

DISABILITY NEWS

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SPECIAL POINTS OF INTEREST:

- **NIDD cover competition**
- **NIDD and NPSDD annual reports**
- **NPSDD direct access project**

Progress notes

In the first half of 2009 the DDU focused its attention on securing commitment to the review of NPSDD data. It presented a proposal to the National Physical and Sensory Disability Database (NPSDD) national committee on ways in which the reviews might be undertaken, focusing on those cases that have not been reviewed for 5 years or more. Discussions have been ongoing with the HSE and the Department of Health and Children about the reviews and how they can be progressed in HSE local areas.

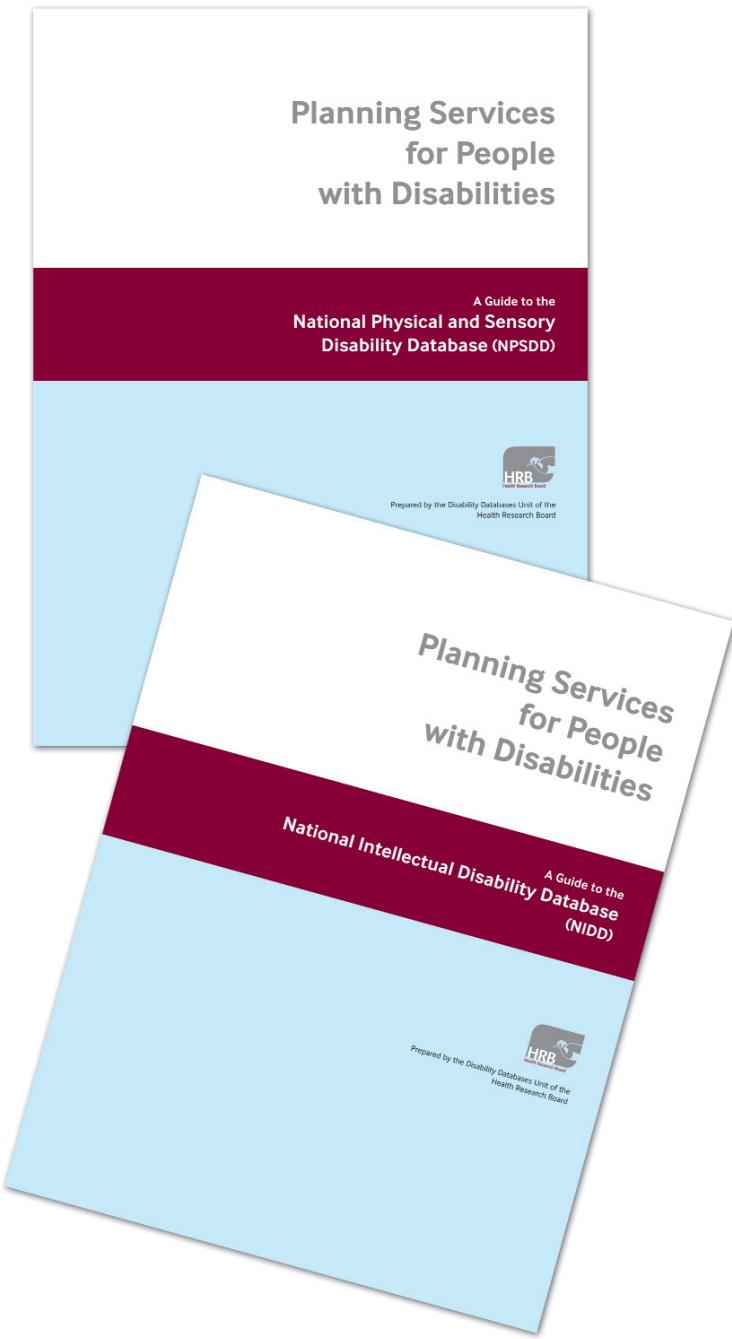
In April 2009 the DDU published another HRB trends paper entitled 'Trends in demand for services among those aged 50 years and over with an intellectual disability, 2003–2007'. This paper outlines key trends in demographics, in service usage and in service need of those aged 50 years and over who are registered on the National Intellectual Disability Database (NIDD). The data for the paper were obtained from the NIDD datasets for the years 2003–2007. Census data were used to compare life expectancy and morbidity in older age groups in the general population with those of people aged 50 years and over registered on the NIDD.

This paper was undertaken to inform service planners of the need for joined up services for this particular group on the NIDD. It was also undertaken to contribute to the growing interest internationally and at home, in the needs of people with intellectual disability as they age. Research on the onset of age-related conditions found that these can occur earlier in people with intellectual disability, thereby impacting on the services they are likely to require. The literature on ageing and intellectual disability also shows that intellectual disability services may be unprepared for the changing needs of older people with intellectual disability, while services for older people are not readily accessible to people with intellectual disability.

While people with intellectual disability are living longer their life expectancy remains significantly lower than that of the general population. Comprehensive studies such as the Intellectual Disability Supplement to the Irish Longitudinal Study of Ageing (TILDA) will help to establish why this is so. The DDU of the HRB is a member of the Advisory Group to the TILDA Intellectual Disability Supplement which is being funded by the HRB. The TILDA project will use the data on the NIDD to draw a sample for inclusion in the study. As a backdrop to the TILDA study, our trends paper was compiled to provide an overall profile of the service needs of older people with intellectual disability. A copy of the paper can be obtained from Sarah Craig at 234 5113, scraig@hrb.ie or online at www.hrb.ie.

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Accessible information leaflets

At the beginning of this year, the DDU produced easy-to-read information leaflets for both the NIDD and the NPSDD.

These were developed in conjunction with St. Michael's House and with Inclusion Ireland. The leaflets are available by contacting Fionnola Kelly at 234 5115, fkelly@hrb.ie or at www.hrb.ie.

NIDD developments

Annual report 2008

The 2008 annual report will be published in July 2009. If you are not on our mailing list and would like to receive a copy please contact **Caraiosa Kelly** at 234 5194 or ckelly@hrb.ie.

NIDD cover competition

Judging of the art competition for the NIDD annual report cover was held in Galway in May. A large number of entries were received and as with every year the standard of art work was very high. Thanks are due to the National Federation of Voluntary Bodies who organised the competition and facilitated the judging of entries. A prize-giving ceremony for the winner of the competition will be held in September of this year.

NIDD committee membership

Two new members have joined the committee which is responsible for overseeing the work on the NIDD. Ms Elizabeth Doherty, Area Disability Specialist, HSE West has replaced Ms Marion Meany of the HSE and Mr Paul Ledwidge, St. Michael's House representing the National Federation of Voluntary Bodies has replaced Mr Patrick Mc Ginley. Sincere thanks are due to both Marion and Patrick for their commitment to the work of the NIDD in the last number of years.

NPSDD work

Annual report 2008

The NPSDDC annual report 2008 is now available on the HRB website (www.hrb.ie). This is an on-line publication only and no hard copies are available this year.

Agency access

The pilot project for direct access to NPSDD commenced early in 2009. Four agencies are on board and are currently in the process of collecting and inputting information. The pilot will be completed by September 2009. A report reviewing the pilot will be prepared and presented to the national committee. The long term goal is to have all agencies directly accessing the Database. For further information on this, please contact Mary-Ann O'Donovan (modonovan@hrb.ie).

Rehabilitation and Society article

Mary-Ann O'Donovan and Anne Doyle of the NPSDD team along with Dr. Pamela Gallagher of Dublin City University recently had an article published in the peer-reviewed journal Rehabilitation and Society. The article explores the participation and functioning experience of people registered on the NPSDD. The article reference is O'Donovan, MA, Doyle, A, Gallagher, P (2009) 'Barriers, activities and participation: Incorporating ICF into service planning datasets', *Rehabilitation and Society*, 1-8.

WHO functioning and disability reference group (FDRG)

Mary-Ann O'Donovan of the DDU attended a further meeting of this group in Geneva in May 2009. The purpose of the meeting was to progress the writing of guidance notes for the use of the ICF in population and case-based data streams. The document is due to be finalised in Autumn 2009.



Events

NDA annual conference 2009

The National Disability Authority (NDA) is currently engaged in a multi-annual programme of work exploring independent and community living options for people with disabilities. NDA's recent work in this area has focused on policy and practice in promoting independent and community living options for people with intellectual disabilities. Future work will broaden this focus to include those with other disabilities in the course of this multi-annual programme. Its annual conference 2009 entitled: *Promoting independent and community living for people with intellectual disabilities* will be hosted at the Croke Park conference centre, Dublin 3 on Tuesday 6 October 2009.

A call for papers was issued recently on this theme in the following areas:

- 1) Using technology to promote independent and community living
- 2) Sexuality, intimate relationships and parenting
- 3) Innovation in systems and practices to promote independent and community living

For further information contact Emma Doyle at emdoyle@nda.ie.

Policy focus

In May 2009, the Health Information and Quality Authority (HIQA) launched its national quality standards for people with disabilities. These standards have been developed for the purposes of registration and inspection of residential services for people with disabilities. They will assist service providers to assess the quality of the service they provide in advance of inspection. They will also act as a guide to individuals and families as to what they can reasonably expect of a residential service. The standards were developed following a period of consultation to which the DDU contributed. The areas that are addressed by the standards are:

- Quality of life
- Staffing
- Protection
- Development and health
- Rights
- The physical environment
- Governance and management

Copies of the standards document are available for download from www.hiqa.ie



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