of impairment or condition.
 - **Another optional question** which can be included on surveys if required will monitor disability by looking at the barriers faced by people with impairments.
6. In order to monitor people with potential rights under the DDA the suite will have to adopt the definition of disability used in the Act. This is not necessarily a definition which would be widely understood, for example, it includes as disabled anyone who has ever been diagnosed with cancer or someone who had a longstanding, limiting illness in the past but is no longer affected. Further details of the definition of disability in the DDA can be found here - <http://83.137.212.42/sitearchive/DRC/pdf/DefnOfDisability.pdf>
7. The optional question will allow departments to monitor the impact of their policies on disabled people in line with the definition of disability used in the 2005 Prime Minister's Strategy Unit report³¹ - *'Disability is defined as disadvantage experienced by an individual ...resulting from barriers to independent living or educational, employment or other opportunities ...that impact on people with impairments and/or ill health.'*
8. By using the three questions in the suite departments can assess whether their policies are having an impact on disabled people and also crucially whether the barriers faced by disabled customers are decreasing over time. For example, using the three questions in the suite a transport survey could ask questions around the barriers faced by people with impairments when accessing buses or trains. It could use this data to inform policy and improve services for people who are DDA disabled and who are experiencing disadvantage due to the way transport services are currently provided. The suite would provide information about the different experiences of people with different types of impairment.

³¹ Prime Minister's Strategy Unit (2005) *'Improving the life chances of disabled people'*

9. The intention is that the core questions will be designed so that they can also be asked of children but it will need further testing to ensure that the questions are appropriate.

Workshop Discussions

There were three main sessions held during the day. The first considered priorities for the suite, the second discussed the limitations of the draft suite and the third focused in more detail on the uses of the data and specific breakdowns required.

Exercise 1 – Priorities of the suite

Groups (by table) were firstly asked to comment upon perceived priorities for question design. There then followed an opportunity to comment upon the question suites as presented.

Findings

Group 1

- To monitor people with potential rights under the DDA. Current disability had greater relevance if choices had to be made, as it encompassed the majority of the population covered under the DDA and had greater commonality with European needs. The population whose adverse effects on normal activities were mitigated or eradicated through medication were considered less relevant for service provision than those that remained substantially limited regardless of medication status.
- To meet user needs – Users were identified primarily as government depts. such as Department of Health and below that, local authorities and primary care trusts.
- To maintain current time-series and have the agility to meet needs for new indicators (e.g. EU Disability Free Life Expectancy breakdowns by force of limitation and provision at lower geographical scales).

Group 2

- To identify the population covered under the DDA.

Group 3

- IHS Core – The EU Regulation (Mini European Health Module (MEHM) in all EU surveys from 2010) was raised as a constraint to prioritising UK specific data needs.
- Census – DDA – Important to be able to measure/understand the difference between census and other surveys.
- Options for modifications to MEHM (feeding into SILC) to increase compatibility with the DDA to be explored with Eurostat).

Overview of Session 1

10. The priorities for data coverage in UK surveys has both national and European dimensions: a fusion of these needs into a cohesive whole will have an effect on the common measures of prevalence traditionally used to inform service need assessment, population health status and the monitoring of progress towards Public Service Agreement indicators.
11. The distinction between disability in terms of disadvantage experienced by individuals with impairments and the DDA definition of disability which focuses on long standing illness, impairment or health condition was accepted. It was agreed that we need to be very clear what the definition used in the suite covers and why it has been designed in that way.
12. The need to cover people with rights under the DDA was supported by groups 1, 2 and 3. This will enable public bodies to be in a better position to meet their Disability Equality Duty (DED) legislative requirements. The DED is a legal duty requiring all public bodies to have due regard to the need to promote equality of opportunity for disabled people when carrying out their functions. This means that public bodies will need to understand the impact of their policies, practices and procedures on equality for disabled people and take action to address disadvantage.
13. If component parts had to be prioritised, then it was agreed that current disability should have greater weight.
14. Service provision assessment would benefit from being able to separate out those whose normal activities were substantially affected regardless of medication status and those whose normal activities were unaffected because of medication effects.
15. The requirement for EU surveys to meet the Mini European Health Module harmonisation standard was also identified as a priority (see annex 1 for the questions and EU guidance).
16. However, there are going to be limitations in the extent to which a suite can meet all these priorities. For instance there are differences in terminology, routing and time period between the DDA and EU MEHM.
17. The discontinuity that harmonisation, in any of its forms, will introduce to established time series was recognised and the impact on indicators of these changes to questions must be adequately understood. The relationship between the new harmonised data, the census and existing data sources must be tested.

Wider Group Discussion

In a wider group discussion, following on from the table sessions, attendees were asked about their priorities in designing a single question.

18. The single question should try to capture as many people who are likely to have rights under the DDA as possible. The most appropriate way to do so seems to be to measure the prevalence of current impairment, based on a 12 month period, and also activity limitation and the (substantial) effects including a specification for where it would be limiting without medication or treatment.
19. It was suggested that the response category *not minor or trivial adverse effects* could be used to reflect the underlying meaning of substantial documented in the guidance accompanying the DDA. However, this would preclude the ability to measure severity of adverse effects.
20. The need to establish whether variability in the prevalence of limitation in day to day activities arises from specification of either a 6 or 12 months time period was mentioned: the absence of a statistically significant difference in prevalence would solve the DDA / SILC time period conflict, but knowledge of the scale of difference would also be useful for adjustment purposes.
21. Some workshop participants also mentioned the desirability of including past conditions, and progressive illnesses to give a more complete picture of people with potential rights under the DDA. However, given the space constraints and the fact that at the moment most surveys tend to ask two questions about impairments and activity limitations it would seem that a suite which attempts to align this is a good starting point. From a practical perspective it does offer more scope to harmonise with MEHM.

Exercise 2 – The draft question suite

22. The draft suite used as a starting point for discussion was formed of the following three questions –

Question 1 – to monitor people with current long-standing illnesses, impairments or disabilities, in line with the Disability Discrimination Act

Are your day-to-day activities limited because of any physical or mental health conditions or disabilities which have lasted or will last at least 12 months?

If on medication please consider the effects without.

Yes substantially
Yes not substantially
No

Question 2 – to monitor people who have had an illness, impairment or disability in the past and would still have rights under the DDA.

Have your day-to-day activities ever been limited in the past because of any physical or mental health conditions or disabilities which lasted at least 12 months?

- Yes substantially
- Yes not substantially
- No

Question 3 – breakdown by type of impairment

Do any of the following categories apply to you (you may indicate more than one).

1. Physical impairment, such as difficulty using your arms or mobility issues which means using a wheelchair or crutches
2. Sensory impairment, such as being blind / having a serious visual impairment or being deaf / having a serious hearing impairment
3. Mental health condition, such as depression or schizophrenia
4. Learning disability / difficulty, (such as Down's syndrome or dyslexia) or cognitive impairment (such as autistic spectrum disorder)
5. Long-standing or progressive illness or health condition such as MS, cancer, HIV, diabetes, chronic heart disease, or epilepsy

The group who would be included in a definition of those with rights under the DDA would be those who respond 'Yes substantially' to questions 1 or 2 or 'Yes' to question 3 part 5.

Findings

Group 1

- Most important to measure the prevalence of impairment in order to allow detection of change over time. This view is based on the admittedly limited traditional model of disability data collection.
- Measuring barriers faced by people with impairments would be a useful tool where survey space allows. It may also be of interest to policy makers to understand the barriers faced by people with no impairments, for example a parent of a DDA disabled child may also face significant social barriers such as finding suitably flexible employment.

- There is also the issue of organisations that disabled people interact with and how adaptations can be linked to organisations. Extensive lists of organisations will preclude feasibility within the IHS core, but could be implemented within the LDSGB module.

Group 2

- The suite should start with proposed question 3 which focuses on impairment types first and could be asked of all people. However the categories presented in the draft suite are too broad, e.g. 'visual/hearing impairments' and 'learning disabilities and difficulties' should be split.
- There is also the need to measure impairment severity either in this question or in a following question.
- Some options are too prescriptive esp. physical impairment.
- Language should be explored to reflect capability such as focusing on specific activities like washing, cooking and dressing rather than 'do you use a wheelchair'.
- Progressive illnesses need to be identified as only some are included as disabled for the purposes of the DDA.
- The impairment type question should be followed with a version of question 1 that checks for both substantial and long-term adverse effects.
- There is a need for an alternative to 'substantial' e.g. restrict (as this fits with the DDA guidance which states substantial refers to non-trivial adverse effects on day to day activities).

Group 3

- In question 1, the term 'substantially' may not be understood – the DDA itself is confused on this as the guidance explains that this means 'non-trivial' which is different to what most people would understand by substantial.
- The FRS has 'substantially' in the question rather than the answer – this would need to be tested if adopted.
- Remove the link between condition and activity limitation 'do you have a physical...?' Followed by question 2.
- Look at the ordering effects of impairment type.
- Have no filter – everyone answers impairment questions.
- Could we just use Q3 with a medication option instead of the other questions?
- In question 2. useful to keep 'substantially/not' to measure the wider disabled population.

- In question 3, have an 'Other' box (Who would code these?). There should be more thought on part 5 because of its sensitivity – Perhaps disaggregate it – Can admin data supply this?

Overview of Session 2

23. Space constraints in surveys were an important issue that stakeholders had already identified in a previous workshop. Having considered how we could derive a measure of disability and the number of questions necessary to do so it was agreed that this is unlikely to be feasible for the 2 or 3 core questions.
24. Therefore the discussions mainly focused on how to design a suite with a core set of questions which could adequately identify people with illnesses, impairments or health conditions and who are likely to have rights under the DDA. Additional questions on disability will also be included in the suite to ensure that where surveys do want to monitor the barriers faced by their customers they can ask a standardised question to do so. Otherwise the linkage of impairments with social barriers will be possible through the collection of impairments on the IHS core, and barriers on the LDSGB.
25. The list of impairments types (see annex 2) was thought too broad and should be separated out (e.g. hearing impairment and visual impairment should be separate categories). The inclusion of adverse effects/capabilities categorised by severity level was supported, but may be better to work into the impairment question rather than the more general question. However, another approach would be to capture adverse effects by severity in a follow-up routed question allowing adverse effects to be linked to impairment of specific condition. Impairment type 5 (long-standing health condition) should either be restricted to DDA specific conditions, or expanded to cover DDA conditions and other conditions.
26. The interpretation of *substantial* among survey respondents and the DDA's interpretation may conflict as the latter defines *substantial* as exceeding only minor or trivial adverse effects on day to day activities. This would suggest the DDA threshold for inclusion is lower than that encompassed by the term *severe* for example contained within MEHM. Inclusion of the categories *substantially limited* and *limited but not substantially*, may cause unwanted interpretation anomalies and the categories *substantial adverse effects (limitations)* and *minor adverse effects (limitations)* may improve the accuracy of capture. Alternatively, including the term *substantial* in the question and having a dichotomised response category would comply with the FRS and simplify the algorithm for case definition.
27. Whether the terms *substantially limited*, and *limited, but not substantially*, are comparable to the MEHM terms *severely limited*, and *limited, but not severely* is uncertain and would need to be tested. In addition the link between the

terms 'adversely affected' and 'limited' may also need to be tested because someone's activities could be adversely affected but not limited due to the way they manage their situation.

28. The explicit link between activity limitation and impairment was criticised. It was suggested that the first question should elicit the prevalence of conditions and the limitation in activities should be captured in a routed second question.
29. The view that the ordering effects of the third question should be looked at seems superfluous as this question includes independent response categories which shouldn't be affected by ordering.
30. The impairment question's absence of a filter from activity limitation was supported as this would provide prevalence of impairment category which could then be used to link with social barrier information collected in other modules of the IHS.
31. Another option was to use only the impairment type question, with a medication appendage. However, this wouldn't capture substantial adverse effects.

Exercise 3 – Uses of the Disability Data

In table sessions attendees were asked to comment upon the following areas; users, geographies, breakdowns, mode Issues and communication.

Findings

a) Users

Group 1

- Service providers
- Local Authorities
- Public authorities
- Commissions/ers

Group 2

- Service providers and public bodies

Group 3

- Equality IA
- Inequality – ODI, EHRC
- Local Authorities, by impairment on outcomes, e.g. employment/education
- Academics – DDA interest

Group 4

- Ministers
- Govt Depts.
- External bodies, variety
- Local Authorities and GORs
- Private Orgs providing public services
- Public bodies
- Eurostat
- Academics, 'Think-tanks' and researchers
- WHO, UN and other international orgs
- Media

b) Geography

Group 1

- Primary care organisations
- Local Authority/Unitary Authority
- National
- Equivalent geographical areas for devolved administrations
- UK
- EU – data sharing

Group 2

- Urban/rural.

Group 3

- Local Authorities – barriers of survey collection, but have other possibilities to collect data
- Census currently only source to inform and update LA estimates and is therefore crucial
- International – data sharing

Group 4

- UK
- Regional
- LA
- GORs
- Ward
- International – data sharing

c) Breakdowns

Group 1

- By condition
- Age/Sex
- By force of limitation/adverse effect

Group 2

- Prevalence
- Impairment type
- Type of barrier

Group 3

- Impairment across most/all surveys feeds into barriers.
- Barriers: important to communicating approach.
- Specific surveys – Citizenship survey?

Group 4

- Various
- Disability by gender, ethnicity etc.
- Outcomes e.g. poverty, education, employment.

d) Mode Issues

Group 1

- Scope to provide show cards
- Language issues
- Neutral wording?

Group 2

- Face-to-Face – Privacy/household interviews.
- TU – Length of show cards.
- Longitudinal

Group 3

- N/A.

Group 4

- Proxy responses
- Show cards (are they needed? How accessible are they?).
- Surveys e.g. can you ask about mental health conditions, BSL.

e) Communication

Group 2

- Social vs. Medical model.
- Purpose of survey – Questions that are used.

Overview of Session 3

32. It was noted that the data range required for each user group was different, but the elements of commonality should guide IHS priorities. National and local government bodies were considered the heaviest users of the data and would benefit most from data enhancements linked to statutory requirements.

Recommendations for question suite

Given the discussions that took place during the workshop the following approach was agreed as most appropriate for the question suite:

24. The consensus was that the priority for the suite should be –
 - To monitor people with potential rights under the Disability Discrimination Act (DDA)
 - To meet user needs
 - To be able to meet EU requirements wherever possible
25. It was agreed that this suite should be composed of:
 - **Two core questions** which are recommended for inclusion on all surveys and will measure the number of people with potential rights under the DDA i.e. people who currently have longstanding illnesses, impairments or

- health conditions and substantial adverse effects on normal activities. It will also provide a breakdown by type of impairment or condition.
- **Another optional question** which can be included on surveys if required will monitor disability by looking at the barriers faced by people with impairments.
- Additional people with potential rights under the DDA, such as those with past DDA disabilities, will be collected in an alternative source or module.
 - A twelve month time period should be the standard for the question suite as it links to the census and DDA. The differences in prevalence that arise with a six month time period should be evaluated using existing data where possible.
 - Impairment types, if collected second, should not be routed from the question eliciting adverse effects. This will allow true prevalence of impairments to be collected and the proportion whose normal activities are unaffected by their impairment.
 - The list of impairments is valued and should be included, but an expansion of the fifth category to differentiate DDA conditions and other long-standing conditions should be considered.

Areas for Testing

27. A method to disentangle the effect of medication on capacity to undertake normal activities should be tested. For example we could consider including medication effects as a response category. This would allow comparison with EU requirements as well as meeting DDA needs.

28. The terms health condition and disability should be included in a question aimed at measuring substantial adverse effects. Eurostat are not averse to its inclusion in their global activity limitation indicator as it is meant to capture disability, but they disapprove of its inclusion in the question capturing chronic illness. This suggests non-routing of impairments and substantial adverse effects on normal activities.

29. The response categories could encompass a dichotomised severity level which is distinct from substantial (the latter only excludes minor, non trivial adverse effects) which probably encompasses the spectrum of limitations captured in the EU GALI.

30. The intention is that the core questions will be designed so that they can also be asked of children but it will need further testing to ensure that the questions are appropriate.

Next Steps

This note provides a summary of what was discussed at the workshop. We would like attendees' comments on the contents and agreement on the recommendations for the question suite. We are also keen to incorporate the views of those who were unable to attend the workshop. Once these have been considered the note will be revised to produce a final agreed version with the suite of questions to be tested with a view to then using this as the template for all surveys across government.

Annex 1

MEHM questions (excluding general health status) for implementation to comply with EU regulation

The MEHM is recognised as a general measure of health status and is included in the Health Survey for England and many other member state national health surveys. The three questions selected for use in the health status module are based on items used in the EU-Statistics on Income and Living Conditions covering general health, chronic illness and activity limitation (currently collected on the IHS core and GLF module), but some differences are present which are being tested on Omnibus. Harmonisation with MEHM will require the IHS core chronic illness and activity limitation questions to alter their current terminology, routing and time period. Eurostat guidance on the use of those indicators derived from MEHM is unclear: cross-country comparisons require a higher level of consistency between Member States than within country time series.

HS.2 CHRONIC ILLNESS

1) Question

Do you have any longstanding illness or longstanding health problem? [By longstanding I mean illnesses or health problems which have lasted, or are expected to last, for 6 months or more]

Yes _ 1 don't know _ 8
 No _ 2 refusal _ 9

2) Guidelines

- **General concept:** self-reported longstanding illnesses and longstanding health problems
- **Can be used for children below 15 (optional national initiative):** yes
- **Use of proxy interview:** allowed
- **Use for institutionalized persons (optional national initiative):** to be completed
- It is necessary to keep in mind that the recommended wording contains 'alternatives'. For instance:
 - 'chronic' or 'longstanding' should be chosen according to what is 'best understood' in a country/language
 - it is intended to ask if people 'have' a chronic condition, not if they really suffer from it. But it seems that in some countries/languages it would be strange to use the word 'have' and that they 'suffer' means the same as 'have'
 - 'health problem' seems not to be understood in some countries/languages and therefore 'illness or condition' is the alternative
 - The main characteristics of a chronic condition are that it is permanent and may be expected to require a long period of supervision, observation or care
- **Longstanding (or chronic):** illnesses or health problems should have lasted or are expected to last for 6 months or more; therefore, temporary problems are not of interest
- **Illness or health problem (or condition):** only problems of ill-health but not solely diseases (e.g. pain).
- The words "**disability, handicap, impairment**" should not be included in the question. However, for consequences of injuries/accidents, consequences of congenital conditions, birth defects, etc. code 1 should be used.
- If needed, the interviewer can stress that the questions refer to all longstanding health problems and illnesses, not only those diagnosed by a doctor
- In case the respondent has/had a longstanding disease that doesn't/didn't bother him/her or it is/was kept under control with medication, the interviewer should mark with code 1. For instance, for a person with a high blood pressure, code 1 has to be marked

people usually do.

- Specification of health concepts (e.g. physical and mental health) should be avoided.
- The purpose of the instrument is to measure the presence of long-standing limitations, as the consequences of these limitations (e.g. care, dependency) are more serious. A 6 months period is often used to define chronic or long-standing diseases in surveys.
- The answer to this question is yes (1 or 2) if the person is currently limited and has been limited in activities for at least the last 6 months.
- In the response categories, a distinction is made in three levels of severity (yes strongly limited, yes limited, no not limited).
- If the problem is seasonal or recurring the interviewee has to think in general over the at least the last 6 months, would you say it has limited you severely, somewhat or not at all.

**Office for Disability Issues – Research and Analysis
Life Opportunities Survey (LOS) – briefing pack**

From: Fraser Macleod
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Date: March 2009

Issue

The purpose of this paper is to update progress in the development of the Life Opportunities Survey (LOS), formerly known as the Longitudinal Disability Survey of Great Britain.

The paper is written for ODI Senior Management. It covers:

1. What is the Life Opportunities Survey?
2. Why do we need a new survey?
3. What will LOS deliver?
4. What are the risks?
5. What is the timetable?

Background information is included in the following annexes:

- A: Developing the survey
- B: Co-production and collaboration

Key points

- The Life Opportunities Survey is ODI's largest single research project in terms of costs, scope and complexity. It will be the largest national study of disability for 10 years and the first by the UK government to explore socially disabling barriers.
- LOS is on course to start in June 2009. The baseline survey will take 2 years to complete. Interim results from the baseline survey are expected in June 2010. Final results are expected in June 2011.
- We have commissioned the Office for National Statistics (ONS) to carry out the survey and have been working with a range of stakeholders to develop the survey. This includes disabled people, other government departments and academic experts.
- Development work on two related projects is ongoing in 2009. These are a qualitative research project involving in-depth interviews with LOS participants and a survey of communal establishments.

1. What is the Life Opportunities Survey (LOS)?

The Life Opportunities Survey or LOS is a major new national survey of disability in Britain. It will be run by the Office for National Statistics as part of its Integrated Household Survey (see Annex A below). LOS is a longitudinal survey, meaning it will track the experiences of disabled people over time to assess transitions through key life stages, such as moving from childhood to adulthood or in and out of work, and people's experience of receiving a range of benefits and services.

Survey topics include work and learning, health, transport, community and social life, leisure, use of key services, caring and domestic life, hate crime and discrimination, income and benefits.

The survey will also include non-disabled people so that we can compare the life opportunities of disabled and non-disabled alike. This will also allow us to observe changes that occur with the onset of impairment. It will be the first major UK government survey to explore disability in terms of social barriers.

Participants will be followed up yearly and the survey will continue as long as is necessary (ie as policy information needs dictate) in order to measure progress to equality 2025.

Frequently Asked Question

Q: If the survey is about disability why not call it a disability survey?

A: The project was originally known as the Longitudinal Disability Survey of Britain. The word 'Longitudinal' is research jargon so we decided it should be removed. It basically means repeating the survey over time (every year in this case) but with the same participants (where possible). This means that people's life course can be tracked over time. Most annual surveys such as the Family Resources Survey (which we currently use for disability prevalence data) randomly select different participants every year.

'Disability' is of course a focus of the survey but non-disabled people will also be taking part. This is important so that we can compare the opportunities afforded to both groups. As a longitudinal survey we can also track onset of impairment and see how people's life opportunities might change as a result. The survey title is also important because the survey will focus on socially disabling barriers that affect people's opportunities and moves us away from the medical focus on disability. It is the interaction of these social barriers with a range of impairments that we are interested in finding out about. Finally the survey will also be a source of information on all the equality strands, not just disability.

2. Why do we need a new survey?

The Life Opportunities Survey is a key part of meeting our commitment to improve the evidence base on disability issues. It is based on specific recommendations made in the 2005 report 'Meeting DWP's long-term information needs on disability: A feasibility report'³².

In taking forward the recommendations made in the feasibility report the Office for Disability Issues (ODI) identified 5 reasons why a new survey was needed:

1. **Existing data is outdated.** The last major dedicated disability survey of disability (1997 follow-up to FRS) was conducted over 10 years ago. Government and other stakeholders are currently reliant on piecemeal data from general social surveys.
2. **Existing surveys provide inadequate coverage of disability.** Existing general social surveys do not provide fully inclusive data on the disabled population because; groups such as the severely disabled and those in communal establishments are largely excluded; measurement of disability is limited to global definitions which vary considerably and do not differentiate between types of impairment. Existing surveys also fail to recognise the importance of socially disabling barriers in defining disability.
3. **Government commitment to measure progress to equality by 2025.** The government commitment to achieve equality for disabled people by 2025 means it needs a full set of outcomes indicators on which progress can be measured. Though existing sources can be used to underpin some outcome indicators, improvements in data sources are needed if we want robust and meaningful comprehensive measures.
4. **Little evidence exists on monitoring disability and transitions over time.** There is a need to establish an evidence base on the onset of disability and transitions over time. The Life Chances report³³ set out agreed recommendations to monitor the life chances of disabled people such as what happens when people become disabled, transitions from childhood to adulthood, employment dynamics and the need to guard against potential 'cliff edges' in the provision of benefits and services.
5. **Survey will provide new source of equality data for use across the sector.** Public bodies have a duty to promote equality and gather evidence. The survey would provide departments with important high level evidence on the impact of their policies in the future. The new survey will also create a rich new source of data to help monitor

³² Meeting DWP's long-term information needs on disability: A feasibility report, (2005), Department for Work & Pensions.
<http://www.dwp.gov.uk/asd/asd5/rports2005-2006/rrep267.pdf>

³³ Improving the Life Chances of Disabled People, Cabinet Office (2005)
http://www.cabinetoffice.gov.uk/strategy/work_areas/disability.aspx

progress towards equality and will help to address some of the gaps identified in the Equalities Data Review³⁴ which ODI is committed to.

3. What will LOS deliver?

The outputs from LOS are closely linked to the reasons outlined above. In particular LOS will fill the following evidence gaps:

- PREVALENCE of disability in the UK, including DDA definition plus detailed information on types of impairment, levels of severity and social barriers.
- OUTCOME-BASED INDICATORS to underpin the new cross-government target to achieve substantive equality by 2025 and to support the DED across government.
- WHAT HAPPENS WHEN PEOPLE BECOME DISABLED and when disabled people lives CHANGE in terms of their conditions and their outcomes.

What is the timetable?

Table 2 sets out the timetable for the survey showing when each ‘wave’ of the survey starts and ends and when results are expected. The baseline survey will be wave ‘1’.

Table 2: Timetable and key milestones

Date	Event
June 2009	Survey launch – this is the ‘baseline’ survey or wave ‘1’
March 2010	First half of baseline complete
June 2010	First set of LOS results based on half baseline sample; Second half of baseline begins; Wave 2 begins.
March 2011	Baseline survey interviews completed.
June 2011	Second set of LOS results based on full baseline sample; Second half of wave ‘2’ begins; Wave 3 begins.

³⁴ Report from the Review of Equality Data

<http://www.ons.gov.uk/about-statistics/measuring-equality/equality-data-review/index.html>

Annex A: Developing the survey

Survey design

The survey will involve household interviews with three main groups of a) disabled people, b) comparison group of non-disabled people and c) an 'onset screening sample' of people who experience the onset of impairment over time. The survey will start with a baseline random sample of between 45,000 to 50,000 people in around 37,500 households across Britain (England, Scotland and Wales). This baseline survey will take 2 years to complete.

The sample size is necessary to ensure an adequate sample of the population and key sub-groups particularly to differentiate between types of impairment and represent all the principal equality strands.

The baseline survey will interview all adults in the household – with face to face interviews. It will also collect key data about children in the household from parents or guardians.

Integrated Household Survey - benefits

The baseline survey will be run as a module on the ONS Integrated Household Survey (IHS). IHS brings together the ONS' continuous household surveys into a single module-based survey. There are a number of benefits from using the IHS including: reduced field management costs from integrating existing field forces; economies of scale in survey management overheads, data processing and quality assurance and; better precision of estimates because of using an un-clustered design to produce estimates to the required level of precision. It will also: make better use of data already collected; provide better quality and more reliable estimates at national, regional and sub-regional.

ONS also bring considerable expertise and experience in terms of accessible interviewing, ensuring that we can be as inclusive as possible. This is highlighted in the LOS Equality Impact Assessment.

Longitudinal Design

The longitudinal design has the advantage of following three distinct groups over time. The number in brackets shows our estimate of how many people will fall in each group:

1. Disabled group (around 10,000)
2. Non-disabled comparison group, matched to control for age, gender and location (5,000)
3. A much larger non-disabled group, monitored for the onset of disability over time (35,000)

Respondents will be followed up individually every 12 months, whether they have left the household or not. One of the big challenges of a longitudinal survey, especially on such a large scale, is being able to contact participants in future years. ONS are experienced in different methods to keep in touch. However at certain points in the future it will be necessary to refresh the samples.

The baseline survey will involve face-to-face interviews for every participant but this will change in subsequent waves. Only the first two groups will be interviewed face-to-face. The third group will be monitored over time via a shorter telephone interview to check for onset of impairment. These participants will then be asked to participate in a face-to-face interview in the next wave.

Accessible interviewing

As a disability survey it is critical that interviewing is accessible. Indeed LOS should become an exemplar of accessible interviewing. This is not restricted to accessible formats such as an easy read version of the survey but includes fully trained interviewers and offering flexibility in terms of time and location of interview.

Frequently Asked Question

Q: What is the Integrated Household Survey?

A: LOS will be part of the Integrated Household Survey. This survey will bring together the ONS continuous household surveys into a single module-based survey. Initial surveys to be included are the Labour Force Survey, the General Household Survey, the Expenditure and Food Survey, the Omnibus Survey and the English Housing Survey. Respondents will answer a set of core questions common to all these surveys (known as the IHS 'Core' questions) covering basic household and personal information (age, ethnicity, religion, employment status etc) before answering more detailed questions from one of the modules – this might be LOS, it might be the Expenditure & Food Survey.

The advantages of integrating LOS into the IHS include:

- cost savings through economies of scale in survey management costs, quality assurance, and development costs
- an un-clustered design allows sample size reductions for topics to achieve the same level of precision (this is possible because of the very large overall IHS sample)
- opportunities for cross-topic analysis
- availability of socio-demographic information collected by a standard set of core questions
- coherence and increased precision through calibration weighting to the larger IHS sample.

Revised on 2nd February 2009 following agreement on disability question suite testing

Health and Disability Questions Harmonisation Sub-Group: Road Map to Harmonisation

1. Introduction

1.1 Harmonisation is desirable for a number of reasons: it avoids wasteful duplication and frees up space to address other policy relevant data needs, reduces the likelihood of biases arising from ordering effects and data collection methods, clarifies timing schedules for data releases and promotes coherence in national statistics. This road map is the first step in taking forward the aspiration to achieve a suite of harmonised questions covering chronic morbidity, disability and domains of illness and impairment to be used across all surveys.

1.2 The introduction of the Integrated Household Survey (IHS) provides an opportunity to extend the scope of outputs relating to disability to sub-national populations. It is desirable to embed a revised question suite on the IHS core module before 2011 to enable comparisons with the census of 2011 and provide an alternative source to set a baseline for intercensal updating.

1.3 When we refer to harmonisation, we are talking about how we can align the consistent approach work programme, which is being taken forward in response to ONS's Review of Equality Data, with other data requirements such as EU-SILC.

2. Context

2.1 This paper follows on from the position paper produced by ODI and aims to set out a timeline for agreeing a consistent harmonised approach to disability.

2.2 There is a legislative requirement to monitor the population prevalence of disability, defined under the Disability Discrimination Act (DDA) 1995 (as amended): questions included in the Family Resources Survey (FRS) and Omnibus survey provide data to attempt to measure this population. The Office for Disability Issues' position paper on disability definitions guides the necessary question suite required to measure both DDA defined disability and current disability, taking account of the recommendation in the Equality Data Review for ODI, GEO, ONS and devolved administrations to agree a consistent approach to the gathering of information on disability.

2.3 In addition a recent aspiration of the European Union is to harmonise the questions which feed into the European Health Interview Survey (EHIS) (collected on the Health Survey for England) with EU-SILC

collected on the General Household Survey (GHS). Although the existing questions asked on the GHS are similar to the questions proposed by EHIS, differences in terminology, time periods, routing and content are present. These differences have implications for ONS key outputs such as Disability-Free Life Expectancy, and are likely to change the time series prevalence estimates used by UK OGD's.

2.4 A workshop of the National Statistics Harmonisation Working Group (NSHWG) on 5/10/07 discussed the complexities associated with harmonising chronic morbidity, long-standing illness, activity limitation and disability questions asked on surveys. A plan for testing the adequacy of a harmonised question suite to meet the stated data needs of stakeholders is urgent to inform IHS core module and other survey content.

3. What is needed

3.1 We need to ensure that the work of the Health and Disability Questions Harmonisation Sub-Group is consistent and does not overlap with the work ONS, ODI, GEO and the devolved governments are doing to address the recommendation in the Equality Data Review.

3.2 Previously, sub-group members agreed the compilation of a road map to harmonisation was a priority for ONS and should encompass the following elements:

- a) A position statement of where we are (e.g. what surveys are currently collecting information on illness, activity limitation, disability and how they differ)
- b) A statement of where we want to be by 2010
- c) An overview of data needs
- d) The definition of disability (current and planned), coverage within surveys, capability of existing coverage for essential and desirable breakdowns
- e) Identifying the range of question suite options capable of measuring the definition (or subsets)
- f) Agreeing the scope of testing through prioritisation of implementable options
- g) Testing the capability of selected question variants to measure the needed definitions required to meet data needs through the construction of an analysis plan that synchronises with survey planning cycles, allowing recommendations to be considered, agreed and implemented
- h) Resource issues and level of stakeholder involvement - joining up planned definition testing
- i) An assessment of what is implementable within the IHS core (a question suite that meets case definition, or a component that is useful to stakeholders)
- j) Other national and local surveys able to harmonise with the IHS questions to allow analyses by other factors not collected in the HIS
- k) Gaps in the measurement of disability using the IHS question suite are known, allowing informed decisions about question content in other surveys

3.3 Sections a through d already been covered as part of the consistent approach work and are discussed in ODI's position paper. The workshop arranged for 17th June is aiming to address section e and subsequent work will then involve agreeing an approach to testing the agreed question suite.

4. Circumstances

4.1. Harmonisation with SILC

4.1.1 The testing of EU-SILC proposed question changes for the collection of chronic morbidity and disability is now complete. The findings were presented to the Health and Disability Harmonisation Sub-group in 2008.

4.1.2 The SILC questions on chronic morbidity and activity limitation are reproduced below.

Do you have any long-standing illness or (long-standing) health problem? By long-standing I mean illnesses or health problems which have lasted or are expected to last for six months or more?

- (1) Yes
- (2) No

For at least the past six months, to what extent have you been limited because of a health problem in activities that people usually do? Would you say you have been...?

- (1) Severely limited
- (2) Limited, but not severely
- (3) Not limited at all

4.1.3 The SILC question on chronic illness does not intend to capture disability nor infirmity and is focussed on capturing the prevalence of chronic illness in the period spanning the past six months and expected to continue into the next six months. Disability, defined as *limitations in the activities people usually do*, is captured in the second question, which is referred to as a Global Activity Limitation Indicator, and asked of the whole sample. It is the long-term nature of the limitation (i.e. that has lasted as least six months) that is cardinal, not the long-term nature of the health problem or illness.

4.1.4 While there was little difference in reported levels of limiting long-standing illness between the existing GHS, proposed SILC and modified SILC questions, greater variation was found in questions eliciting activity limitation: more people reported a moderate activity limitation under the modified SILC question. However due to very low sample numbers, the reliability of these estimates is questionable. The Health and Disability Harmonisation sub-group recommended:

- Further analysis should be performed to ascertain the nature of the reported health problems/disabilities to investigate this issue. In addition it was suggested that testing should be undertaken to explore the difference between an explicit 6 month and 12 month time frame in the disability/activity limitation question.
- The use of the term substantial rather than severe may be understood differently by the general population and should be investigated.

4.1.5 There is currently work underway to investigate the latter issue, as well as other issues surrounding conceptual understanding in Census question testing and this work can inform further question testing on force of limitation measurement.

4.2 Harmonisation with the Census of England and Wales

4.2.1 The proposed census question on long-term illness and disability was subject to a lengthy consultation process. Most stakeholders expressed the importance of this topic area for informing resource allocation on the basis for need for health and social care services, improving access to health, education and leisure facilities, and for capturing information relevant to the core principles of the DDA (monitoring progress towards disability equality and reducing social barriers resulting from impairment); in particular identifying the need for adaptations to housing and in the workplace to mitigate barriers. The latter requirement stresses the importance of separating out data on disability and chronic morbidity, which is a weakness of the GHS approach to the collection of activity limitation which is routed from the question that encompasses long-standing illness, disability or infirmity.

4.2.2 The census health topic group concluded that information on long-term illness and disability should be collected from the 2011 Census to meet the user requirements that are not currently satisfied by alternative sources. However, the constrained space limits the scope of this aspiration.

4.2.3 The current census question tested in wave 6 is reproduced below:

Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last at least 12 months?

Include problems which are due to old age.

- (1) **Yes, limited a lot**
- (2) **Yes, limited a little**
- (3) **No**

4.3 The differences between questions

4.3.1 SILC questions are not routed, exclude the terms disability and infirmity and limit the period under investigation to six months.

4.3.2 The current IHS questions exclude a specific time period, cannot capture domains of limitation or impairment, and cannot measure previous (but not current) illness, disability, infirmity that limits day-to-day activities or limitations that are prevented due to access to medication or other ameliorative devices. Consequently, the current IHS question suite will not meet the data needs presented by DDA legislation. Table 1 shows the population prevalence of activity limitation for 2004-06 in the United Kingdom by age and sex, using the current questions asked on the IHS.

Do you have any long-standing illness, disability or infirmity? By long-standing, I mean anything that has troubled you over a period of time or is likely to affect you over a period of time?

- (1) Yes
- (2) No

Does this illness or disability/Do any of these illnesses or disabilities limit your activities in any way?

- (1) Yes
- (2) No

Would you say your activities are limited or strongly limited?

- (1) Limited
- (2) Strongly limited

Table 1 Prevalence of limiting long-standing illness, disability or infirmity, men and women 2004-06

Men			Women		
Age-group	Per cent with limitation	n	Age-group	Per cent with limitation	n
0-4	4.5	2351	0-4	3.8	2215
5-14	8.4	5011	5-14	6.9	4866
15-24	7.0	3491	15-24	8.7	3881
25-34	9.7	3870	25-34	11.0	4565
35-44	13.8	4625	35-44	16.6	5449
45-54	20.4	4117	45-54	22.9	4721
55-64	31.5	4112	55-64	30.4	4406
65-74	35.5	2920	65-74	39.0	3263
75+	44.3	2044	75+	50.2	2754
All	18.0	32541	All	20.0	36120

Source: General Household Survey and Continuous Household Survey

4.3.3 The census question concurs with the time frame recommended by ODI for capture of DDA disability and makes explicit the inclusion of limitations that are due to old age. However, this question format will not provide estimates of health problems and disabilities not causing a limitation in day-to-day activities and will exclude the population with past but not present health problem(s) and disability(ies) that cause an activity limitation, and the population with limitations that would arise without prophylactic treatment. The ODI believe that the census question, as it currently stands, would under-estimate the number of people with rights under the DDA and limit the extent to which the Census can be used to meet DED requirements as this is estimated to be in the region of 27% from the Family Resources Survey.

4.3.4 The ODI's question suite currently running on the Omnibus survey captures: the presence long-standing illness, disability and infirmity with and without limitations; domains of impairment and limitation, the role of medication in preventing illnesses and disabilities limiting day-to-day activities, and previous illness, disability or infirmity limiting activities. This question suite is too detailed to incorporate onto the IHS core module, and clearly distinct from the census question, which precludes the valid generation of local authority estimates of DDA disability from census data.

4.4 Overview of data needs and where we want to be by 2010(11)

This overview is not exhaustive and can be added to by stakeholders at the workshop.

4.4.1 Office for National Statistics

The aspiration is to embed a suite of questions on the IHS core module for data collection in 2010, and no later than 2011, that will reliably capture the population of disabled people in a way which is consistent with the Equality Data Review principles and meets inter-departmental data needs. The question suite we recommend should meet the following criteria:

- Is feasible for collection within the IHS core;
- Is based on evidence of effectiveness in delivering the range of data needs and takes account of equality and diversity guidelines set out in the Review of Equality Data;
- The relationship with other similar questions in other sources such as the census is known;
- Space in other sources can be freed for savings or alternative data needs to be met;
- Is supported by the majority of UK stakeholders;
- EU-SILC needs are met within the scope of national surveys
- The valued Health expectancy time series is maintained and extended to encompass lower level geographies
- Is cost neutral

The enhanced sample of the Integrated Household Survey provides scope for producing reliable estimates of ill-health, disability and activity limitation at local authority level intercensally through pooling. This opportunity for improving the availability of information at local level must be exploited as the advantages for service planning, through the provision of reliable and adequately precise intercensal trends and between authority comparisons, cannot be over-emphasised.

The Office for National Statistics uses the questions on chronic illness, disability and infirmity and associated activity limitation, currently asked on the IHS core and previously asked on the General Household Survey, to construct national estimates of disability free life expectancy, supplemented with census data on limiting long-term illness for the communal establishment population of the UK and data

from the Continuous Household Survey for Northern Ireland. This indicator, of the time spent free of disability, is a valued enhancement to life expectancy information, and informs policy makers of trends in compression or expansion of morbidity which is relevant for health and social care provision. A trend in disability-free life expectancy has now been established using revised methodology from 2001 for the UK and constituent countries, and changing the form of this question will cause a discontinuity in this series. While this is an inconvenient consequence of harmonisation, it can be mitigated by understanding and quantifying the relationship between the existing question set used in the construction of the indicator and the future harmonised question suite. Ideally, the future harmonised question suite should be capable of allowing the derivation of the prevalence measured from the existing question through clever wording solutions. The separating out of limitations into 'substantial/severe' and 'limited, but not substantially/severely' provides the opportunity to deliver DFLE estimates broken down by force of limitation, and possibly by capacity domain.

Estimates of disability-free life expectancy have also been constructed for local authorities and electoral wards in England and Wales for 2001 using census data. A data need highlighted, and currently not realisable from existing historic sources, is to provide disability-free life expectancy estimates for local authorities to complement the life expectancy estimates. Consequently, a question suite that delivers the prevalence of current disability in households which can be combined with the prevalence of disability within communal establishments derived from the census question is a key data need for ONS to continue the valid and reliable measurement of disability-free life expectancy at a number of geographical scales.

ONS currently supplies data annually to Eurostat to meet the Regulation (EC) No 1177/2003 concerning Community Statistics on Income and Living Conditions (EU-SILC). The sample size needed for the UK is 13,700 individuals nested within 7,500 households aged 16 years and over for cross-sectional feeds and 10,500 individuals nested within 5,750 households for longitudinal feeds. SVS have estimated the General Lifestyle (GLF) module sample will contain 10,000 households and 19,000 individuals across all ages. The 2007 GHSL sample contains 9091 households and 17,123 individuals aged 16 years and over. The capacity to meet SILC needs through the GLF must be appraised before the development of a testing plan.

4.4.2 Office for Disability Issues and Department for Work and Pensions

All public bodies, including ODI and DWP, have a requirement to meet their Disability Equality Duty and as such have to take steps to ensure they have sufficient data to do so. The ODI has compiled the range of disability information collected across the UK, broken down by source and method of data collection. Of key importance is the need for departments to be aware of the heterogeneity of disability, and therefore the importance of gathering data on type of impairment, capability constraints and/or social barriers, depending on the particular policy emphasis of specific departments. The relationship between impairment, capability and barriers is a fundamental data requirement of the ODI. The EHRC have provided guidance on the collection of independent types of impairment which the ODI support, and is viewed as a valuable enhancement to available data and documented on page 12 of their position paper.

There is also a need to gather information on communal establishment populations which is outside the scope of household surveys. Intercensal measurement of DDA defined disability within communal establishments is being investigated as part of the Longitudinal Disability Survey of Great Britain.

The Department for Work and Pensions has a number of indicators relevant to disabled people under the Opportunities for all Programme. For example, indicator 19 covers the employment rate of disadvantaged groups compared with the national average, and use a definition of disability derived from questions asked on the Labour Force survey, but the indicator calculation excludes people with work-limiting disability from 2002. Whether this population can be adequately derived from a harmonised question suite in the IHS core or whether a separate question needs to be additionally asked on the Labour Force Survey is debatable and may need inclusion in the proposed testing project.

Fitness for work beyond the State Retirement Age is also of relevance and may be adequately informed through a harmonised question suite asked on the IHS core.

4.4.3 Department of Health

The Department of Health have expressed interest in the provision of intercensal updates of DFLE at primary care organisation level. The enhanced sample of the IHS should allow estimates to be provided and updated intercensally, allowing progress to be measured and relative variations between organisations to be compared.

4.4.4 Government Equalities Office

The Office needs robust estimates of the disabled population to inform their equalities PSA which covers discrimination and unfair treatment at work, engagement in public life, provision of public transport adaptations that promote and assist their usage by disabled people, and overcoming the barriers to independent living.

4.4.5 Devolved administrations and local government

Devolved administrations require a standard to be established in national surveys for the collection of information on illness, disability and activity limitation to enable them to harmonise with their national surveys. A key issue for local government is whether to harmonise their local surveys with the measurement of chronic morbidity, disability and infirmity in the 2011 census or national surveys. The potential of the IHS for generating intercensal estimates is beneficial for local government but the measurement from the IHS must be cross-validated with the census question to allow the valid melding of household and communal establishment prevalence at LA level. In addition, for Local Authorities to effectively adapt their services for disabled people to better reflect the population covered under the DDA, the census question covering activity limitation is unlikely to meet this need; there will be a lack of detail on impairment types and barriers/capabilities. Ideally a harmonised question suite collected through the IHS will include a condensed impairment type component such as at the impairment categories suggested by the DRC, which can be cross-classified with barriers and capabilities collected on the Longitudinal Disability Survey of Great Britain.

4.4.6 European Union

The European Union's Task Force on Health expectancies publishes cross-country comparisons by EU member states using data collected from the Minimum European Health Module (MEHM). To ensure comparisons are valid and reliable the European Union has decided to include a small set of health

expectancies among its European Community Health Indicators (ECHI) to provide synthetic measures of disability, chronic morbidity and perceived health. Therefore the Minimum European Health Module (MEHM), composed of 3 questions covering these dimensions, has been introduced into the Statistics on Income and Living Conditions (SILC) to improve the comparability of health expectancies between countries. In addition, life expectancy without long term activity limitation, based on the disability question, was selected in 2004 to be one of the structural indicators for assessing the EU strategic goals (Lisbon strategy) under the name of “**Healthy Life Years**” (HLY). A distinctive characteristic from the UK’s traditional questions on long-standing illness and disability is the lack of linkage of questions covering chronic morbidity and activity restriction in MEHM. Consequently, MEHM’s definition of disability was linked to activity restriction, and this is measured with a Global Activity Limitation Indicator question asked of all survey respondents. Another important difference is the time frame of the questions which adopt a six month time reference, distinct from the DDA 12 month time reference, and the vague ‘period of time’ used in existing General Household Survey Questions.

5. Definition

5.1 The word ‘disability’ is widely perceived as synonymous with impairment or general ill-health: a link which conforms to a medical model of disability (see Box). The medical model promotes the view of a disabled person as dependent and needing to be cured or cared for: it justifies the way in which disabled people have been systematically excluded from society. However, the Prime Minister’s strategy unit in 2005ⁱ clarified the differences between the terms impairment and disability: impairment is defined as a loss of actual attributes of a person, whether in terms of limbs, organs or mechanisms, including psychological functioning; disability refers to the restrictions caused by society when it does not give equivalent attention and accommodation to the needs of individuals with impairments. These disadvantages experienced by an individual result from barriers to independent living, and access to education, employment and other opportunities. A ‘disabled person’, therefore, can be described as someone who is disadvantaged by the way in which the wider environment interacts with their impairment or ill-health.

Models of Disability

Medical Model

Under the medical model, disabled people are defined by their impairment or health condition, which is perceived as causing dependence and a need for treatment or care. The consequence is constraints placed on independent living and special arrangements imposed to access benefits, housing, education, leisure and employment.

Social Model

Under the social model, disability is caused by society: the physical, organisational and attitudinal barriers created by society, either deliberately or accidentally, compromise the ability of a person with impairment or illness to live independently and have the opportunity to participate in educational, employment and leisure activities.

5.2 A fundamental prerequisite to achieving coherent national statistics on the subject of disability, which is capable of meeting the range of users needs, is for relevant government bodies across the United Kingdom to settle on a harmonised definition that can be applied in key administrative and survey data sources.

5.3 The ODI have adopted a social model based definition of disability for the purposes of the Life Opportunities Survey of Great Britain. as restrictions caused by society when it does not give equivalent attention and accommodation to the needs of individuals with impairments. Alternatively, the DDA defines disability as:

'the presence of a physical or mental impairment/illness that causes substantial difficulties in carrying out normal day-to-day activities (e.g. shopping, social activities, washing, dressing, preparing food, travelling by public or private transport) in the capacity domains recorded above which have lasted for at least 12 months'.

The population with rights under the DDA is extended to those:

Who would meet the above definition without medication;

Who have a medical diagnosis of cancer, and/or HIV and/or multiple sclerosis;

Who have met the above definition in the past, but currently do not.

5.4 These criteria classify a case under the 2005 act and will be the gold standard to test against. These criteria are capable of identifying the population with physical or mental long-term illness, disability or infirmity that are either not limited, or limited but not substantially, as well as people who would or would not be substantially limited without treatment and people who are currently disabled only. All these population subsets are useful for policy formation and service planning.

6. Question suite options to be prioritised for testing and cross-classification with data needs

6.1 ONS in conjunction with ODI have compiled a list of preferred question suite options for discussion at a future workshop for stakeholders to reach agreement on content and scope and priorities for testing. These options are a starting point to guide potential in meeting data needs.

6.2 Option 1 aiming to measure DDA defined disability

Q1a. Do you have any long-standing physical or mental illness or disability that has limited your day-to-day activities over a period of at least 12 months or is likely to over a period of at least 12 months? Please include limitations that are due to old age.

Would you say you are:

a). Substantially limited

b). Limited, but not substantially

c). Not limited now, but was substantially limited for a period of at least 12 months in the past

d). Not limited at all

If responds d above

Q1b. Do you receive any medication or other treatment without which your health conditions would substantially limit your day-to-day activities?

- a) Yes; b) No; c) Don't know

Q2. Do you have any of the following impairments or health conditions?

- a). a physical impairment such as difficulty using your arms or mobility difficulties which require you to use a wheelchair or other mobility aid
- b). a sensory impairment such as serious vision difficulties or blindness, or deafness
- c). a mental health condition, such as depression or schizophrenia that has lasted or is expected to last 12 months or more
- d). a learning difficulty or disability such as down's syndrome or dyslexia or a cognitive impairment such as autistic spectrum disorder
- e). Diagnosed as having HIV, Cancer or Multiple Sclerosis
- f). Other long-term illness or health condition that has lasted or is expected to last 12 months or more

6.2 Option 2 aiming to measure current disability

Q1. Are your day-to-day activities limited because of a physical or mental health problem or disability which has lasted, or is expected to last at least 12 months?

Include limitations you would experience without medication or treatment and limitations that are due to old age.

- (1) Yes, limited substantially
- (2) Yes, limited but not substantially
- (3) No

If responds 1 or 2 above

Q2. Do you have any of the following impairments or health conditions?

- a). a physical impairment such as difficulty using your arms or mobility difficulties which require you to use a wheelchair or other mobility aid
- b). a sensory impairment such as serious vision difficulties or blindness, or deafness
- c). a mental health condition, such as depression or schizophrenia that has lasted or is expected to last 12 months or more
- d). a learning difficulty or disability such as down's syndrome or dyslexia or a cognitive impairment such as autistic spectrum disorder
- e). Diagnosed as having HIV, Cancer or Multiple Sclerosis
- f). Other long-term illness or health condition that has lasted or is expected to last 12 months or more

6.3 Option 3 aiming to measure current disability to meet both UK and EU-SILC data requirements

Q1a. Over the past 6 months, to what extent have you been limited in activities that people usually do because of a health problem or disability? Would you say you have been...?

- a). Severely limited
- b). Limited, but not severely
- c). Not limited at all

If a or b

Q1b. If you are limited, have these limitations lasted for 12 months or more?

- a). Yes
- b). No

If c

Q1c. If you receive medication or treatment for a health problem or disability, would your day to day activities be severely limited without this medication or treatment?

- a). Yes
- b). No
- c). Don't have a health problem or disability

Q2. Have you ever been diagnosed with any of the following health conditions?

- a). HIV
- b). Cancer
- c). Multiple sclerosis
- d). None of these

6.4 Option 4: aiming to measure current disability to meet UK data requirements - most condensed format

Q1. Are your day-to-day activities substantially limited because of any physical or mental health conditions or disabilities which have lasted or will last at least 12 months?

If on medication please consider the effects without.

- a). Yes
- b). No

6.5 A cross classification of disability definitions, survey data availability and the adequacy for meeting data needs is presented in the following two tables.

MEASUREMENT OF DISABILITY ON SURVEYS				
Definition	Components	Survey	Prevalence	Option designed to capture
DDA	<p>A person with 'a physical or mental impairment which has a substantial and long-term (i.e. 12 months or more) adverse effect on his ability to carry out normal day-to-day activities.' and</p> <ul style="list-style-type: none"> • would meet the above criteria in the absence of medication; • has been diagnosed as having cancer, HIV infection or multiple sclerosis; • where in the past the person was disabled; 	Omnibus*	27 per cent	1
Current	<p>A person with 'a physical or mental impairment which has a substantial and long-term (i.e. 12 months or more) adverse effect on his ability to carry out normal day-to-day activities.' and</p> <ul style="list-style-type: none"> • would meet the above criteria in the absence of medication; • has been diagnosed as having cancer, HIV infection or multiple sclerosis; 	Omnibus* subset	24 per cent	2
Existing IHS	<p>Captures a person who has a long-standing illness, disability or infirmity that has lasted a period of time and whether this causes the person to be either limited or severely limited</p>	IHS	Limited 19 per cent*, Strongly Limited 10 per cent*	Can be captured with all options
EU-SILC †	<p>Captures a person who for at least the past six months is Limited or Severely Limited in the activities people usually do because of a health problem (not necessarily long-standing health problem)</p>	Omnibus* and GLF?	28.8 per cent and 10.5 per cent	3
Census	<p>Captures a person with either a limitation or severe limitation in day-to-day activities because of a health problem or disability that has lasted at least 12 months and includes health problems and disabilities that are due to old age</p>	Census testing	18 per cent	1, 2
Exclude past disability and diagnoses of HIV, cancer or multiple sclerosis	<p>A person's day-to-day activities are substantially limited because of a physical or mental health condition(s) or disability(ies) which have lasted or will last at least 12 months or would be in the absence of medication</p>	NA	?	4

MEASUREMENT OF DISABILITY ON SURVEYS

Component	DDA		Definition of disability		EU-SILC	Census	Prevalence	Survey	Option 1	Option 2	Option 3	Option 4
	Current	DFLE indicator	Could be used with testing	Could be used with testing								
Long-standing illness or health problem expected to last 6 months or more	†	†	Could be used with testing	X	0	37 PER CENT (AGED 16 YEARS +)	Omnibus (being tested)	†	†	0	0	0
Long-standing illness, disability or infirmity	†	†	X	†	0	31 PER CENT (AGED 16 YEARS +)	IHS	†	†	0	0	0
Long-standing illness, disability or infirmity lasting or expected to last for at least 12 months	X	X	Could be used with testing	†	0	?	Omnibus	X	X	0	0	0
Long-standing physical or mental impairment, illness, or disability over a period of at least 12 months or likely to affect you over a period of at least 12 months.	X	X	†	†	0	28 PER CENT	FRS	†	†	0	0	0
Ever had a long-term illness lasting for a year or more	X	0	0	0	0	2 PER CENT	Omnibus and FRS	X	0	0	0	0
Diagnosis of HIV, cancer, multiple sclerosis	X	X	0	0	0	?	Omnibus	X	X	X	X	0
Activities limited because of a health problem in past six months	†	†	Could be used with testing	X	†	29 PER CENT (aged 16 +)	Omnibus (being tested)	†	†	X	X	†
Activities limited because of a long-standing illness, disability or infirmity (routed no specific time period)	†	†	X	†	†	18 PER CENT	IHS	†	†	†	†	†
Physical or mental illness or disability limits your activities (Routed 12 month time period)	X	X	Could be used with testing	†	†	18 PER CENT	Omnibus and FRS	X	†	†	†	†
Substantial difficulties with list of capabilities	X	X	†	†	†	19 PER CENT	Omnibus and FRS	X	X	0	0	0
Activities would be substantially limited without medication or treatment	X	X	0	0	0	6 PER CENT	Omnibus and FRS	X	X	X	X	X
Day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last at least 12 months: to include problems and disabilities due to old age	†	†	Could be used with testing	†	X	18 PER CENT	Census testing	X	X	X	X	X

Key

x = covered in full, † = covered in part, 0 = not covered

7. Workshop on Disability definitions and harmonisation June 2008

This workshop encompassed a meeting of the Health and Disability harmonisation sub-group which was also due to meet in June.

7.1 Attendees

Welsh Assembly Government
The Scottish Government
Department for Children, Schools and Families
Department for Work and Pensions
Communities and Local Government
Equality and Human Rights Commission
Office for National Statistics
Office for Disability Issues

7.2 Aim of the workshop

7.2.1 The aim of this workshop was to progress recommendation 4.3 of ONS's Equality Data Review- *'The Office for Disability Issues and the Government Equalities Office in partnership with ONS and devolved governments, urgently agree a consistent approach to collecting information on disability, and champion this widely across Government and the wider public sector.'*

7.2.2 In order to agree a consistent approach ONS, ODI, GEO and the devolved governments are developing an agreed **suite of questions** to be used on all surveys which will ensure there is a consistent approach to collecting disability data across government.

7.2.3 Prior to the workshop an initial suite was circulated which was the focus of discussions during the day. The rationale for this suite is set out in ODI's position paper which was circulated in early June 2008.

7.3 Recommendations for question suite

7.3.1 Given the discussions that took place during the workshop the following decisions on question suite content and format were reached.

7.3.2 The consensus was that the priority for the suite should be:

- To monitor people with potential rights under the Disability Discrimination Act (DDA)
- To meet user needs

- To be able to meet EU requirements wherever possible

7.3.3 It was agreed that this suite should be composed of:

- **Two core questions** which are recommended for inclusion on all surveys and will measure the number of people with potential rights under the DDA i.e. people who currently have longstanding illnesses, impairments or health conditions. It will also provide a breakdown by type of impairment or condition.
- **Another optional question** which can be included on surveys if required will monitor disability by looking at the barriers faced by people with impairments.
- Additional people with potential rights under the DDA, such as those with past DDA disabilities, will be collected in an alternative source or module.
- A twelve month time period should be the standard for the question suite as it links to the census and DDA. The differences in prevalence that arise with a six month time period should be evaluated using existing data where possible.
- Impairment types, if collected second, should not be routed from the question eliciting adverse effects. This will allow true prevalence of impairments to be collected and the proportion whose normal activities are unaffected by their impairment.
- The list of impairments is valued and should be included, but an expansion of the fifth category to differentiate DDA conditions and other long-standing conditions should be considered.

8. The recommended suite of questions

8.1 Revised disability question suite following workshop recommendations

ONS in conjunction with ODI have taken on board on the findings from the June workshop and compiled a question suite which has the following specification (see table below on page 17:

Q1a. Do you have any long-standing physical or mental health condition, impairment or disability that has lasted or is expected to last 12 months or more? Please include those that are due to old age

1. Yes
2. No

Q1b. Do you have any long-standing physical or mental health condition, impairment or disability that has lasted or is expected to last 12 months or more? Please include those that are due to old age

1. Yes
2. No

IF 1:

What is the nature of your physical or mental health condition, impairment or disability?

0. Open text - code up to 6 replies

Q1c. Do you have any of the following long-standing physical or mental health conditions or impairments that have lasted or are expected to last 12 months or more? Select all that apply. Please include those that are due to old age

1. Blindness, deafness or other communication impairment
2. Mobility impairment, such as difficulty walking
3. Learning difficulty or disability, such as Down's syndrome
4. Mental health condition, such as depression
5. Long-term illness, such as Multiple Sclerosis or cancer
6. Other long-standing health condition or disability
7. None

Q2a. Are your day-to-day activities limited because of any physical or mental health condition, impairment or disability? Please include those that are due to old age.

Would you say you are:

1. Severely limited
2. Limited but not severely
3. Not limited at all

IF Q2 = 1 or 2

Q2b. Do your physical or mental health condition(s), impairment(s) or disability(ies) mean that your day-to-day activities are limited? Please include those that are due to old age. Would you say you are:

1. Severely limited
2. Limited but not severely
3. Not limited at all

Q3. How long have your day-to-day activities been limited?

1. Less than 6 months
2. At least 6 months but less than 12 months
3. At least 12 months

IF 1 or 2:

Do you expect your day-to-day activities to be limited for 12 months or more altogether?

1. Yes
2. No

IF 1 to Q1b or 1 thru 6 to Q1c AND 2 or 3 to Q2:

Q4. Do you take any medication for your long-standing health condition(s) or disability(ies)?

1. Yes
2. No

IF 1:

If you did not have this medication, do you think your activities would be limited by your long-standing health condition(s) or disability(ies)?

1. Severely limited
2. Limited but not severely
3. Not limited at all

- **question 1** versions establish the presence of conditions, impairments and disabilities, with open and prescribed breakdowns elicited in version b and c respectively.
- **question 2** aims to establish the presence of limitations in day to day activities the respondent experiences: the questions differ in the strength of linkage of the condition or impairment with the limitation and in routing; version b is routed from q1 and version a isn't.
- **question 3** aims to place the limitations in daily activities into a time frame consistent with DDA and European data needs, 12 months or more in case of the DDA and for at least six months in the case of EU-SILC.
- **question 4** asks the respondent whether he is taking medication for his condition or impairment and if s/he answered no to question 2 whether her/his daily activities would be limited without it.

8.2 Further questions developed based on the social model of disability

8.2.1 Social Barriers question suite

Q5a. There are many reasons why people can't take part in activities as much as they would like to. Are you limited in the following areas of life for any reason...

Individual Prompt – Code all that apply

- 1) Education?
- 2) Work?
- 3) Transport?
- 4) Personal relationships?
- 5) Leisure?
- 6) None of these

Q5b. There are many reasons why people can't take part in activities as much as they would like to. Do you have any difficulty taking part in the following areas of life for any reason...

Individual Prompt – Code all that apply

- 1) Education?
- 2) Work?
- 3) Transport?
- 4) Personal relationships?
- 5) Leisure?
- 6) None of these

If Qa = 1 thru 5

Q5a. SHOWCARD

Q6a What limits you in these areas?

Code all that apply

- 1) Financial reasons
- 2) Too busy/not enough time
- 3) A health condition, illness or impairment
- 4) A disability
- 5) Poor services
- 6) Lack of assistance or equipment
- 7) Badly designed buildings
- 8) Attitudes of others
- 9) Lack of information

Other reasons

If Q5b = 1 thru 5

Q5b. SHOWCARD

Q6b What causes you difficulty in these areas?

Code all that apply

- 1) Financial reasons
- 2) Too busy/not enough time
- 3) A health condition, illness or impairment
- 4) A disability
- 5) Poor services
- 6) Lack of assistance or equipment
- 7) Badly designed buildings
- 8) Attitudes of others
- 9) Lack of information
- 10) Other reasons

8.2.2 ODI's forthcoming Life Opportunities Survey uses a social definition of disability based on the social barriers and disadvantages to independent living and community participation (such as work, education, leisure, use of transport and other features of participation) faced by people. In this definition a distinction is drawn between impairment (referring to the actual attributes or loss of attributes of a person, in terms of limbs, organs or mechanisms, including psychological functioning) and disability which refers to the restrictions caused by society when it does not give equivalent attention and accommodation to the needs of individuals with impairments. The Prime Ministers Strategy Unit defined 'disabled people' as "anybody who is disadvantaged by the way in which the wider environment interacts with their impairment or ill health." To elicit relevant information on these restrictions across surveys, the following two question variants have been developed and will be incorporated into the testing plan. Both questions seek to measure the presence of restraints to participation, and the social and functional factors influencing these restraints. Such information will assist local jurisdictions in monitoring compliance with their Disability Equality Duty.

9. Revised question suite testing intentions

9.1 The DDA classifies people who would be limited in daily activities without medication as disabled. A method to disentangle the effect of medication on capacity to undertake normal activities will form part of the testing, but this population will be difficult to capture succinctly in a response category. However, it cannot form part of the body of the question eliciting activity limitation as this would conflict with EU definitions of disability. It likely that the medication adjusted population will need to be elicited with separate questions, establishing whether they take medication for their condition(s) and whether they believe they would be limited without it.

9.2 The terms health condition and disability can be included in a question aimed at measuring substantial adverse effects. Eurostat are not averse to its inclusion in their global activity limitation indicator as it is meant to capture disability, but they disapprove of its inclusion in the question capturing chronic illness. This suggests non-routing of questions on health conditions and impairments and the question on substantial adverse effects on normal activities is necessary.

9.3 The response categories in the activity limitation question encompass a dichotomised severity level which encompasses the substantial difficulties defined in

the DDA (the Act states substantial difficulties cover all difficulties of a non-trivial nature): the EU preference for the spectrum of limitations captured in the EU GALI is therefore met by this suite.

9.4 The intention is that questions can be asked of proxies and children.

9.5 The relationship between the elements put forward for testing and the data needs encompassed by other sources is shown below:

EU SILC DEFINITIONS		
Test elements for Question 1 > <i>terms mental/disability/impairment</i> > <i>longer time frame</i> > <i>categories</i>	Test elements for Question 2&3 > <i>old age related limitations</i> > <i>routing of time period</i> > <i>mean or because</i>	Test elements for Question 4 > <i>none so long as medication effects are captured in a separate question</i>
CENSUS 2011 DEFINITIONS		
Test elements for Question 1 > <i>none</i>	Test elements for Question 2&3 > <i>routing of time period</i> > <i>mean or because</i> > <i>force of limitation terms</i>	Test elements for Question 4 > <i>none so long as medication effects are captured in a separate question</i>
DDA DEFINITIONS		
Test elements for Question 1 > <i>effect of categories</i>	Test elements for Question 2&3 > <i>old age related limitations</i> > <i>routing of time period</i> > <i>mean or because</i>	Test elements for Question 4 > <i>capture of medication status</i> > <i>routing of effect without</i>
EXISTING DEFINITION		
Test elements for Question 1 > <i>terms mental & impairment</i> > <i>unspecified time period</i> > <i>categories</i>	Test elements for Question 2&3 > <i>old age related limitations</i> > <i>Globality v routed</i> > <i>mean or because</i> > <i>strongly v severe</i>	Test elements for Question 4 > <i>none so long as medication effects are captured in a separate question</i>

10.1 Draw on findings of previous testing (Census 2011 and EHIS)

Appraise available evidence of interpretability of components of proposed suite from previous research to avoid wasteful duplication and focus the testing on what is uncertain.

10.2 Cognitive Testing

10.2.1 The changes to questions required to harmonise data across surveys present uncertainty about how they will be understood in the field and whether the wording, routing and categorisation will validly and reliably define the target population. Following the changes to questions, made after consultation with stakeholders, there is a requirement to cognitively test the suite to ensure terminology is clear for respondents to answer accurately. Issues of concern with the proposed suite that require testing of interpretability are:

- the terms impairment and category of condition or impairment if asked to fit within specific response categories or open responses;

- the length of time daily activities have been limited (past and future);
- the linkage of medication with condition, impairment or disability asked about in question 1 and question 2;
- the requirement to speculate on whether and what level of severity daily activities would be limited without medication.

10.2.2 Aim of Question 1 and test requirements

Question 1, in its various forms, aims to collect data on long-standing health conditions, impairments, disabilities and infirmities. This will fulfil the continuity of the question used by the department of health for estimating service need based on the prevalence of chronic health conditions. The breakdown of conditions will also assist the DH in separating out long-term health conditions as opposed to impairments, and will assist ODI in their need for impairment breakdowns to help formulation and evaluation of policies related to disability. It will also clarify the links with severity of disability of different health conditions captured in question 2.

Cognitive testing must assess the scale of inclusion of acute short-term conditions such as a broken leg or influenza or other infection with the potential for the generation of false positives. There is also the question of whether less serious, but nevertheless long-standing impairments are included by respondents such as short-sightedness, astigmatism, long-sightedness etc. which would not have been included in response to the existing question.

The inclusion of the terms physical and mental health conditions is different to the traditional question and establishing the types of mental health conditions respondents include would be informative. There is also the need to assess the comparability of the terms *illness* and *health condition* and *impairment* and the link to the term *disability*. What do people understand by the terms impairment and disability: are they synonymous and is disability more understandable to the general population.

Question 1b and question 1c elicit information on category of chronic conditions, impairments and disabilities. It is important to establish that respondents understand only current conditions\ impairments or disabilities are relevant and only if they had lasted or are expected to last 12 months or more. The question is not aimed to capture conditions or impairments a respondent has ever had. There is no show card for this question so the importance of guidance for the respondent to identify the most important six conditions\impairments should be tested. There is also the need to test whether respondents can differentiate between symptoms of a condition or impairment such as pain and the conditions and impairments themselves.

Finally, we need to assess whether providing respondents with distinct categories to select from concurs with the type of conditions or impairments they would include in question 1b.

10.2.3 Aim of Questions 2a and 2b and test requirements

To identify the prevalence of disability identified through a global single measure of disability that assumes activity and participation restriction following the transition through the disablement process. The proposed EU global activity limitation indicator

question is intended to give an overview of disability and provide a measure of self-perceived, long-term functional limitation in the respondents' usual activities **because of** health conditions. The DDA, however, requires this question to elicit whether conditions, impairments or disability **mean** that the person experiences a substantial adverse effect on normal activities. There is a subtle difference between the more explicit link of the health condition to the disability in the EU definition and the more implicit link in the DDA definition.

The impact of the additional terms physical and mental health condition, impairment and age related conditions or impairments on responses does require investigation. There is the risk of question order effects as question 1 asks whether the respondent has a physical or mental health condition, impairment or disability and this is repeated in question 2 although the focus of the question is different as it asks whether they have any condition or impairment and whether it impacts on daily activities. The process of adaptation is also relevant here: we should test whether prefixing daily activities with normal pertaining to the present should be inserted to avoid the bias that may be present from the adaptation process.

Interpretation of the terms severely limited and limited, but not severely should be checked: what practical scenarios are offered by respondents as appropriate for classification to either state, and how much consistency is there with alternative terms such as a little or a lot?

Another issue is question order and effects on interpretation of the subsequent question. Do respondents link questions 2a and 2b with question 1 variants? Question 1 imposes a time period and implies a chronic condition or disability whereas question 2 elicits activity restriction resulting from any health condition or disability. Consequently, are respondents using question 1 to determine their response to question 2 variants, and would the order of questions 1 and 2 change how an individual would respond to this question.

10.2.4 Aim of Question 3 and test requirements

Question 3 is designed to place the disability into a defined time frame. Again there are differences between the EU data needs and the DDA data needs. In the case of the former, survey respondents are asked to judge whether they have experienced limitation that has lasted for at least the past 6 months; however, there is no requirement for the respondent to assess whether their activities will be limited in the future. The DDA, conversely is interested in eliciting whether the individual expects his/her activities to be limited in the future and for the past and future to be equal to or exceed 12 months duration.

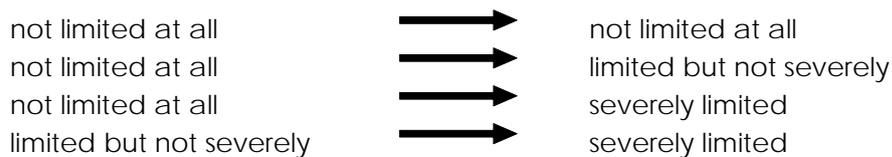
This difference in time period and future expectation has required question 3 to be split into two components. We need to cognitively test whether respondents realise the second part of the question relates to their answer in the first part and whether their future expectation of activity limitation means that the period they will have been limited would equal or exceed 12 months. We also need to establish whether people are comfortable about making predictions about future activity limitation and whether they consider limitations worsening in the future changing the force of limitation across time. Does eliciting future limitations confuse the respondent about which category of limitation applies to him/her.

It is also necessary to establish whether individuals perceive the time period to relate to the activity restriction or the health condition\impairment or both. The routing of

the question and the explicit reference to activity limitations should constrain linking to the duration of the health condition but this needs to be established.

10.2.5 Aim of Question 4 and test requirements

The DDA covers the population of people who would experience limitation in normal day to day activities without taking medication. Consequently, this question aims to identify this population. The previous questions filter those people with a long-standing condition or impairment or disability who are either limited but not severely or not limited at all. This population are being asked to assess whether their activity limitation status would change without medication. The transitions are:



Are people comfortable making a judgement about their activity status without medication? What reasons do they cite for limitation transitions?

10.2.6 Aim of Question 5 and 6

The aim of questions 5 and 6 is to collect a high-level indicator of social model disability. Under the social model, people may have health conditions or impairments which cause them to function differently, but they are not necessarily disabled by them. Instead, they are disabled by the social and environmental barriers imposed on them by aspects of society which take little or no account of their needs. These questions are an attempt to recognise that there is not necessarily a direct link between impairment and disability. Rather than asking 'does your impairment limit you', they allow a respondent to choose what limits them from a range of social and environmental barriers.

In essence, these questions are based on the International Classification of Functioning (ICF). The ICF partitions disability into a series of components:

1) Body functions and structures (for example a defect in the structure of the ear)

This is measured in questions relating to impairments and health conditions which are broadly captured in questions 1a, 1b and 1c.

2) Activity limitations (for example inability to work or shop) which is collected in questions 2a and 2b.

3) Participation restrictions (for example difficulty finding employment), measured by 5a and 5b.

4) Contextual factors (including environmental and personal factors) measured in 6a and 6b.

Questions 5a and 5b are attempting to measure the ICF concept of 'participation restrictions'. Questions 6a and 6b attempt to provide some of the most common contextual factors which influence participation restrictions. Contextual factors

include social/environmental factors such as poor services, as well as individual factors such as health conditions.

The questions recognise that it is a combination of these contextual factors, and the interactions between them, that disable individuals.

For testing purposes we would like to establish the following:

Question 5a and 5b

- 1) What does "activity" mean to the respondent?
- 2) What does "limited" mean to the respondent? (5a)
- 3) What does "difficulty" mean to the respondent? (5b)
- 4) What do respondents think each answer category means to them?
- 5) Are there any categories missing?
- 6) How did the respondent formulate their answer?
- 7) What kind of reasons for limitations/difficulties do respondents have in mind when answering the question?

Question 6a and 6b

1. What does "limit" mean to the respondent? (6a)
2. What does "difficulty" mean to the respondent? (6b)
3. How does the respondent distinguish answers 3 and 4?
4. How does the respondent allocate his/her answer to the categories?
5. How did the respondent formulate their answer?
6. Are respondents able to fit the reason for their limitation into these categories? If not, what other categories need to be added to the showcard?

10.2.7 Summary of cognitive testing requirements

Qs**Test actions**

- 1a** Assess understanding that term long-standing applies to condition or disability they currently have, not conditions they no longer have but had had in the past 12 months.
- Would subjects include acute conditions in response to this question e.g. broken leg, or recently diagnosed potentially chronic conditions such as angina or hypertension. What reasons do they give for inclusion, i.e. will last at least 12 months because not curable, or will need remedial treatment over long period.
- Do respondents understand the term impairment and do they associate it with disability?
- Do respondents understand the relationship between infirmity and conditions or impairments due to old age.
- Do respondents include relatively minor long-standing impairments such as short-sightedness, long-sightedness which they would not have included in response to the existing question.
- 1b** What bundle of conditions would they include in answering yes to this question?
- Do respondents understand only current conditions\impairments that have lasted or are expected to last for at least 12 months or more should be included?
- Do respondents include most important (in their opinion) conditions or impairments, or do they impose a chronology?
- Are well managed conditions or impairments not reported?
- Do respondents only include(ask whether to only include) conditions\impairments diagnosed by professional ?
- Do respondents include symptoms such as pain, breathlessness or time or situation specific conditions such as allergies when recalling specific conditions?
- 1c** Do respondents understand only current conditions\impairments that have lasted or are expected to last for at least 12 months or more should be included?
- Are well managed conditions or impairments not reported?
- Do respondents only include or ask whether to only include only conditions and impairments diagnosed by a professional ?
- How do respondents interpret the categories? i.e. do the partially sighted or the partially hearing include themselves in category 1. Is there a common threshold for inclusion i.e. difficulty walking (upstairs? 100 metres or more etc.). Do allergies or symptoms occur in response to category 6?
- 2a & 2b** What do respondents believe is the focus of this question: activity restriction or conditions\impairments?
- Does the inclusion of the term mental health condition alter the likelihood of reporting activity restriction compared with the existing GHS(L) question?
- Is there an adaptation effect: respondents do not report restrictions in activities because of adaptation? Would prefixing the term normal change their response?
- What do respondents understand by the term *severely* ? What does it mean in practice and how does it differ from limited but not severely?
- Does more explicit linkage to the condition\impairment or disability change response behaviour?
- Is there linkage between question 1 variants and question 2 variants so that response to question 2 is determined by response to question 1?
- Would responses change if the order was reversed?
- 3** Do respondents link the second part of question to first when assessing total time they have been limited?
- What are respondents' views about the validity of making a personal assessment of the likelihood of limitations continuing into the future? How do they justify statements of future limitations?
- What problems arise when expectation of limitation in the future has a different force than current and past?
- Do respondents understand the time period relates to the duration of the activity limitation and not the health condition or impairment?
- 4** Are respondents able to assess a change in activity limitation status following withdrawal of medication?
- What factors do they quote to justify a transition?
- 5+6** What does "activity" mean to the respondent?
- What does "limited" mean to the respondent? (5a)
- What does "difficulty" meant to the respondent? (5b)
- What do respondents think each answer category means to them?
- Are there any categories missing?
- How did the respondent formulate their answer?
- What kind of reasons for limitations/difficulties do respondents have in mind when answering the question?

10.2.8 Criteria for sample recruitment

	Men					
Communication impairment (blind, deaf or partially)	Yes			No* can be used for all categories for those without a condition		
Age	18-34	35-59	60+	18-34	35-59	60+
Achieved ints	1	0	1	1	1	1
Mobility impairment	Yes					
Age	18-34	35-59	60+			
Achieved ints	0	1	1			
Learning difficulty or disability	Yes					
Age	18-34	35-59	60+			
Achieved ints	1	0	0			
Mental health condition	Yes					
Age	18-34	35-59	60+			
Achieved ints	1	1	0			
Long-term illness such as multiple sclerosis or cancer	Yes					
Age	18-34	35-59	60+			
Achieved units	0	1	2			
Condition severely limits day to day activities	Yes			No		
Age	18-34	35-59	60+	18-34	35-59	60+
Achieved ints (selected from above with a condition)	0	1	1	0	0	0
Has condition and it limits activities but not severely	Yes			No		
Age	18-34	35-59	60+	18-34	35-59	60+
Achieved ints (selected from above with a condition)	1	1	1	0	1	1
No limitations and no conditions	Yes			No		
Age	18-34	35-59	60+	18-34	35-59	60+
Achieved ints (selected from above without a condition)	1	1	1	NA	NA	NA
Duration of limitations ≥ 6 months if has a limitation	Yes			No		
Age	18-34	35-59	60+	18-34	35-59	60+
Achieved ints (all selected from above with a condition and limitation)	1	1	1	0	1	0
Would be limited without medication	Yes			No		
Age	18-34	35-59	60+	18-34	35-59	60+
Achieved ints (selected from above with a condition, taking medication for condition and no limitation)	0	1	1	1	1	0
TOTAL INTERVIEWS	18-34 - 4		35-59 - 5		60+ - 4	

	Women
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Communication impairment (blind, deaf or partially)	Yes			No* can be used for all categories for those without a condition		
Age	18-34	35-59	60+	16-34	35-59	60+
Achieved ints	0	1	0	1	1	1
Mobility impairment	Yes					
Age	18-34	35-59	60+			
Achieved ints	1	0	1			
Learning difficulty or disability	Yes					
Age	18-34	35-59	60+			
Achieved ints	0	1	0			
Mental health condition	Yes					
Age	18-34	35-59	60+			
Achieved ints	1	1	1			
Long-term illness such as multiple sclerosis or cancer	Yes					
Age	18-34	35-59	60+			
Achieved units	0	1	1			
Condition severely limits day to day activities	Yes			No		
Age	18-34	35-59	60+	18-34	35-59	60+
Achieved ints (selected from above with a condition)	0	1	1	0	0	0
Has condition and it limits activities but not severely	Yes			No		
Age	18-34	35-59	60+	18-34	35-59	60+
Achieved ints (selected from above with a condition)	1	1	1	0	1	1
No limitations and no conditions	Yes			No		
Age	18-34	35-59	60+	18-34	35-59	60+
Achieved ints (selected from above without a condition)	1	1	1	NA	NA	NA
Duration of limitations ≥ 6 months if has a limitation	Yes			No		
Age	18-34	35-59	60+	18-34	35-59	60+
Achieved ints (all selected from above with a condition and limitation)	1	1	1	0	1	0
Limited without medication?	Yes			No		
Age	18-34	35-59	60+	18-34	35-59	60+
Achieved ints	1	1	1	0	1	0
TOTAL INTERVIEWS	18-34		35-59		60+	
	3		5		4	

The above suggests a total of 25 interviews. We need to recruit people with and without conditions, people with conditions with and without limitations, people with

conditions and limitations that have lasted 6 months or more and less, and people with a condition, taking medication for their condition and not limited.

10.3 Quantitative Testing

10.3.1 The quantitative testing will aim to assess the comparability of the question suite with existing questions on the GHSL and FRS, the EU SILC proposed questions and the intended census question in terms of prevalence. A test to compare the comparability of the EU-SILC questions on chronic morbidity and activity limitation and the existing questions on the GHSL has already been undertaken with results available for comparison. The FRS also contains the question suite used to measure the population prevalence of DDA defined disability with prevalence estimates readily available for comparison.

10.3.2 Question 1 variants b and c will be used as question 1 a is derivable from question 1 b.

10.3.3 The elements put forwarded for testing are summarised below:

- to compare prevalence of LSI, impairment and disability using dichotomous and independent response categories with existing prevalence estimates calculated from existing data sources to assess the question variants fitness for use in meeting DDA, EU-SLIC and DH time series data needs;
- to assess the internal consistency in range and number of reported conditions, impairments and disabilities using an open text and an independent category response format;
- to assess the consistency in capturing activity limitation and its severity when using a stronger/weaker link to the condition, impairment or disability – inform utility in meeting EU-SILC data needs and any departure from estimates based on the census question;
- to compare the performance of questions 2a and 2b in meeting EU-SILC GALI and DH time series data needs and consistency with proposed census question on disability using prevalence estimates of the EU-SILC GALI question from Omnibus survey in 2007-08, the existing GHSL question from Omnibus testing 2007-08 and GHSL 2007 sample and the Census question testing estimates from the dress rehearsal;
- to assess consistency in prevalence of activity limitation and its severity when time period is identified in the body of the question or elicited as a routed discrete response category in a separate question or not identified at all;
- To assess the effect on prevalence of activity limitation and its severity when respondents are asked to combine past and expected time
- To assess the change in prevalence of activity limitation and its severity without medication if receiving it for the condition, impairment or disability previously identified
- to measure the reliability of the questions to elicit presence of long-standing illness, impairment and disability, and activity limitation in individuals will be tested by administering these questions to the same respondents six weeks following the first administration by CATI.

Standard	Criterion to judge adequate question suite performance	Outcome (met, partly met, not met)
<p>Both independent and dichotomous response categories in questions 1b and 1c produce estimates of prevalence fit for use in delivering DDA, EU-SILC and DH time series data needs</p> <p>The conditions, impairments and disabilities captured provide robust estimates of population prevalence regardless of format of data capture.</p>	<p>Variance doesn't exceed random error</p> <p>The conditions, impairments and disabilities captured with an open text format are classifiable to independent categories in question 1c.</p> <p>Health conditions and illnesses captured in historical GHS samples have a similar prevalence and range by age, sex and Socioeconomic position to question 1b and question 1c.</p>	
<p>Respondents reliably report conditions, impairments, disabilities or their absence reliably when the question is re-administered at an interval of six weeks.</p>	<p>The intra-class correlation coefficient for a 10 per cent sample of the original sample exceeds 0.7.</p>	
<p>The terms <i>because</i> and <i>mean</i> produce similar prevalence estimates</p>	<p>Variance is sufficiently precise to detect real differences</p>	
<p>The routing from question 1b or 1c has no effect on prevalence estimates of activity limitation or its severity.</p>	<p>Variance is sufficiently precise to detect real differences</p>	
<p>Proposed question suite, SILC, existing GHSL questions and proposed census question produce similar estimates of activity limitation and severity</p>	<p>The variance of each estimate is sufficiently precise to detect real differences</p>	
<p>SILC and DDA past activity limitation data needs can be met through eliciting time period in a separate routed question with period specific response categories</p>	<p>The prevalence of activity limitation in the past is consistent, whether time period is identified in the body of the question or in a separate routed response category</p>	
<p>Respondents reliably report activity limitation and its force or absence reliably when the question is re-administered at an interval of six weeks.</p>	<p>The intra-class correlation coefficient for a 10 per cent sample of the original sample exceeds 0.7.</p>	
<p>DDA needs for expectation of activity limitation in the future as well as the past can be elicited through a further routed response category</p>	<p>mapping from responses 1 and 2 in question 3 part 1 to yes responses in part 2 occurs in a predictable way based on previous data on long-standing illness, impairment or disability and severity of activity limitation</p>	
<p>The effects of medication on activity limitation prevalence is satisfactorily measured</p>	<p>Estimates of prevalence are consistent with FRS estimates from 2007 in ten year age and sex groupings</p>	

10.2.4 Test Design

A two arm experimental design is required to enable comparison of questions 1b and 1c and 2a and 2b. This will reduce the available sample size with which to compare question suite estimates internally within the Opinions Survey (i.e. 2,400 sample over 4 months) and with estimates calculated from external sources and will consequently require additional months of data to be collected to ensure sufficient precision to make reliable comparisons. The internal validity compromises made in comparing external non-contemporaneous sources is also a factor influencing the validity of comparisons. These defects need to be set against the considerable costs of running the range of questions internally within the Opinions survey and the time constraints for reporting results and making recommendations for question implementation onto the IHS.

Dimension	Morbidity, Impairment, Disability				Activity Limitation and Medication	
Question	Q1B	Q1C	Existing GHSL	Existing FRS	Q4	FRS medication question
Data Source	Opinions 4 months (Sept-Dec 09)	Opinions 4 months first third (09-10)	GHS(L) 06/7 sequencing Opinions/Omnibus survey months	FRS 06/7 sequencing Opinion /Omnibus survey months	Opinions 4 months (Sept-Dec 09)	FRS 06/7 sequencing Opinions/Omnibus survey months
Dimension	Activity Limitation and Severity					
Question	Q2a & Q3	Q2b & Q3		Existing GHSL	Existing FRS	Proposed census
Data Source	Opinions 4 months (Sept-Dec 09)	Opinions 2 months (Sept-Dec 09)		GHS(L) 06/7 sequencing Opinions/Omnibus survey months	FRS 06/7 sequencing Opinions/Omnibus survey months	Dress Rehearsal

Issues for design effectiveness

The following should be considered before the plan should be shared with ODI:

- GHSL, FRS and Census dress rehearsal vs. Opinions survey data: The GHSL and FRS and census collect information on all adults in the household, whereas the Opinions survey randomly selects one person per household. Health is known to cluster in households, so the impact of comparing other sources and Opinions data probably needs a correction factor applied. It is possible that this can be overcome by randomly select one adult per household from the other sources to reduce the need for current Opinions survey data collection.
- Opinions timing may be an issue regarding capacity to run these questions within our timescales (see timetable). We would like the quantitative

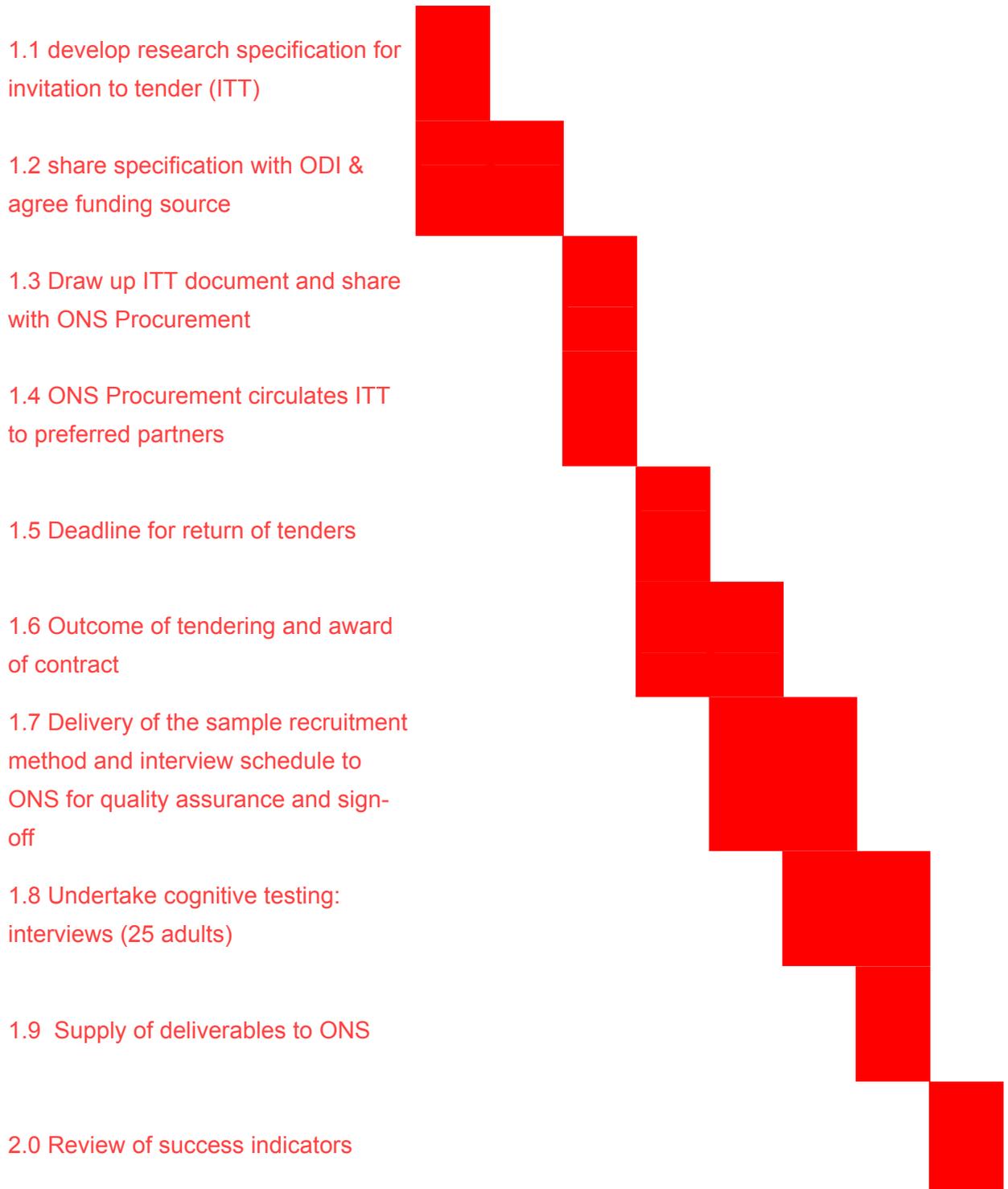
testing to be completed by September 2009 to enable a case to be built for implementing the new question onto the IHS by 2010 on the basis of evidence. It is estimated that splitting the sample in two will reduce the sample size to around 700-800 for those reporting a long-standing illness or activity limitation. Looking at this by age and/or categories of conditions, impairments or disabilities the sample sizes are likely to contract further to around 100 cases. This may compromise the ability to detect important differences if they are present.

11. Timetable

2008-09

Nov Dec Jan Feb Mar Apr May Jun

1. Cognitive testing data collection



2. Quantitative testing data collection

- 2.1 develop specification, test design & costings with Opinions Survey team
- 2.2 share specification & costings with ODI & determine funding source
- 2.3 identify opinion survey capacity for question running in 2008-09, 2009-10: decide on need for external provider slots
- 2.4 Run questions on survey
- 2.5 Receive data

3. Analysis and report writing

- 3.1 Data analysis
- 3.2 Report writing
- 3.3 Report sharing with ODI & delivery to IHS Steering Group

4. Implementation of question suite

Nv Dc Jn Fb Mr Ap My Ju Jl Ag Sp Ot Nv Dc Jn Ap

