



HRB Statistics Series 34

Annual Report of the National Physical and Sensory Disability Database Committee 2016 Main Findings

Anne Doyle and Sarah Hourigan

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'Under the sea' by Olga Forde
NPSDD Cover Design Winner 2016

My name is Olga Forde, I live in Kinvara in Co. Galway. It is by the sea. I like reading, cycling and listening to music. I love music from the 70's and 80's. I attend the 'Dolmen Centre' in Kinvara during the day. I love the music and art and craft classes there. I like going out for coffee and meeting friends in the café on the quay. I like discos and parties. I love computers and have my own iPad and a laptop. I listen to music and look up things.



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About the HRB

The Health Research Board (HRB) is the lead agency supporting and funding health research in Ireland. We also have a core role in maintaining health information systems and conducting research linked to these systems. Our aim is to improve people's health, build health research capacity, underpin developments in service delivery and make a significant contribution to Ireland's knowledge economy.

Our information systems

The HRB is responsible for managing five national information systems. These systems ensure that valid and reliable data are available for analysis, dissemination and service planning. Data from these systems are used to inform policy and practice in the areas of alcohol and drug use, disability and mental health.

The **HRB Statistics Series** compiles data on problem alcohol and drug use, disability and mental health from a single point or period in time.

Previous reports associated with this series are:

- » Activities of Irish Psychiatric Units and Hospitals
- » National Physical and Sensory Disability Database Committee Annual Reports
- » National Intellectual Disability Database Committee Annual Reports

The **Disability Databases Team** manages two national service-planning databases for people with disabilities on behalf of the Department of Health (DoH): the National Intellectual Disability Database (NIDD), established in 1995, and the National Physical and Sensory Disability Database (NPSDD), established in 2002. These databases inform decision-making in the planning of specialised health and personal social services for people with intellectual, physical or sensory disabilities.

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- » staff at the Disability Unit, Department of Health;
- » the Health Service Executive, in particular the database coordinators and the database administrators/managers;
- » service providers;
- » all service users throughout Ireland.

The Committee would also like to acknowledge the outgoing Chairperson, Gráinne Duffy, for her enthusiasm and support for the databases over the past four years and to welcome Ms Patsy Carr as its new Chairperson.

Members of the National Physical and Sensory Disability Database Committee in 2016

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<p>Ms Margaret Dorney (Secretary) Disability Unit Department of Health</p>	<p>Mr Gerard Tully National Disability Unit Health Service Executive</p>
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1

Introduction

Background

This report is based on a review of current service provision and future service requirements of those registered on the National Physical and Sensory Disability Database (NPSDD). The objective of the NPSDD is to assist with service planning in relation to the specialised health and personal social service needs of people with a physical, sensory, neurological, speech or language disability. Information is collected from people with a disability who are currently receiving a specialised health or personal social service, and/or a specialised hospital service, or have a requirement for these service types within the next five years. For individuals to be eligible to register on the NPSDD they must meet all five registration criteria. These individuals must:

1. have a persistent physical, sensory, neurological, speech or language disability arising from disease, disorder or trauma;
2. in the case of dual disability, have a predominant disability that is one of the above disabilities;
3. are less than 66 years of age;
4. are receiving, or require, a specialised health or personal social service, and/or a specialised hospital service, which is related to their disability; and
5. have consented to be included on the database.

When interpreting the data contained in this report, it is important to note the following:

- » The primary focus of the NPSDD is to facilitate service planning and provision
- » As this report is a planning tool for *disability* service planners and providers, it does not include those who were aged 66 years or over at the time of reporting.

- » Participation in the NPSDD is voluntary. Also, not every individual in Ireland who has a physical or sensory disability is availing of, or requiring, a specialised health and personal social service. The database cannot provide any definitive epidemiological statement on the number of people with a particular type of disability or diagnosis, nor does it cover the proportion of people living in Ireland who have a physical or sensory disability and have chosen not to register.
- » The data contained in this report represent the situation in December 2016. Coverage for the NPSDD has been uneven for several groups and areas, therefore the data cannot give a representative picture of all service use and service need. However, they are an important indication of the pattern of current service use and estimated future requirements.

NPSDD structure and management

The NPSDD is owned by the Department of Health (DoH) and managed by the Health Research Board (HRB). The Health Service Executive (HSE) and disability service providers are responsible for the collection and return of the data to the HRB.

At the end of each year the HRB takes a snapshot of anonymised information within the database, which forms the national dataset for that year. This report is based on the dataset for 2016.

The analysis in this report provides an outline of the following:

- » A summary of the 21,763 registrations is provided in **Section 2 – Summary of numbers registered**. It is recommended that a full review of each NPSDD record takes place on an annual basis. At present, rates of review are lower than anticipated, and some of the data have not been updated annually. Of the 21,763 registrations, 11,911 (54.7%) records were registered or reviewed in the five year period 2012–2016. The numbers of registrations and reviews carried out are influenced by staffing levels within each area.
- » **Section 3 – Profile of new registrations and recent reviews** is based on these 11,911 registrations.
- » **Section 4 – Measure of Activity and Participation (MAP)** is based on 8,092 people aged over 16 years and registered or reviewed in the five year period 2012–2016.
- » **Section 5 – Current service use and future service requirements** is based on 6,111 (28.1%) people who were either registered or reviewed in 2016. This approach ensures that an up-to-date picture is established.

The 2016 annual report differs to previous years as it summarises the main findings from the NPSDD. Additional supplementary tables are available on the HRB website www.hrb.ie

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Summary of numbers registered

Registrations and reviews

A total of 21,763 people were registered on the NPSDD in December 2016. New registrations decreased from 562 in 2015¹, to 550 in 2016. The number of reviews of existing records increased by 19.8% from 4,459 in 2015 to 5,561 in 2016.

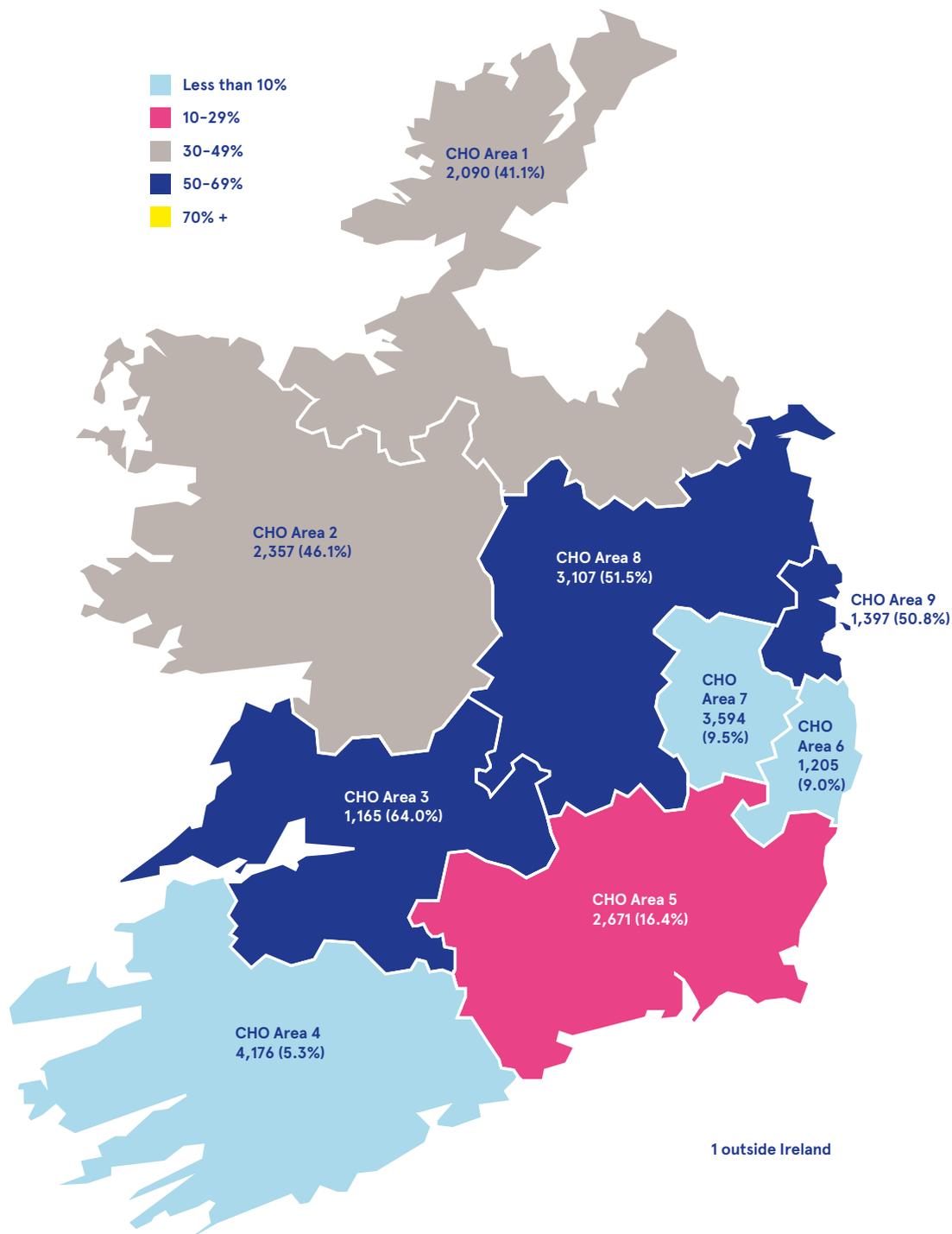
In addition to the work carried out by the HSE, the NPSDD records of 3,630 people (16.7% of the total number registered) were directly managed by 33 service providers in 2016. These service providers completed 28.4% of the total number of registrations (156) and 38.2% of the total reviews (2,124) carried out within the year. In total, 73.7% of the data managed by these service providers was up-to-date by 2016 year end. Moreover, most of the NPSDD records managed by service providers were updated between 2012 and 2016 (3,424, 94.3%).

CHO Area of Residence

Figure 1 shows the total number of people registered on the NPSDD in 2016 by CHO area of residence, along with the percentage of records in that CHO that were up-to-date. The rate of 2016 registrations/reviews varied by HSE CHO area, and was highest in CHO area 3 - Clare, Limerick, North Tipperary (64.0%), CHO area 8 - Laois/Offaly, Longford/Westmeath, Louth, Meath (51.5%) and in CHO area 9 - Dublin North, Dublin North Central, Dublin North West (50.8%). Many areas had significantly lower review rates.

¹ Hourigan S, Doyle A and Carew A (2016) *Annual Report of the National Physical and Sensory Disability Database Committee 2015*. HRB Statistics Series 31. Dublin: Health Research Board.

Figure 1 Total number of people registered, and percentage registered/reviewed by HSE CHO area of residence (21,763 records), NPSDD 2016



3

Profile of new registrations and recent reviews (2012–2016)

Tables and figures presented in this section of the report exclude records of those registered or last reviewed prior to 2012.

This section is based on 11,911 (54.7%) records which were registered or reviewed in the period 2012–2016.

Type of disability

The three most common types of disability recorded on the NPSDD were neurological disability (36.6%), multiple disabilities (31.9%) and physical disability (16.7%) (Table 1).

Table 1 Number of people registered by type of disability and gender (11,911 records), NPSDD 2016

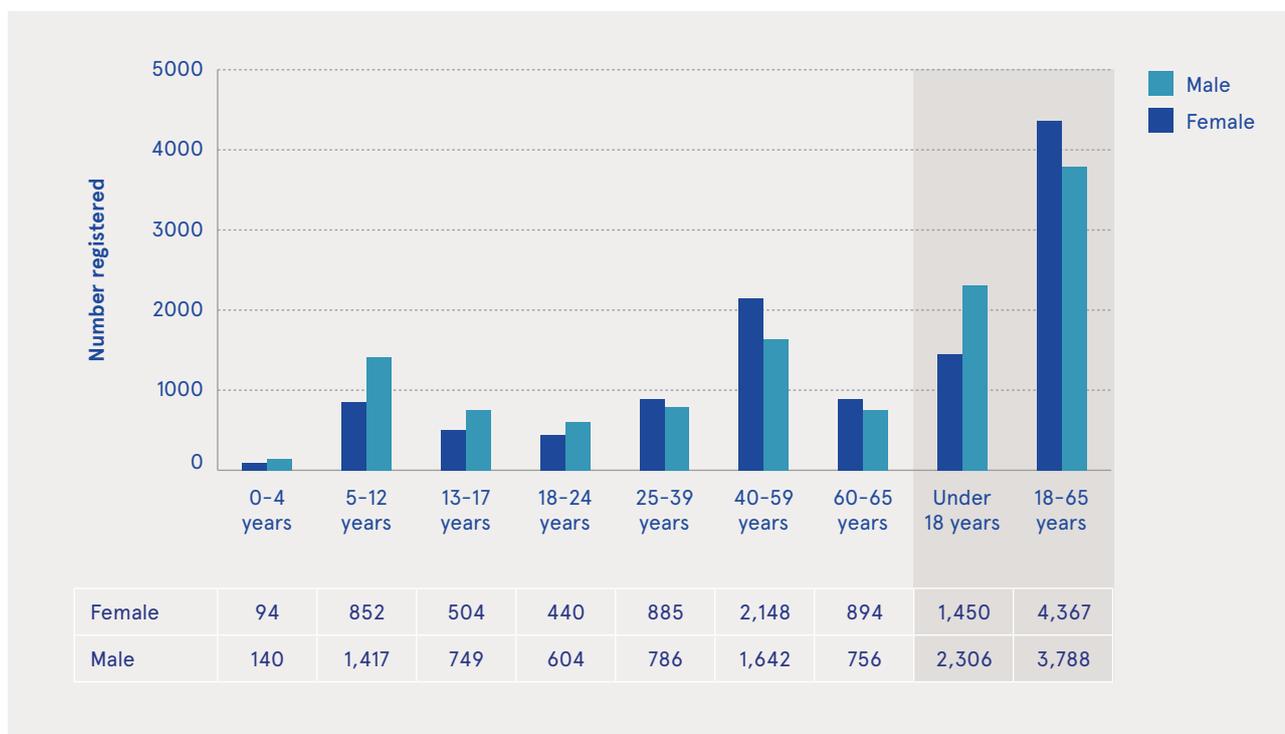
Type of disability	Gender				Total	
	Female		Male		n	%
	n	%	n	%		
Neurological disability	2,282	39.2	2,073	34.0	4,355	36.6
Multiple disabilities	1,764	30.3	2,032	33.2	3,796	31.9
Physical disability	999	17.2	990	16.2	1,989	16.7
Speech and/or language disability	182	3.1	430	7.1	612	5.1
Hearing loss/deafness	313	5.4	273	4.5	586	4.9
Visual disability	277	4.8	296	4.9	573	4.8
Total	5,817	100.0	6,094	100.0	11,911	100.0

Age and gender

The majority (8,155, 68.5%) of those registered on the NPSDD were aged 18 years or over and more than half (6,094, 51.2%) were male.

Males outnumbered females in all age groups under 24, whilst in the 25 years and older age groups females outnumbered males (Figure 2).

Figure 2 Number of people registered by age group and gender (11,911 records), NPSDD 2016



Living accommodation and living arrangements

The majority of people (9,065, 76.1%) lived in private accommodation, 20.1% (2,395 people) lived in rented accommodation and 3.3% (398 people) lived in full-time residential settings. Fifty three people (0.4%) described their living accommodation as 'other'.

The majority of people (10,087, 84.7%) lived with family members, 1,264 people (10.6%) lived alone and 160 people (1.3%) lived with non-relatives such as friends, neighbours, a foster family, or with 'others'. The living arrangements for two individuals was not provided.

Primary diagnosis

The most commonly reported primary diagnostic categories² were the nervous system (6,177, 51.9%), followed by communication (1,295, 10.9%) and musculoskeletal system (1,038, 8.7%).

The primary diagnosis varied with the person's age and gender. For example, those whose primary diagnosis was communication were mostly male (931, 71.9%), and aged five to twelve years (542, 41.8%). Those with a diagnosis from the musculoskeletal group were mostly female (581, 56.0%), commonly aged 40-59 years (213, 20.5%). Table 2 shows high numbers of people in the nervous system diagnostic category across all age groups.

² Diagnostic categories recorded on the NPSDD are based on a modification of the International Classification of Diseases (ICD-10), World Health Organization (WHO), (1992), 10th Revision.

Table 2 Primary diagnostic category by age group (11,911 records), NPSDD 2016

Primary diagnostic category	Age group									Total	%
	0-4 years	5-12 years	13-17 years	18-24 years	25-39 years	40-59 years	60-65 years	Under 18 years	18-65 years		
Behavioural	0	0	~	~	~	0	~	~	~	5	0.0
Blood and blood forming organs	~	5	6	~	5	~	~	12	14	26	0.2
Circulatory system	~	20	12	13	9	37	50	35	109	144	1.2
Communication	22	755	382	118	16	~	~	1,159	136	1,295	10.9
Congenital	17	134	95	61	15	13	~	246	91	337	2.8
Digestive system	~	14	7	6	~	7	5	22	20	42	0.4
Ear complaints	12	101	88	108	169	313	104	201	694	895	7.5
Endocrine and metabolic	~	37	22	33	22	22	8	60	85	145	1.2
Eye complaints	10	66	68	69	162	323	154	144	708	852	7.2
Genito-urinary system	~	~	8	0	~	26	11	14	40	54	0.5
Infectious and parasitic	0	0	~	~	~	18	34	~	58	59	0.5
Intellectual/developmental	87	283	18	6	0	0	0	388	6	394	3.3
Musculoskeletal system	11	117	87	91	106	370	256	215	823	1,038	8.7
Neoplasms	0	13	5	6	15	37	17	18	75	93	0.8
Nervous system	66	677	391	453	1,035	2,584	971	1,134	5,043	6,177	51.9
Respiratory system	0	38	60	72	104	30	28	98	234	332	2.8
Skin disease or disorders	~	5	~	~	~	5	7	8	15	23	0.2
Total	234	2,269	1,253	1,044	1,671	3,790	1,650	3,756	8,155	11,911	100.0
Percentage	2.0	19.0	10.5	8.8	8.8	31.8	13.9	31.5	68.5	100.0	

~ To protect against the risk of indirect identification of individuals, values in cells containing less than five cases have been suppressed.

Secondary diagnosis

The NPSDD records primary diagnoses and, if applicable, a secondary diagnosis. Information on multiple diagnoses allows for a broader understanding of the individual’s diverse circumstances and needs. 43.6% (5,197 people) reported a secondary diagnosis in addition to their primary diagnosis. Those most likely to report a secondary diagnosis had a primary diagnosis from the genitourinary system, circulatory system and neoplasm groups.

While slightly more people with a secondary diagnosis were male (2,696, 51.9%), females were more likely to report a secondary diagnosis related to the neoplasm groups, skin disease or disorders or infectious and parasitic groups. Males were more likely than females to report a secondary diagnosis from the behavioural, communication or intellectual/developmental groups.

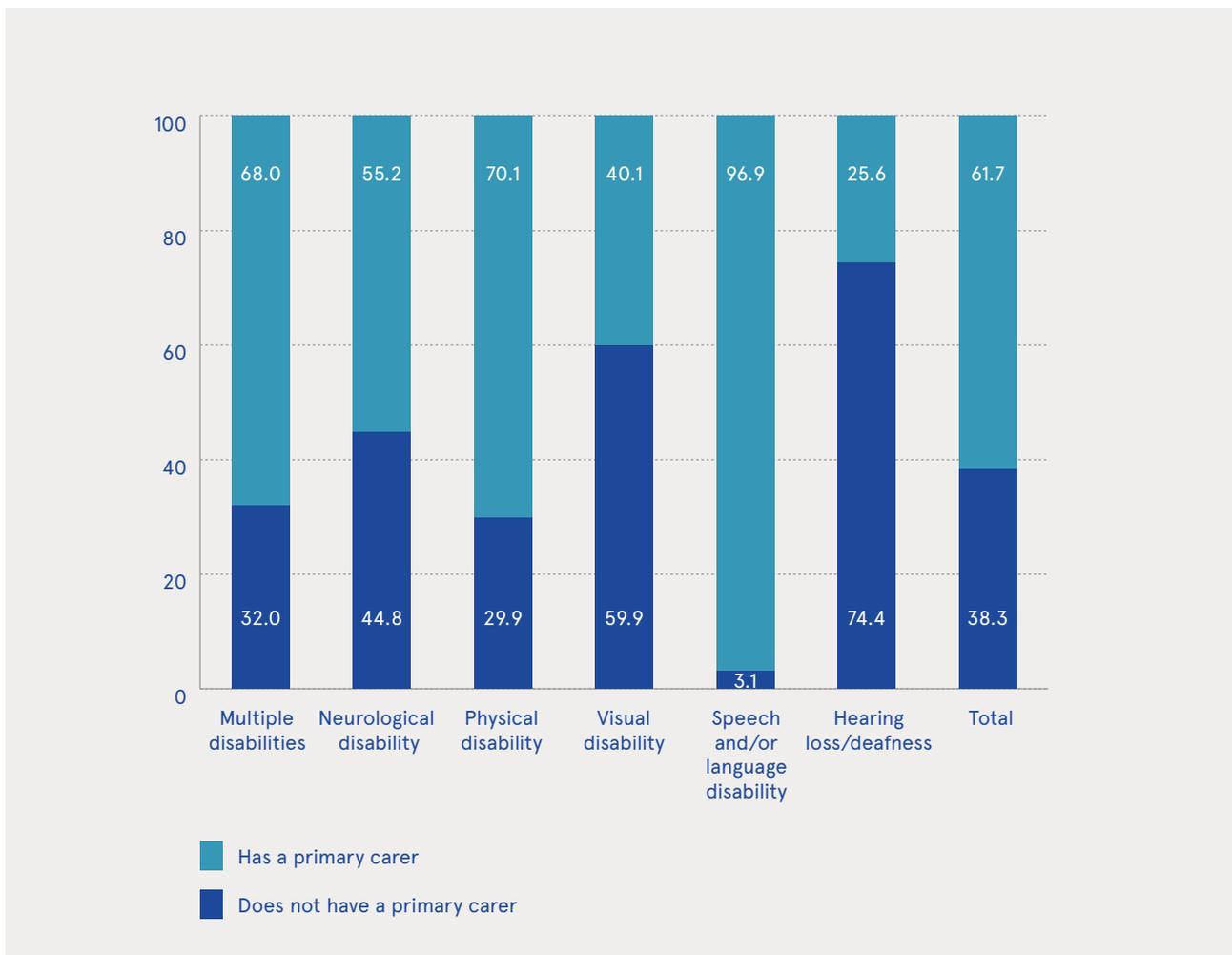
Primary carers

Primary carers play an important role in the lives of many people with a disability, providing essential supports either in place of, or in addition to, service providers. A primary carer may be a family member, a friend, or a neighbour who provides regular, sustained care and assistance to the person requiring support. Information about primary carers of this type is recorded on the NPSDD if an individual has a carer who provides

domestic, personal, or social care other than the formal support provided by a personal assistant, the HSE or a non-statutory service provider.

More than half of the people (7,352, 61.7%) registered on the NPSDD, whose records were reviewed in the period 2012-2016, reported having a primary carer. Not surprisingly, those most likely to report having a primary carer were aged less than 18 years. 96.4% (7,090 people) lived with their primary carer.

Figure 3 Primary carer by type of disability (11,911 records), NPSDD 2016



Relationship of primary carer

The majority of primary carers were parent(s) providing care to those aged under 18 years. Those aged 18 years and older who had a primary carer were predominately cared for by a parent or spouse/partner. However, as the age of the individual increased, the likelihood of a spouse being identified as their carer also increased. Being cared for by a spouse or partner was the most common informal care arrangement for those aged 60 years and over (527, 76.0%).

126 people with a primary carer (1.7%) reported being cared for by a son or daughter; however, the proportion increased as the age of the person increased. Approximately one in ten (69, 9.9%) people aged 60 to 65 years with a primary carer were cared for by a son or daughter.

Age of primary carer

The majority of primary carers (5,164, 70.2%) were aged 19 to 49 years.

Out of 631 (8.6%) primary carers aged 60–69 years, 293 (46.4%) were the spouses or partners of the individual. Parent(s) accounted for 284 (45.0%) of carers aged 60–69 years, while twenty nine (4.6%) carers aged 60–69 years were a sibling. 194 (2.6%) primary carers were aged 70 years and over and a small number of primary carers were aged 18 years or younger (7, 0.1%).

4

Measure of Activity and Participation (MAP)

The Measure of Activity and Participation (MAP) was introduced on the NPSDD data form in 2004 and consists of three self-reported sections:

- » Barriers and challenges – the barriers to participation that the individual experienced in the previous twelve months. Barriers include income, transport, physical environment, and people’s attitudes.
- » Participation restriction – the extent to which participation in major life areas, such as education, employment, socialising, and shopping was restricted in the previous twelve months.
- » World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) – the extent to which the individual experienced difficulty, in the previous 30 days, with daily activities such as washing, dressing, communicating and concentrating. This is a standardised measure developed by the WHO, which is based on the International Classification of Functioning (ICF) principles, and is available in a number of formats. The NPSDD incorporates the 12-item version.

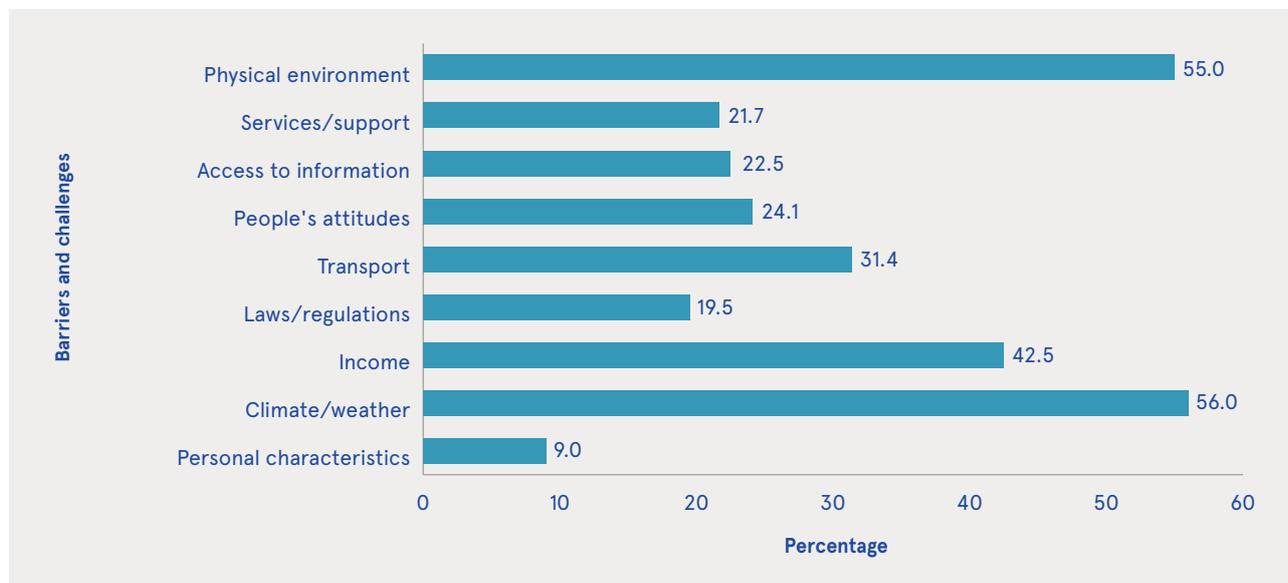
The MAP provides a more holistic definition of disability based on the WHO’s ICF, and has the potential to track the impact of service interventions on the participation and functioning experience of people registered on the NPSDD. It provides the ability to compare, for example, the participation and functioning experience of individuals pre- and post-service provision. The hope is that the provision of services will impact positively on the individuals’ participation and functioning experience.

The MAP captures information on people aged 16 years or over. The figures presented below are based on the 8,092 (68.0% of 11,911) people who completed this section when their records were registered or reviewed in the five-year period, 2012-2016. The figures below provide high-level data on the percentage of people who completed this section.

Barriers and challenges

Figure 4 shows the percentage of people who encountered barriers to their participation, in the twelve months prior to their NPSDD interview. The climate/weather (4,532, 56.0%) and the physical environment (4,452, 55.0%) were found to be the greatest barriers to participation, followed by income (3,436, 42.5%).

Figure 4 Barriers and challenges (8,092 records), NPSDD 2016



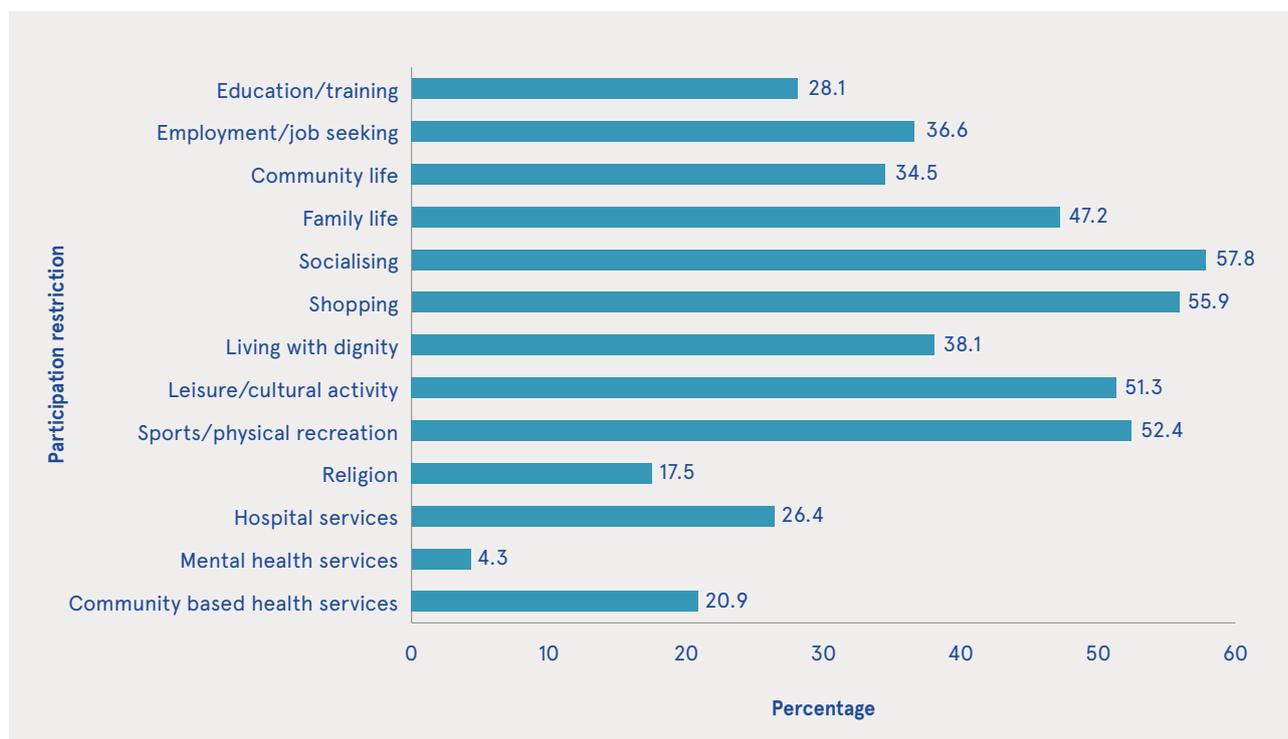
Participation restriction

Figure 5 presents information on the level of participation restriction in various areas of life. The reported extent of restriction experienced by individuals can be none, mild, moderate, severe, extreme/cannot do, not applicable or a person may refuse to answer the question. The data presented

combines mild, moderate, severe, extreme/cannot do into one group of 'some' restriction.

As the graph illustrates, socialising (4,680, 57.8%), shopping (4,522, 55.9%), and sports or physical recreation (4,241, 52.4%) were the areas where participation restriction was most likely to be experienced.

Figure 5 Participation restriction (8,092 records), NPSDD 2016

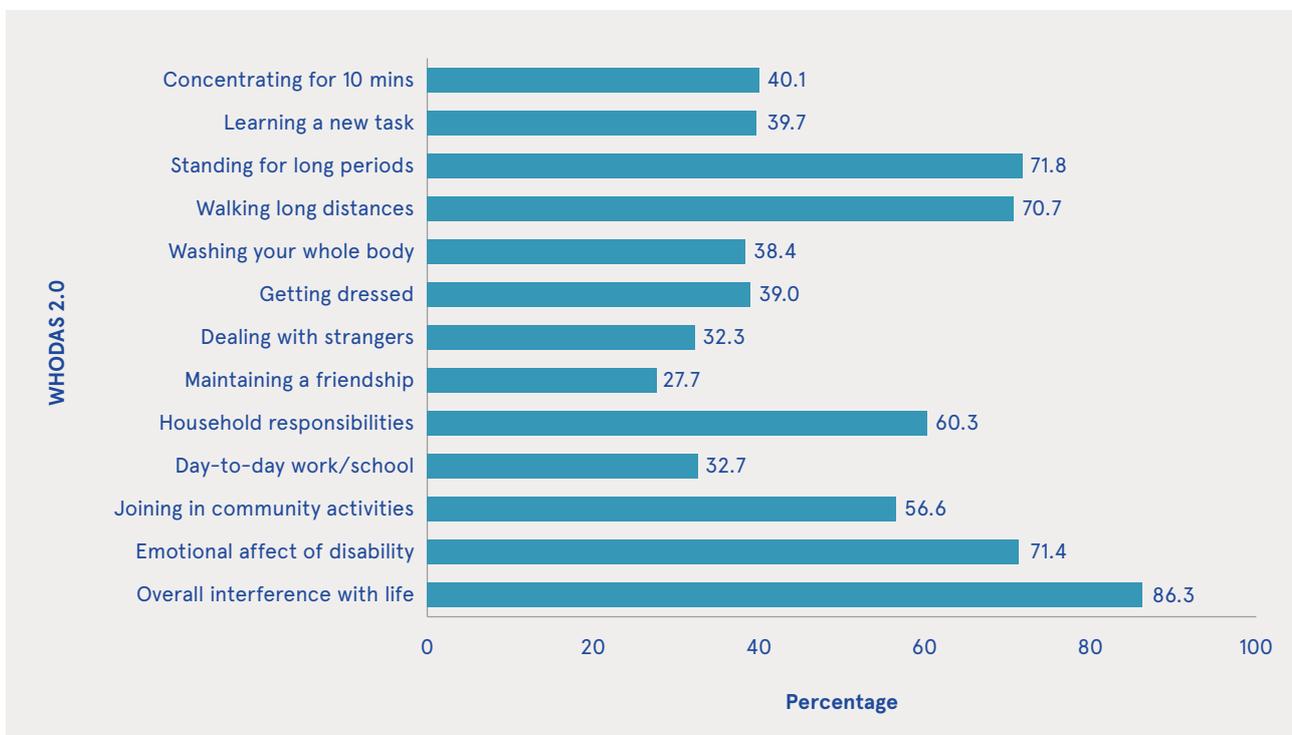


Difficulty with daily activities

The WHODAS 2.0 captures information on the extent of difficulty with functioning in daily activities. As with participation, the extent of difficulty can be recorded as mild, moderate, severe, extreme/cannot do. The data presented below groups these four categories into one category of 'some' difficulty.

The majority of people (6,980, 86.3%) reported that their difficulties 'interfered with their lives overall'. The greatest areas of difficulty, in the 30 days prior to the NPSDD interview, were the emotional effect of disability (5,774, 71.4%), standing for long periods (5,810, 71.8%), and walking long distances (5,720, 70.7%).

Figure 6 WHODAS 2.0 – World Health Organization Disability Assessment Schedule (8,092 records), NPSDD 2016



5

Current service use and future service requirement

Data presented from this point forward include records registered or reviewed in 2016 only.

This section outlines current service use and future service requirements, and is based on the 6,111 people (28.1%) whose NPSDD records were either registered or reviewed in 2016. This approach ensures that a clear indication of current service use and future service requirement is established.

It is assumed that those currently availing of a service will require that service into the future, however, this is not reported unless the requirement is for an enhancement or change to an existing service.

Self-reported future requirements are presented as 'unmet need for service' and 'enhanced/alternative service' in the case of the following service types: therapeutic intervention and rehabilitation services; personal assistance and support services; and residential services.

- » 'Unmet need for service' consists of those who (a) require assessment of need for a service, (b) were assessed and placed on a waiting list to get the required service, or (c) were assessed but were unable to avail of the service.
- » 'Enhanced/alternative service' consists of those who (a) are already using a service but require assessment for an enhanced service, (b) were assessed as requiring an enhanced service, or (c) were assessed as requiring an enhanced service but were unable to avail of the service.

Therapeutic intervention and rehabilitation services

The majority of people (5,593, 91.5%) used at least one therapeutic intervention and rehabilitation service, with the greatest number availing of:

- » physiotherapy (2,692, 44.1%)
- » community resource work (2,567, 42.0%)
- » occupational therapy (2,301, 37.7%).

1,791 people (29.3%) require one or more therapeutic intervention and rehabilitation services. The majority of this requirement is immediate and the most frequently required were:

- » physiotherapy (652 people, 10.7%)
- » occupational therapy (487 people, 8.0%).

Personal assistance and support services

Personal assistance and support services were used by 1,719 people (28.1%) and the most frequently used services were:

- » home help (552, 9.0%)
- » personal assistant (491, 8.0%)
- » peer support (469, 7.7%).

455 people (7.4%) require one or more personal assistance and support services. The requirement for these services is mostly immediate. The most commonly required services were:

- » home help (166, 2.7%)
- » personal assistant (127, 2.1%).

Day services or activities

Over half (3,417, 55.9%) were in receipt of day services or activities. The most frequently reported day services or activities were:

- » mainstream primary school (995, 16.3%)
- » open employment (758, 12.4%)
- » day activation services (489, 8.0%).

581 people (9.5%) require one or more day service or activity. The most commonly required services were:

- » mainstream secondary school (107, 1.8%)
- » third level education (98, 1.6%).

Residential services

Residential services were used by 204 people (3.3%), the most commonly used were:

- » nursing homes (85, 1.4%)
- » dedicated high support services with nursing care (20, 0.3%).

Fifty people (0.8%) require one or more residential service. The most commonly required residential service is to 'live independently in the community with low support'; 0.1% (nine people) require this service between 2017 and 2021.

Respite service

9.7% (593 people) availed of one or more planned respite service. The type of respite most commonly used was:

- » holiday respite placement (175, 2.9%)
- » planned residential respite with high support (139, 2.3%)
- » planned residential respite with low support (115, 1.9%).

Emergency respite was used by thirty nine people (0.6%).

274 people (4.5%) require one or more respite service. The most required respite services were:

- » holiday respite placement (116, 1.9%)
- » planned residential respite with high support (60, 1.0%).

Assistive products

Assistive products were used by 4,347 people registered on the NPSDD (71.1%), and the most commonly used products were:

- » special furniture and other aids to personal care (5,307, 36.2% of the 14,642 assistive products used)
- » aids to mobility (4,941, 33.7%).

791 people (12.9%) require one or more assistive products (1,120 total aids and appliances required). In the next five years, the most frequently required assistive products are:

- » aids to hearing (325 items, 29.0% of total 1,120),
- » special furniture and other aids to personal care (289 items, 25.8%).

Additional tables and figures exploring this data in further detail are available on the HRB website www.hrb.ie

