

# NPSDD Notes

An update on the National Physical and Sensory Disability Database



## Welcome

Welcome to the first edition of NPSDD Notes, a newsletter designed to keep you up to date with the progress of the National Physical and Sensory Disability Database (NPSDD). National implementation of the NPSDD began in January 2002. Four years on, we have a new data collection form with an exciting new module, the measure of ability and participation, new software and the first publications from the NPSDD. This newsletter provides you with more detail on each of these developments. We intend to produce intermittent newsletters to provide updates on NPSDD developments as they occur.

**Disability Databases Division  
Health Research Board**

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## Bringing you up to date with the NPSDD

The primary purpose of the database is the provision of information to plan service developments, prioritise service needs and assist in resource allocation decisions at national, regional and local level.

The NPSDD is designed to provide a picture of the specialised health and personal social service needs of people with a physical or sensory disability by monitoring current service provision and future service requirements. This data is collected and analysed to help ensure solid evidence is provided to disability service planners to help them make informed decisions about planning services on a national basis. This information is also a foundation for policies and interventions that will improve the lives of people with physical and sensory disabilities.

The ongoing success of the NPSDD is dependent on the continuing commitment of all services and agencies involved and of course the participation of individuals eligible to register on the database. There are currently in excess of 25,000 people registered on the NPSDD. While this figure is highly commendable, it is still somewhat off the potential target of 38,190 as outlined in the 2001 pilot implementation of the database. This figure was updated to 41,248 following publication of the 2002 census of population. To ensure the success of the NPSDD, individuals under 66 years, who currently receive and/or require specialised health and personal services within the next five years and have a persistent physical or sensory disability are urged to participate (contact details for local HSE areas are listed on page 8).

## First publications from the National Physical and Sensory Disability Database

The first publications from the NPSDD are based on data extracted from the NPSDD in June 2004 when there were 20,825 people registered on the National Physical and Sensory Disability database (NPSDD). The data from two Health Service Executive areas who were still in the early stages of data collection were excluded (737 records) together with data from all people aged 66 years and over at the time of reporting (411 records) as responsibility for the provision of services for this group of people lies within Older Peoples Services in the Department of Health and Children and the Health Service Executive (HSE) rather than within Disability Services. Excluding these records reduced the number of active records analysed in the publication to 19,677.

## National Physical and Sensory Disability Database

### A preliminary analysis

In December 2004 the first publicly available data from the NPSDD was released (Galligan and Mulvany 2004) and is available to download at [www.hrb.ie](http://www.hrb.ie). The purpose of this preliminary analysis was to provide evidence to inform decision-making by disability service planners in relation to resource allocation for 2005.



## National Physical and Sensory Disability Database Committee

### Annual Report 2004



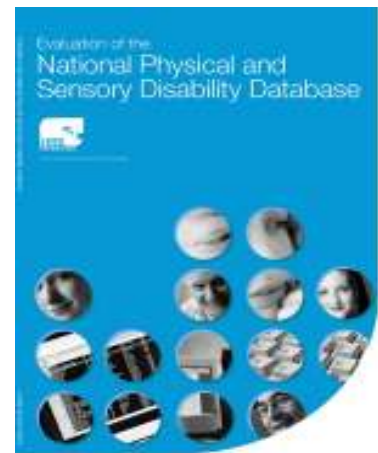
The first annual report of the National Physical and Sensory Disability Database Committee (NPSDDC) has just been published. This report highlights both current trends in service use and future requirements for specialised health and personal social services as identified in 2004. The information contained in the Annual Report is a more comprehensive analysis of the data produced in the December 2004 bulletin (above).

The National Physical and Sensory Disability Database enables those involved with the planning and delivery of services to identify not only the level of need amongst those awaiting services, but also the service changes required by those already in receipt of services. The service-planning period covered by this report is 2005-2009.

A summary of the 2004 report is reproduced on pages 4-5 of this newsletter.

## Evaluation of the National Physical and Sensory Disability Database

In July 2005 the report on the Evaluation of the National Physical and Sensory Disability Database was published. This report documents the findings of a comprehensive and detailed evaluation of all aspects of the database that was undertaken by a working group of the NPSDD Committee. The evaluation included the experiences and views of all interested stakeholders including people who are registered on the database, umbrella and representative bodies, government departments and statutory agencies, coordinating committees and database teams from the former health boards. The contribution of everyone involved proved invaluable to the success of this evaluation process. It is anticipated that the ongoing enhancement of the NPSDD, along the lines recommended in this report, will ensure that participation levels in the database will continue to increase, allowing for more precise targeting of resources to areas of most need. Since the report was published, a sub-committee of the NPSDDC has commenced work on the development of an action plan to address the report's recommendations (see below).



### Key recommendations arising from NPSDD Evaluation

The key recommendations from the Evaluation report are outlined below:

- ⇒ Implementation of the NPSDD in a standardised manner should be a priority with health service management in an effort to increase database coverage in areas where progress has been slow. Efforts should also be made to target potential participants who are currently outside the existing network of specialised health services.
- ⇒ The NPSDDC should become more strategic in its approach in the coming years.
- ⇒ There has been a long period of development for the NPSDD during which high expectations have been raised. It is therefore crucial to recognise that there is a long history of people feeling that their needs have not been adequately met and consequently participants and potential participants need to start seeing the relevance and impact of the NPSDD, the Health Service Executive needs to use the information, and the Department of Health and Children needs to make sure this is happening.
- ⇒ The image of the NPSDD needs to be enhanced. The negative connotations associated with the existing name of the NPSDD are acknowledged and consideration will be given to changing this to a more publicly accessible name.
- ⇒ The current voluntary nature of NPSDD participation is seen as a significant barrier to comprehensive identification of the specialised health service needs of people with physical or sensory disabilities. The NPSDDC should explore the potential for a statutory mandate to record and maintain a minimum dataset pertaining to all service users.
- ⇒ The existing data form should be reviewed and an effort made to group hearing impairment, visual impairment and physical disability services for children and physical disability services for adults, together in blocks to facilitate form completion.
- ⇒ The feasibility of developing a unified disability services database should be explored.
- ⇒ The Department of Health and Children should convene a stakeholder network of government departments and agencies, based on their potential use of relevant NPSDD statistical information and their role in promoting the NPSDD.
- ⇒ Each HSE area should implement the approved management structures for the disability databases to enable the recommendations of this report to be implemented.

## Summary of findings: Annual Report 2004

The NPSDD provides a picture of the specialised health and personal social service needs of people with a physical or sensory disability by monitoring current service provision and future service requirements over a five-year period. Individuals under the age of 66 years who currently receive specialised health and personal social services and/or require such services within a five-year period are included, with their consent, on the database.

Specialised health and personal social services refer to therapeutic intervention and rehabilitation services, personal assistance and support services, respite, day and residential services. The information for the database is collated by the HSE through interviews with individuals who meet the registration criteria and it is managed nationally by the Health Research Board.

In June 2004 there were 20,825 people registered on the National Physical and Sensory Disability Database (NPSDD). The data from two Health Service Executive (HSE) areas who were still in the early stages of data collection were excluded (737 records). Data from all people aged 66 years and over at the time of reporting (411 records) were also excluded, as responsibility for the provision of services for this group of people lies within Older Peoples' Services in the Department of Health and Children and the HSE rather than within Disability Services. The 2004 Annual Report is based on the remaining 19,677 records.

In interpreting the data in the NPSDDC annual report, it is important to note the following:

- The primary focus of the NPSDD is to facilitate service planning and provision.
- The NPSDD does not provide any definitive epidemiological statement on the number of people with a particular type of disability.
- Participation in the NPSDD is voluntary.
- As implementation of the NPSDD is ongoing, these data are not intended to provide a comprehensive picture of service use and possible future need.
- The NPSDD does not include those who were aged over 65 years at the time of reporting as responsibility for their service provision lies with Services for Older People rather than Disability Services.

### Demographic profile

Males accounted for a higher percentage of registrations than females. A total of 10,373 males and 9,304 females were registered, representing 52.7% and 47.3% respectively of all NPSDD registrations.

The majority of people (16,965, 86.2%) were residing with family members; 9.3% (1,829 of all registrations) were living alone; 2.5% (500) were living in full-time residential services; 0.3% (56) were living with foster families, and 0.7% (147) were living with non-relatives.

A total of 15,244 people (77.5% of all registrations) were living in private accommodation; 3,753 people (19.1%) were in rented accommodation, and 485 persons (2.5%) were in full-time residential services.

More than half the people registered on the NPSDD, (11,387, 57.9%) reported that they had a primary carer.

The most frequently reported types of disability were physical disability only (16,246 people, 82.6% of all NPSDD registrations), hearing loss/deafness only (1,347 people, 6.8% of all NPSDD registrations) and visual disability only (1,193 people, 6.1% of all NPSDD registrations).

## Summary of Findings: Annual Report 2004 continued

### Service provision in 2004

Of the 19,677 people registered on the NPSDD by June 2004, 89.5% were accessing at least one of the following service groupings: therapeutic intervention and rehabilitation services, personal assistance and support services, respite, day and residential services. Service provision to those registered on the NPSDD as of June 2004 may be summarised as follows:

- 15,492 people with a physical and/or sensory disability were in receipt of therapeutic intervention and rehabilitation services; this group represents 78.7% of all NPSDD registrations.
- 5,255 people (26.7%) were in receipt of personal assistance and support services.
- 10,092 people (51.3%) were in receipt of day services and activities.
- 628 people (3.2%) were availing of residential services.
- 2,060 people (10.5%) were availing of planned respite services.

### Service requirements in 2004

The service requirements of those registered on the NPSDD at June 2004 may be summarised as follows:

#### Therapeutic intervention and rehabilitation services

- 11,740 people (59.7% of all NPSDD registrations) required assessment for therapeutic intervention and rehabilitation services
- 1,299 people (6.6%) were assessed and placed on a waiting list
- 133 people (0.7%) were assessed but were unable to avail of these services for a variety of reasons.

#### Personal assistance and support services

- 6,262 people (31.8%) required assessment for personal assistance and support services.
- 359 people (1.8%) have been assessed and wait-listed for personal assistance and support services.
- 126 people (0.6%) were assessed but unable to avail of these services for a variety of reasons.

#### Day services or activities

- 2,972 people (15.1%) who were availing of day services or activities required some changes/additions made to their existing services.
- 1,748 people (8.9%) are not availing of day services or activities, but required such supports.

#### Residential services

- 451 people (2.3%) of those registered on the NPSDD were not availing of residential services but required these supports.
- 25 people (0.1%) were availing of residential services and needed some changes made to their existing services.
- 154 people (0.8%) required an alternative or additional residential services.

#### Respite services

- 4,365 people (22.2%) required assessment for respite services.
- 211 people (1.1%) had already been assessed and were wait-listed for respite services.
- 96 people (0.5%) had been assessed as requiring a respite service but were unable to avail of the service for a variety of reasons.

The various services listed above were required by individuals across the period 2005-2009, though most service needs arise in the earlier years of this planning period. This first annual report from the NPSDD, which is based on almost 20,000 people who were registered on the NPSDD by June 2004, represents the cumulative specialised health service needs of this group of people. Achieving more comprehensive coverage will further enhance the value of the NPSDD as a planning tool and the HSE regions which are lagging behind in the implementation of the NPSDD will need to prioritise this important task if we are to maximise the benefits for all that can be derived from this information system.

## Information collected

To protect client confidentiality, all identifying information (in *italics*) is removed from the database before statistical records are made available to the HRB and the Department of Health and Children.

The database form consists of the following information:

- Personal details including *name, address, telephone number*, personal identification number, date of birth, gender, *next of kin details*, HSE area/community care area/district electoral division, present service location/convenient service location, type of living accommodation, living arrangements and primary carer.
- Administrative details contains details about the NPSDD process including the name of the person who administered the data form, when it was last completed and the individuals preferred method of correspondence
- Barriers and challenges
- Participation
- Therapeutic intervention and rehabilitation services
- Personal assistance and support services
- Respite services
- Day services
- Residential services
- Technical aids and appliances
- Additional specialised health and social services
- Details of disability
- WHODAS II
- Additional information
  - Medical card holder
  - Long term illness card holder

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## New fields in the database form for 2005/2006

It is essential that the NPSDD is as relevant and up-to-date as possible and as a result, the content of the data form is constantly reviewed and revised in order to ensure that it continues to capture relevant information. In June 2005, new items were added to the 2005/2006 database form in the *Administrative Details 2* section under the heading **Additional Specialised Health and Personal Social Services**.

On an ongoing basis, requests have been submitted to the national committee seeking the inclusion of additional services on the database form. The national committee suspended decision-making on the addition of new services until the release of the disability bill as it was felt that the outcome of this bill could have implications for the structure and content of the data form. As an interim solution, the committee sanctioned the inclusion of three new fields “Additional Health and Personal Social Services fields”.

The addition of these fields allows a service-user to report specialised health and personal social services that they are currently receiving but are not currently captured on the database form, or specialised services that they require in the future that are not currently captured on the data form. The data from these fields will be reviewed by the NPSDDC and may result in specific services being added to the NPSDD form.

The image shows the cover of the 'Physical and Sensory Disability Database Form 2005/2006'. The cover is white with black text. At the top, it says 'NATIONAL COMMITTEE ON DISABILITY SERVICES'. Below that, it says 'PHYSICAL AND SENSORY DISABILITY DATABASE FORM 2005/2006'. At the bottom right, it says 'NATIONAL COMMITTEE ON DISABILITY SERVICES'.

## Measure of ability and participation

In 2004 an important new module was added to the NPSDD which will enable service planners to distinguish between groups of people with diagnosed conditions who have no impairment of function and those with substantial impairment.

In developing what is essentially a measure of disability, a working group of the NPSDDC adopted the International Classification of Functioning, Health and Disability (ICF), which was published by the World Health Organization (WHO) in 2001. The adoption of this classification represents best practice internationally and is supported by Disabled Persons International as a framework that reflects the social model of disability.

The measure itself reflects the fact that disability is created by an individual's reduced functioning or activity limitations (represented by the WHODAS score) and the environment represented by the section on barriers and challenges. The disability itself is represented by the extent to which a person's participation in major life activities is restricted.

Thus the database will be able to relate service needs and health condition with the degree of activity limitation and participation restriction that a person is experiencing. Further, it will be possible to identify the environmental factors implicated in creating the disability. The implication of this new module is that planners will have the potential to assess the extent to which the introduction of new services results in health or social gains.

## NPSDD software

One of the key challenges highlighted by the Evaluation report was the need for a good software package to support the NPSDD. As a result, centralised, web-enabled software was implemented in February 2004, with an emphasis on user-friendliness and the highest level of security (as only authorised users can access the website). The web-based software means information can be updated as changes happen. It also ensures that up-to-date information is available to service planners outside of the scheduled benchmarking period.

The software contains:

- validation rules that check the data as it is entered into the database
- built-in service planning reports
- a user-friendly report generator for ad-hoc reporting requirements.



Software training has been made available to all database personnel with modules covering the basic functions of the NPSDD workflow, and report generation. In 2006 the HRB will begin the process of extending access to the database to authorised users within physical and sensory service providers in accordance with the Access Protocol for the Disability Databases.

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