

## Measure of Activity and Participation (MAP): Disability data sources in Ireland



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### Background

The National Physical and Sensory Disability Database (NPSDD) was set up in 1998 by the Department of Health (DoH) with the task of developing a national database to collect information on the specialised health and social service needs of people with physical or sensory disability. Implementation of the NPSDD on a nationwide basis began in 2002.

At the same time, the DoH became signatories to the WHO's International Classification of Functioning, Disability and Health (ICF), which is a more holistic way of looking at disability and it sought to expand data collection on the NPSDD to include indicators of participation based on the ICF. The ICF measures were introduced in 2004 in the Measure of Activity and Participation (MAP) section of the NPSDD and consist of three components (barriers and challenges in relation to life activities, participation in areas such as education and training, employment and social life and a WHO measure; the WHO Disability Assessment Schedule or WHODAS 2.0 which captures data on difficulties experienced in everyday tasks such as washing and dressing). This is an innovative addition to an administrative database and recognised as such internationally as it enables tracking of the impact of service interventions on the participation and functioning experience of people with disabilities over time. This tracking can then contribute to more effective service planning and prioritisation decisions.

This is the fifth publication in the MAP Bulletin series. Previous bulletins can be found on the Health Research Board (HRB) website [www.hrb.ie/publications](http://www.hrb.ie/publications).

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## Executive Summary

There is an increasing focus on evidence-based decision making for the planning and delivery of disability services. This has been illustrated with the instigation of the Value for Money review of disability policy and services in 2010 by the Department of Finance and the Department of Health. Recommendations of this review are expected late 2011. In addition, the recent press release from the Minister for Health, Dr James Reilly stated that "every health policy developed during the time that I'm in office is going to be based on knowledge derived from research" (Department of Health, May 2011).

Evidence based decision making requires access to consistent, comparable and accurate information sources by key decision makers. There are currently a range of data sources on disability available in Ireland (National Disability Authority audit of disability data sources, 2007, unpublished) but there is a lack of clarity regarding which sources to use and when. International standards state that a more complete picture of disability is required to better inform decision making rather than an emphasis on diagnosis alone, with neither the medical model nor social model enabling such complete description of disability in isolation. The World Health Organization's International Classification of Functioning, Disability and Health (WHO ICF) provides a framework for describing disability in this more holistic way.

Two major data sources in Ireland - the National Disability Survey (NDS) and the National Physical and Sensory Disability Database (NPSDD) - have been guided by the ICF both conceptually in defining disability and in question development. This bulletin presents a comparison of both sources to determine how comparable they are in their use of the ICF. In addition, the potential for decision makers to mine the data from both sources for more effective decision making is explored.

The NDS, a one-off national survey with strong methodological underpinnings, provides baseline data on profile, activity, participation and service information. The NPSDD is an on-going administrative service planning database which also includes information on activity, participation and environmental factors. Using the ICF as the yard stick, 13 areas of commonality were found. This potentially offers policy makers and service planners a mechanism for benchmarking changes in data over time and for using this information as a strong evidence base for decision making.

## Introduction

The requirement for information on the health service needs of people with physical or sensory disabilities was first highlighted in 1994 in the health strategy document 'Shaping a Healthier Future'. This was further noted in 1996 in 'Towards an Independent Future' when the lack of reliable information on the number of people with physical and sensory disabilities and their service needs, was emphasised. However, a number of data sources on disability now exist. These range from administrative data sources (for example, Disability Allowance records, National Physical and Sensory Disability Database), Census of Population data (2002, 2006), national surveys (for example, National Disability Survey, SLAN) to assessment information (Assessment of Need under the Disability Act, for 0-5 years only at present). Between 1994 and 2011 Ireland has seen a growth in these information sources. However, as outlined in O'Donovan and Good (2010), "the diversity in the definition of disability employed in research, legislation and eligibility determination is clearly evident not alone between countries, but also within countries. In Ireland, this inconsistency serves to restrict the extent to which national data from different sources can truly be compared".

Thus, as service providers, planners and policy makers increasingly look for evidence on which to base decisions and inform policy, a lack of clarity exists regarding which data source to use. It may be that numerous data sources are required to answer a range of different questions. It may not be feasible or advisable to have a 'one size fits all' approach but, at a minimum, data sources should have a core set of information that is compatible and comparable. One way to ensure consistent, compatible and comparable data is to use a common definition of disability.

In 2001, the World Health Organization launched the ICF (WHO, 2001). It proposed a new way of defining disability which combined elements of the medical and social models. Central to this conceptualisation is the presence of a health condition with disability viewed as the interaction between the individual with a health condition and his/her environment. The Department of Health (DoH) are signatories to this classification which means that all health information sources which capture data on disability ought to be framed within the ICF. Indeed, any data on disability whether they are within the realm of health or other sectors such as education, transport, communication, ought to be informed by the international standard adopted by the Department of Health.

To date two major data sources in Ireland have adopted the ICF in defining disability and in guiding the development of question content - the NDS ([http://www.cso.ie/nds/nds\\_purpose.htm](http://www.cso.ie/nds/nds_purpose.htm)) and the NPSDD (<http://www.hrb.ie/health-information-in-house-research/disability/npsdd/>). The NDS was a one-off national survey which captured a wide range of information on the profile, participation and service use/needs of individuals identified as having a disability. The second, the NPSDD is an administrative data source that captures information on an on-going basis on profile, participation and service use/need. The main purpose of the NPSDD is to inform service planning and so the majority of the information collected is service focused; capturing the same breadth of data as the NDS is not feasible. However, the NPSDD is concerned with on-going data collection; each individual's information is updated over time through personal or telephone interview.

This bulletin compares the two information sources in terms of the ICF information captured with a particular emphasis on activity, participation and environmental factors. The bulletin has two main objectives:

- First, it seeks to uncover if there are any variables that are the same or similar across both sources and to investigate the potential of these sources to provide a complementary picture of disability experience in Ireland.
- Second, the bulletin explores the extent to which the baseline data captured through the NDS in 2006 can be tracked over time using the on-going collection and update of corresponding variables on the NPSDD in order to identify any changes or trends in experience.

This comparison of data sets is important for a number of reasons. First, there is no indication if a follow up National Disability Survey will be conducted in the near future. Thus, although there are baseline data available there is no indication of how improvements in experience for people with disabilities will be tracked. Second, Article 33 of the UN Convention on the Rights of People with Disabilities states that countries must monitor the implementation of the Convention and Article 31 specifically identifies the need for statistics to capture appropriate data to inform the implementation of the Convention and to identify barriers to participation experienced by people with disabilities. This implies the need for on-going data collection and monitoring. The NPSDD collects and updates data on an on-going basis. Though established specifically to inform service planning and policy decisions by the DoH and the HSE, the data captured could potentially be mined to fulfil other purposes. This bulletin is the first step in exploring the comparability of the NDS and the NPSDD as statistical data sources.

## National Disability Survey data 2006

The first ever National Disability Survey in Ireland was carried out by the Central Statistics Office in 2006, following the 2006 Census. It provides a detailed profile of people with disabilities in Ireland across nine different types of disabilities as well as detailed information on daily activities, experience of participation and service use/need. The sample total was 16,069, identified from the 2006 Census of Population questions on disability. This consisted of 14,518 people identified as having a disability in Census 2006 (the 'yes' sample) and 1,551 selected from the general population who were not identified as having a disability (the 'no' sample). The breakdown of the sample is presented in Table 1.

**Table 1: NDS Sample**

Ranking	16-24 years	Sample achieved
Census disability sample		14,518
resident in private households		13,868
resident in communal establishments		650
General population sample		1,551
<b>TOTAL</b>		<b>16,069</b>

(Adapted from CSO (2008) National Disability Survey 2006 – First results. Dublin: Stationery Office)

Based on the sample of 16,069 people estimates of disability prevalence in the population were made and are presented in the first (<http://www.cso.ie/releasespublications/nationaldisabilitysurvey06first.htm>) and second volume of results (<http://www.cso.ie/releasespublications/nationaldisabilitysurvey06vol2.htm>). The data presented from the NDS in this bulletin is based on the population estimates presented in Volume 2 of the data release. The estimates from the Census disability sample are based on a margin of error of +/- 2,300 and the estimates from the general population sample are based on margin of error of +/- 70,000 (CSO, 2008)

The ICF guided the development of the survey instruments both at a conceptual level, in terms of the overall definition of disability, and the specific level, in terms of question wording and content. All questions were mapped to the ICF codes during the development process and coding is included on the questionnaire for reference. One of the main goals of using the ICF as a standard classification on health and disability is to enable comparison of disability data across and within countries. Such comparisons have been rare, if indeed impossible in the past due to the varying definitions of disability employed by countries and by different sectors within countries.

## National Physical and Sensory Disability Database (NPSDD)

The National Physical and Sensory Disability Database (NPSDD) is an administrative service planning database, owned by the DoH, managed nationally by the Health Research Board (HRB) and regionally by the Health Service Executive (HSE). When the DoH became signatories to the ICF in 2001, it was agreed that the Database should be reviewed in light of this framework and appropriate questions introduced. The Measure of Activity and Participation (MAP), is an ICF based module which was introduced onto the Database in 2004. The MAP section includes the WHO Disability Assessment Schedule 2.0 (WHODAS 2.0) (WHO, 2010) which is a standard measure of difficulty with daily activities developed and tested by the WHO. In addition there are questions on barriers to participation and extent of restriction experienced in participating in particular life areas developed specifically for the NPSDD and based on the ICF. Other information recorded includes profile data, detailed service use and service need data, type of

disability and diagnostic information. In 2009, there were 26,169 people under the age of 66 years registered on the Database and 11,365 people completed the MAP section of the form. Data are collected on an on-going basis and reviewed regularly with current protocols recommending an annual review of each individual's information. To be eligible to register on the Database a person must:

- Have a persistent physical, sensory or speech and/or language disability;
- In the case of dual disability, the predominant disability must be physical, sensory or speech and/or language;
- Use or need in the next five years of a specialised personal health and social service;
- Have consented to be registered on the Database;
- Be aged under 66 years of age.

The MAP section of the form is completed by those aged 16 years and over but it is envisaged that a corresponding children's measure will be developed in time.

The data from the NPSDD presented in this bulletin are based on the official extract of data taken in January 2009 and includes only those on the NPSDD who completed the MAP section of the data form up to that date.

### ICF coding

Table 2, adapted from O'Donovan and Good (2010), shows the extent of ICF coding mapped to questions and response categories in both data sources. Both are strong in the coverage of environmental factors. This is a positive development in the collection of disability data and highlights a move away from a medical, individualised approach to data collection towards a focus on society as disabling. The NDS also has a strong focus on activity and participation domains. The NPSDD covers activity and participation but to a lesser extent. It should be borne in mind though that the NDS was an in-depth national survey with scope to capture a broader range of issues and also to investigate the ICF domains in depth, while the NPSDD is an administrative data source with a focus on service planning. Thus the scope for including the same breadth and depth of information as a national survey is greatly reduced. On a positive note, the inclusion of ICF based information in a national health information system provides an unique opportunity to identify the impact of service interventions on the participation and functioning of people with disabilities over time, thereby providing a potent evidence base to inform service planning, delivery and resource decisions that ensure the most positive outcome for service users.

*Table 2: Frequency of occurrence of ICF codes*

	NDS	NPSDD
<b>Body structures</b>	0	0
<b>Body functions</b>	51	23
<b>Activity and participation</b>	160	32
<b>Environment</b>	298	106
<b>Personal factors</b>	19	55
<b>Total</b>	528	216

(Adapted from, O'Donovan, MA; Good, A (2010) 'Towards comparability of data: using the ICF to map the contrasting definitions of disability in Irish surveys and census, 2000-2006')

## Data comparison

As the focus of this paper is to assess the comparability and compatibility of both data sources in terms of how disability is defined and captured focusing on ICF based information, service use/need information was not examined. Also there is a particular focus on environment, participation and activity; data on body function and personal factors were not included. Volume 2 of the NDS Report 2006 (2010) was compared to the NPSDD 2009 data. The areas of environment (barriers), participation and activity were compared across both data sets. Initially, all relevant questions related to these ICF domains were listed for each data set. Next, a mapping exercise was undertaken to link the questions from the NDS to the NPSDD to identify questions deemed to be the same or similar in the information captured. A total of 13 questions were identified; nine were classed as asking the 'same' information and four as asking 'similar' information. Table 3 presents the nine questions classed as capturing the same information to the extent that some descriptive comparison is possible.

**Table 3: Questions identified as the same**

IFC domain	NDS 2006	NPSDD 2009
<b>Environment</b>		
Attitudes	Avoiding doing things because of how other people reacted	Have attitudes represented a barrier to participation in past 12 months?
Built Environment	Accessibility difficulties outside the home	Has the physical environment represented a barrier to participation in the past 12 months?
<b>Participation</b>		
Education	Stopped education sooner than they wanted to	To what extent has your participation in education and training been restricted in the past 12 months?  Difficulty with your day to day work/school (WHODAS)
Shopping	Difficulties in going to town/shopping	To what extent has your participation in shopping being restricted in the past 12 months?
Socialising	Difficulties in socialising in public venue	To what extent has your participation in socialising been restricted in the past 12 months?
Religion	Difficulties in attending religious ceremonies	To what extent has your participation in religion been restricted in the past 12 months?
Community life	Difficulties in taking part in community life	How much of a problem do you have joining in community activities in the same way as anyone else? (WHODAS)
<b>Activity</b>		
Washing	Taking a bath or shower by yourself	Difficulty washing your whole body (WHODAS)
Dressing	Dressing yourself	Difficulty getting dressed (WHODAS)

In looking at data, a few words of caution are required. The data presented on the NDS covers all age groups in private households across a spectrum of disability which includes emotional, psychological and intellectual as well as mobility, seeing, hearing, speech, breathing and pain. The data on the NPSDD, however, are limited to those in private households aged 16-65 years with physical, sensory, or speech and/or language disability only.

On the NPSDD private households refers to those people whose type of living accommodation was not full time residential, homeless or 'other'. Thus the total number of people included in the analysis of NPSDD data is 10,878 people.

Physical disability refers to a range of diagnostic categories which would incorporate the NDS categories of mobility, breathing and pain in addition to others. Thus, the make-up of the sample in both is quite different and as such comparison of the data is limited by this. In addition, the margin of error presented for the NDS is based on the sample and not each individual question. Thus any analysis based on this margin of error would provide conservative estimates only. The presentation of rates in Table 4 is descriptive only. It highlights where potential similarities may exist across both data sets. However, no definitive statement of comparability can be made at this point. Access to the micro data is required so that the data can be investigated further. This investigation would exclude those groups (disability and age groups) not common to both and would compare similar groups within the two data sets. This exercise would serve to confirm (or otherwise) the findings regarding comparability.

**Table 4: Data comparison on questions identified as the same**

ICF domain	NDS 2006	%	NPSDD 2009	%
<b>Environment</b>				
Attitudes	Avoiding doing things because of how other people reacted	n=247,000 (24.0)	Have attitudes represented a barrier to participation in past 12 months?	n=10,878 (25.2)
Built Environment	Accessibility difficulties outside the home	n=264,600 (46.2)	Has the physical environment represented a barrier to participation in the past 12 months?	n=10,878 (54.2)
<b>Participation</b>				
Education	Stopped education sooner than they wanted to	n=85,200 (31.7)	To what extent has your participation in education and training been restricted in the past 12 months?	n=10,878 (31.2)
Shopping	Difficulties in going to town/shopping	n=300,200 (56.0)	To what extent has your participation in shopping being restricted in the past 12 months?	n=10,878 (54.5)
Socialising	Difficulties in socialising in public venue	n=300,200 (48.6)	To what extent has your participation in socialising been restricted in the past 12 months?	n=10,878 (55.4)
Religion	Difficulties in attending religious ceremonies	n=300,200 (48.6)	To what extent has your participation in religion been restricted in the past 12 months?	n=10,878 (17.3)
Community life	Difficulties in taking part in community life	n=300,200 (53.5)	How much of a problem do you have joining in community activities in the same way as anyone else? (WHODAS)	n=10,878 (54.0)
<b>Activity</b>				
Washing	Taking a bath/shower by yourself	n=300,200 (30.5)	Difficulty washing your whole body (WHODAS)	n=10,878 (35.0)
Dressing	Dressing yourself	n=300,200 (21.4)	Difficulty getting dressed (WHODAS)	n=10,878 (35.1)

At a descriptive level we can see that the experience of attitudes, built environment, education, shopping, socialising, washing and community life appear to be comparable. Participation in shopping and community life indicating a greater comparability across the two data sets than other areas. However, this is indicative only and further exploration of the data as outlined above is required.

## Baseline versus trend data

There are many potential barriers to participation that may be experienced by people with disabilities in addition to a wide range of activities and life areas that people with disabilities may wish to participate in but experience difficulty or restriction in doing so. The data common to both the NDS and NPSDD do not represent the complete list but what is presented are key environmental, activity and participation factors that impact on the lived experience of people with disabilities in Ireland – attitudes, built environment, shopping, socialising, washing, dressing, community life and, to a lesser extent, religion. The NDS presents baseline data on these variables and the NPSDD has the potential to track changes in the experience of people with disabilities across these variables over time as data collection and update are on-going. In addition, the NPSDD records detailed information on the services used or needed by people with disabilities, and so there is also the potential to examine the impact of service interventions on any changes that may occur in participation experience over time. For example, if it is found that, over time, the number of people experiencing restriction in shopping has reduced on the NPSDD compared to the NDS, it is possible to examine if a particular intervention has occurred which may have enabled such positive change. Other variables that could be investigated further to ascertain the comparability between both data sets are transport, work and training, sport and exercise and maintaining friendships.

## Conclusion

This bulletin indicates that further investigation into the type of data captured and the extent of comparability between the NDS and the NPSDD is warranted. With the increasing need for an evidence base to support service planning, delivery and policy development, further interrogation of both data sets is not only required but essential. There is a wealth of information captured on disability and the disabling experience and it is opportune to mine these data to fully uncover their potential uses. As noted above, the comparison presented was based on published NDS data and the NPSDD 2009 data. This had implications in terms of age and type of disability profile which were not entirely comparable. A more detailed matching of data on the basis of age, gender and type of disability would provide an even better assessment of the comparability of both sets of data and, in turn, this would provide a more complete picture of the similarities and differences.

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