

**AN EXERCISE IN SURVEYING A NON-UNIVERSALLY DEFINED GROUP IN THE  
POPULATION**

**THE NORTHERN IRELAND SURVEY OF ACTIVITY LIMITATION AND DISABILITY**

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**Abstract:** Developing policy and delivering services to people with disabilities is an important aspect of our society. As with all areas of policy and service provision, accurate, timely and reliable data are fundamental to the setting, monitoring and examination of that provision. Market and non-market service providers, advocacy groups and the general population seek increasingly detailed data on the prevalence, nature, severity and life circumstances of those people in our society who experience disability. However, disability is complex and difficult to measure. Whilst most people ‘know’ what disability means there is little consensus as to a complete but concise definition of the concept that could be employed in censuses, surveys or other data and research instruments. This paper explores the recent experience of the Northern Ireland Statistics and Research Agency in defining, identifying and surveying this seemingly growing group in our society. Previous survey instruments as well as current international models are examined. Experiences of surveying in the usual arena of the household are compared with the survey process experienced in communal establishments such as long-stay hospital wards and care homes. The key results from analyses to date are also highlighted.

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## **1. BACKGROUND**

At its most objective level disability is a continuum, a line along which everyone in a population can be placed. However, an individual’s position on this line is likely to change over their lifetime. Additionally, their position at any one point in time is not necessarily clear. At one end of the line is a group of individuals whom most people would agree are not disabled. At the other end of the line is another group of individuals about whom there would be general consensus that they are disabled. However, between these two extremes lies a third and potentially sizeable group, constituting people whose classification is more ambiguous and is effectively a matter of judgement. This lack of clarity of definition raises many issues when social scientists are asked to provide hard evidence and authoritative data upon which to develop and assess policy and service provision for people with disabilities.

In Northern Ireland, as in many developed countries, disability statistics are available from a range of different sources and meeting a range of definitions of disability. Further detail on these sources is provided in Annex 1. These data are sought for and used by a wide range of groups and individuals from policy makers through to disability rights groups and lobbyists. There can be

surprise and confusion when the statistics purported by one group are challenged by another, using alternative and equally defensible sources. This variation leads to the question – which, if any, of the sources are correct? Unfortunately there is no single answer to this question and it often comes down to what the data are to be used for. Disability is a complex and difficult to measure concept partly because it can take many forms and partly because the subjective ideas and standards of what constitutes disability vary greatly from person to person, across time, and across societies.

### *1.1 Prevalence rates from current sources*

A brief selection of estimates of disability is presented below from sources for Northern Ireland as well as estimates for other countries. Prior to the 2006 Northern Ireland Survey of Activity Limitations and Disabilities (NISALD), a survey dedicated to collecting information on disability was last conducted in Northern Ireland during 1989 / 90. That study was conducted by the Policy Planning and Research Unit (PPRU) of the Department of Finance and Personnel, Northern Ireland. This unit was the predecessor of the Northern Ireland Statistics and Research Agency. The PPRU study used a complex definition of disability consistent with that used by the Office for Population Censuses and Surveys (OPCS) in Great Britain in a similar study conducted around the same time. The definition was based on the World Health Organisation's International Classification for Illness, Disease and Handicap (ICIDH). The study found a disability prevalence rate of 16 per cent amongst adults living in private households in Northern Ireland.<sup>1</sup>

The majority of more recent sources of disability estimates are based on the definition of a limiting long-term illness (LLTI) or, in the case of the Labour Force Survey, the definition as used for the purposes of the Disability Discrimination Act.<sup>2</sup>

Over the past two decades, estimates of the proportion of the household population who have a limiting long-standing illness have been available from the Northern Ireland Continuous Household Survey. This is a general household survey designed to provide a regular source of information on a wide range of social and economic issues relevant to Northern Ireland. This source provides estimated prevalence rates amongst adults of somewhere between 20 per cent and 27 per cent over this twenty year period.<sup>3</sup>

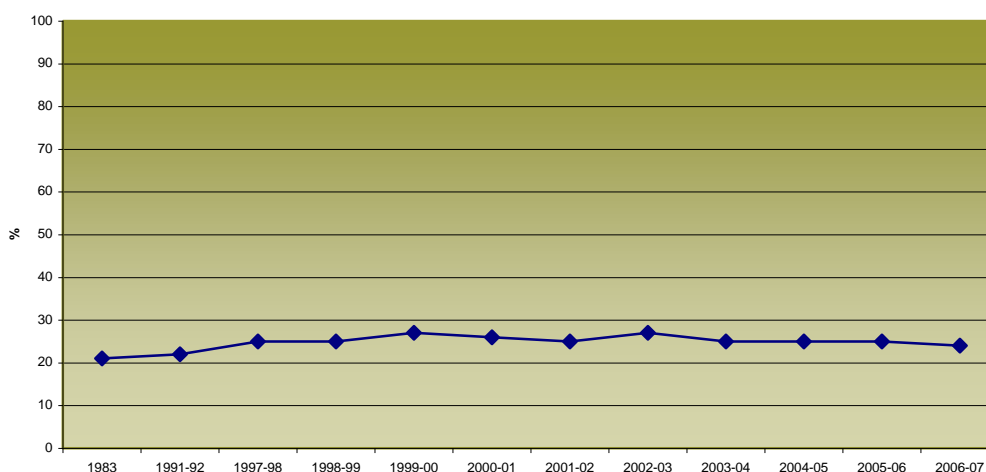
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<sup>1</sup> D. McCoy and M. Smith, January 1992, *PPRU Survey of Disability Report 1: Prevalence of Disability Among Adults in Northern Ireland*, Policy Planning and Research Unit, Statistics and Social Division.

<sup>2</sup> For more information on the Disability Discrimination Act see:  
[http://www.equalityni.org/sections/default.asp?cms=Your+Rights+Disability+discrimination&cmsid=2\\_142&id=142&secid=2](http://www.equalityni.org/sections/default.asp?cms=Your+Rights+Disability+discrimination&cmsid=2_142&id=142&secid=2)

<sup>3</sup> Central Survey Unit, Northern Ireland Statistics and Research Agency, *Continuous Household Survey 1983-2006/07*: <http://www.csu.nisra.gov.uk/survey.asp2.htm>

**Proportion of adults aged 16 and above with a limiting long-standing illness  
Northern Ireland Continuous Household Survey 1983 to 2007**



The 1991 and 2001 Northern Ireland Censuses of Population asked respondents if they had a long-term illness, health problem or handicap/disability which limited their activities or the work they could do (LLTI). In the 1991 census, 12 per cent of the total population (adults and children) indicated that they had an LLTI;<sup>4</sup> in 2001 the figure was 20 per cent.<sup>5</sup> This increase is likely to be due to a number of factors, some of which might include an ageing population; an increasing tendency to report such an illness or disability; and a slight change in the wording of the question, whereby the 2001 Census replaced the word ‘handicap’, used in the 1991 question, with ‘disability’.

The 2001 Northern Ireland Life and Times Survey<sup>6</sup> estimated the prevalence of LLTI at around 18 per cent of the adult household population aged 18 and over. In the same year, the 2001 Health and Social Well-being Survey<sup>7</sup> estimated that 28 per cent of the adult household population in Northern Ireland had an LLTI.

The Labour Force Survey (LFS) for Northern Ireland provides a further source of disability estimates. The definition of disability used for the LFS is that which is in place for the purposes of the Disability Discrimination Act and the estimates are provided for the sub-set of the population who are of working age, i.e. males aged 16-64 and females aged 16-59. Recent estimates for this population from this source suggest prevalence rates of around 18 to 20 per cent.<sup>8</sup>

<sup>4</sup> Northern Ireland Statistics and Research Agency, 1991 Census: [www.nisra.gov.uk](http://www.nisra.gov.uk)

<sup>5</sup> Northern Ireland Statistics and Research Agency, 2001 Census: [www.nisra.gov.uk](http://www.nisra.gov.uk)

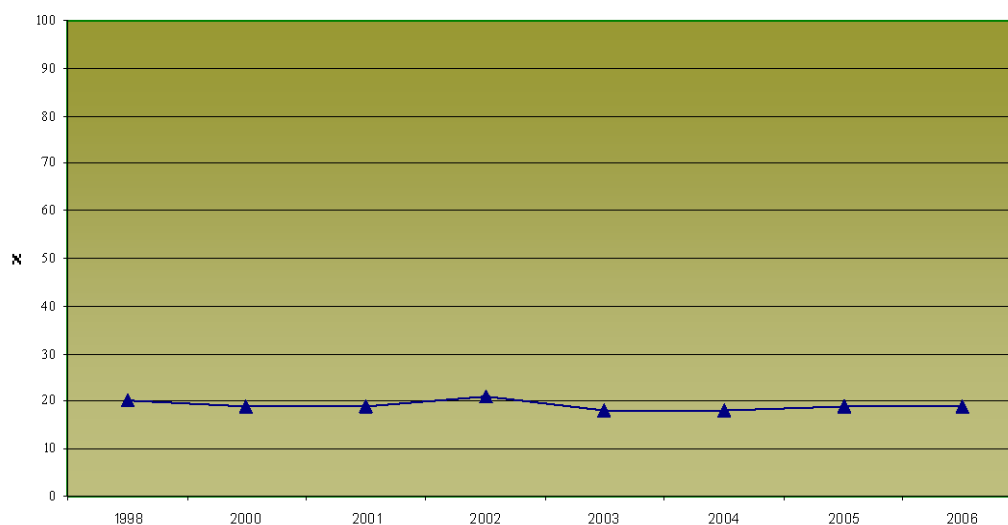
<sup>6</sup> ARK. *Northern Ireland Life and Times Survey, 2001* [computer file]. ARK: [www.ark.ac.uk/nilt](http://www.ark.ac.uk/nilt) [distributor], June 2002.

<sup>7</sup> Department of Health, Social Services and Public Safety, *Health and Social Wellbeing Survey 2001*: <http://www.csu.nisra.gov.uk/survey.asp51.htm>

<sup>8</sup> Department of Enterprise, Trade and Investment, *Labour Force Survey*: [http://www.detini.gov.uk/cgi-bin/get\\_builder\\_page?page=3637&site=4&parent=136](http://www.detini.gov.uk/cgi-bin/get_builder_page?page=3637&site=4&parent=136)

A similar variation in estimates of the prevalence of disability can be seen in international comparisons. For instance, the OPCS study conducted in England and Wales during the 1980s estimated the prevalence of disability at around 14 per cent.<sup>9</sup> In the 1991 census around 15 per cent of adults living in private households in Great Britain indicated that they had an LLTI. In the 2001 census this figure had increased to 21 per cent.<sup>10</sup> As illustrated below, recent estimates from the General Household Survey suggest that around 20 per cent of the household population in Great Britain have an LLTI.<sup>11</sup>

**Proportion of household population with a limiting long-term illness  
Great Britain General Household Survey 1998 to 2007**



Prevalence rates of disability in Australia are generally sourced from the Australian Survey of Disability, Ageing and Carers (SDAC). This disability survey was conducted in Australia in 1981, 1988, 1993, 1998 and 2003. The next study is planned for 2009 with a six yearly cycle thereafter. Estimated disability prevalence rates from this source are around 20 per cent for all persons.<sup>12</sup>

In New Zealand, a dedicated disability survey has been conducted on three occasions in recent years, generating prevalence estimates of 20 per cent in 1996/97 and 17 per cent in 2006.<sup>13</sup>

<sup>9</sup> J. Martin, H. Meltzer & D. Elliot, *OPCS Surveys of Disability in Great Britain, Report 1: The Prevalence of Disability Among Adults*, London: HMSO, 1988.

<sup>10</sup> Office for National Statistics, 1991 and 2001 Census (GB): <http://www.statistics.gov.uk/census/>

<sup>11</sup> Office for National Statistics, *General Household Survey 2006*: <http://www.statistics.gov.uk/StatBase/Product.asp?vlnk=5756&Pos=2&ColRank=1&Rank=272>

<sup>12</sup> Australian Bureau of Statistics, *Survey of Disability, Ageing and Carers*: <http://www.abs.gov.au/Websitedbs/c311215.nsf/20564c23f3183fdaca25672100813ef1/fe0fac52c066e805ca2572f30014ca3c!OpenDocument>

<sup>13</sup> New Zealand, *2006 Disability Survey*: <http://www.stats.govt.nz/products-and-services/media-releases/social-conditions/2006-disability-survey-mr.htm>

Ireland's two most recent censuses have provided estimates of the proportion of the population with a disability at 8 per cent in 2002 and 9 per cent in 2006.<sup>14</sup>

Statistics Canada has also conducted dedicated disability surveys for a number of years. Recent estimates of disability prevalence rates for Canada from this source are 12.4 per cent for 2001, and 14.3 per cent for 2006.<sup>15</sup> Other sources within Canada generate much higher estimated prevalence rates, at around 18 per cent from the census, 20 per cent from the Survey of Labour and Income Dynamics, and 31 per cent from the 2001 Canadian Community Health Survey.<sup>16</sup>

The information above has been included only to illustrate the variance in disability estimates across countries. It should be noted that the data are not directly comparable. A number of adjustments would be required to enable direct comparisons to be made, including standardisation of the data to account for variation in the population structures of different countries.

As suggested from the above, the definitions used, the context within which survey questions are asked, the mode of administration and actual changes in society will all give rise to differences in disability prevalence rates within a country, across countries and over time. This paper examines these issues by looking at the processes and the results of the recent Northern Ireland Survey of Activity Limitation and Disability (NISALD).

## 2. NISALD DEVELOPMENT AND CONCEPTUAL FRAMEWORK

A review of existing disability information and sources within Northern Ireland was produced for the Northern Ireland Statistics and Research Agency (NISRA) in 2003 by MSA Secta Ferndale.<sup>17</sup> This concluded that high level information on prevalence is available from a range of sources but that:

- there is a lack of good quality information on people in Northern Ireland with a disability, especially in terms of their multiple identities and their experiences across a range of social and economic contexts such as education, employment, transport and claiming of benefits; and
- user needs are varied and there are significant difficulties surrounding the definition (or definitions) of disabilities, including the conflict between the medical and social models.

The review made a number of recommendations, primary amongst them being:

- to conduct a comprehensive survey looking at the prevalence and types of disabilities as well as the experiences and views of people with disabilities.

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<sup>14</sup> Central Statistics Office, Ireland, 2002 and 2006 Census:  
<http://www.cso.ie/census>

<sup>15</sup> Statistics Canada, *2001 and 2006 Participation and Activity Limitation Survey*:  
<http://www.statcan.ca/cgi-bin/imdb/p2SV.pl?Function=getSurvey&SDDS=3251&lang=en&db=IMDB&dbg=f&adm=8&dis=2>

<sup>16</sup> Susan Stobert (July 2006) *Measuring Disability at Statistics Canada* (powerpoint presentation):  
([http://www.icdr.us/disabilitydata/Day2\\_SessIV/S\\_Stobert\\_Session%20I.ppt#256,1,Measuring%20Disability%20at%20Statistics%20Canada](http://www.icdr.us/disabilitydata/Day2_SessIV/S_Stobert_Session%20I.ppt#256,1,Measuring%20Disability%20at%20Statistics%20Canada))

<sup>17</sup> MSA Ferndale (April 2004) *Review of Disability Information – Project for DFP NISRA*:  
<http://www.equality.nisra.gov.uk/publications/>

The outcome of this review coincided with the establishment of a Ministerial commissioned group whose remit was “to examine the barriers to employment; education; transport; housing; access to information; and lifelong learning, for people with disabilities in Northern Ireland and to make recommendations on how these barriers might be removed”. The development of NISALD was, therefore, taken forward collaboratively between this Promoting Social Inclusion (PSI) Group<sup>18</sup> for people with disabilities and the survey development team within NISRA. There were, as a result, very close links between the policy needs and the development of the evidence base.

### *2.1 Medical vs Social model*

As noted by the MSA Ferndale review, in the field of disability research there is often conflict between two underlying conceptual frameworks for the assessment of an individual’s disability status. The most commonly used model in recent data collection has been the medical model where the impairment is identified as the problem and disability is broadly defined as ‘any long-standing disability, illness or infirmity that limits the respondent’s activities in any way’. This definition places the focus on the person and their impairment. The social model, conversely, places the focus on the surrounding environment in which the person lives and how this affects their ability to carry out everyday activities. In this model, the structures within society are identified as the problem. This model argues that if appropriate adaptations are made, a person with an impairment may be able to carry out the same activities as a person without an impairment. If adaptations are not made it is argued that it is actually the environment that is causing the disability.

### *2.2 ICF*

There are benefits and problems associated with each model and perhaps the ideal would be to take the best elements from each. To this end, the World Health Organisation (WHO) developed an International Classification of Functioning, Disability and Health (ICF for short)<sup>19</sup> which was endorsed by all participating countries of the WHO in May 2001. The ICF updates and indeed supersedes the previous classification system ICIDH – International Classification of Impairments, Disabilities and Handicaps. Across the WHO countries many organisations representing people with disabilities were consulted with and signed up to the new ICF.<sup>20</sup>

The ICF is a complex classification system made up of a number of domains and components to reflect the multi-faceted nature of disability and the array of factors that can have an impact upon it. It attempts to make use of both the medical and social models of disability illustrating how health and environmental issues combine and interact to produce disabilities.

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<sup>18</sup> PSI Disability Working Group

<sup>19</sup> For more information on the International Classification of Functioning, Health and Disability please visit the ICF homepage of the World Health Organisation’s website at the following address: <http://www.who.int/classifications/icf/site/icftemplate.cfm>

<sup>20</sup> WHO (2002) *Towards a Common Language for Functioning, Disability and Health, ICF*. Geneva, World Health Organisation

### 2.3 ICF components and domains

The main components of the ICF are:

1. body functions (physiological functions of the body),
2. body structures (anatomical parts of the body),
3. activities (tasks carried out by people), and participation (involvement in a life situation) and
4. finally, environmental factors (how the surrounding environment facilitates or provides barriers to a person's functioning).

Within each of these components there are a number of domains and in turn domains are made up from blocks, forming a hierarchy of classification.

Whilst the ICF provides a useful conceptual framework within which to undertake disability research, it is important to note that it does not offer an off-the-shelf measurement or assessment instrument. Rather the ICF can be used to develop a survey instrument which is based on this overarching model but is tailored to and reflects the needs of the particular country and society in focus.

### 2.4 Approach to surveying disability internationally

Background research undertaken for the development of NISALD revealed that ICF had been used as the survey base amongst those in the lead and with previous experience in disability research, namely the Australian Bureau of Statistics and Statistics Canada. ICF was also under active consideration as the conceptual framework amongst countries progressing comparable surveys, including New Zealand and Ireland. Both Canada and Australia had been running periodic national surveys on disability prior to the development of ICF. These earlier studies had been generally based on the ICIDH – the immediate predecessor to ICF and were subsequently revised to take account of the move to ICF. A disability survey has been carried out by Statistics New Zealand on three occasions. Similarly to the situation in Australia and Canada, two survey runs, in 1996/97 and again in 2001 were based on the ICIDH. New Zealand's most recent disability survey was conducted in 2006 and was revised to reflect the ICF.

Ireland's experience was tracked closely by the NISALD survey development team, given the potential for comparability of any studies carried out in both areas at similar points in time. Within Ireland, the National Disability Authority had commissioned a pilot study for a national survey of disability.<sup>21</sup> The main aim of the pilot was to develop a suitable survey instrument, also based on ICF, which would examine the prevalence and impact of disability within Irish society. As a result of this pilot study, it was decided to undertake a full national disability survey using the 2006 Census to establish the sample frame. Estimates of disability prevalence have been produced as part of the 2006 census outputs. A report from the follow-up disability survey will be published in due course.

Within Great Britain the need for a disability survey was also under active consideration. The Department for Work and Pensions (DWP) commissioned NatCen to carry out a review of

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<sup>21</sup> Economic and Social Research Institute and Centre for Disability Studies (October 2003) *Designing And Piloting An Irish Disability Research Instrument Based On WHO ICF* – Project for National Disability Authority:  
<http://www.nda.ie/cntmgmtnew.nsf/0/F6D0B29EC738D268802570660054EC10?OpenDocument>

disability estimates and definitions, which reported in 2004.<sup>22</sup> This was a largely technical review of existing information. To supplement this, DWP commissioned a feasibility study assessing options for the future collection of information on people with a disability.<sup>23</sup> It was recommended that a survey dedicated to disability should be developed. However, it was expected to be at least 2006 before England and Wales would be in a position to begin developing a survey instrument and some time after that before a survey would be in the field. Due to this time lag and the pressing policy need for the information in Northern Ireland, the decision was taken to continue with the development of a survey instrument for use in Northern Ireland. Contact was maintained throughout with officials in DWP to maintain awareness of progress in the rest of the United Kingdom. The final recommendation to Ministers in England and Wales was for the development of a new longitudinal survey with an initial cross-sectional base-line survey. The Office for National Statistics was awarded the contract to develop and run the survey. A questionnaire is currently under development with a number of tests scheduled for the coming year. It is expected that the baseline survey will be conducted during 2009/10 with top-line results being made available in 2010.

The Washington Group on Disability Statistics was formed as a result of the United Nations International Seminar on Measurement of Disability in June 2001.<sup>24</sup> An outcome of that meeting was the recognition that statistical and methodological work was needed at an international level in order to facilitate the comparison of data on disability cross-nationally.

The following objectives were agreed and used to guide the development of a work plan:

1. To guide the development of a small set(s) of general disability measures, suitable for use in censuses, sample based national surveys, or other statistical formats, which will provide basic necessary information on disability throughout the world.
2. To recommend one or more extended sets of survey items to measure disability or principles for their design, to be used as components of population surveys or as supplements to specialty surveys. These extended sets of survey items will be related to the general measures.
3. To address the methodological issues associated with the measurement of disability considered most pressing by Group participants.

To date the group have produced a draft short set of questions for use primarily in national censuses. Standardised pre-tests of this short set of questions have been held in 15 countries worldwide. Minor amendments are still being made to the questions following the pre-tests; further testing and analysis of the testing is underway; development work on an alternative option for measuring upper body function is in progress; and there is a planned investigation into the use of the short set as a screener.

A proposed extended set of questions for use in general surveys has also been drafted. This set of questions is currently being tested.

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<sup>22</sup> Madhavi Bajekal, Tim Harries, Rachel Breman and Kandy Woodfield, NATCEN (March 2004) *Review of Disability Estimates and Definitions*, A Study Carried out for the Department of Work and Pension. In-House Report 128 (<http://www.dwp.gov.uk/asd/asd5/ih2003-2004/IH128.pdf>).

<sup>23</sup> S. Purdon in collaboration with M. Bajekal, C. Bromley, C. Bryson, M. Doyle, G. Nicolaas, K. Sproston (September 2005) Department of Work and Pensions Research Report No. 267: *Meeting DWP's long-term information needs on disability: A feasibility report*:  
[http://www.dwp.gov.uk/asd/asd5/report\\_abstracts/rr\\_abstracts/rra\\_267.asp](http://www.dwp.gov.uk/asd/asd5/report_abstracts/rr_abstracts/rra_267.asp)

<sup>24</sup> The Washington City Group on Disability Statistics, National Centre for Health Statistics:  
<http://www.cdc.gov/nchs/citygroup.htm>



### 3. IDENTIFYING THE NISALD SAMPLE

Given the background of ICF amongst disability studies internationally, it was established, in consultation with policy-makers and key stakeholders, that ICF would also form the theoretical backdrop for the Northern Ireland questionnaire. Notwithstanding the development of the actual survey instrument itself, a number of other outstanding methodological issues remained. The most significant amongst these were:

- establishing a sample frame; and
- agreeing the survey mode.

#### *3.1 Sample frame*

In the light of the earlier discussion of the difficulty of defining disability, it is not surprising that there is no single, nor indeed even a complete collection of registers or such like of people with disabilities in Northern Ireland. The only register to exist contains only a small proportion of the target population. From a survey perspective this means there is no established sample frame. In these circumstances, common approaches are to use a large scale filtering or sift process to identify likely members of the target population or to use a population census to identify sample members for subsequent follow-up.

General household surveys carried out by NISRA are usually conducted by drawing a sample of private addresses from the property valuations database held by Land and Property Services. Estimates of the number of people with disabilities from other sources suggested a disability prevalence rate of around 1 in 5 people or 20 per cent of the general household population. Any general population survey could therefore be expected to generate a wastage rate of up to 80 per cent of individuals contacted. A full survey of households would, as a result, require very large initial contact numbers to provide a robust sample of achieved interviews with people with disabilities.

One option for overcoming this is to conduct the survey in stages. The first stage would involve drawing a large sample of households to be administered with a filtering questionnaire. This stage would identify and exclude those individuals who were not likely to be disabled as defined in the full survey instrument and would identify those who did potentially meet the disability definition. This latter group of individuals would effectively constitute the sample for the full disability survey, although it could be expected that a number may have been identified as disabled by the filtering questionnaire but would not meet the more precise criteria applied in stage two of the process. In stage two a fuller set of filtering questions would be asked regarding each individual's disability and only those positively screened at this stage would continue to the final stage. The final stage would then encompass detailed interviewing with those individuals identified as disabled at stage two.

An alternative to this completely survey based approach would be to use a population census to identify the sample frame. This is the approach that has been taken in Canada and most recently in Ireland. This method requires considerable preparatory work to obtain a question set suitable for administration on a self-completion, paper census form and that gives sufficient information to identify an appropriate sample frame. Whilst the approach appears to work well in some countries, other countries have deemed it unsuitable for their purposes. It is not, therefore, a 'given' that using the census as a sampling frame for disability research would work for Northern Ireland.

From the perspective of disability research, one of the clearest advantages of using a census to identify the sampling frame is that the census covers the whole population not just that part of the population who reside in private addresses, as generally covered by household surveys. A census of population covers the population resident in communal establishments. Other studies (PPRU 1989) have highlighted the higher prevalence of disability amongst residents of communal establishments and, further, that their experiences and needs may be sufficiently different from those within the household population to merit specific examination and thus, inclusion in any survey focusing on disability.

The last Census in Northern Ireland was undertaken in 2001 and included a question on limiting long-standing illness but did not include questions specifically designed for identifying a sample frame for a follow-up survey. Additionally, unlike Ireland which takes a census at five yearly intervals, Northern Ireland's census is decennial, with the next scheduled for 27 March 2011. Even if it were possible to devise a suitable question set, it was clear that the timescales for the next Census would not meet the existing need for disability information. For the future, the legislation surrounding the censuses in the United Kingdom is being examined to ensure that the census could be used as a sample frame for follow-up work accessing hard to reach groups such as those with disabilities.

Notwithstanding the potential advantages in using the census, on the basis of the other issues set out above, it was agreed that the Northern Ireland survey of disability would not be a census follow-up. NISALD would be conducted using a staged approach to household interviewing supplemented by a similar staged approach to interviewing within communal establishments. However, unlike the household population, which can be reached via the established sampling frame of the property valuations database, no such single database or sampling frame exists for communal establishments. For the purposes of the NISALD, communal establishments were deemed to include residential care homes and long-stay hospital wards. Substantial efforts were required to identify and contact all such establishments in order to generate the sampling frame for this element of the survey.

### *3.2 Survey mode*

Survey interviewing takes place via an increasing number of mediums, including telephone, internet, and face-to-face approaches, and using various methods including paper based and computer based; self-completion or interviewer assisted. It was agreed from the outset that the full and detailed questioning of disabled people in NISALD would be conducted by trained interviewers using computer assisted interviewing. The complexity and envisaged length of this questionnaire negated the possibility of self-completion, either by paper or computer, for this stage of the process.

When estimating the required sample size several factors were taken into consideration. Around 3,500 final interviews would be needed to produce the level of detailed analysis required from the survey. Estimated household and individual disability prevalence rates from the Continuous Household Survey were applied to this desired final number of 3,500 to work backwards to an overall total. Estimates of non-response and ineligibility from the 1989 PPRU Surveys of Disability were also applied, producing an estimated total initial sample size of 12,000 households.

The 1989 study of disability in Northern Ireland involved a similar staged approach to that proposed for NISALD. In 1989 the initial sample of approximately 40,000 households were contacted by post to complete a brief paper-based filter questionnaire which was also to be returned by post. This was, at the time, the most cost efficient and the quickest method of accessing such a large sample. However, response rates to postal surveys have fallen

considerably in recent years with non-response running typically at 80 per cent. The survey development team had concerns over the potential bias that could ensue with such high levels of non-response. A postal approach to filtering was thus ruled out at an early stage of development. However, it was recognised that using a face-to-face approach to a sample of up to 12,000 households at the initial stage would be logistically challenging and likely to be prohibitively expensive. A mixed-mode approach to filtering was proposed, combining telephone, free-phone, and face-to-face interviewing to maximise efficiency and minimise cost.

### 3.3 Piloting NISALD filter

Both the approach, with the variety of interviewing modes in use, and the proposed filtering questions were tested through a pilot exercise. The three methods under examination in the pilot were:

1. Interviewers contacting a sample of addresses by telephone, where telephone numbers could be matched with address;
2. Respondents invited to contact interviewers using a free-phone number, where telephone numbers could not be obtained for addresses;
3. Interviewers contacting, face-to-face, the remaining addresses which were not covered via either of the above modes.

A sample of 500 addresses was drawn for the pilot. The table presents the key sample statistics. In summary, 404 households out of an effective sample of 458 participated in the survey, yielding an effective response rate of 88 per cent.

#### Response rates to NISALD filter - pilot

	N	% of sample	% of effective sample
Total sample addresses	500	100	
Ineligible addresses	42	8	
Effective Sample	458	92	100
Completed filter	404	81	88
Refused filter	29	6	7
Non contact	25	5	6

The following table presents the key figures on the number and percentage of completed filters for each mode of interviewing. As was expected, face-to-face interviewing accounted for the majority of contacts. However, the piloting suggested that a sufficient proportion (around 40 per cent) of households could be contacted using the other telephone based, less resource intensive, modes.

#### Number of completes for each mode of sift

Mode of sift	Number of completed filters	% of completed filters
Telephone sift	130	32
Freephone sift	41	10
Face-to face sift	233	58
<b>TOTAL</b>	<b>404</b>	<b>100</b>

The initial filtering questions proposed were those in use in Canada. The Canadian coverage of disability / activity limitation domains was very similar to that proposed for NISALD so it was deemed appropriate to test questions which were already in use and validated, albeit elsewhere. The questions administered at the household level were thus:

- 1 Does anyone in your household have any difficulty hearing, seeing, communicating, walking, climbing stairs, bending, learning or doing any similar activities?
- |               |   |
|---------------|---|
| Yes sometimes | 1 |
| Yes, often    | 2 |
| No            | 3 |
- 2 Does a physical condition or mental condition or health problem reduce the amount or kind of activity you, or anyone in your household, can do....
- (a) At home?
- |               |   |
|---------------|---|
| Yes sometimes | 1 |
| Yes, often    | 2 |
| No            | 3 |
- (b) At work or at school?
- |               |   |
|---------------|---|
| Yes sometimes | 1 |
| Yes, often    | 2 |
| No            | 3 |
- (c) In other activities, for example, transport or leisure?
- |               |   |
|---------------|---|
| Yes sometimes | 1 |
| Yes, often    | 2 |
| No            | 3 |

### 3.4 Results of pilot

45 per cent of households (182 in total) answered yes to at least one of the filter questions, that is, they ‘filtered in’ to the main survey. The remaining 55 per cent (222 households) answered no to both of the filter questions, or in other words ‘filtered out’ of the full NISALD.

In relation to the mode of contact, it was expected that there would be some bias towards households filtering in amongst those contacting by free-phone. This can be seen in the table below, although it was not a large effect. Most reassuringly, the results of this pilot indicated that there was no inherent bias in the outcome of the filter whether the initial contact was made by telephone or face-to face.

#### Percentage filtered in or out by type of sift

Method of Sift	Filtered in?		Number of completed filters	% of completed filters
	Yes (%)	No (%)		
Telephone sift	44	56	130	32
Freephone sift	56	44	41	10
Face-to face sift	44	56	233	58
<b>TOTAL</b>	<b>45</b>	<b>55</b>	<b>404</b>	<b>100</b>

It is possible that a number of the individuals for whom the household respondent indicated that they had one of the difficulties listed in the filter, may not have a disability when questioned themselves or questioned in more detail. This is referred to as the potential for ‘false positives’.

This can be dealt with in survey research by building in an estimate of attrition due to false positives when calculating the required initial sample size. A more fundamental concern for a survey of this nature surrounds false negatives, that is, those who filtered out but should have filtered in. Households filtering out of the pilot were, therefore, asked a follow-up more detailed questionnaire to measure the rate of false negatives. The follow-up questionnaire probed for difficulties in each of the following areas:

- Seeing
- Hearing
- Communicating / speaking
- Mobility
- Pain
- Chronic illness
- Breathing
- Learning
- Intellectual / developmental
- Memory
- Emotional / psychological / mental health
- Other

The result of this detailed follow-up was that 56 per cent of households reported no difficulties in any of these areas. These households could then be assumed to be correctly identified as negatives by the initial filter. However, 44 per cent of households indicated that at least one household member had a difficulty in at least one of the above areas. In other words, the initial set of filtering questions had incorrectly identified these individuals as filtering out, i.e. false negatives. This suggested that the proposed filtering questions could generate a false negative rate as high as 23 per cent. This level of false negatives had not been predicted nor expected and unfortunately no follow-up was planned to explore the possible reasons for such a high rate.

As the rate of false negatives was found to be potentially sizeable, the initial mode of filtering was re-examined. The table below shows that there were no significant differences in the rates of false negatives between the modes of interviewing.

**False negative rate by method of sift**

Method of Sift	False negative?		% of filtered out [n=212]
	Yes (%)	No (%)	
Telephone sift	46	54	32
Freephone sift	50	50	9
Face-to face sift	43	57	60
<b>TOTAL</b>	<b>44</b>	<b>56</b>	<b>100</b>
<b>% of completed filters [n=404]</b>	<b>23</b>	<b>32</b>	

The outcome of this pilot was that the mixed-mode approach to initial contact was deemed to be suitable, but the proposed filter questions were not sufficient for use in Northern Ireland. A further more detailed set of filter questions covering the same 15 domains as the full questionnaire were thus developed and tested. These questions are detailed in Annex 2, and the domains covered are listed below:

- Seeing
- Hearing
- Communication
- Mobility

- Dexterity
- Pain
- Chronic illness
- Breathing
- Learning
- Intellectual/developmental
- Social/behavioural difficulties
- Memory
- Emotional/psychological/mental ill health
- Head injury, stroke or other brain injury
- Other

Further testing, which included inclusiveness, comprehensibility and time taken to complete the extended filter questions, was carried out. Analysis of the testing showed that the more detailed questions were suitably inclusive and the overall length of the filter interview was, on average, seven minutes and, therefore, deemed to be reasonable. It was also found that the eligibility rules appeared to work for any households that were filtered out.

In parallel to the pilot tests, the main questionnaire was developed through comprehensive consultations with representatives from departments and relevant voluntary and community sector organisations (content is described in the next section). A dress rehearsal of the full questionnaire was also completed prior to fieldwork commencing. This focused on the flow of the questions, the time taken for completion, use of plain and non-offensive language and how effective routing could be used to reduce the overall length of the questionnaire.

When all testing was completed a sample of 12,000 households was drawn from the Land and Property Services database. These households were contacted using the mixed-mode method (i.e. telephone, freephone and face-to-face) and filter interviews on behalf of over 23,000 individuals were completed using the extended filter questions (later sections describe the results obtained).

#### 4. CONTENT OF NISALD

##### 4.1 Choice of domains for disability

The content of the NISALD questionnaire was developed from international research on comparable studies and the direct input of policy makers and other key stakeholders. A broad range of domains of disability / activity limitation were included with cognisance being given to the need to balance respondent burden with the need to obtain as much information as possible. The following table summarises the disability domains included in NISALD as well as those included in comparable studies both in Northern Ireland (specifically the 1990 PPRU study) and internationally.

	International Disability Studies					
	NISALD 2006	PALS, Canada	ABS, Australia	New Zealand	Ireland	PPRU, NI 1990
Seeing	✓	✓	✓	✓	✓	✓
Hearing	✓	✓	✓	✓	✓	✓
Communicating / speaking	✓	✓	✓	✓	✓	✓

	International Disability Studies					
	NISALD 2006	PALS, Canada	ABS, Australia	New Zealand	Ireland	PPRU, NI 1990
Mobility	✓	✓	✓	✓	✓	✓
Dexterity	✓	✓	✓	✓	✓	✓
Breathing	✓		✓		✓	
Learning	✓	✓	✓	✓	✓~	
Intellectual	✓	✓		✓	✓~	✓
Memory	✓	✓		✓	✓	
Social/ behavioural	✓					✓
Emotional / Psychological / Mental ill health	✓	✓	✓*	✓	✓	
Pain	✓	✓	✓		✓	
Chronic illness	✓					
Head injury / stroke	✓		✓			
Other	✓		✓	✓		
Blackouts, fits, loss of consciousness			✓			✓
Incomplete use of arms or fingers			✓			
Incomplete use of feet or legs			✓			
Disfigurement or deformity			✓			✓
Eating, drinking and digestion						✓
Continence						✓
Reaching and stretching						✓
Personal care						✓

\* In SDAC there were two separate categories, one for emotional and one for mental illness ~ combined

#### 4.2 Coverage of social and economic circumstances and experiences

The main questionnaire also includes sections dedicated to collecting extensive information on the socio-economic experiences of the respondents and their perceptions of the environment in which they live. Separate questionnaires were developed for adults and for children as well as for household residents and residents of communal establishments. Information was sought across broadly the same spectrum, except in those which would not be relevant, such as employment in the case of the children's questionnaires. The questions were specifically adapted and tailored to suit residential status and child or adult status. Below is a brief overview of the information sought in these additional sections. Further detail can be found in annex 3.

- Support received – any help received such as advice, financial assistance, information, practical help from professionals, organisations and family and friends
- Care provided for others
- General health and experiences of the health and social care system
- Education – if, and how affected
- Economic activity and inactivity - employment status, opportunities and barriers to economic activity and employment
- Leisure and social participation – experience and participation in sports, shopping, social activities, the impact of the attitudes of others
- Travel and transport - type of transport most used, adjustments needed/available, barriers to using public/private transport
- Housing - type of housing, adjustments needed and / or made
- Experience and fear of crime
- Cost of being disabled and general financial circumstances – additional costs associated with disability, sources of income, benefits claimed
- General demographic information; including age, gender, marital status and religion

#### 4.3 Disability as defined in NISALD

As already noted the NISALD asked respondents a series of questions relating to any difficulties they experienced across a wide range of functions and illnesses. The domains included in the questionnaire covered seeing; hearing; communication; mobility; dexterity; pain; chronic illness; breathing; learning; intellectual; social / behavioural; memory; emotional / psychological / mental health; and head injury. For each of these areas, respondents were asked if they experienced any difficulty. They were then asked how often, if at all, that the amount or kind of activities that they could do were reduced or affected.

Respondents provided information across each of these areas about the intensity of the difficulty they had, ranging from no difficulty through mild, moderate, severe and, for some areas, complete e.g. total blindness or deafness. As well as this, they detailed the frequency with which their activities were limited, ranging from never through rarely, sometimes, often, and always.

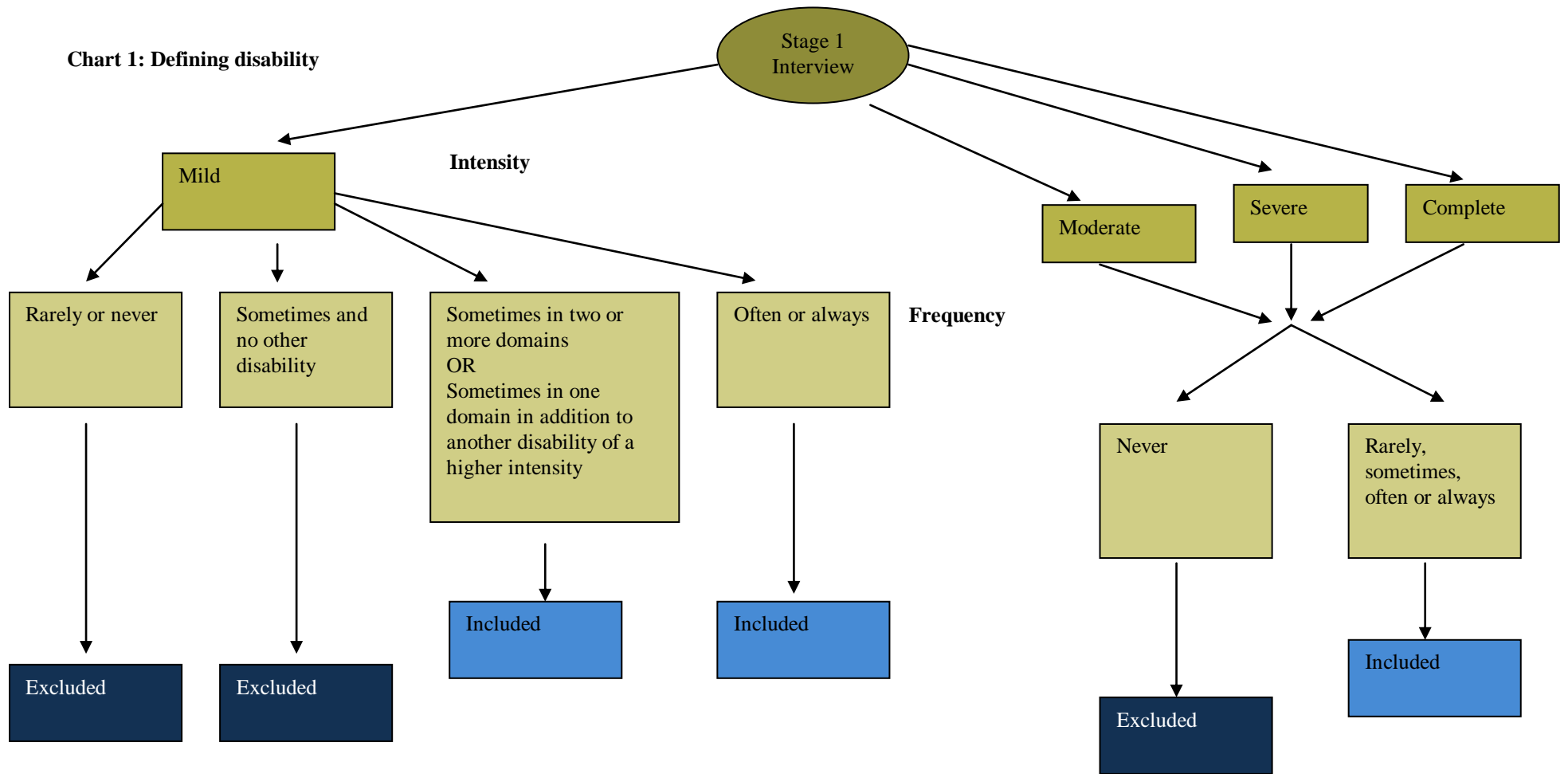
Respondents were included in the full NISALD if they indicated, firstly, that they experienced either moderate, severe or complete difficulty within at least one of these domains and, secondly, that their activities were limited as a result.

Respondents who indicated that they had a mild level of difficulty in only one of the domains with their activities being limited 'rarely' or 'sometimes' were not included in the full NISALD. However, some respondents indicated that they had a number of 'mild' difficulties with each limiting their activities 'sometimes'. These respondents *were* included in the full NISALD given the potential for a number of 'lower level' disabilities to have a greater impact in combination than individually. In practice, a relatively small number of respondents reported a series of mild only disabilities, at around 250 out of the total of over 4,000.

The following diagram (Chart 1) provides a graphical representation of the definition used:-



Chart 1: Defining disability



#### 4.4 NISALD results to date

Following in-depth testing and a full dress rehearsal of the study, fieldwork for the household element of the survey began with the filtering stage in March 2006.

The following tables provide details on the response rates to the various stages of the household survey. Rates are given for households and individuals as appropriate.

Households			
Addresses in initial sample	12,000		
Number of ineligible addresses	1,016	Eligible addresses	10,984
		of which	
		Non contact	4%
		Refused filters	12%
		Completed filter interviews	84%

At the filter stage of the survey, one respondent answered on behalf of all members of the household and the average length of time taken to complete the filter questionnaire was seven minutes. The single household respondent at the filter stage was asked to identify all those in the household who had difficulties in any of the domains surveyed. Each of these individuals were then approached separately and invited to participate in the full NISALD. The length of time taken to complete the main questionnaire was generally between 40 and 60 minutes.

A relatively small proportion (397) of those who went on to answer the main questionnaire were found, at that stage, to not meet the definition of disability as used within NISALD and their interviews were terminated at that point. In other words, these individuals were ‘false positives’ from the filter process. The known false positive rate was calculated at 10 per cent based on these individuals. In the table below these false positives are not included in the figure of 3,543 fully completed NISALD interviews.

Further, another group of people (698) who completed the filter stage, were found to meet the definition and were invited to take part in the full survey but declined, meaning that a full interview was not achieved for these individuals. As they had already been found to have a disability in the filter stage, it was correct that this group should be included in the total number of respondents with a disability when calculating the prevalence rate. However, assuming this group was typical of respondents who completed a full interview, it could be expected that a proportion of this group were also falsely identified at the filter stage as having a disability. Therefore, the known false positive rate of 10 per cent was applied to the 698 and identified 70 as ‘false positives’ who were then not included in the overall total of people with a disability.

The figure of 4,185 presented in the table below is, therefore, an adjusted figure reflecting these modifications and includes the 3,543 who filtered through correctly and completed full interviews; 13 who filtered through and participated in most of the full interview process but did not complete it; and the adjusted figure of 628 who filtered through but declined to participate in the full interview after accounting for false positives.

	Individuals
Filter interviews achieved in respect of	23,689
adults	18,517
children	5,172
Number of people identified from filter as having a disability	4,185
adults	3,865
children	320
Number of people who completed full NISALD interviews	3,543
adults	3,262
children	281

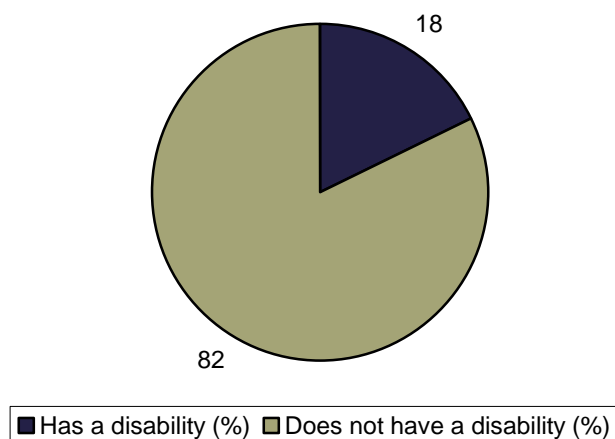
As noted, a number of individuals who were identified as having a disability as a result of the filtering process *chose* not to participate in the full survey. This is different from the group of ‘false positives’. The individuals who did not complete the survey, out of choice, *are* included for the purposes of calculating overall prevalence rates quoted below (albeit factored down by the known false positive rate). However, further information on these individuals’ experiences and circumstances could not be obtained. As a result, the more detailed analyses available from the survey are based only on the responses of those who completed full NISALD interviews.

#### 4.5 Results

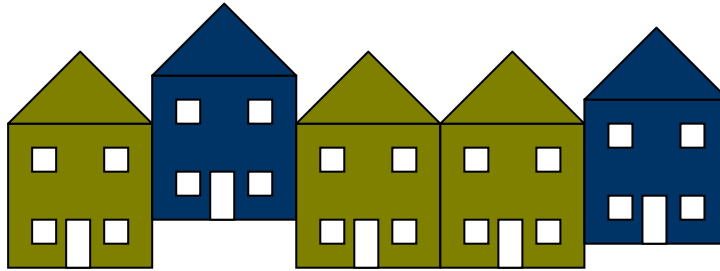
The 2006 NISALD produced an all persons (adults and children) disability prevalence rate of 18 per cent for the Northern Ireland household population.

Figure 1 illustrates that 18 per cent of the population in Northern Ireland are limited in their daily activities for reasons associated with a disability or long-term condition.

**Figure 1: Prevalence of disability amongst the Northern Ireland household population**



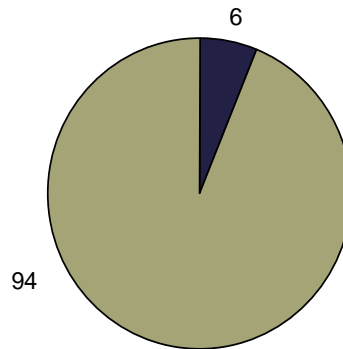
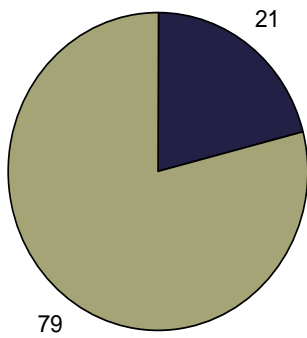
At a household level the results of NISALD show that almost two out of every five (37 per cent) Northern Ireland households include at least one person with a disability.



Looking only at the adult population, it can be seen that over one-fifth (21 per cent) of adults in Northern Ireland have at least one disability. Amongst children, 6 per cent are affected by a disability.

**Figure 2: Prevalence amongst adults living in private households**

**Figure 3: Prevalence amongst children living in private households**

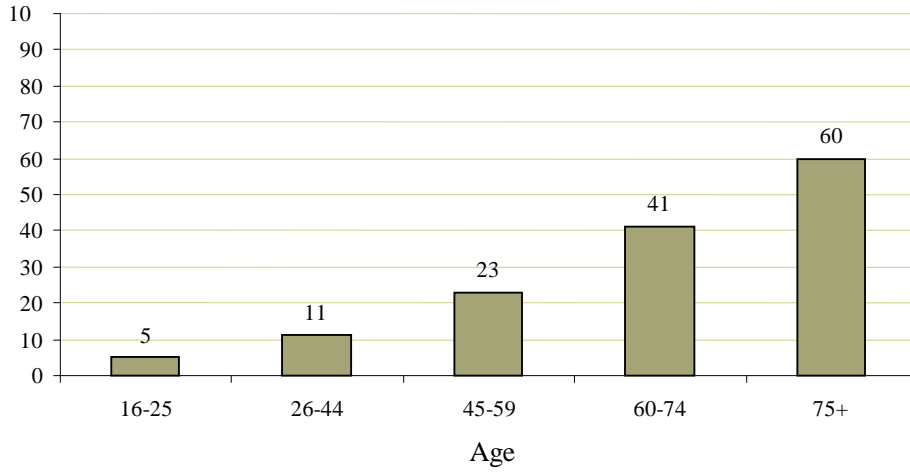


■ Has a disability (%) ■ Does not have a disability (%)

■ Has a disability (%) ■ Does not have a disability (%)

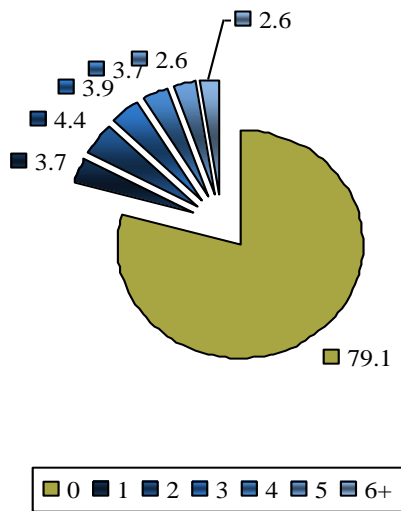
As figure 4 highlights, the prevalence of disability amongst adults varies significantly with age, ranging from a low of 5 per cent amongst young adults aged 16-25 to 60 per cent amongst those aged 75 and above. Indeed, amongst the very elderly, aged 85 and above, the prevalence of disability increases to almost 67 per cent.

**Figure 4: Prevalence rates by age group**

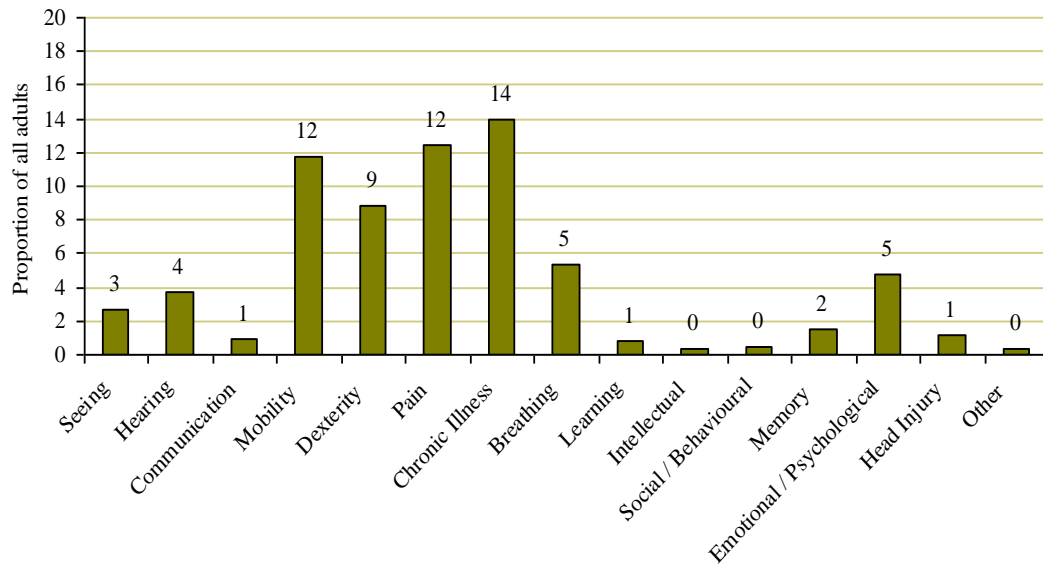


Amongst adults overall, 21 per cent have at least one disability. Further analysis shows that around 4 per cent of adults indicated that they had a disability in one domain only. Over 5 per cent of adults highlighted disabilities across five or more domains (Fig 5).

**Figure 5 Incidence of single and multiple disabilities  
Prevalence rates for all adults**



**Figure 6 Prevalence of each type of disability amongst the adult household population**



\*Note: Figures in the above chart of 0% indicate that the prevalence rate for these particular disabilities is under 0.5%.

Figure 6 shows that the most common disability reported amongst adults in NISALD is that associated with a chronic illness (14 per cent of adults) followed by pain (12 per cent) and mobility (also 12 per cent). There may or may not be relationships between these domains for different individuals. That is, a number of those adults who indicated that they had a mobility disability also indicated that they had a pain disability and, some a chronic illness also. For example, a respondent may suffer from arthritis (a chronic illness) which causes pain and associated mobility difficulties. In this instance, all three disability domains will have been noted. However, it is also possible that people may have a disability that is associated only with a chronic illness or with pain. Indeed around 8 per cent of the adult respondents to this survey who did have disabilities, indicated that their experience of disability was solely identified with either the domain of chronic illness or pain.

#### 4.6 Severity of disability

As noted previously, survey respondents also provided detailed information on the intensity and frequency with which they experienced each disability. This provides a wealth of valuable information which should be drawn upon in analysis. In addition to this very specific level of detail, it can be helpful to have a single measurement variable for each individual of the combined impact of experiencing disability across a number of domains. The latter can provide a basis for analysis and examination at a broader level. A combined or global 'severity' measure can be constructed from the intensity and frequency responses given within each of the individual domains.

As NISALD had separate questionnaires for adults and children, it was necessary to develop a severity scale for each of the following groups:

- Adults aged 16 and over
- Children aged 15 and under

Severity scores were calculated for all those who were identified as disabled at the filter stage. The scores were based on individuals' answers to the intensity and frequency questions for each of the domains. As noted previously, a number of individuals were identified as disabled at the filter stage but did not wish to participate in the full interview. As the filter questions were based on sections A-O (the disability domains) in the full questionnaire, it was possible to use the information collected at the filter stage to calculate severity scores for these incomplete interviews. The following section describes how the frequency and intensity scores were combined to produce an overall severity score.

Consistent with the methodology used for the Participation and Activity Limitation Survey conducted in Canada, participants were asked to rate, on a scale, the intensity of the difficulty they experience in relation to their disability (mild, moderate, severe, cannot do) and the frequency with which the difficulty affects their activities (rarely, sometimes, often, always) for each domain. These scales were assigned scores and the resulting intensity and frequency scores were combined and standardised to give an overall score of severity for that disability domain. The scores for each domain were then combined to produce an overall global severity score. The global scores were then divided into deciles, the distribution was plotted and split into 4 categories (mild, moderate, severe, very severe).

For each domain, separate scores were assigned to the intensity and frequency responses using the following scales:

Intensity. This relates to the level of difficulty the respondent has in the particular domain (e.g. level of difficulty hearing what is said in a conversation with one other person)

- Mild level of difficulty = 1
- Moderate level of difficulty = 2
- Severe level of difficulty = 3
- Cannot do the activity or function = 4
- Other (no difficulty, refusal, don't know) = 0

Frequency. This refers to the frequency with which the type or amount of everyday activities the respondent can do are affected (how often the hearing difficulty limits the amount or kind of activities the individual can do)

- Rarely = 1
- Sometimes = 2
- Often = 3
- Always = 4
- Other answer (never, don't know...) = 0

For each domain, individuals were asked about the intensity and the frequency of their difficulty. To combine these, the product of the two scores was used to obtain the overall score for that area of functioning i.e.

$$S_d = F_d \times I_d$$

where:

S= severity  
d= domain  
F=frequency score (0 to 4)  
I=intensity score (0 to 4)

#### 4.7 Intensity in different contexts

For some domains the intensity of the disability was asked in more than one context within NISALD. For example within the hearing domain respondents were asked about levels of difficulty hearing what is said (i) in a conversation with one other person, (ii) with at least three other people or (iii) hearing what is said in a phone conversation. Within such domains, an extra step was included to obtain a single score as a measure of intensity for the domain overall. To achieve this, a mean intensity score for each across the contexts was calculated.

$$\text{Mean intensity score} = \frac{\text{Sum of all intensity scores}}{\text{Number of contexts}}$$

By way of illustration, where a person has a mild level of difficulty hearing what is said in a conversation with one other person, a moderate level of difficulty hearing what is said in a conversation with at least three other people and a moderate level of difficulty hearing what is said in a phone conversation, the mean intensity score would be calculated as follows:

$$\begin{aligned} &= \frac{1 + 2 + 2}{3} \\ &= \frac{5}{3} \\ &= 1.667 \end{aligned}$$

This intensity score was then multiplied by the related frequency score to calculate a single score for hearing.

An alternative approach for such domains would be to take the highest score, i.e. the score for the context within which the individual experienced the greatest level of difficulty. This option will be examined as part of the series of sensitivity testing around these methodologies.

A single standardised score was required for each disability type. Where there was a measure of intensity and a measure of frequency the following worked example shows the methodology that was employed to obtain a standardised score.

The individual with the hearing difficulties noted in the previous illustration indicated that their hearing difficulties limit their activities sometimes. Therefore the formula to obtain a single standardised score for the hearing domain for this individual is:

$$\text{Standardised Score} = \frac{\text{Intensity} \times \text{Frequency}}{\text{Highest Possible Intensity Score} \times \text{Highest Possible Frequency Score}}$$

$$\begin{aligned} SS_d &= \frac{I_d \times F_d}{\text{MaxI} \times \text{MaxF}} \\ &= \frac{1.67 \times 2}{4 \times 4} \end{aligned}$$



$$= \frac{3.33}{16}$$

$$= 0.21$$

#### 4.8 Relationships between domains

Before a global severity score could be calculated, the individual domain severity scores were examined for any strong relationships between domains. It was proposed that, where any strong relationships were found between paired domains, only the scores from one of the domains, where both were present, would be incorporated into the global score.

In order to measure the relationship between two disabilities, a simple correlation was explored initially. The severity scores were first checked for normal distribution to determine the method of correlation that would be most suitable. The severity scores were found to be not normally distributed. Various transformations of the data were applied to achieve normality but it was found that the data could not be transformed into a normal distribution. The scores were, therefore, correlated using Spearman's Rho. Disability domains were paired according to hypothesised potential relationships, and correlated. While some of the paired domains were shown to be related, none were found to have significantly strong relationships using this simple correlation method.

A further examination of the proportions in paired domains was carried out. This analysis highlighted that there are a number of potential relationships between the domains which need to be examined further, including the domains of head injury and dexterity; head injury and mobility; and learning and intellectual. A further issue raised by this analysis was the relationship of chronic illness to a number of other domains. Preliminary exploration of these relationships has commenced with further work required.

#### 4.9 Global score and overall severity categories

Scores for each disability domain were combined to produce a global severity score for each individual respondent, that is not at this stage adjusted for any of the relationships discussed above. The global severity score was calculated by taking the mean of the individual's standardised scores and dividing by the total number of domains within which the individual reported a disability:

$$\text{Global score} = \frac{\text{Sum of standardised individual scores for disability domains}}{\text{Total number of disability domains for the individual}}$$

$$GS = \frac{\sum SS_d}{N_d}$$

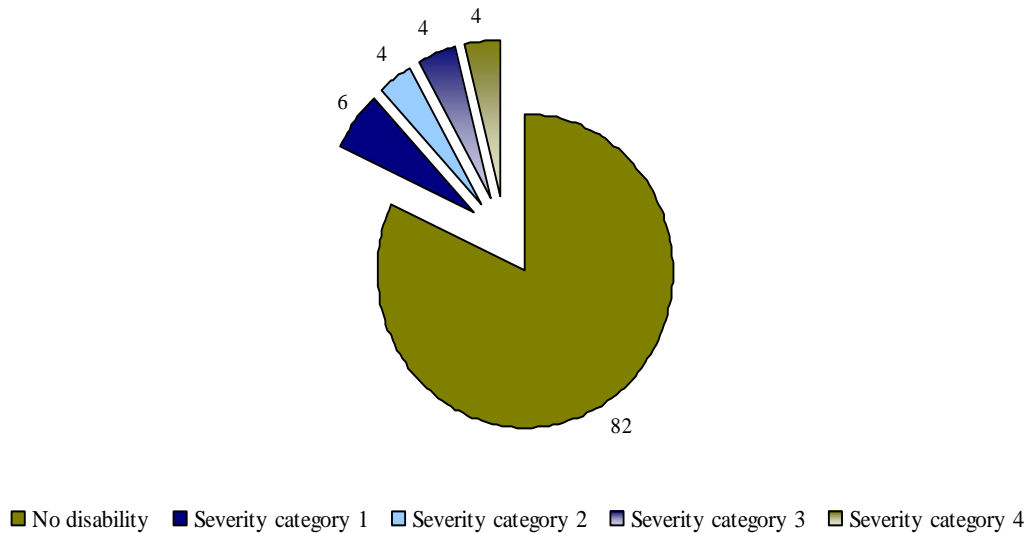
d=domain (sight, hearing, communication, mobility, dexterity, pain, chronic illness, breathing, learning, intellectual, social, memory, psychological, head injury, other)

The final stage in the process of constructing global severity measures was in splitting the scores into classes. Most discussion of the severity of impact of disability tends to split severity into three or four classes. Four classes were agreed for the NISALD. The distribution of the computed global score was examined and split into four severity classes using the following method:

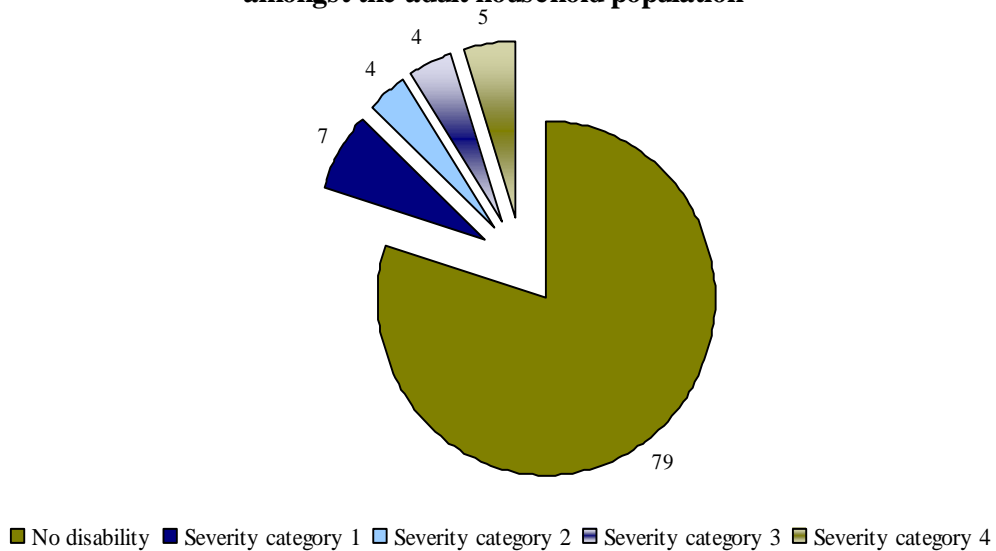
- Firstly the global scores were grouped into deciles and plotted on a graph
- The graph was examined and a natural change in distribution was found at around the 60<sup>th</sup> centile, where the linearity of the curve began to break down. This became the central cut-off point, producing a ‘less severe’ / ‘more severe’ two-way split in the data.
- Further changes in the distribution were observed at the 40<sup>th</sup> centile and the 80<sup>th</sup> centile, thus marking the boundaries of severity classes 1 and 2 along with 3 and 4.

Figure 7 illustrates the prevalence of disability by severity amongst the Northern Ireland household population that results from the above. Severity category 1 represents the least severe and severity category 4, the most severe. The chart shows that least severe disabilities are most prevalent with 6 per cent of the population having category 1 disability(s) compared with 4 per cent having disabilities in each of the other categories.

**Figure 7 Prevalence and overall severity of disability amongst the household population<sup>P</sup>**

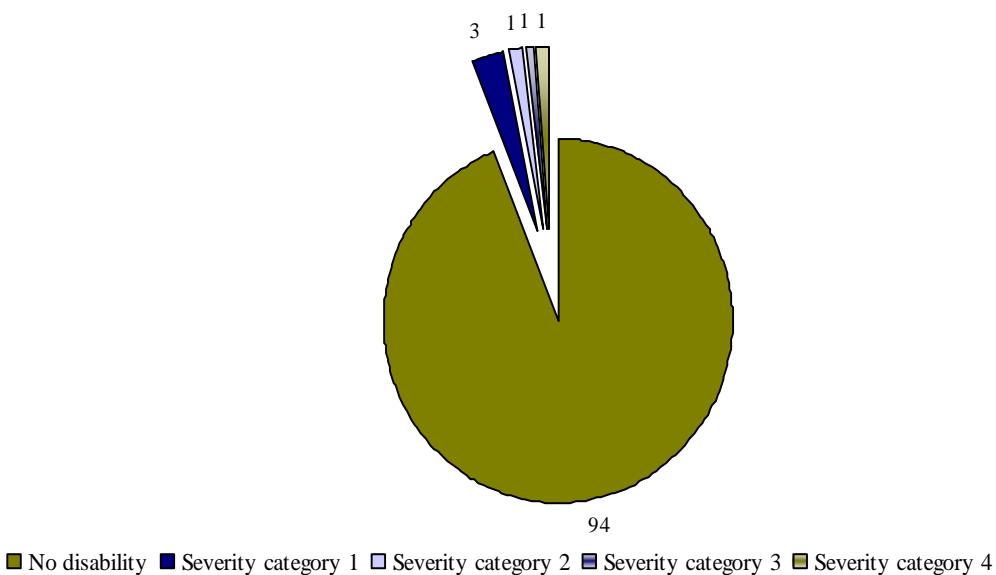


**Figure 8 Prevalence and overall severity of disability amongst the adult household population<sup>P</sup>**



Figures 8 and 9 present the prevalence rates by severity for (a) adults and (b) children. Similarly to the population as a whole, the highest prevalence for both adults and children are category 1 disabilities, 7 per cent and 3 per cent respectively, although around 5 per cent of adults in Northern Ireland have the most severe disabilities.

**Figure 9 Prevalence and overall severity of disability amongst the child household population<sup>P</sup>**



<sup>P</sup> – the severity results presented in figures 7 to 9 are provisional, they are not yet published

#### *4.10 Sensitivity analyses*

The difficulties surrounding the definition of disability were outlined at the beginning of this paper. These difficulties can be resolved but not solved. It should, therefore, be remembered that regardless of how much research and stakeholder inclusion are incorporated into the design of a study such as NISALD, the fundamental definition still has a substantial subjective element. To illustrate this, a number of ‘what if’ scenarios have been applied to the NISALD data focusing on the impact on the overall and adult prevalence rates.

##### *4.10.1 Impact of mild disabilities*

As explained previously, respondents were not included in the NISALD prevalence rates if they indicated a mild level of disability in only one domain. Respondents, however, were included if they had, for example, mild levels of disability in two domains that each affected their activities sometimes or more often. It could be argued that such individuals should also be excluded on the basis that this sets the threshold for disability at a very low level. To examine the effects of this, all those individuals who had more than one mild disability (but no more intense disability in any domain) were removed. This amounted to almost 250 individuals and reduced the total household prevalence rate from 18 per cent to 17 per cent. The degree of the impact was similar for both adults and children. The adult prevalence rate was reduced from 21 per cent to 20 per cent, whilst that for children went from 6 per cent to 5 per cent.

Looking at the global severity score, the vast majority of those who had only mild disabilities were assigned to severity category 1, the least severe category. Five individuals had only mild disabilities but the combined effects of these together with the frequency with which they affected the respondents activities resulted in a severity score within categories 2 or 3.

##### *4.10.2 Impact of ‘rarelys’*

Similarly to the above which focused on the intensity of the disability, a subjective cut-off was established in relation to the frequency measure collected in NISALD. Specifically, all those who indicated any number of mild level disabilities that rarely affected their activities were excluded from the quoted prevalence rates. However, an individual who had any more intense disability was included in the prevalence figures even if they indicated that their activities were ‘rarely’ affected. Only 36 individuals had a moderate, severe or complete level of disability which they said only rarely affected them. This particular cut-off, therefore, had no impact on the calculated prevalence rates.

##### *4.10.3 Exclusion of certain domains*

The domains included in NISALD were outlined previously. Whilst the majority of the domains could be said to relate to aspects of functioning, such as breathing and seeing, a number do not and could be argued to be collecting somewhat different information. The particular domains of interest here are pain, chronic illness and head injury / stroke or other brain injury. Figure 6 presented earlier showed that pain and chronic illness were the two most prevalent domains amongst adults in NISALD. It is of no surprise, therefore, that exclusion of these domains together with head injury / stroke / brain injury reduces the NISALD prevalence rate amongst adults from 21 per cent to 18 per cent.

A final sensitivity analysis focused on removing those domains from NISALD which were not included in the Canadian PALS study, namely the domains of breathing, chronic illness, social / behavioural, and head injury / stroke / other brain injury. The original NISALD prevalence rate for adults in private households was somewhat higher at 21 per cent than the Canadian rate of 17

per cent. A more like-for-like comparison in relation to the coverage of the domains results in the NISALD prevalence rate falling to 19 per cent and thus becoming more comparable with that found in Canada, although it should be noted again that this is only a comparison of crude rates with no age-standardisation applied to the figures.

The results of these alternative scenarios briefly illustrate the range of estimates and results that can be generated even from one source by simply changing the definition slightly or applying slightly different threshold cut-off points.

In addition to the sensitivity analyses associated with the definition, further work will also be undertaken around the method of combining the domains in the global severity index to assess the impact of any relationships identified between the domains. Furthermore, investigations into the construction of the severity classes will be carried out.

#### *4.11 Communal establishments*

As noted earlier the NISALD was designed as a survey of two components, firstly the household element for which the fieldwork is completed and reported on above. The second component is implementing the survey within selected communal establishments including residential homes and long-stay hospital wards. The fieldwork for the communal establishment element of the study is ongoing. This has been a particularly challenging aspect of the research process with many difficulties and significant time delays arising from gaining research ethics, research governance and accessing individuals who are unable to consent for themselves. The NISALD survey team have concerns over the completeness and validity of this aspect of the study. This is unfortunate as there is general agreement on the desirability of including the communal establishment population in statistical and social inquiries more generally. Whilst it may be possible to undertake focused studies with this population, experience of implementing NISALD casts strong doubts over the practical possibility of incorporating communal establishments into wider statistical collections.

## **5. CONCLUSIONS**

It is clear that the definition of disability and the method of obtaining information on people with disabilities will continue to be tailored to meet the needs of the particular country, area, or data purpose of the time. However, it is useful to implement some degree of commonality and to attempt to contain the definitions and methodologies in use for many reasons, not least so that they do not each become a tool with which to undermine the others, thereby undermining disability or social research more generally. Within the United Kingdom efforts are currently underway to produce a greater degree of harmonisation in the definition and collection of disability related information. Perhaps Australia offers a model of how this might be achieved. There, a single dedicated disability survey, the Survey of Disability, Ageing and Carers (SDAC), is conducted on a regular and relatively frequent basis. This source is viewed as providing the authoritative estimates of disability prevalence for Australia and its territories. This survey is supplemented with two other sources. The population censuses provide information for small geographies on what is termed the 'core activity need for assistance' and is broadly equivalent to the SDAC's 'profoundly and severely disabled' group. Secondly, a restricted series of questions have been produced, based on the disability survey, but much reduced and for the specific purpose of being added on as a module to other, eg general household or health based, surveys. This is known as the Australian Bureau of Statistics Short disability module.

Notwithstanding the outcome of the Washington City Group's efforts, it is unlikely that there will be a single universal definition that could be applied in all instances for researching and surveying people with disabilities.

### ANNEX 1 – SOURCES OF DISABILITY INFORMATION

The details below were taken from the Review of Disability Information (2004) carried out by Secta MSA Ferndale for NISRA.

Source	Custodian	Disability Information
PPRU Northern Ireland Disability Study (1989/90)	NISRA	<p>Disability was defined as “the restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being...disability is concerned with abilities...that are accepted as essential components of everyday life”.</p> <p>According to the definitions and measurements used in the surveys, the proportion of the population estimated to be disabled was 13.7% (based on 1991 census population figures). This represents a total estimate of 201,000 disabled persons (adults) in Northern Ireland.</p> <p>The surveys used a 13 type classification of disability based on the World Health Organisation’s International Classification of Impairments, Disabilities and Handicaps (ICIDH). A five fold classification of the severity of disability was reported.</p>
Census	NISRA	<p>Within the 2001 census the following question was asked in relation to disability:</p> <ul style="list-style-type: none"> <li>• Do you have any long-term illness, health problem or disability which limits daily activities or work?</li> </ul> <p>This self-assessment question was the only specific reference to disability within the census. The question is closed with only a yes/no answer possible.</p> <p>Information is collected on whether the respondent provides unpaid care but there is no question to capture information relating to whether or not they are actually cared for.</p>
Continuous Household Survey	NISRA	<p>Within the general health section of the CHS the following questions were asked in relation to disability (both adults and children):</p> <ul style="list-style-type: none"> <li>• Do you have any long-standing illness, disability or infirmity?</li> <li>• Would you mind telling me what this illness or infirmity is?</li> <li>• Does this illness or disability limit your activities in any way?</li> <li>• Do you have any health problem or disability that substantially limits your ability to carry out day-to-day activities?</li> </ul> <p>Within the Income and Benefits Section, there are questions in relation to disability benefits and tax credits received.</p>

Health and Social Wellbeing Survey	DHSSPS	<p>Within the general health section of the 2005 survey the following questions were asked in relation to disability:</p> <ul style="list-style-type: none"> <li>• Do you have any long-standing illness, disability or infirmity?</li> <li>• Does this illness or disability limit your activities in any way?</li> <li>• Would you mind telling me what this illness or infirmity is?</li> <li>• Think about the two weeks ending yesterday. During those two weeks, did you have to cut down on any of the things you usually do (about the house or at work or in your free time) because of (LONG-STANDING ILLNESS or some other) illness or injury?</li> <li>• Would you say that you cutting down was a temporary cut down or not temporary:</li> <li>• How many days was this in all during these 2 weeks, including Saturdays and Sundays</li> </ul> <p>The following questions were also asked in relation to children:</p> <ul style="list-style-type: none"> <li>• Does your child have any long-standing illness, disability or infirmity?</li> <li>• Would you mind telling me what this illness or infirmity is?</li> <li>• Does this illness or disability limit his/her activities in any way?</li> </ul> <p>Within the income and benefits section respondents were asked to indicate state benefits received, including disability related benefits.</p>
Labour Force Survey	DETI	<p>Within the health section of the LFS the following six questions were asked in relation to health problems/disability:</p> <ul style="list-style-type: none"> <li>• Do you have any health problems or disabilities that you expect will last for more than one year?</li> <li>• Does this health problem affect the KIND of paid work that you might do?</li> <li>• Does this health problem affect the AMOUNT of paid work that you might do?</li> <li>• Do you have (16 conditions stated plus 'other health problems or disabilities')?</li> <li>• Which of these is your main health problem/disability?</li> <li>• Do these health problems or disabilities, when taken singly or together, substantially limit your ability to carry out normal day-to-day activities?</li> </ul> <p>If the respondent has multiple disabilities, these are ranked through self-classification, although counted under each separate heading. No information is collected in relation to carers.</p>

<p>Omnibus Survey</p>	<p>Undertaken by NISRA but individual modules commissioned by various departments and organisations</p>	<p>Within the 2001 Survey there was a disability module which included 56 questions in relation to health and disability. Specific questions in relation to disability included:</p> <ul style="list-style-type: none"> <li>• Do you have any long-standing illness, disability or infirmity?</li> <li>• Does this illness or disability limit your activities in any way?</li> <li>• Do these health problems or disabilities, when taken singly or together, substantially limit your ability to carry out normal day-to-day activities?</li> <li>• When did this illness or disability start to limit your activities in any way?</li> <li>• What is/was the matter with you? (17 conditions to choose from)</li> <li>• Which illness or disability most limits your activities?</li> <li>• Does your health problem/disability make it difficult for you to do (range of activities on showcard) any of the things mentioned on this card?</li> <li>• Over the last 12 months have you wanted to use any of the services (range of services on showcard) mentioned on the card, but had great difficulty or been unable to use them because of your health problem/disability?</li> <li>• Has anyone ever refused to sell or rent you a house or flat because of your health problem or disability?</li> <li>• There is a law relating to disabled people called the Disability Discrimination Act. Have you heard about this law?</li> <li>• If you were treated unreasonable as a result of your disability or health problem, what if anything, would you do (range of options on showcard)?</li> <li>• If you were treated unreasonable as a result of your disability or health problem, and wanted to get advice about it, who would you go to (range of options on showcard)?</li> <li>• A new organisation has recently been set up relating to disabled people called the Disability Rights Commission. Have you heard of this organisation?</li> <li>• Can you tell me what the Disability Rights Commission does?</li> </ul>
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Family Resources Survey	DSD	<p>Questions on disability are included in the section about health and ability to work. Current questions asked include the following:</p> <ul style="list-style-type: none"> <li>• Do you have a long-standing illness, disability or infirmity?</li> <li>• Does it limit your activities in any way? In what way?</li> <li>• Are you on the register for disabled people? Also asks about children.</li> <li>• Are you restricted in the amount/type of work undertaken because of a disability?</li> <li>• How long have you been restricted due to injury/illness/disability?</li> <li>• When did you stop working?</li> <li>• If restricted - how many hours could you work?</li> </ul> <p>In relation to carers the following is asked:</p> <ul style="list-style-type: none"> <li>• Is there anyone in the household who requires help/looking after?</li> <li>• Are there people outside of the house that require looking after?</li> <li>• How frequently do they require help?</li> </ul>
Poverty & Social Exclusion Survey	OFMDFM (QUB/UU)	<p>There is a section on health involving a showcard with a range of ailments/impairments i.e. hearing/speech defects, arthritis etc. Participants are asked:</p> <ul style="list-style-type: none"> <li>• If they have any of the listed ailments/impairments?</li> <li>• Which one affects the individual most?</li> <li>• How severe?</li> <li>• At what age did the individual start having problems? How does it affect mobility, personal care, paid work etc?</li> </ul> <p>Carers</p> <ul style="list-style-type: none"> <li>• Are you a carer?</li> <li>• Do you care for someone within your household?</li> <li>• Do you care for someone outside of your household?</li> </ul>
Northern Ireland Travel Survey	DRD (Roads Service)	<p>Four separate questions are asked: Do you have a disability or a long-standing illness that prevents you from travelling (1) 'on foot', (2) 'by car', (3) 'by train' or (4) 'by bus'?</p>

Northern Ireland Crime Survey	NIO	Two questions are asked: <ul style="list-style-type: none"> <li>• Do you have a long-standing illness, disability or infirmity?</li> <li>• Does this illness/disability limit your activities?</li> </ul>
Secondary School Census	DE	No specific questions on disability. There is a code that each school follows (set out by the ELBs) regarding statements. This 5 stage statmenting process is to identify learning difficulties and to respond to them.
School Leavers Census	DE	No specific questions on disability. There is a code that each school follows (set out by the ELBs) regarding statements. This 5 stage statmenting process is to identify learning difficulties and to respond to them.
Further Education Leavers Survey	DEL (TEASB)	Range of disabilities (tick box): No known disability; dyslexia; blind/partially sighted; deaf/hard of hearing; wheelchair/mobility; mental health disability; unseen disability (diabetes, epilepsy, asthma); multiple; disability not listed above; and information not sought, not known. On college side there is a free text field (50/60 characters although this is not passed on to DEL).
Farmers Survey	DARD	Two questions are asked: <ul style="list-style-type: none"> <li>• Do you have any long-standing illness, disability or infirmity?</li> <li>• Does this illness or disability limit your farm work activities in any way?</li> </ul> Employment is covered but not in relation to disability. Questions relating to benefits received i.e. incapacity, DLA etc. Education is covered but not in relation to disability.

## ANNEX 2 – FILTER QUESTIONS

We ask to speak with someone in the household who is in a position to complete the filter questions for all members of the household.

We firstly ask the number of people who live in the household, their relationship to the respondent and their name(s), sex and age.

Then we ask the following filter questions. These are administered by telephone or face-to-face by a trained interviewer using Computer Assisted Personal Interviewing (CAPI).

**FILTER 1)** Do any of the people in your household have any difficulty seeing, wear glasses or contact lenses to assist their vision or cannot see at all?

**INTERVIEWER: IF YES, PLEASE IDENTIFY THESE PEOPLE FROM THE HOUSEHOLD GRID**

You may choose 17 out of the possible answers

- 1 Person 1's name
- 2 Person 2's name
- 3 Person 3's name
- 4 Person 4's name
- 5 Person 5's name
- 6 Person 6's name
- 7 Person 7's name
- 8 Person 8's name
- 9 Person 9's name]
- 10 Person 10's name
- 11 Person 11's name
- 12 Person 12's name
- 13 Person 13's name
- 14 Person 14's name
- 15 Person 15's name
- 16 Person 16's name
- 17 No one has a difficulty seeing      >> **GO TO FILTER 2**

**IF YES TO FILTER 1 THEN FOR EACH PERSON TICKED THEY ARE ASKED**

A1) Can I just Clarify, does ^name wear glasses or contact lenses?

- 1 yes      **GO TO A2**
- 2 no      **GO TO A3**

A2) With glasses or contact lenses, how would you describe ^name's difficulty seeing?

Would you say is was .....

**RUNNING PROMPT**

1 No difficulty	<b>GO TO FILTER 2</b>
2 A mild level of difficulty	<b>GO TO A4</b>
3 A moderate level of difficulty	
4 A severe level of difficulty/cannot see	

A3) How would you describe ^name's difficulty seeing?

Would you say it was .....

RUNNING PROMPT

1 A mild level of difficulty	<b>GO TO A4</b>
2 A moderate level of difficulty	
3 A severe level of difficulty/cannot see	

A4) How often does this seeing difficulty limit the amount or kind of activities that ^name can do?

1 Always	<b>GO TO FILTER 2</b>
2 Often	
3 Sometimes	
4 Rarely	
5 Never	

**FILTER 2)** Do any of the people in your household have any difficulty hearing, use a hearing aid or cannot hear at all?

INTERVIEWER: IF YES, PLEASE IDENTIFY THESE PEOPLE FROM THE HOUSEHOLD GRID

You may choose 17 out of the possible answers

- 1 Person 1's name
- 2 Person 2's name
- 3 Person 3's name
- 4 Person 4's name
- 5 Person 5's name
- 6 Person 6's name
- 7 Person 7's name
- 8 Person 8's name
- 9 Person 9's name]
- 10 Person 10's name
- 11 Person 11's name
- 12 Person 12's name
- 13 Person 13's name
- 14 Person 14's name
- 15 Person 15's name
- 16 Person 16's name
- 17 No one has a difficulty hearing >> **GO TO FILTER 3**

B1) Can I just clarify, does ^name use a hearing aid?

- 1 yes **Go to B2**
- 2 no **Go to B3**

B2) With a hearing aid, how would you describe ^name's difficulty hearing?

Would you say it was .....

RUNNING PROMPT

1 No difficulty	<b>GO TO FILTER 3</b>
2 A mild level of difficulty	<b>GO TO B4</b>
3 A moderate level of difficulty	
4 A severe level of difficulty/cannot see	

B3) How would you describe the level of difficulty that ^name experiences hearing?

Would you say it was .....

RUNNING PROMPT

1 A mild level of difficulty	<b>GO TO B4</b>
2 A moderate level of difficulty	
3 A severe level of difficulty/cannot hear	

B4) How often does this hearing difficulty limit the amount or kind of activities that ^name can do?

1 Always	<b>GO TO FILTER 3</b>
2 Often	
3 Sometimes	
4 Rarely	
5 Never	

**FILTER 3)** Do any of the people in your household have any difficulty speaking or making themselves understood, use aids or specialised equipment to assist them to communicate or cannot speak at all?

Do not include children who cannot yet speak unless there is a specific problem.

INTERVIEWER: IF YES, PLEASE IDENTIFY THESE PEOPLE FROM THE HOUSEHOLD GRID

You may choose 17 out of the possible answers

- 1 Person 1's name
- 2 Person 2's name
- 3 Person 3's name
- 4 Person 4's name
- 5 Person 5's name
- 6 Person 6's name
- 7 Person 7's name
- 8 Person 8's name
- 9 Person 9's name]
- 10 Person 10's name
- 11 Person 11's name
- 12 Person 12's name
- 13 Person 13's name
- 14 Person 14's name
- 15 Person 15's name
- 16 Person 16's name
- 17 No one has a difficulty speaking or making themselves understood >> **GO TO FILTER 4**

C1) Can I clarify, does ^name use any specialised equipment to communicate with others such as a voice amplifier or a keyboard device?

- 1 yes **GO TO C2**
- 2 no **GO TO C3**

C2) With his/her specialised equipment, how would you describe ^name's difficulty communicating?

Would you say it was .....

RUNNING PROMPT

1 No difficulty	<b>GO TO FILTER 4</b>
2 A mild level of difficulty	
3 A moderate level of difficulty	
4 A severe level of difficulty/cannot see	

C3) How would you describe ^name's level of difficulty communicating?

Would you say it was .....

RUNNING PROMPT

1 A mild level of difficulty	<b>GO TO C4</b>
2 A moderate level of difficulty	
3 A severe level of difficulty/cannot speak	

C4) How often does this difficulty speaking or making yourselves understood limit the amount or kind of activities that ^name can do?

1 Always	<b>GO TO FILTER 4</b>
2 Often	
3 Sometimes	
4 Rarely	
5 Never	

**FILTER 4)** Do any of the people in your household have any mobility difficulties for example moving about, walking, climbing stairs etc.; use specialised equipment or have personal support services such as a home help or personal assistant to help them to be mobile; or are not mobile at all?

INTERVIEWER: IF YES, PLEASE IDENTIFY THESE PEOPLE FROM THE HOUSEHOLD GRID

You may choose 17 out of the possible answers

- 1 Person 1's name
- 2 Person 2's name
- 3 Person 3's name
- 4 Person 4's name
- 5 Person 5's name
- 6 Person 6's name
- 7 Person 7's name
- 8 Person 8's name
- 9 Person 9's name]
- 10 Person 10's name
- 11 Person 11's name
- 12 Person 12's name
- 13 Person 13's name
- 14 Person 14's name
- 15 Person 15's name
- 16 Person 16's name
- 17 No one has a difficulty walking, climbing or bending >> **GO TO FILTER 5**

D1) Can I clarify, does ^name use any specialised equipment or have personal support services such as a home help or personal assistant to help them to be mobile?

- 1 yes **GO TO D2**
- 2 no **GO TO D3**

D2) With this specialised equipment or personal support services, how would you describe ^name's difficulty moving about, walking, climbing stairs etc.?

Would you say it was .....

**RUNNING PROMPT**

1 No difficulty	<b>GO TO FILTER 5</b>
2 A mild level of difficulty	
3 A moderate level of difficulty	
4 A severe level of difficulty/cannot move	

D3) How would you describe ^name's difficulty moving about, walking, climbing stairs etc.?

Would you say it was .....

**RUNNING PROMPT**

1 A mild level of difficulty	<b>GO TO D4</b>
2 A moderate level of difficulty	
3 A severe level of difficulty/cannot move	

D4) How often do mobility difficulties limit the amount or kind of activities that ^name can do?

1 Always	<b>GO TO FILTER 5</b>
2 Often	
3 Sometimes	
4 Rarely	
5 Never	

**FILTER 5)** Do any of the people in your household have any dexterity difficulties (by that I mean lifting, carrying, grasping or holding objects); use specialised equipment to help them with these actions; or cannot lift, carry, grasp or hold at all?

**INTERVIEWER: IF YES, PLEASE IDENTIFY THESE PEOPLE FROM THE HOUSEHOLD GRID**

You may choose 17 out of the possible answers

- 1 Person 1's name
- 2 Person 2's name
- 3 Person 3's name
- 4 Person 4's name
- 5 Person 5's name
- 6 Person 6's name
- 7 Person 7's name
- 8 Person 8's name
- 9 Person 9's name]
- 10 Person 10's name
- 11 Person 11's name

- 12 Person 12's name
- 13 Person 13's name
- 14 Person 14's name
- 15 Person 15's name
- 16 Person 16's name
- 17 No one has a difficulty lifting, grasping or holding >> **GO TO FILTER 6**

E1) Can I clarify, does ^name use any specialised equipment to assist him/her to lift, carry, grasp or hold objects?

- 1 yes **GO TO E2**
- 2 no **GO TO E3**

E2) With these aids or specialised equipment, how would you describe ^name's difficulty lifting, carrying, grasping or holding objects?

Would you say it was .....

**RUNNING PROMPT**

1 No difficulty	<b>GO TO FILTER 6</b>
2 A mild level of difficulty	<b>GO TO E4</b>
3 A moderate level of difficulty	
4 A severe level of difficulty/cannot lift or grasp objects	

E3) How would you describe ^name's difficulty lifting, carrying, grasping or holding objects?

Would you say it was .....

**RUNNING PROMPT**

1 A mild level of difficulty	<b>GO TO E4</b>
2 A moderate level of difficulty	
3 A severe level of difficulty/cannot lift or grasp objects	

E4) How often does these dexterity difficulties limit the amount or kind of activities that ^name can do?

1 Always	<b>GO TO FILTER 6</b>
2 Often	
3 Sometimes	
4 Rarely	
5 Never	

**FILTER 6)** Do any of the people in your household experience long-term pain or discomfort that is always present or reoccurs from time to time; or take medication to manage any long-term pain or discomfort?

**INTERVIEWER: IF YES, PLEASE IDENTIFY THESE PEOPLE FROM THE HOUSEHOLD GRID**

You may choose 17 out of the possible answers

- 1 Person 1's name
- 2 Person 2's name
- 3 Person 3's name
- 4 Person 4's name



- 5 Person 5's name
- 6 Person 6's name
- 7 Person 7's name
- 8 Person 8's name
- 9 Person 9's name]
- 10 Person 10's name
- 11 Person 11's name
- 12 Person 12's name
- 13 Person 13's name
- 14 Person 14's name
- 15 Person 15's name
- 16 Person 16's name
- 17 No one has pain or discomfort >> **GO TO FILTER 7**

F1) Can I clarify, does ^name take medication to manage this long-term pain or discomfort?

- 1 yes GO TO F2
- 2 no GO TO F3

F2) With the medication, how would you describe the level of pain or discomfort that ^name experiences?

Would you say ^name has.....  
 RUNNING PROMPT?

1 No pain or discomfort	<b>GO TO FILTER 7</b>
2 A mild level of pain or discomfort	<b>GO TO F4</b>
3 A moderate level of pain or discomfort	
4 A severe level of pain or discomfort	

F3) How would you describe the level of pain or discomfort that ^name experiences?

Would you say ^name has.....  
 RUNNING PROMPT?

1 A mild level of pain or discomfort	<b>GO TO F4</b>
2 A moderate level of pain or discomfort	
3 A severe level of pain or discomfort	

F4) How often does this pain or discomfort limit the amount or kind of activities that ^name can do?

1 Always	<b>GO TO FILTER 7</b>
2 Often	
3 Sometimes	
4 Rarely	
5 Never	

*Now I'd like to talk about chronic health conditions.*

**FILTER 7)** Do any of the people in your household have any of the following long-term conditions that have lasted or are expected to last six months or more and that have been diagnosed by a health professional?

INTERVIEWER NOTE: PLEASE READ OUT AND MARK ALL THAT APPLY  
 You may choose 16 out of the possible answers

- 1 Asthma or severe allergies
- 2 Heart condition or disease
- 3 Kidney condition or disease
- 4 Cancer
- 5 Diabetes
- 6 Epilepsy
- 7 Cerebral Palsy
- 8 Spina Bifida
- 9 Cystic Fibrosis
- 10 Muscular Dystrophy
- 11 Multiple Sclerosis
- 12 Migraines
- 13 Paralysis of any kind
- 14 Missing or malformed arms, legs, fingers or toes
- 15 Complex medical care needs
- 16 Any other long-term condition that has not been diagnosed by a health professional not already covered?

Any of 1 to 16 above >>**GO TO G1**

17 none of these >> **GO TO FILTER 8**

G1) Please specify the other long-term condition: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

G2) Can you tell me who in the household has one or more of these long-term conditions?

INTERVIEWER: IF YES, PLEASE IDENTIFY THESE PEOPLE FROM THE HOUSEHOLD GRID

You may choose 16 out of the possible answers

- 1 Person 1's name
- 2 Person 2's name
- 3 Person 3's name
- 4 Person 4's name
- 5 Person 5's name
- 6 Person 6's name
- 7 Person 7's name
- 8 Person 8's name
- 9 Person 9's name]
- 10 Person 10's name
- 11 Person 11's name
- 12 Person 12's name
- 13 Person 13's name
- 14 Person 14's name
- 15 Person 15's name
- 16 Person 16's name

G3) Can I clarify, does ^name take medication, receive medical assistance or use specialised equipment to manage this (these) chronic health condition(s)?

- 1 yes GO TO G4
- 2 no GO TO G5

G4) With medication, medical assistance, or specialised equipment, how would you describe the difficulty ^name experiences as a result of this (these) chronic health condition (s)?

1 No difficulty	<b>GO TO FILTER 8</b>
2 A mild level of difficulty	
3 A moderate level of difficulty	
4 A severe level of difficulty	

G5) How would you describe the difficulty ^name experiences as a result of this (these) chronic health condition (s)?

1 No difficulty	<b>GO TO FILTER 8</b>
2 A mild level of difficulty	
3 A moderate level of difficulty	
4 A severe level of difficulty/cannot move	

G6) How often does the chronic health condition(s) that ^name has limit the amount or kind of activities that he/she can do?

1 Always	<b>GO TO FILTER 8</b>
2 Often	
3 Sometimes	
4 Rarely	
5 Never	

**FILTER 8)** Do any of the people in your household have shortness of breath or difficulty breathing; or use specialised equipment such as a nebuliser, oxygen concentrator or cylinder or ventilator to assist with breathing?

INTERVIEWER: IF YES, PLEASE IDENTIFY THESE PEOPLE FROM THE HOUSEHOLD GRID

You may choose 17 out of the possible answers

- 1 Person 1's name
- 2 Person 2's name
- 3 Person 3's name
- 4 Person 4's name
- 5 Person 5's name
- 6 Person 6's name
- 7 Person 7's name
- 8 Person 8's name
- 9 Person 9's name]
- 10 Person 10's name
- 11 Person 11's name
- 12 Person 12's name
- 13 Person 13's name
- 14 Person 14's name
- 15 Person 15's name
- 16 Person 16's name
- 17 No one has a difficulty breathing >> **GO TO FILTER 9**

H1) Can I clarify, does ^name use a nebuliser, oxygen concentrator or cylinder or ventilator to assist his/her breathing?

- 1 yes           GO TO H2
- 2 no            GO TO H3

H2) With these aids or specialised equipment, how would you describe ^name's difficulty breathing or shortness of breath?

Would you say it was .....

RUNNING PROMPT

1 No difficulty	<b>GO TO FILTER 9</b>
2 A mild level of difficulty	
3 A moderate level of difficulty	
4 A severe level of difficulty	

H3) How would you describe ^name's difficulty breathing or shortness of breath?

Would you say it was .....

RUNNING PROMPT

1 A mild level of difficulty	<b>GO TO H4</b>
2 A moderate level of difficulty	
3 A severe level of difficulty	

H4) How often does ^name's shortness of breath or breathing difficulty the amount or kind of activities that ^name can do?

1 Always	<b>GO TO FILTER 9</b>
2 Often	
3 Sometimes	
4 Rarely	
5 Never	

**FILTER 9)** Do any of the people in your household have difficulty learning for example at school, college, work or in other places? This may be due to a condition such as dyslexia or Attention Deficit Hyperactivity Disorder or it may not have a name.

INTERVIEWER: IF YES, PLEASE IDENTIFY THESE PEOPLE FROM THE HOUSEHOLD GRID

You may choose 17 out of the possible answers

- 1 Person 1's name
- 2 Person 2's name
- 3 Person 3's name
- 4 Person 4's name
- 5 Person 5's name
- 6 Person 6's name
- 7 Person 7's name
- 8 Person 8's name
- 9 Person 9's name]
- 10 Person 10's name
- 11 Person 11's name
- 12 Person 12's name
- 13 Person 13's name
- 14 Person 14's name
- 15 Person 15's name
- 16 Person 16's name
- 17 No one has a learning difficulty >> **GO TO FILTER 10**

I1) How would you describe the level of severity of this learning difficulty?

1 Mild	<b>GO TO I2</b>
2 Moderate	
3 Severe	

I2) How often does this learning disability or difficulty reduce the amount or kind of activity ^name can do?

1 Always	<b>GO TO FILTER 10</b>
2 Often	
3 Sometimes	
4 Rarely	
5 Never	

**FILTER 10)** Do any of the people in your household have an intellectual difficulty or developmental delay? This may not have a name but include things like Down's syndrome, autism, Fragile X Syndrome and other conditions?

INTERVIEWER: IF YES, PLEASE IDENTIFY THESE PEOPLE FROM THE HOUSEHOLD GRID

You may choose 17 out of the possible answers

- 1 Person 1's name
- 2 Person 2's name
- 3 Person 3's name
- 4 Person 4's name
- 5 Person 5's name
- 6 Person 6's name
- 7 Person 7's name
- 8 Person 8's name
- 9 Person 9's name]
- 10 Person 10's name
- 11 Person 11's name
- 12 Person 12's name
- 13 Person 13's name
- 14 Person 14's name
- 15 Person 15's name
- 16 Person 16's name
- 17 No one has a intellectual or developmental difficulty >> **GO TO FILTER 11**

J1) How would you describe the level of severity of this intellectual difficulty or developmental delay?

1 Mild	<b>GO TO J2</b>
2 Moderate	
3 Severe	

J2) How often does this intellectual difficulty or developmental delay reduce the amount or kind of activity ^name can do?

1 Always	<b>GO TO FILTER 11</b>
2 Often	
3 Sometimes	
4 Rarely	
5 Never	

**FILTER 11)** Do any of the people in your household have a social or behavioural difficulty, for example difficulty making friends or aggressive outbursts etc.? These may not have a name but

may be associated with Attention Deficit Disorder, Autism, Asperger's Syndrome or have no apparent cause?

INTERVIEWER: IF YES, PLEASE IDENTIFY THESE PEOPLE FROM THE HOUSEHOLD GRID

You may choose 17 out of the possible answers

- 1 Person 1's name
- 2 Person 2's name
- 3 Person 3's name
- 4 Person 4's name
- 5 Person 5's name
- 6 Person 6's name
- 7 Person 7's name
- 8 Person 8's name
- 9 Person 9's name]
- 10 Person 10's name
- 11 Person 11's name
- 12 Person 12's name
- 13 Person 13's name
- 14 Person 14's name
- 15 Person 15's name
- 16 Person 16's name
- 17 No one has a social or behavioural difficulty >> **GO TO FILTER 12**

K1) How would you describe the level of severity of ^name's social or behavioural difficulty?

1 Mild	<b>GO TO K2</b>
2 Moderate	
3 Severe	

K2) How often does this social or behavioural difficulty reduce the amount or kind of activity ^name can do?

1 Always	<b>GO TO FILTER 12</b>
2 Often	
3 Sometimes	
4 Rarely	
5 Never	

**FILTER 12)** Do any of the people in your household have frequent periods of confusion or difficulty remembering things? These difficulties may be associated with diseases such as Alzheimer's, dementia or as a result of a brain injury or stroke?

INTERVIEWER: IF YES, PLEASE IDENTIFY THESE PEOPLE FROM THE HOUSEHOLD GRID

You may choose 17 out of the possible answers

- 1 Person 1's name
- 2 Person 2's name
- 3 Person 3's name
- 4 Person 4's name
- 5 Person 5's name
- 6 Person 6's name
- 7 Person 7's name
- 8 Person 8's name

- 9 Person 9's name]
- 10 Person 10's name
- 11 Person 11's name
- 12 Person 12's name
- 13 Person 13's name
- 14 Person 14's name
- 15 Person 15's name
- 16 Person 16's name
- 17 No one has a memory problem >> **GO TO FILTER 13**

L1) How would you describe the level of severity of this condition?

1 Mild	<b>GO TO L2</b>
2 Moderate	
3 Severe	

L2) How often does this condition reduce the amount or kind of activity ^name can do?

1 Always	<b>GO TO FILTER 13</b>
2 Often	
3 Sometimes	
4 Rarely	
5 Never	

**FILTER 13)** Do any of the people in your household have any emotional, psychological or mental ill health conditions that have lasted, or are expected to last, 6 months or more. These include things like obsessive or compulsive behaviours, anxiety, extreme phobias, depression, schizophrenia, drinking or drug problems or eating disorders?

**INTERVIEWER: IF YES, PLEASE IDENTIFY THESE PEOPLE FROM THE HOUSEHOLD GRID**

You may choose 17 out of the possible answers

- 1 Person 1's name
- 2 Person 2's name
- 3 Person 3's name
- 4 Person 4's name
- 5 Person 5's name
- 6 Person 6's name
- 7 Person 7's name
- 8 Person 8's name
- 9 Person 9's name]
- 10 Person 10's name
- 11 Person 11's name
- 12 Person 12's name
- 13 Person 13's name
- 14 Person 14's name
- 15 Person 15's name
- 16 Person 16's name
- 17 No one has any emotional, psychological or mental health conditions >> **GO TO FILTER 14**

M1) How would you describe the level of severity of ^name's emotional, psychological or mental health condition?

2 Mild	<b>GO TO M2</b>
3 Moderate	
4 Severe	

M2) How often does this limit the amount or kind of activity ^name can do?

1 Always	<b>GO TO FILTER 14</b>
2 Often	
3 Sometimes	
4 Rarely	
5 Never	

**FILTER 14)** Do any of the people in your household have any difficulty carrying out everyday activities as a result of a head injury, stroke or any other sort of brain damage?

INTERVIEWER: IF YES, PLEASE IDENTIFY THESE PEOPLE FROM THE HOUSEHOLD GRID

You may choose 17 out of the possible answers

- 1 Person 1's name
- 2 Person 2's name
- 3 Person 3's name
- 4 Person 4's name
- 5 Person 5's name
- 6 Person 6's name
- 7 Person 7's name
- 8 Person 8's name
- 9 Person 9's name]
- 10 Person 10's name
- 11 Person 11's name
- 12 Person 12's name
- 13 Person 13's name
- 14 Person 14's name
- 15 Person 15's name
- 16 Person 16's name
- 17 No one has had a head injury >> **GO TO FILTER 15**

N1) How would you describe ^name's difficulty carrying out everyday activities as a result of the head injury, stroke or other brain damage?

1 A mild level of difficulty	<b>GO TO N2</b>
2 A moderate level of difficulty	
3 A severe level of difficulty	

N2) How often does this limit the amount or kind of activity ^name can do?

1 Always	<b>GO TO FILTER 15</b>
2 Often	
3 Sometimes	
4 Rarely	
5 Never	



**FILTER 15)** Do any of the people in your household have any other difficulties or limitations because of a physical condition, mental health condition or health problem that we have not already covered? Please think of difficulties or limitations that have lasted, or are expected to last 6 months or more?

**INTERVIEWER: IF YES, PLEASE IDENTIFY THESE PEOPLE FROM THE HOUSEHOLD GRID**

You may choose 17 out of the possible answers

- 1 Person 1's name
- 2 Person 2's name
- 3 Person 3's name
- 4 Person 4's name
- 5 Person 5's name
- 6 Person 6's name
- 7 Person 7's name
- 8 Person 8's name
- 9 Person 9's name]
- 10 Person 10's name
- 11 Person 11's name
- 12 Person 12's name
- 13 Person 13's name
- 14 Person 14's name
- 15 Person 15's name
- 16 Person 16's name
- 17 No one has any other difficulty >> **END**

O1) Can you tell me what ^name's difficulty (ies) is/are?:

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O2) How would you describe the level of severity ^name has with this condition?

1 Mild	<b>GO TO O3</b>
2 Moderate	
3 Severe	

O3) How often does this limit the amount or kind of activity ^name can do?

1 Always	<b>GO TO END OF FILTER</b>
2 Often	
3 Sometimes	
4 Rarely	
5 Never	

### ANNEX 3 – CONTENT OF THE QUESTIONNAIRE

Below is further detail on the information sought by NISALD in respect of the respondents social and economic circumstances and experiences:

#### **Section P: Support**

The provision of support to the individual to assist them with their disability / limitation and the individual's satisfaction with this. This includes identifying gaps in support provided and the type of support individuals would like to have received.

#### **Section Q: Care Received and Care Provided**

Details are collected on the extent to which the individual has difficulty (if any) with a series of daily tasks such as housework, cooking, shopping, managing finances, administering own treatment etc. Information is sought as to any help they get and need with these.

Similar questions to those above on care received are also asked of the individual with the disability or limitation in respect of any such care that they may be providing to others.

#### **Section R: Health**

Information is sought on the respondent's general health (these are harmonised questions and can thus be compared with other sources such as the Continuous Household Survey of the general population).

Information is collected on the frequency of contact and satisfaction with service provision with both primary and secondary health care providers. This includes the full range of such service providers.

#### **Section S: Education**

The individual is asked if their education or educational opportunities have been affected in any way for reasons associated with their disability. For those whose education has been affected, information is sought on their educational experiences.

#### **Section T: Employment and Training**

A series of questions are asked to establish the respondent's economic status – these are consistent with the International Labour Organisation (ILO) definitions. For those respondents who are unemployed, information is sought on any previous employment and any particular measures needed for them to take up employment.

Respondents who are inactive are asked if they would like to work, what would encourage them to look for work and if they have ever had a job.

Respondents in employment are asked details of their employment which will enable their Standard Occupational and Standard Industrial Classifications to be derived – again these are harmonised questions so the results can be compared with the general population Labour Force Survey. Respondents are also asked about their career and development within their job.

#### **Section U: Social Participation, Leisure and Attitude of Others**

The questionnaire then seeks to collect information on the individual's participation in a range of social activities, any difficulties they encounter with such participation and what changes could be made to enable them to participate more or at all (if they wish to do so). Information is sought on any services or facilities that the individual is unable to access. Respondents are asked if they

have been unable to vote in a national or council election for reasons associated with their disability.

Information is then collected on the attitudes of others to the individual and whether these attitudes prevent them from doing things they otherwise would.

#### **Section V: Transport**

Under transport and travel the respondent is asked what modes of transport they would usually use (this includes walking), their reasons for using modes of transport, preferred methods and availability of alternatives. Information is sought on any difficulties experienced using the various modes of transport.

#### **Section W: Housing**

The questionnaire then asks a series of questions related to the individual's place of residence, specifically asking about type of accommodation and tenure. Information is collected on whether any modifications have been made or are needed.

#### **Section X: Crime**

There are a small number of questions on crime and fear of crime which are directly comparable with the Northern Ireland Crime Survey.

#### **Section Y: Additional Costs, Income and Benefits**

Information is then collated on any goods, services, facilities, equipment or medication that the individual faces additional costs over. They are also asked if there are areas where they need to spend more on, for reasons associated with their disability or limitation, but cannot afford to.

General income information is also collated, including total household income, identification of the sources of income received by the household, any social security benefits being received by the individual (or on their behalf), and availability of benefits to the individual themselves as opposed to becoming part of the total household income.

#### **Section Z: Demographics**

Demographic information is collected regarding the individual's living arrangements (ie the other people in the house); their age, marital status (to include civil partnership status), dependents, community background, and country of birth.

## VOTE OF THANKS PROPOSED BY DR ANNE GOOD, NATIONAL DISABILITY AUTHORITY

I would like to thank the SSISI for inviting me to propose this vote of thanks to Kevin Sweeney and Michelle Furphy, of the Northern Ireland Statistics and Research Agency, for their paper *An exercise in surveying a non-universally defined group in the population: The Northern Ireland Survey of Activity Limitation and Disability*. This presentation has been most thought provoking and stimulating, especially for those of us working in the field of disability research.

I would like to make a few comments and proposals for discussion, about aspects of the paper, most especially in relation to the context and the implications of the survey. Firstly, I would reiterate the speakers' emphasis on the importance of reliable and comprehensive research in the continued development of evidence-based policy planning and service delivery for people with disabilities. Such research is a key facet of the work of the National Disability Authority at national and international levels ([www.nda.ie](http://www.nda.ie)).

The 1999 National Disability Authority Act listed one of the main functions of the NDA as being:

*To undertake, commission or collaborate in research projects and activities on issues relating to disability and to assist in the development of statistical information appropriate for the planning, delivery and monitoring of programmes and services for people with disabilities*  
(Article 8(2) b).

Accordingly, improvement of disability research and data collection has been a primary responsibility of the NDA since its foundation in 2000. Development of a sound knowledge base underpins the policy and standards role of NDA in the context of our National Disability Strategy (2004). It is also a key component of our international responsibilities under such initiatives as the EU Disability Action Plan 2004 – 2010 and the UN Convention on the Rights of Persons with Disabilities.

The NISRA survey contributes to the development of this kind of comprehensive knowledge base for Northern Ireland policy makers and planners. As such it must be a very welcome development for all stakeholders, from people with disabilities and their organizations, to civil servants and service providers. Today's paper is also timely as we anticipate the imminent publication of our own National Disability Survey, which will similarly raise our knowledge base on disability to a new level ([www.cso.ie](http://www.cso.ie)).

These two disability surveys, which went into the field in 2006 involved regular liaison and cooperation between the CSO and NISRA in their planning. They will allow for useful cross border comparisons and learning from their similarities and their differences.

Three aspects strike me as of particular interest, and I will say a little about each

- The use of the WHO International Classification of Functioning Disability and Health (ICF, WHO: 2001)
- Methodological choices
- Findings in relation to policy outcomes

## **The ICF**

As indicated by the title of today's paper, disability is a complex and contested concept. National and international data collection has faced major problems for this reason and, until recently, international statistics have been based on widely diverging understandings of disability. When the NDA began the preparatory work for the first Irish national disability survey it did so by commissioning a pilot study. One of the goals of the pilot was to investigate the new ICF which had been developed by the WHO as a common language and conceptual framework for disability research. The report on this pilot *Designing and Piloting an Irish Disability Research Instrument Based on WHO ICF* is available on the NDA website.

Since 2001, the NDA and other Irish government bodies, have been using the ICF in national surveys, administrative databases and needs assessment processes. The NDA has also been participating in two international exercises examining the ICF as an instrument across a range of data collection settings. These are the EU 6<sup>th</sup> Framework project entitled *Measuring Health and Disability in Europe* (Mhadie) which has been assessing the ICF as a tool for improving the comparability and consistency of EU wide data collection exercises in health, education and clinical settings, in relation to disability ([www.mhadie.com](http://www.mhadie.com)). At United Nations level, the NDA has participated with the CSO in the UN Washington Group on Disability Statistics ([www.cdc.gov/nchs/citygroup.htm](http://www.cdc.gov/nchs/citygroup.htm)). This City Group was given the task of improving global disability statistics, most importantly those collected in national censuses, using the ICF as the framework. Thus there is an emerging body of experience to evaluate ICF and propose revisions if necessary. This now includes our two disability surveys.

## **Methodology**

The NISRA and CSO disability surveys will also allow for learning as to the advantages and disadvantages of their respective methodological choices where they have differed. Perhaps the most obvious of these has been the choices with regard to identifying the sample. The CSO chose the post censal method while NISRA used a sifting approach. Each seems to have had advantages and challenges. Future research would benefit from comparative analysis at a later stage.

## **Policy Outcomes**

When the results of both surveys become available, it may be very informative for policy and service planning, North and South, to analyse the similarities and differences in outcomes in the two jurisdictions across a range of policy areas, for example education and employment. We know that people with disabilities are less likely to participate in these and other important areas of social life and are therefore at greater risk of social exclusion and poverty than their non disabled counterparts. Through the findings of the two surveys we should be able to develop a much fuller understanding of the particularities of that exclusion process and of the barriers and enablers which contribute to or reduce disablement. These findings should be very revealing, given that the population structure in the two jurisdictions is quite similar but the policy context is different. For example, we know that inaccessible transport is a key factor in excluding people with disabilities. Policy and service initiatives in the North or the South which are found to improve transport uptake by people with disabilities (such as disability awareness training for staff in the transport sector and provision of transport information in a range of formats) will be of great interest.

I would like to conclude by offering my sincere congratulations to all concerned in organizing today's event, from NISRA and the SSISI, and to say thanks to the authors for a most interesting paper. I hope that we can have a similar session with the CSO in the near future, on the two disability surveys North and South, and on the comparative issues which I outlined above.