

Methodological Preparations for an Irish Post Census National Disability Survey in 2006

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Authors:

Mr Gerry Brady,
Senior Statistician,
Central Statistics Office,
Email: gerry.brady@cs0.ie
Website: www.cs0.ie

Dr Anne Good,
Senior Researcher,
National Disability Authority,
25, Clyde Road, Ballsbridge,
Dublin 4
Email: agood@nda.ie
Website: www.nda.ie

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In 2004, the Irish Government decided that the Central Statistics Office (CSO) would carry out a National Disability Survey (NDS) after the 2006 Census of Population, in order to establish the prevalence and impact of disability and to identify areas in policy and service provision where improvements were needed.

The National Disability Authority had formally proposed this survey to Government in 2002. The NDA had followed up this proposal during 2002-2004 by conducting a large-scale consultation exercise, and by commissioning a pilot survey. Building upon this work, the parent Government Department of the NDA – Justice, Equality and Law Reform – proposed to Government in 2004 that a National Disability Survey should be carried out, using the results of the pilot as a starting point. The Government agreed this proposal and indicated that the survey should be conducted by the CSO as a follow-on survey after the 2006 Census of Population. It stipulated that the questionnaire should be developed in consultation with relevant bodies including Government Departments and the National Disability Authority. The costs for the survey were estimated to be in the region of €2m depending on the sample size.

Preparations are now under way for the 2006 NDS, the first of its kind in Ireland. This paper presents a brief background to disability data collection in Ireland, and discusses various aspects of the methodological preparations, namely:

1. The NDA Pilot Disability Survey and Consultation Exercise, 2002-2004;
2. Census of Population 2002;
3. Census of Population 2006;
4. Post survey micro data linkage to 2006 Census file
5. NDS 2006 sample
6. NDS 2006 questionnaire;
7. Ethical practice in disability surveys.

The Paper draws on the experience of the 2003 NDA pilot exercise as well as the progress in the current preparations for the NDS 2006 in order to address these topics. The Paper ends with a brief Conclusions summary.

Background

To date, only a partial picture of the prevalence and impact of disability in Ireland has been available and, as a consequence, policy and service planning are inadequately informed. Yet, as far back as 1996, this issue had been identified by the Commission on the Status of People with Disabilities¹ as needing urgent action.

The National Disability Authority (NDA) was established in June 2000 to “*promote and help secure the rights of people with disabilities*”. It quickly concluded that one of the major barriers to the successful achievement of its mission was this lack of comprehensive data on the lives of people with disabilities in Ireland.

¹ The Commission on the Status of People with Disabilities was a Government established expert commission, which consulted widely with the sector and worked within the framework of the UN Standard Rules. It reported to government in 1996.

In the intervening years this lack of data has been somewhat addressed by the inclusion of disability questions in the 2002 Census, and in a number of national surveys including the EU-wide labour force survey (QNHS)². In addition, for health service planning purposes, a National Intellectual Disability Database of those using or assessed as needing intellectual disability services, has been in place since 1996. Work is in progress on compiling a National Physical and Sensory Disability Database, to assess the service needs of people aged under 65 with these particular disabilities

Nonetheless, the NDA took the view that an NDS was also needed to provide a comprehensive picture of the prevalence and experience of disability. The NDS will probe the labour force status and living standards of those affected by disability, their need for health, education and personal social services, their participation in different areas of life, and the contextual factors and constraints which impact on their daily lives. This will provide a rounded picture of both the prevalence of disability, and its impact on persons with a disability. It will, therefore, provide key data to policy makers to enable them to ensure that there is greater equality and integration of persons with a disability into all aspects of society.

1. NDA Pilot Disability Survey and Consultation Exercise, 2002-2004

During 2002-2004, in preparation for a decision by Government on the proposed NDS, the NDA consulted with a broad range of stakeholders and commissioned a pilot exercise, which involved drafting and testing a disability survey questionnaire. It was decided that this pilot questionnaire would be based on the new International Classification of Functioning, Disability and Health (ICF), which had been developed by the World Health Organization during the 1990s. The ICF's main innovation was to incorporate a social understanding of disability and it was developed in co-operation with international disability organisations.

The WHO General Assembly formally adopted the ICF in 2001. Its aim is to provide a language and framework for the description of health and health-related states that can be used consistently across different countries and settings. Such a framework is indispensable if valid data comparisons within and across countries are to be possible. Central to the ICF definition of disability is the relationship between the individual (with an impairment) and environmental factors (physical, social and attitudinal). If a person with a given impairment lives in an environment characterised by barriers at every level their performance and participation will be restricted; but if a person lives in a facilitating environment this will serve to increase their performance and participation. This understanding of disability paralleled that being adopted by the Irish state and seemed to make the ICF worth investigating as a useful framework for Irish disability data collection.

Pilot Questionnaires

Two questionnaires were developed and tested during the pilot, one for adult respondents and one for children. The process of designing the pilot questionnaires involved a literature search of international instruments and recent methodological papers. A key aspect to the design process was how best to link the ICF into the questionnaire in terms of the elements to choose and the level of detail necessary.

² where a permanent disability question has been added to the first quarter survey.

Three surveys from overseas were particularly useful to initial design. These were the Survey of Disability, Ageing and Carers 2001, undertaken by the Australian Bureau of Statistics; the PALS 2001 Survey, undertaken by Statistics Canada, and the New Zealand Household Disability Survey 2001, undertaken by Statistics New Zealand. The ICF was used as a conceptual framework in this design process. Through the consultation process, decisions were made on the levels to be included.

Although separate questionnaires were developed for adults and children, their structures were broadly similar and were derived from the ICF. The main differences between the adult and child questionnaires related to removing from the children's questionnaire issues such as marital status; labour market experience; transportation and driving; and intellectual development. Table 1 shows the components of the questionnaires.

Table 1: Components of ICF domains in NDA Pilot Survey 2003 Questionnaires

Body Functions & Structures	Vision Hearing Speech Breathing Pain
Activities & Participation	Communication Mobility Agility Self Care
Major Life Areas	Education Employment Leisure / Social Participation
Environmental Factors	Products and Technology Support and Relationships Attitudes Services, Systems and Policies

Source: adapted from Browne et al, 2003:49, Table 15

Filter questionnaire

Piloting the adult questionnaire required a sample size of about 100 persons who had an activity limitation according to the definition applied. A sifting of the national population was undertaken to identify relevant respondents for the main pilot survey. The filter questions chosen had their basis in the disability filter questions used in the 2001 Canadian Census, which were extensively tested.

In July 2003, the filter questionnaire³ was administered by telephone to a sample of 953 households. Counties surveyed were Dublin; Westmeath, Meath; Mayo and Kerry, selected to ensure a reasonable rural/urban mix. Random digit dialling was used. Out of the 951 households contacted a total of 81% (770) completed the survey with only 181 (19%) refusing to do so.

Over 64% of the sample (representing 497 households) was classified as having no one with a disability/activity limitation on the basis of the definitions employed (i.e. they answered 'no' to all four screen questions). A further 30% of households (229

³ See www.nda.ie for report including questionnaires

cases) recorded 1 person with a disability while the remaining 6% of households recorded 2 or more persons.

The total number of individuals resident in the 770 households, which successfully completed the pilot sift was 2,439. A total of 317 of these were identified as having a disability. This gives a disability prevalence rate among individuals of the order of 13% (as compared with the census 2002 rate of 8.7%).

Households in which a person with a disability was identified, were asked if they would be willing to participate in the main pilot survey. Of these, 54% (143) were willing and provided contact details while 46% (123) were unwilling to take part for a variety of reasons, most frequently because they could see no benefit to so doing.

Interviewer training

The main survey was implemented on a personally administered basis by interviewers visiting the respondents in their own home. The NDA took the view that interviewers would need some specialised training in interviewing persons with a disability, both to ensure the interaction was appropriately sensitive and to maximise the quality of the response. This element was therefore included in the pilot through a half-day special briefing session by the team. It is intended that this training, along with the interviewer guidelines produced as part of the pilot, will provide the basis for training the NDS interviewers⁴.

Data collection

A total of 88 of the 93 interviews with adults were completed directly by the respondent. One interview was a facilitated interview (the respondent was present but was assisted in completing the interview by a parent/guardian/facilitator) and four interviews were completed by proxy. The average duration of the adult interviews was just under 40 minutes.

Only 1 of the 13 child questionnaires completed was based on direct responses from the child, the remainder being conducted with the parent or guardian of the child. The average length taken for completion was 41 minutes.

In order to learn more from the pilot exercise, the respondents' reactions to the survey were investigated in a structured way on both the adult and child questionnaires. A total of 90 out of the 106 respondents completed the feedback section of the questionnaire. These responses were then analysed along with those from the interviewers.

Respondent and interviewer feedback

In general, there was a very positive response to the survey with very few problems arising. High levels of satisfaction with the interview process were recorded in terms of courtesy, clarity and pace, and relevance of the content. However, 6% of respondents expressed some level of dissatisfaction with the relevance of the questionnaire. The sensitivity of the questions appears not to have been a problem. Of the 88 respondents who answered this item, only 3 said that they were uncomfortable with particular questions. One mentioned age, two mentioned the

⁴ See www.nda.ie for the full report including interviewer guidelines. These guidelines are being used by the WG in its piloting exercise.

questions on financial situation, and one noted that depression/mental illness was a sensitive topic generally.

When respondents were asked about issues not covered in the questionnaire that they considered should have been, some useful comments were received. Over one-third of respondents mentioned at least one issue that was relevant to their situation. There was no clear pattern – each issue tended to be mentioned by only one respondent. In view of the length of the questionnaire, it was proposed that the potential issues could form the basis of further consultation prior to fielding the survey nationally. This is now being done by the CSO.

Interviewers reported no particular problems in the field arising from the specific nature of the survey. No particular problems for those who responded were raised in the respondent reaction section to the survey. In addition, an ex post 'spot check' on approximately 15% of respondents was carried out and revealed no problems. On this basis, the assessment was that a survey of this type could be feasibly conducted by fieldworkers drawn from a panel of interviewers trained and experienced in work on general surveys oriented towards the social sciences, given appropriate training.

Finally, some minor issues relating to the precise wording of specific questions on the pilot questionnaire were identified. Having made these minor amendments, the team concluded that the questionnaire as piloted provided a sound base for the full-scale National Disability Study. The appropriately modified pilot questionnaires were used as the starting point for consultations on the drafting of the 2006 NDS questionnaires.

2. Census of Population 2002

Disability questions were asked in a Census of Population in Ireland for the first time in 2002⁵. They were virtually the same questions as used in the 2000 United States Census of Population. Question 14 was asked of all persons enumerated in the Census while question 15 focussed on specific age groups (see Figure 1).

Figure 1: Disability Questions used in Census of Population 2002

14 Do you have any of the following long-lasting conditions?		
	Yes	No
(a) Blindness, deafness or a severe vision or hearing impairment?	1 <input type="checkbox"/>	2 <input type="checkbox"/>
(b) A condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting or carrying?	1 <input type="checkbox"/>	2 <input type="checkbox"/>
 15 Because of a physical, mental or emotional condition lasting 6 months or more, do you have any difficulty in doing any of the following activities?		
	Yes	No
Answer (a) and (b) if aged 5 years or over.		
(a) Learning, remembering or concentrating?	1 <input type="checkbox"/>	2 <input type="checkbox"/>
(b) Dressing, bathing or getting around inside the home?	1 <input type="checkbox"/>	2 <input type="checkbox"/>
Answer (c) and (d) if aged 15 years or over.		
(c) Going outside the home alone to shop or visit a doctor's surgery?	1 <input type="checkbox"/>	2 <input type="checkbox"/>
(d) Working at a job or business?	1 <input type="checkbox"/>	2 <input type="checkbox"/>

⁵ The Census was originally scheduled for 2001. Censuses in Ireland are conducted every 5 years.

A total of 323,707 persons, representing 8.3% of the total population, indicated that they had a long-lasting health problem or disability. This rate was calculated by identifying every person who answered 'Yes' at least once to one of the six sub-questions - Q.14a, Q.14b, Q.15a, Q.15b, Q.15c or Q.15d.

Some statistics from the 2002 Census disability results are:

- ◆ Around 58% of persons with a disability had more than one disability;
- ◆ Around 42% of those with a disability were aged 65 years or over whereas that age group represented only 11% of the population (see Table 2);
- ◆ One-fifth of persons with a disability living in private households were living on their own;
- ◆ Around 11% of persons with a disability were enumerated in communal establishments – over one-third of persons enumerated in communal establishments had a long-lasting health problem or disability; and
- ◆ There was little difference between the disability rate in rural areas (8%) compared to urban areas (8.5%).

Table 2: Profile of persons with a disability by age group, Census of Population 2002

Age	2002 total persons	All multiple disabilities	All disabled persons	% of relevant age group with a disability
0-4	277,630	2,391	2,029	0.7%
5-9	264,090	10,700	7,017	2.7%
10-14	285,708	11,480	8,265	2.9%
15-19	313,188	17,651	8,835	2.8%
20-24	328,334	21,693	10,890	3.3%
25-29	312,693	22,903	11,442	3.7%
30-34	304,676	26,748	13,579	4.5%
35-39	290,906	31,025	15,678	5.4%
40-44	271,984	34,784	17,511	6.4%
45-49	249,604	39,518	19,696	7.9%
50-54	230,843	46,879	23,287	10.1%
55-59	197,294	50,755	25,067	12.7%
60-64	154,252	51,042	24,715	16.0%
65-69	133,474	51,225	23,517	17.6%
70-74	112,129	61,527	26,141	23.3%
75-79	89,815	80,540	30,288	33.7%
80-84	58,857	83,706	27,847	47.3%
85+	41,726	101,266	27,903	66.9%
Total	3,917,203	745,833	323,707	8.3%

There were 36,223 persons with a disability enumerated in communal establishments on Census night. Table 3 shows that almost three-quarters of these were enumerated in a nursing home or hospital. The selection of the NDS sample will be limited to persons who were enumerated at their usual place of residence (to facilitate call-back), and only certain communal establishments (such as nursing homes) will be included in the sample frame.

Table 3: Persons with a disability enumerated in communal establishments, Census 2002

Type of Establishment	Total persons	Total persons with a disability
Hotel	27,053	1,319
Guest house, boarding house and B&B	9,641	625
Hostel ⁶	7,472	1,643
Campsite	56	6
Educational establishment	6,191	283
Religious community	7,013	1,821
Children's home	429	131
Nursing home	16,749	13,490
Hospital	23,219	13,337
Prison	3,237	286
Civilian ships, boats and barges	369	9
Other, incl. not stated	6,256	3,273
Total	107,685	36,223

3. Census of Population 2006⁷

Figure 2 shows the two disability questions that will be used in the 2006 COP. These questions will be asked of every person present in the household or communal establishment on census night.

Figure 2: Disability Questions for Census of Population 2006

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

	Yes	No
(a) Blindness, deafness or a severe vision or hearing impairment?	1 <input type="checkbox"/>	2 <input type="checkbox"/>
(b) A condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting or carrying?	1 <input type="checkbox"/>	2 <input type="checkbox"/>
(c) A learning or intellectual disability?	1 <input type="checkbox"/>	2 <input type="checkbox"/>
(d) A psychological or emotional condition?	1 <input type="checkbox"/>	2 <input type="checkbox"/>
(e) Other, including any chronic illness?	1 <input type="checkbox"/>	2 <input type="checkbox"/>

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

	Yes	No
(a) Learning, remembering or concentrating?	1 <input type="checkbox"/>	2 <input type="checkbox"/>
(b) Dressing, bathing or getting around inside the home?	1 <input type="checkbox"/>	2 <input type="checkbox"/>
(c) Going outside the home alone to shop or visit a doctor's surgery?	1 <input type="checkbox"/>	2 <input type="checkbox"/>
(d) Working at a job or business or attending school or college?	1 <input type="checkbox"/>	2 <input type="checkbox"/>
(e) Participating in other activities, for example leisure or using transport?	1 <input type="checkbox"/>	2 <input type="checkbox"/>

⁶ Hostels includes a mixture of tourists, and homeless and other socially disadvantaged persons.

⁷ A temporary field force of around 4,500 enumerators will distribute census questionnaires to every household and communal establishment in the State. The enumerators will examine the questionnaires, at the time of collection, to ensure that they are correctly completed. Where necessary, they will assist householders to complete the form. Special arrangements will be put in place to assist visually impaired persons and persons with literacy difficulties to fill out their Census forms.

The Census disability questions for 2006 have been amended from the 2002 Census. The equivalent of Q.14 in COP 2002 has been extended to include three extra categories of disability including a broad "Other" category. In 2006 persons should only answer the equivalent Q.15 from 2002, if they have answered at least one 'Yes' to Q.15 in 2006. The disability questions were tested in a Census pilot survey in April 2004, which covered 8,000 households. The proportion of persons with a disability in the 2004 Census pilot was 10.6% of the population. If the categories, which were added to the 2002 Census disability questions, are excluded, the prevalence rate falls to 9.2%, which is a small increase on the 8.3% reported in 2002.

The Census 2006 will also be used to identify a sample of around 2,000 persons who stated that they did not have a disability. These persons will be included in the NDS to examine the effectiveness of the Census questions in identifying all persons with a disability.

4. Post survey micro data linkage to 2006 Census file

The COP questionnaire collects a large range of data on the demographic, educational, employment and family situation of each person. Instead of collecting such information again in the NDS, a common unique person identification number will be used in both surveys in order to link both data files at a person level. This approach allows greater scope for the collection of more disability specific data in the NDS (such as barriers to participation including attitudes of other persons). It also means that more valid comparisons can be made with the non-disability population in relation to such data, as the Census will be the only data source used for comparing the education and employment situation of persons with and without a disability. Each person recorded in the Census can be uniquely identified electronically by a combination of four variables:

- ◆ County code;
- ◆ Enumeration area code (EA);
- ◆ D number (taken from the Enumerator Record Book which is a list of all households within an EA including their addresses); and
- ◆ Person number on the census form.

These four variables will comprise the unique person identification number that will be used in both surveys. In addition, the NDS will collect the Personal Public Service Number of persons interviewed in the NDS survey. This identification number is being increasingly used in many public sector administrative data holdings such as social welfare, education, and health data sources. Hence although the PPS Number will not be collected in the Census, it will be possible to match the NDS at an individual person level to significant administrative data holdings. However there may be difficulties arising from non-response to the PPSN question especially among older persons who may not be readily able to locate their PPSN. The CSO may undertake an in-house post-NDS data matching exercise with the PPSN register to verify PPS Numbers and to capture missing numbers.

5. NDS 2006 sample

Final decisions regarding the sampling strategy for the 2006 Survey have not yet been made. However, some broad issues have been decided:

1. The disabled population to be covered will include children and adults of all ages whether living in private households or in communal establishments. Homeless people will not be covered in the NDS;
2. The total sample size will be around 15,000 persons. This includes both persons in private households in permanent housing and persons in communal establishments. It also includes around 2,000 persons who did not report a disability in the Census;
3. The primary sampling unit will be the Electoral Division. These will be selected using the disability results from the 2002 Census of Population.
4. The secondary sampling unit will be a named person in a private household in permanent housing or named persons in selected communal establishments. Only the named person in each private household will be interviewed.
5. The data gathered during the 2006 Census will be used to stratify and select the NDS sample within the selected EDs. A higher proportion of younger persons with a disability will be included in the sample.
6. Around 200 enumerators will be retained from the Census field operation. They will be given special training in disability issues and in general interviewing techniques.

The names and addresses of persons indicating a disability in the census will have to be extracted from the Census forms. The resulting lists will include details such as the unique person identification variables, name and address; date of birth; sex; and accommodation type (private household or type of communal establishment). The enumerators will also extract a sample of persons who had no disability. It is expected that an average Census enumerator list will comprise around 30-40 names. These lists will be returned to the CSO for keying and sample selection.

6. NDS 2006 Questionnaire

Preparations for the 2006 NDS began in Spring 2005 using the NDA Pilot questionnaire as the basis for consultation. Two key areas emerged as needing further attention. The first of these was to ensure that the relevant Government Departments would have their data needs met by the NDS, especially in the context of a new National Disability Strategy that was launched in Autumn 2004. The second was to address perceived shortcomings in the pilot questionnaires, most especially in the complex areas of mental health and intellectual disabilities.

Figure 3 briefly compares the structure of the pilot questionnaire with the latest draft of the NDS questionnaire. The NDS questionnaire has gone through a much broader consultative process particularly in relation to consultation with Government Departments to ensure that the data required to inform policy planning and development is being included in the questionnaire. This consultation was largely

done through the formation of a representative Survey Project Group and through direct consultation with Government Departments and disability organisations.

Section 1 in both questionnaires has much the same basic structure: seeing; hearing; speaking and communication; mobility and dexterity; pain; breathing; learning or intellectual and other developmental difficulties; memory; and emotional, psychological or mental health difficulties. However the questions have been modified based on the feedback to the NDA pilot, and on a developing awareness of what the critical activities and aids questions are.

More prominence has been given to the Built environment and Transport sections in the NDS. The components of Major life areas in the NDA survey (education, employment, and leisure, social participation, transport and housing) have been allocated separate sections. There have also been many changes to the wording of individual questions.

Figure 3: Comparison of Adult Questionnaire layout in NDA Pilot 2003 and NDS 2006

Topic	NDA Pilot 2003	NDS 2006
Section 1	Activities and aids	Type of disability (includes questions on severity)
Section 2	Help from other people and attitudes of other people	Help from other people
Section 3	Background to reduction in activities	Attitudes of other people
Section 4	Major life areas	Built environment
Section 5	Demographic information	Transport
Section 6		Education
Section 7		Employment
Section 8		Social participation
Section 9		Sport and recreation
Section 10		General and demographic information

As previously mentioned, a small sample of persons who indicated that they did not have a disability in the Census will be included in the NDS. The main purpose of this exercise is to examine the disability severity of any of such persons who may indicate that they have a disability in the NDS. The exercise may also shed light on gaps in the Census disability questions. It is intended that these persons will be asked the full NDS questionnaire rather than given an intermediate filtering questionnaire.

7. Ethical practice in disability surveys

The NDA is committed to two core principles in relation to its research programme: a social model of disability, and empowerment of people with disabilities (NDA 2000, p. 16-18). It is also aware of the specific challenges which are posed in applying ethical guidelines to disability research. The NDA ensured that these principles were honoured during the pilot exercise in a number of ways:

- ◆ An Advisory Group, which included people with disabilities, was established for the project;
- ◆ Several consultation seminars were organised by the NDA for a range of stakeholders;

- ◆ An expert advisor from the WHO was available to assist the research team and to address the consultative seminars;
- ◆ A structured consultation process around the pilot survey itself formed a key element of the project.

In a separate but related exercise, the NDA also produced a new set of NDA Ethical Guidelines for Disability Research in 2004 partly as a response to ethical issues raised during the NDS consultation process.

The remainder of this section will discuss firstly the consultation process and secondly the main provisions of the NDA ethical guidelines.

The Consultation Process

The various consultation exercises focussed on a range of issues, including the benefits or otherwise of conducting this kind of survey; the pros and cons of using the ICF as framework and the ethical dimension. The latter proved to be of particular importance to people with disabilities who reported having had negative experiences of participating in research in the past. Three over-arching issues of importance emerged from the consultations, along with this general concern about ethical research practice.

First, it was apparent that participants believed themselves not fully informed and some suggested that the proposed survey instrument were impositions on people with disabilities. This view existed despite the fact that these instruments were the direct outcomes of recommendations specifically stated in the Report of the Commission on the Status of People with Disabilities. This report was based on the broadest consultation process ever undertaken with people with disabilities in Ireland.

A second issue reflected current debates in disability research. Many participants referred to changes in the ways disability is construed and to the treatment of people with disabilities historically. They were concerned that these understandings should underpin the proposed NDS and remained to be convinced that using the ICF as a framework would ensure that this was the case. Some perceived the ICF as remaining within a medical understanding of disability and rejected its claim to have incorporated the social model.

Third, it was apparent that frustration and scepticism about current political activity related to disability issues permeated many responses. In brief, many did not see a link between the proposed national disability study and their well-being.

Ethical Guidelines

The NDA ethical guidelines⁸ were written as a response to dissatisfaction expressed at various consultation meetings with the short guidelines included in the ICF (WHO, 2001:). This dissatisfaction was raised in the context of the issues outlined above, most especially those of prior bad experiences of research and fears that research might be used to underpin a negative approach to disability, expressed most usually in a fear of eugenics policies.

⁸ Available on www.nda.ie

The guidelines were developed during 2003-2004 through a separate consultation exercise that included researchers, policy-makers, service providers and disability organisations. The guidelines advocate the following core values to underpin disability research:

- ◆ Respect for the human rights, dignity, equality and diversity of all those involved in the research process;
- ◆ Advancement of social justice for people with disabilities within the wider community;
- ◆ Promotion of the well-being of those participating, involved in or affected by the research process;
- ◆ Avoidance of harm to those involved in the research process or to the wider community;
- ◆ Facilitation of the participation of people with disabilities in research and research dissemination, including those for whom obstacles might make such participation difficult without additional support;
- ◆ Maintenance of the highest professional, legal and ethical standards and competencies; and
- ◆ Comprehension and fulfilment of relevant legal responsibilities.

The guidelines argue that adhering to these general core values presents some specific challenges for disability research and they discuss those challenges in some detail. These guidelines are central to the general consultations being undertaken by the CSO during the preparations of the NDS questionnaire, methodology and interviewer guidelines.

Conclusions

1. The work undertaken by the NDA in commissioning a pilot disability survey was pivotal to the subsequent sanctioning of a National Disability Survey. The pilot questionnaires proved to be a valuable starting point in the forming of the NDS questionnaire. That work, has resulted in regular contact with disability representative groups in connection with acceptance of the value of the compilation of statistics on disability provided that they are collected within acceptable ethical guidelines.
2. The Department of Justice, Equality and Law Reform provided the next major impetus by bringing a Memorandum to Government.
3. The work on disability statistics undertaken by the CSO 2002-2005 laid a good foundation for deciding practical issues such as sample selection and methodology.
4. The work of the ICF and the Washington City Group has resulted in more international based consistency in the definition of disability. This will ensure that the results for Ireland can be validly compared with a selection of other countries.
5. There remain unresolved issues around determining a country's disability prevalence rate. The micro-data links between the Census disability data and the NDS disability data should provide a useful contribution to the possibility of using a multi-purpose household survey to estimate disability prevalence rates.

6. It is hoped to use the PPSN collected in the NDS to examine other administrative databases from a disability perspective. Under the Statistics Act, 1993 the CSO is authorised to perform such data linking for statistical purposes⁹.

⁹ See CSO data protocol, http://www.cso.ie/aboutus/documents/cso_data_protocol.doc