



HRB Statistics Series 36

Annual Report of the National Physical and Sensory Disability Database Committee 2017 Main Findings

Anne Doyle and Anne Marie Carew

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**'Two Birds At Sunset' by Hilary Murray
NPSDD Cover Design Winner 2017**

My name is Hilary Murray. I live in Kinvara, Co. Galway. My family own Green's Pub which I live above with my Mom, Dad and sister. I work in the pub at the weekend. I have 3 brothers, 1 sister, nieces and a nephew. I love to see them come to visit.

I have a lot of friends in Kinvara. We go for coffee, go to the beach, go for dinner and to the cinema and most of all enjoy our girly chats. Recently I was on the Kinvara local radio during St Patrick's weekend. I also organised a group of people to come to our pub on the 1st of February to make St Brigid's crosses.

Art is a nice hobby. I take part in art and pottery classes in the GRETB (Galway and Roscommon Education and Training Board). I enjoy working with colour, using paints, crayons, and markers. I also like bird watching, shopping, taking photos and meeting people.

My picture is a rainbow of colours which represents my personality. I watch the sunset in Kinvara Bay, this inspired me for this art piece. I love birds, watching them fly over the bay and that is why I put the birds in the painting.

My goal is to enter my art work in an exhibition in Gort in September. In the future I would like to work with some local artists and photographers.



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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.

Members of the National Physical and Sensory Disability Database Committee 2017

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1. Replaced Ms Grainne Duffy in April 2017
2. Replaced Ms Claire Collins in September 2017
3. Replaced Mr Gerard Tully in November 2017
4. Replaced Dr Mairín Boland in November 2017
5. Replaced Mr James Rock in November 2017

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, sensory, neurological, speech or language disability is availing of, or requiring, a specialised health and personal social service or specialised hospital 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 disability and have chosen not to be registered.
- » The data contained in this report represent the situation in December 2017. 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 2017. In addition to this report, a complete set of tables and figures is available on the HRB website at www.hrb.ie.

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

- » A summary of the 20,676 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 20,676 registrations, 9,956 (48.2%) records were registered or reviewed in the five year period 2013–2017. 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 9,956 registrations.
- » **Section 4 – Measure of Activity and Participation (MAP)** is based on 6,941 people aged 16 years and over registered or reviewed in the five year period 2013–2017.
- » **Section 5 – Current service use and future service requirements** is based on 5,654 (27.3%) people who were either registered or reviewed in 2017. This approach ensures that an up-to-date picture is established.

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 20,676 people were registered on the NPSDD in December 2017. New registrations decreased from 550 in 2016¹, to 419 in 2017. The number of reviews of existing records decreased by 5.9% from 5,561 in 2016 to 5,235 in 2017.

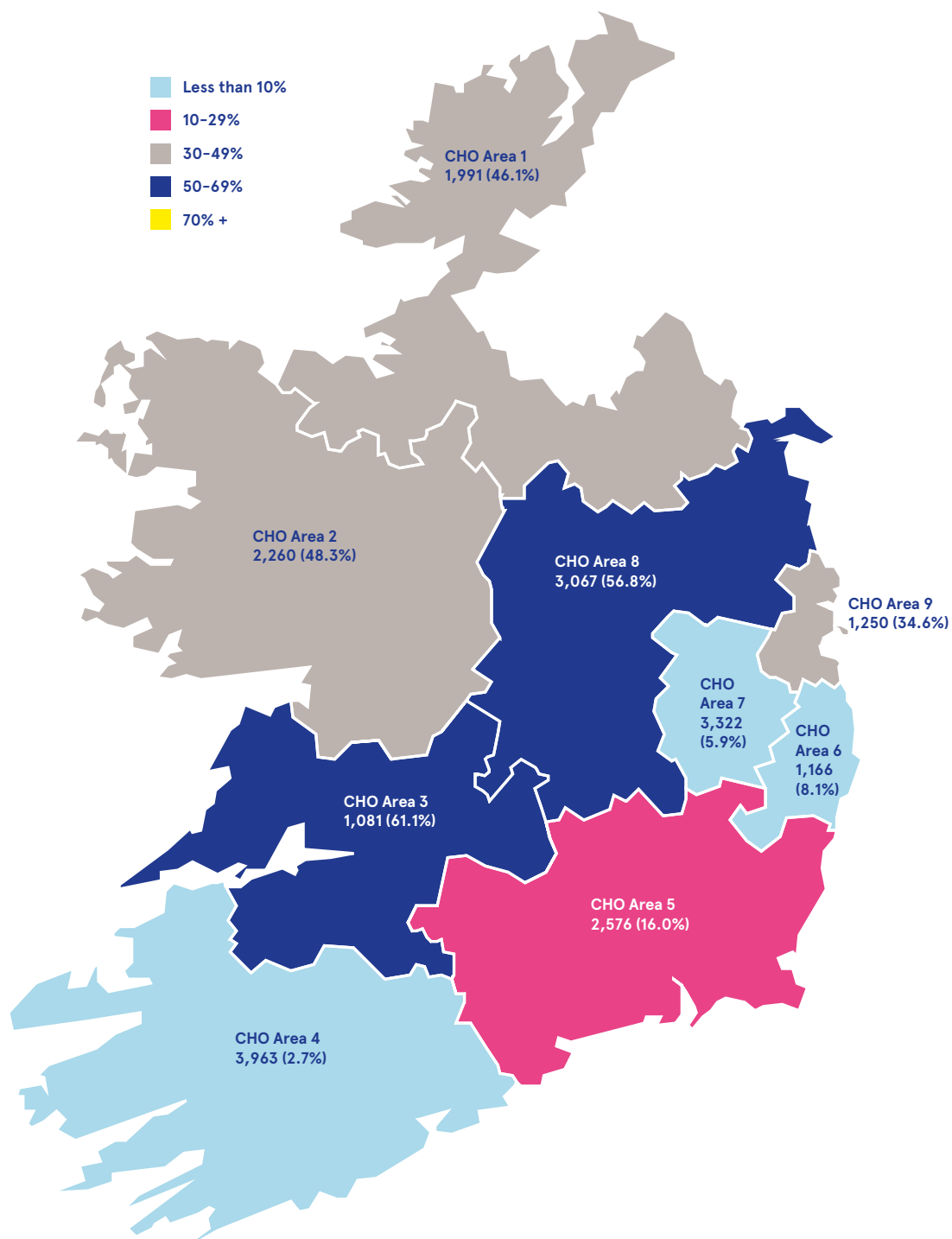
In addition to the work carried out by the HSE, the NPSDD records of 3,582 people (17.3% of the total number registered) were directly managed by 33 service providers in 2017. These service providers completed 25.6% of the total number of registrations (107) and 39.4% of the total reviews (2,061) carried out within the year. In total, 60.5% of the data managed by these service providers was up-to-date by 2017 year end. Moreover, most of the NPSDD records managed by service providers were updated between 2013 and 2017 (3,417, 95.4%).

CHO Area of Residence

Figure 1 shows the total number of people registered on the NPSDD in 2017 by HSE Community Healthcare Organisation (CHO) area of residence, along with the percentage of records in that CHO that were up-to-date. The rate of 2017 registrations/reviews varied by HSE CHO area, and was highest in the CHO areas 3 - Clare, Limerick, North Tipperary (61.1%) and 8 - Laois/Offaly, Longford/Westmeath, Louth, Meath (56.8%) and in CHO 2 - Galway, Roscomon, Mayo (48.3%). Many areas had significantly lower review rates.

¹ Doyle A and Hourigan S, (2017) *Annual Report of the National Physical and Sensory Disability Database Committee 2016 Main Findings*. HRB Statistics Series 34. Dublin: Health Research Board.

Figure 1 Total number of people registered, and percentage registered/reviewed in 2017 by HSE CHO area of residence, (20,676 records) NPSDD 2017



3

Profile of new registrations and recent reviews (2013–2017)

This section is based on 9,956 (48.2%) records which were registered or reviewed in the period 2013–2017.

Type of disability

The three most common types of disability recorded on the NPSDD were neurological disability (38.9%), multiple disabilities (31.0%) and physical disability (15.6%) (Table 1).

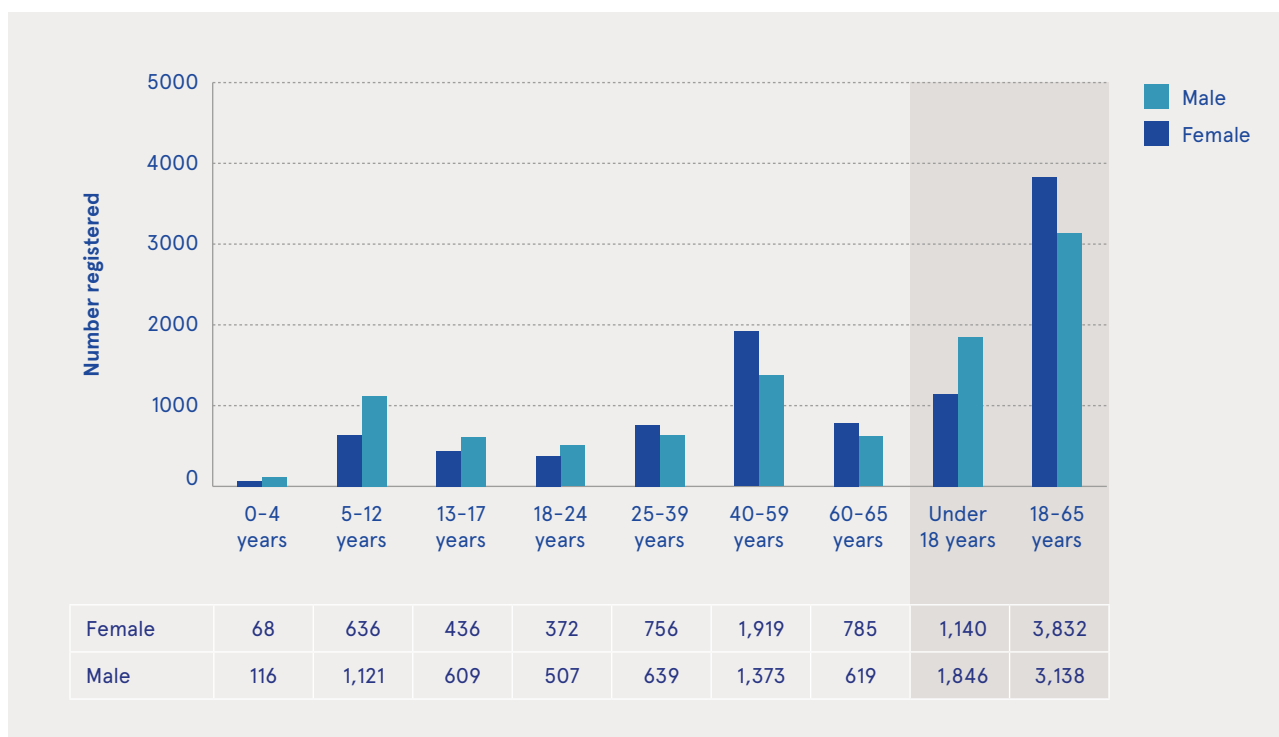
Table 1 Number of people registered by type of disability and gender (9,956 records), NPSDD 2017

Type of disability	Gender				Total	
	Female		Male		n	%
	n	%	n	%	n	%
Neurological disability	2,066	41.6	1,802	36.2	3,868	38.9
Multiple disabilities	1,479	29.7	1,611	32.3	3,090	31.0
Physical disability	779	15.7	778	15.6	1,557	15.6
Hearing loss/deafness	304	6.1	253	5.1	557	5.6
Visual disability	223	4.5	231	4.6	454	4.6
Speech and/or language disability	121	2.4	309	6.2	430	4.3
Total	4,972	100.0	4,984	100.0	9,956	100.0

Age and gender

The majority (6,970, 70.0%) of those registered on the NPSDD were aged 18 years or over and more than half (4,984, 50.1%) 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 (9,956 records), NPSDD 2017



Living accommodation and living arrangements

The majority of people (7,636, 76.7%) lived in private accommodation, 19.7% (1,957 people) lived in rented accommodation and 3.3% (329 people) lived in full-time residential settings. 34 (0.3%) described their living accommodation as 'other'.

The majority of people (8,404, 84.4%) lived with family members, 1,065 people (10.7%) lived alone and 485 (4.9%) 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 (5,383, 54.1%), followed by communication (958, 9.6%) and ear complaints (849, 8.5%).

The primary diagnosis varied with the person's age and gender. For example, those whose primary diagnosis was communication were mostly male (705, 73.6%), and aged five to twelve years (436, 45.5%). Those with a diagnosis from the musculoskeletal group were mostly female (440, 55.6%), commonly aged 40-59 years (166, 21.0%). 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 (9,956 records), NPSDD 2017

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		
All service users											
Behavioural	0	~	0	~	~	0	~	~	~	~	
Blood and blood forming organs	0	~	~	~	~	~	~	5	9	14	0.1
Circulatory system	~	15	6	10	9	32	33	25	84	109	1.1
Communication	16	572	271	84	15	0	0	859	99	958	9.6
Congenital	12	109	83	49	14	11	~	204	76	280	2.8
Digestive system	0	13	~	~	~	~	~	17	15	32	0.3
Ear complaints	11	77	71	94	153	321	122	159	690	849	8.5
Endocrine and metabolic	~	25	24	23	17	20	5	52	65	117	1.2
Eye complaints	6	46	61	59	126	262	109	113	556	669	6.7
Genito-urinary system	0	~	~	~	~	21	9	6	35	41	0.4
Infectious and parasitic	0	0	~	~	~	11	29	~	44	45	0.5
Intellectual/developmental	71	225	14	5	~	0	0	310	6	316	3.2
Musculoskeletal system	10	90	75	70	90	278	179	175	617	792	8.0
Neoplasms	0	10	~	~	10	25	11	13	50	63	0.6
Nervous system	48	540	373	413	866	2,268	875	961	4,422	5,383	54.1
Respiratory system	~	26	50	57	81	32	15	77	185	262	2.6
Skin disease or disorders	~	~	~	~	0	~	9	8	14	22	0.2
Total service users	184	1,757	1,045	879	1,395	3,292	1,404	2,986	6,970	9,956	100.0
Percentage of total users	1.8	17.6	10.5	8.8	14.0	33.1	14.1	30.0	70.0	100.0	

~ To protect against the risk of indirect identification of individuals, values in cells containing less than five cases have been suppressed. The corresponding cells in the % column are blank.

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. 42.7% (4,252 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 (2,153, 50.6%), females were more likely to report a secondary diagnosis related to the neoplasm group, infectious and parasitic group or skin disease or disorders group. Males were more likely than females to report a secondary diagnosis from the behavioural, intellectual/ developmental or communication groups.

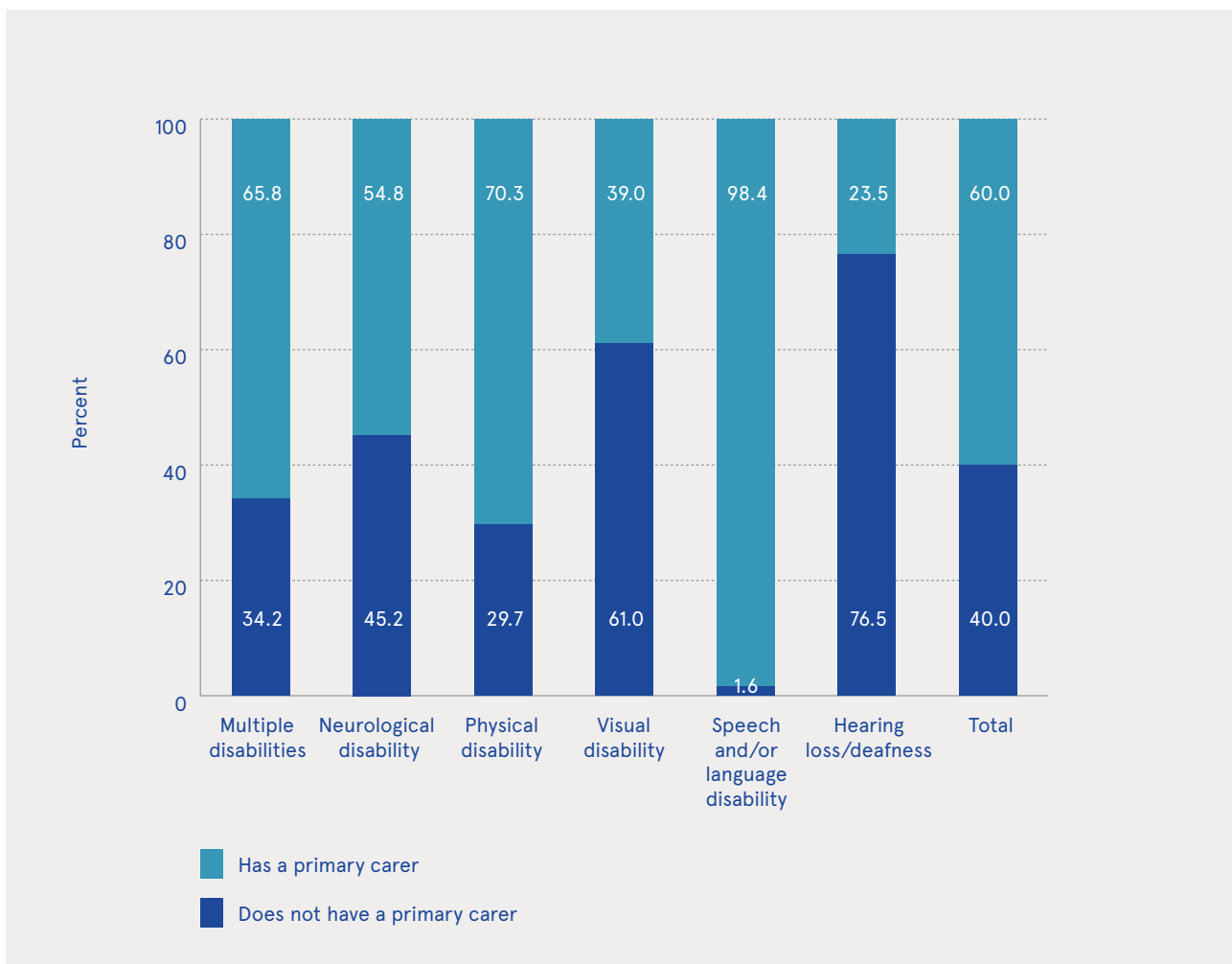
Primary carers

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 (5,977, 60.0%) registered on the NPSDD, whose records were reviewed in the period 2013–2017, reported having a primary carer. 96.0% (5,735 people) lived with their primary carer.

Figure 3 Primary carer by type of disability (9,956 records), NPSDD 2017



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/partner 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 and over (436, 76.0%).

107 people (1.8%) with a primary carer reported being cared for by a son or daughter; however, the proportion increased as the age of the person increased. Approximately one in ten (63, 11.0%) 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 (4,178, 69.9%) were aged between 19 and 49 years.

Out of 542 (9.1%) primary carers aged 60–69 years, 265 (48.9%) were the spouse or partner of the individual. Parent(s) accounted for 236 (43.5%) of carers aged 60–69 years, while 18 (3.3%) carers aged 60–69 years were a sibling. 161 (2.7%) primary carers were aged 70 years and over.

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.

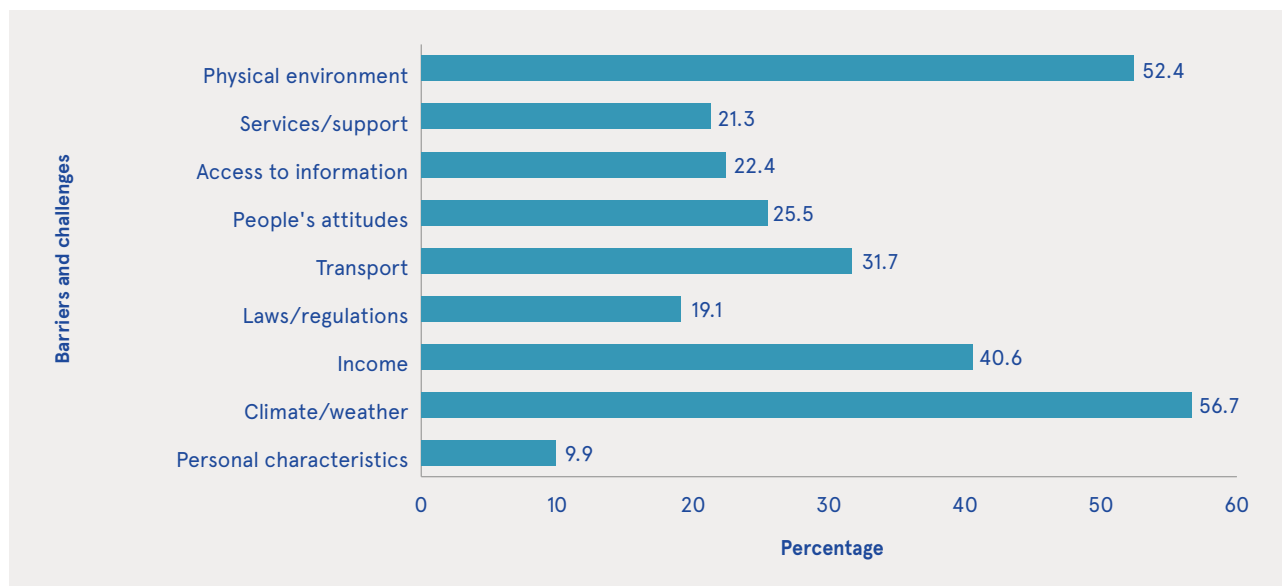
The MAP provides a more holistic definition of disability and has the potential to track the impact of service interventions on the participation and functioning experience of people registered on the NPSDD. It provides the ability to compare, for example, the participation and functioning experience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

The MAP captures information on people aged 16 years or over. The figures presented in this section are based on the 6,941 (69.7% of 9,956) people who completed this section when their records were registered or reviewed in the five-year period, 2013–2017. The figures 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. Climate/weather (3,937, 56.7%) and the physical environment (3,637, 52.4%) were found to be the greatest barriers to participation, followed by income (2,819, 40.6%).

Figure 4 Barriers and challenges (6,941 records), NPSDD 2017



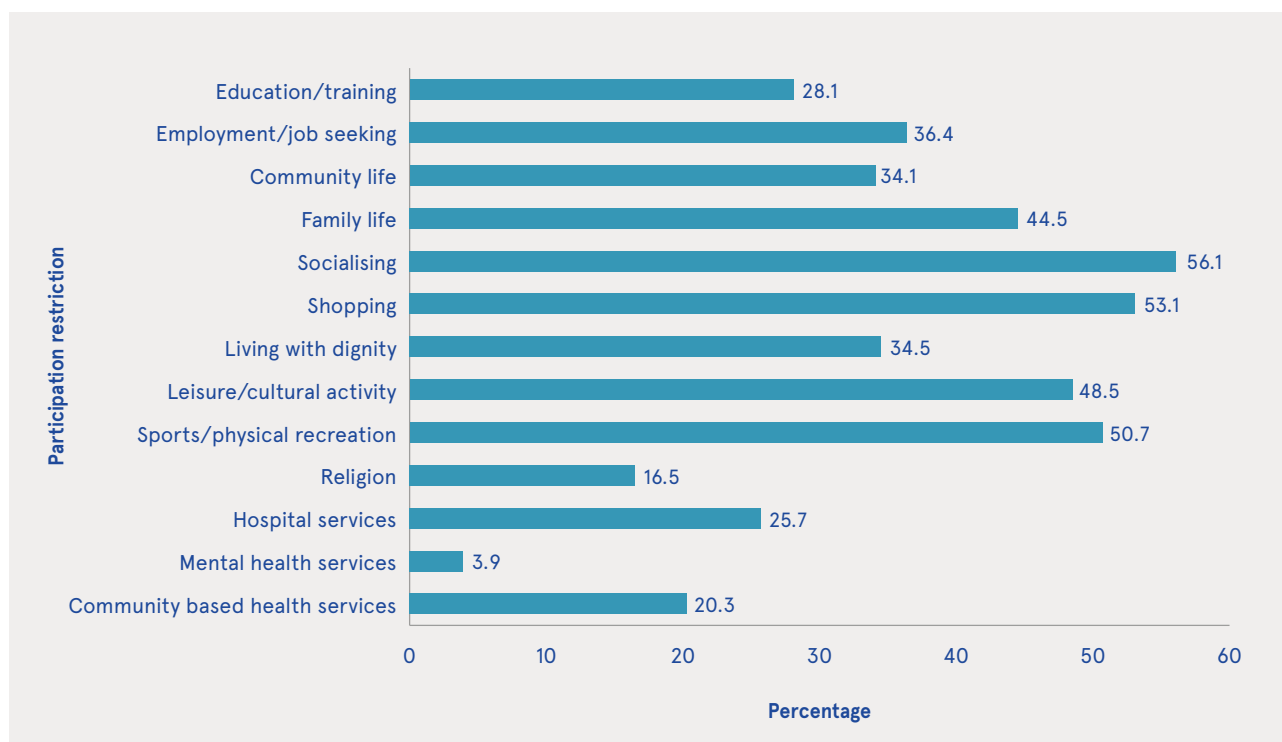
Participation restriction

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 (3,893, 56.1%), shopping (3,683, 53.1%), and sports or physical recreation (3,520, 50.7%) were the areas where participation restriction was most likely to be experienced.

Figure 5 Participation restriction (6,941 records), NPSDD 2017

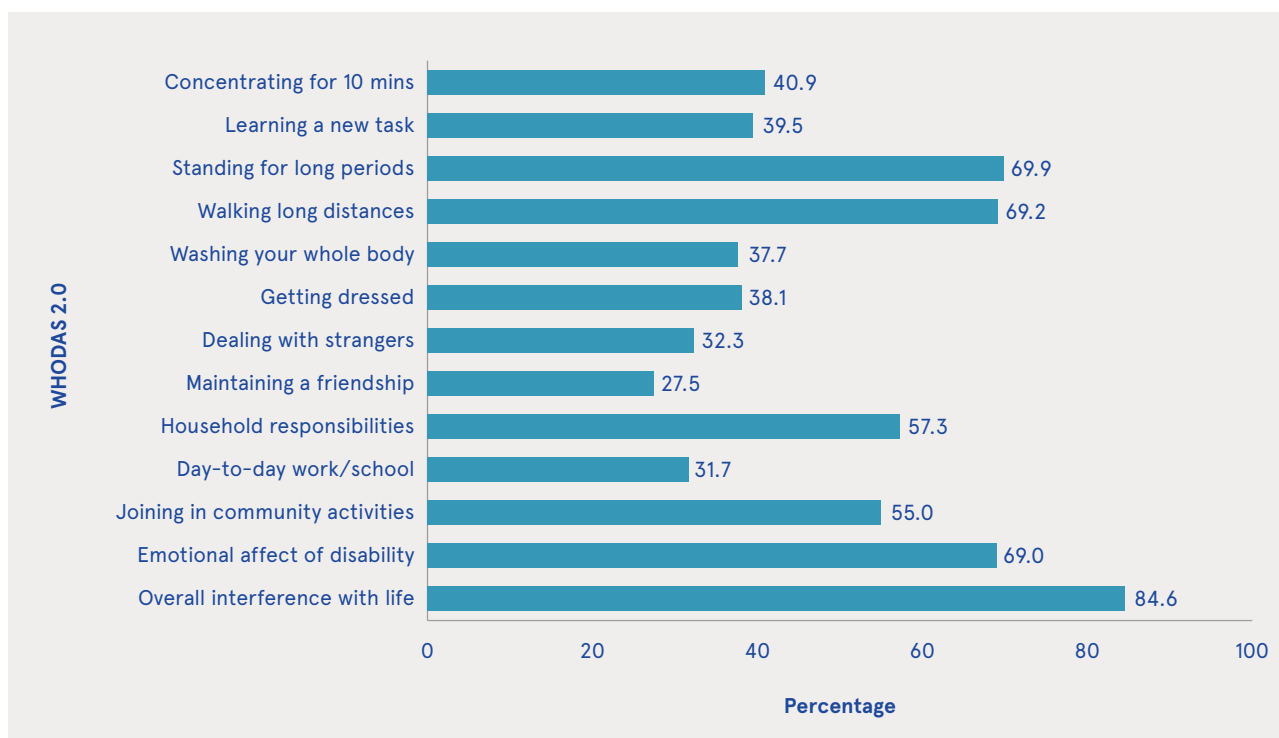


Difficulty with daily activities

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 (5,873, 84.6%) reported that their difficulties 'interfered with their lives overall'. The greatest areas of difficulty, in the 30 days prior to the NPSDD interview, were standing for long periods (4,849, 69.9%), walking long distances (4,800, 69.2%), and the emotional effect of disability (4,786, 69.0%).

Figure 6 WHODAS 2.0 – World Health Organization Disability Assessment Schedule (6,941 records), NPSDD 2017



5

Current service use and future service requirement

Data presented from this point forward include records registered or reviewed in 2017 only.

This section outlines current service use and future service requirements, and is based on the 5,654 people (27.3%) whose NPSDD records were either registered or reviewed in 2017. 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 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 (4,986, 88.2%) used at least one therapeutic intervention and rehabilitation service, with the greatest number availing of:

- » physiotherapy (2,284, 40.4%)
- » community resource work (2,217, 39.2%)
- » occupational therapy (1,998, 35.3%).

1,684 people (29.8%) require one or more therapeutic intervention and rehabilitation services. The majority of this requirement is immediate and the most frequently required are:

- » physiotherapy (640 people, 11.3%)
- » occupational therapy (541 people, 9.6%).

Personal assistance and support services

Personal assistance and support services were used by 1,520 people (26.9%) and the most frequently used services were:

- » peer support (454, 8.0%)
- » home help (431, 7.6%)
- » personal assistant (404, 7.1%).

323 people (5.7%) require one or more personal assistance and support services. The requirement for these services is mostly immediate. The most commonly required services are:

- » home help (96 people, 1.7%)
- » sign language interpreter (85 people, 1.5%).

Day services or activities

Over half of the service users (3,276, 57.9%) were in receipt of day services or activities. The most frequently reported day services or activities were:

- » mainstream primary school (1,071, 18.9%)
- » open employment (722, 12.8%)
- » mainstream secondary school (430, 7.6%).

504 people (8.9%) require one or more day service or activity. The most commonly required services are:

- » mainstream secondary school (119 people, 2.1%)
- » mainstream primary school (88 people, 1.6%).

Residential services

Residential services were used by 172 people (3.0%), the most commonly used were:

- » nursing homes (83, 1.5%)
- » independent unit in a dedicated complex with high support (> 10 hours) (18, 0.3%).

In 2017, no residential requirements were reported.

Respite service

7.8% (443 people) availed of one or more planned respite service. The type of respite most commonly used were:

- » holiday respite placement (121, 2.1%)
- » planned residential respite with high support (112, 2.0%).

Emergency respite was used by 31 people (0.5%).

146 people (2.6%) require one or more respite services. The most required respite services are:

- » planned residential respite with high support (45, 0.8%)
- » holiday respite placement (40, 0.7%)
- » planned residential respite with high support (38, 0.7%).

Assistive products

Assistive products were used by 3,870 people registered on the NPSDD (68.4%), and the most commonly used product groups were:

- » special furniture and other aids to personal care (4,641, 35.7% of the 12,994 assistive products used)
- » aids to mobility (4,151, 31.9% of all products).

599 service users (10.6%) require one or more assistive products (854 total aids and appliances required).

In the next five years, the most frequently required assistive products are:

- » aids to hearing (300 items, 35.1% of total 854)
- » special furniture and other aids to personal care (204 items, 23.9%).

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

