

Measure of Activity and Participation –

The experience of those with a neurological condition registered on the National Physical and Sensory Disability Database

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Introduction

Over 800,000 people in Ireland are living with a neurological condition, a condition affecting the brain and spinal cord (Neurological Alliance of Ireland, 2016). Issue 9 in the Measure of Activity and Participation (MAP) bulletin series focuses on the social participation of people with neurological conditions. This is the largest diagnostic group who have completed the MAP section of the National Physical and Sensory Disability Database (NPSDD). Focusing on a specific diagnostic group highlights the specific experience of restriction in, and barriers to, participation in society for this group. MAP information is recorded on the NPSDD for those aged 16 years and older. This bulletin updates figures presented in MAP Issue 3 (Doyle & O'Donovan, 2008) and examines whether the lives of people with neurological conditions have improved in the eight years since the last bulletin.

Profile

In December 2016, there were 12,384 people registered on the NPSDD who had completed the MAP section of the NPSDD. This bulletin is based on 4,789 (38.7%) people 16 years and over with a neurological condition as their primary diagnosis.

Age and gender

Females outnumbered males with 2,517 (52.6%) females and 2,272 (47.4%) males. The majority (2,498 people, 52.3%) were aged 40-59 years. In general females outnumbered males across all age groups, with the exception of the 16-24 year group where males outnumbered females. Table 1 provides a breakdown of gender and age group.

Table 1 Gender and age group of those with a neurological condition, NPSDD 2016

Age group	Female		Male		Total	
	n	Row %	n	Row %	n	Column %
16-24 years	152	42.2	208	57.8	360	7.5
25-39 years	570	51.2	544	48.8	1,114	23.3
40-59 years	1,371	54.9	1,127	45.1	2,498	52.2
60-65 years	424	51.9	393	48.1	817	17.1
Total	2,517	52.6	2,272	47.4	4,789	100.0

Specific diagnoses

The five most common neurological conditions reported are shown in Table 2, these conditions account for 72.9% of all the neurological conditions.

Multiple sclerosis was the most common accounting for 38.3%. A complete breakdown of all of the conditions within the neurological group is provided in Table A (Appendix). The data showed that 71.8% (3,438 people) reported having a medical card.

Table 2 The most frequently reported primary neurological conditions, NPSDD 2016

	n	%
Multiple sclerosis	1,833	38.3
Cerebral palsy	698	14.6
Head injury	438	9.1
Stroke hemiplegia	314	6.6
Spinal injury	208	4.3

Living accommodation and arrangements

The majority of people (3,638, 76.0%) lived in private accommodation, 16.2% (783 people) lived in rented accommodation, 7.1% (341 people) lived in full-time residential settings and 0.6% (27 people) lived in mobile homes/caravans, were homeless or described their living accommodation as ‘other’.

The majority of service users (3,710 people, 77.6%) lived with family members, 14.1% (673 people) lived alone and 8.4% (406 people) lived with ‘others’ such as foster families, non-relatives or in ‘other’ circumstances.

Table 3 Living arrangements, NPSDD 2016

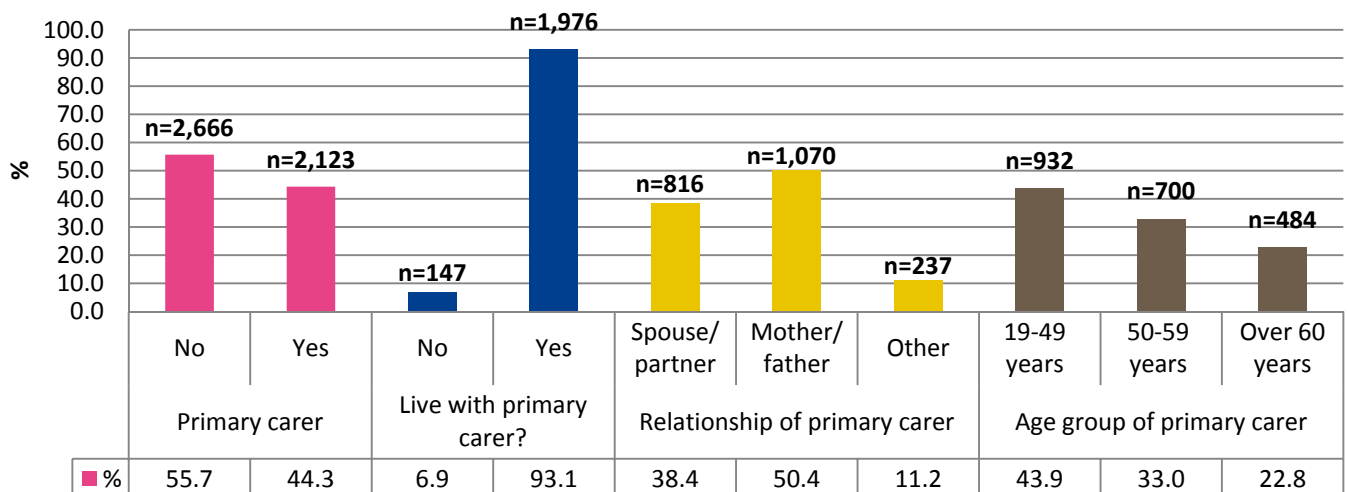
	n	%
Alone	673	14.1
With family	3,710	77.5
With non-family	36	0.7
In full-time residential service	341	7.1
Other	28	0.6
Unknown	1	0.0
Total	4,789	100.0

Primary carer

Of those with a neurological condition *and* who completed the MAP section of the form, 44.3% (2,123 people) reported having a primary carer. Figure 1

shows age groups of primary carers, their relationship to the service user and numbers of service users living with their carers.

Figure 1 Primary carer, NPSDD 2016



Barriers and Challenges

Barriers and Challenges refer to the social and environmental factors that can potentially act as barriers to participation in life activities (see Figure 1 for listing). The areas that represented the largest barriers for people with neurological conditions were:

- Physical environment: 2,730, 57.0%
- Climate/weather: 2,587, 54.0%
- Income: 1,922, 40.1%

These are also the top three barriers identified for the entire group who have completed the MAP section irrespective of diagnosis and mirror the findings in the 2008 bulletin.

Figure 2 Barriers & challenges, NPSDD 2016



Participation Restriction

Respondents are asked to state the level of difficulty they have experienced participating in major life areas such as education, employment and socialising. Low functioning and experience of barriers were indicators of participation restriction (O’Donovan et al, 2009). Table 4 shows the numbers and percentages of those who experienced some restriction in each area (mild / moderate / severe / complete).

Those with a neurological diagnosis experienced the most restriction participating in the following areas:

- Socialising (2,677, 55.9%) (Socialising can include one-to-one encounters including informal conversations and basic human contact); of those experiencing this restriction, 2,449 people (91.5%) indicated that they were bothered to some extent by this experience;

- Shopping (2,595, 54.2%) (examples include physical access to stores, carrying bags, reaching items on shelves, dealing in financial transactions); 2,300 people (88.6%) were bothered to some extent by this restriction;
- Sports or physical recreation (2,555, 53.4%) (examples include going to the gym, walking the dog or doing exercises at home); 2,273 people (89.0%) were bothered somewhat by this restriction.

There were reductions in restriction levels for all areas of participation compared to 2008. The largest reduction was seen in employment and job seeking which decreased by 8.8%, from 47.2% in 2008 to 38.4% in 2016. In addition, the percentage reporting restrictions participating in community life decreased from 39.7% in 2008 to 32.3% in 2016.

One hundred and fifty five people (3.2%) experienced restrictions accessing mental health services. A recent

survey by the Neurological Alliance UK (2017) found that amongst those with a neurological condition, a high percentage also have a comorbidity, commonly a mental health diagnosis. Their patient experience survey reported that just 19% of survey respondents rated the services to meet their needs as ‘good’ or ‘excellent’ and that more needs to be done to meet

additional mental health requirements (Neurological Alliance UK, 2017).

The extent to which this restriction bothered the individual is also captured in Table 6. Unsurprisingly, a large number of respondents found that their experience of restriction bothered them, similar to the results of the 2008 MAP bulletin.

Table 4 Participation restriction and extent of bother of this restriction, NPSDD 2016

Areas of participation restriction	Number & % that experienced participation restriction		Extent to which those who experienced participation restriction were bothered by the restriction*					
			Not at all bothered		A little bothered		Bothered a lot	
	n	%	n	%	n	%	n	%
Education & training	1,335	27.9	117	8.8	524	39.3	688	51.5
Employment or job seeking	1,839	38.4	130	7.1	543	29.5	1,142	62.1
Community life	1,545	32.3	154	10.0	656	42.5	720	46.6
Family life	2,208	46.1	134	6.1	893	40.4	1,162	52.6
Socialising	2,677	55.9	195	7.3	1,158	43.3	1,291	48.2
Shopping	2,595	54.2	273	10.5	1,135	43.7	1,165	44.9
Living with dignity	1,792	37.4	110	6.1	764	42.6	907	46.0
Leisure/cultural activities	2,351	49.1	187	8.0	1,027	43.7	1,113	47.3
Sports or physical recreation	2,555	53.4	258	10.1	995	38.9	1,278	50.0
Religion	686	14.3	103	15.0	270	39.4	304	44.3
Hospital services	962	20.1	74	7.7	368	38.3	506	52.6
Mental health services	155	3.2	92	11.4	320	39.8	378	47.0
Community services	804	16.8	14	9.0	61	39.4	77	49.7

*Any difference in figures is accounted for by refusals to answer a question.

Those with a head injury reported higher levels of restriction than other neurological groups. This should be carefully considered as to the implications on service planning. The top five neurological conditions were examined to ascertain if any differences exist in the experience of participation. Socialising continues to feature in the top three areas of restriction for people with neurological conditions, particularly for those with head injury (319, 72.8%), stroke hemiplegia (211, 67.2%) and spinal injury (131, 63.0%). Sports and physical recreation was reported

as a particular area of difficulty for people with multiple sclerosis (997, 54.4%) and cerebral palsy (314, 45.0%). Shopping is another key area where participation is restricted. For those with MS, 43.8% experienced restriction in ‘family life’, a finding similar to a recent survey by MS Ireland where 35.3% of respondents reported that their MS impacts on family life a lot of the time (MS Ireland, 2017). Their survey also found that almost 25% of respondents reported that their MS impacted their participation in daily life ‘very much’ (MS Ireland, 2017).

Table 5 Participation restriction for the top 5 neurological conditions, NPSDD 2016

	Cerebral palsy (n=698)		Head injury (n=438)		Multiple sclerosis (n=1,833)		Stroke hemiplegia (n=314)		Spinal injury (n=208)	
	n	%	n	%	n	%	n	%	n	%
Education & training	222	31.8	213	48.6	333	18.2	108	34.4	66	31.7
Employment or job seeking	220	31.5	227	51.8	604	33	157	50.0	92	44.2
Community life	185	26.5	202	46.1	540	29.5	137	43.6	66	31.7
Family life	205	29.4	304	69.4	803	43.8	204	65.0	109	52.4
Socialising	306	43.8	319	72.8	977	53.3	211	67.2	131	63.0
Shopping	291	41.7	296	67.6	964	52.6	202	64.3	127	61.1
Living with dignity	220	31.5	226	51.6	565	30.8	173	55.1	98	47.1
Leisure/cultural activities	266	38.1	283	64.6	853	46.5	198	63.1	116	55.8
Sports or physical recreation	314	45.0	275	62.8	997	54.4	181	57.6	130	62.5
Religion	42	6.0	106	24.2	243	13.3	76	24.2	36	17.3
Hospital services	109	15.6	112	25.6	331	18.1	75	23.9	59	28.4
Mental health services	19	2.7	38	8.7	37	2.0	17	5.4	3	1.4
Community services	105	15.0	102	23.3	233	12.7	70	22.3	50	24.0

Those reporting complete restriction were analysed in further detail. Table 9 shows that sports and physical recreation was the highest area of *complete* restriction for people with spinal injury (52, 25.0%), multiple sclerosis (272, 14.8%) and cerebral palsy (68,

9.7%). Almost one third of people with a head injury or stroke hemiplegia were *completely* restricted engaging in employment or job seeking. Education and training, community life and shopping also featured highly when looking at *complete* restriction.

Table 6 Complete participation restriction for the top 5 neurological conditions, NPSDD 2016

	Cerebral palsy (n=698)		Head injury (n=438)		Multiple sclerosis (n=1,833)		Stroke hemiplegia (n=314)		Spinal injury (n=208)	
	n	%	n	%	n	%	n	%	n	%
Education & training	25	3.6	98	22.4	74	4.0	42	13.4	21	10.1
Employment or job seeking	52	7.4	137	31.3	205	11.2	97	30.9	42	20.2
Community life	38	5.4	76	17.4	103	5.6	50	15.9	23	11.1
Family life	11	1.6	68	15.5	52	2.8	30	9.6	10	4.8
Socialising	28	4.0	84	19.2	83	4.5	45	14.3	17	8.2
Shopping	20	2.9	73	16.7	122	6.7	45	14.3	16	7.7
Living with dignity	25	3.6	54	12.3	50	2.7	24	7.6	10	4.8
Leisure/cultural activities	33	4.7	79	18.0	100	5.5	43	13.7	18	8.7
Sports or physical recreation	68	9.7	111	25.3	272	14.8	83	26.4	52	25.0
Religion	5	0.7	33	7.5	36	2.0	12	3.8	~	1.4
Hospital services	~	0.4	13	3.0	26	1.4	~	1.3	~	1.4
Mental health services	~	0.4	6	1.4	~	0.1	~	1.3	0	0.0
Community services	7	1.0	14	3.2	21	1.1	6	1.9	~	1.4

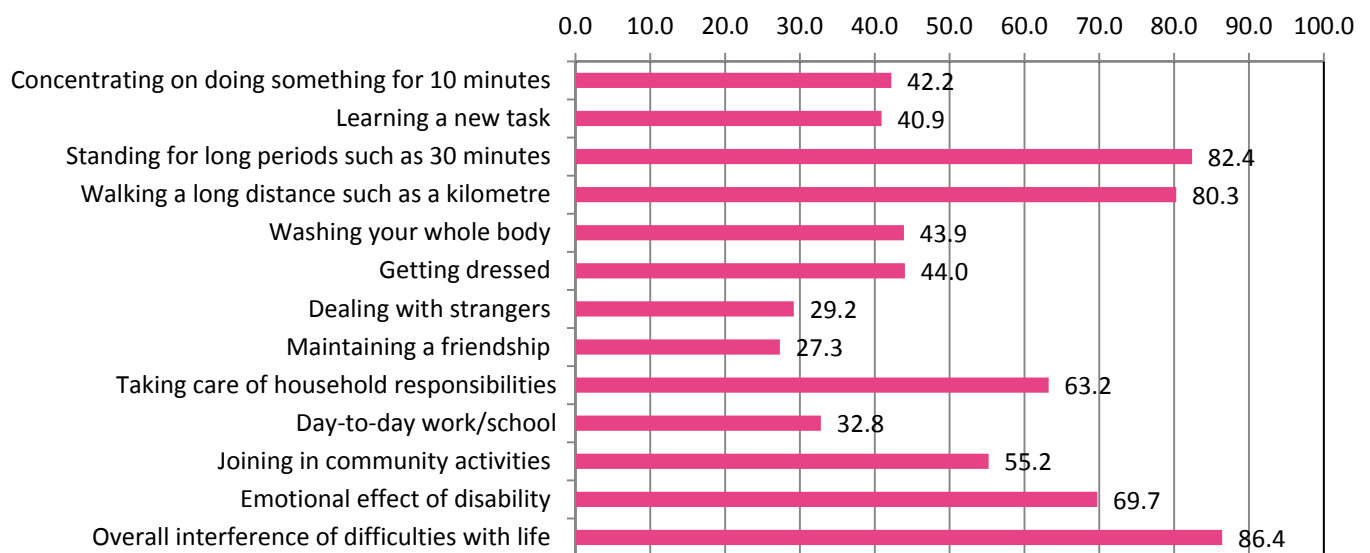
WHODAS 2.0

The World Health Organization’s Disability Assessment Schedule, (WHODAS 2.0) assesses the extent of difficulty an individual has in performing daily activities such as washing oneself, communicating with strangers and maintaining household responsibilities. Figure 2 displays the percentage of those with a neurological condition who have experienced some degree of difficulty (mild/moderate/severe/extreme) in the 30 days prior to completing their NPSDD data form. Similar to the 2008 MAP bulletin, the majority of respondents

stated that the difficulties listed under the WHODAS 2.0 section of the dataform had an overall interference in their lives (4,139, 86.4%). The three areas that individuals experienced the most difficulty in were:

- Standing for long periods such as 30 minutes (3,946, 82.4%)
- Walking a long distance such as a kilometre (3,845, 80.3%)
- Taking care of household responsibilities (3,028, 63.2%)

Figure 3 WHODAS 2.0 - % with neurological condition that experienced some difficulty, NPSDD 2016



Census 2016 captured similar information (Central Statistics Office, 2017). However, comparisons made between the datasets should be interpreted with caution as, unlike the MAP data, which focuses on those with a neurological condition aged 16-65 only and who use or require specialised health and personal social services, Census data refer to a much wider population.

Census data found that 24.4% of people with disabilities experienced difficulty in learning, remembering or concentrating, 21.9% had difficulty in getting dressed and 32.8% had difficulty in working or attending school/college. The WHODAS data found that 41.8% of people had difficulty concentrating on something for 10 minutes, 46.3% experienced difficulty getting dressed and 49.3% experienced difficulty in their day-to-day work/school. Those with a neurological condition who completed the MAP

seem to have higher experience of difficulty than those identified with disability in the census.

Table 7 illustrates the extent of difficulty experienced by people in the top five neurological diagnostic groups. Standing for long periods was reported as the greatest area of difficulty for those with cerebral palsy (572, 81.9%), spinal injury (198, 95.2%), MS (1,514, 82.6%) and stroke hemiplegia (266, 84.7%). Walking long distances was also rated as the top area of difficulty, particularly for those with cerebral palsy (570, 81.7%) and spinal injury (202, 97.1%), MS (1,476, 80.5%). For those with head injury, the emotional effect of their disability was their greatest difficulty (357, 81.5%) followed by concentrating (349, 79.7%). Overall interference of difficulties with their lives reported as a major difficulty (ranging from 81.1% and 93.6% across the groups).

Table 7 WHODAS Number and % experiencing difficulty for the top 5 neurological conditions, NPSDD 2016

	Cerebral palsy (n=698)		Head injury (n=438)		Multiple sclerosis (n=1,833)		Stroke hemiplegia (n=314)		Spinal injury (n=208)	
	n	%	n	%	n	%	n	%	n	%
Concentrating on doing something	220	31.5	349	79.7	771	42.1	194	61.8	51	24.5
Learning a new task	278	39.8	344	78.5	640	34.9	187	59.6	38	18.3
Standing for long periods	572	81.9	315	71.9	1,514	82.6	266	84.7	198	95.2
Walking a long distance	570	81.7	296	67.6	1,476	80.5	251	79.9	202	97.1
Washing your whole body	351	50.3	225	51.4	639	34.9	169	53.8	107	51.4
Getting dressed	361	51.7	210	47.9	637	34.8	178	56.7	111	53.4
Dealing with strangers	242	34.7	263	60.0	336	18.3	149	47.5	33	15.9
Maintaining a friendship	192	27.5	278	63.5	340	18.5	128	40.8	40	19.2
Taking care of household responsibilities	388	55.6	330	75.3	1,136	62.0	231	73.6	146	70.2
Day-to-day work/school	226	32.4	183	41.8	540	29.5	126	40.1	74	35.6
Joining in community activities	354	50.7	315	71.9	928	50.6	228	72.6	118	56.7
Emotional effect of disability	438	62.8	357	81.5	1266	69.1	252	80.3	149	71.6
Overall interference of difficulties with life	566	81.1	410	93.6	1,580	86.2	290	92.4	188	90.4

Service information

The objective of the NPSDD is to provide an overview of the specialised health and personal social service use and requirements of people with a physical, sensory, speech and/or language or neurological disability.

Specialised health and personal social service use and requirement

See Table 11 for the current service use and future service requirement of specialised health and personal social services of those with neurological conditions.

Table 8 Current service use and service requirement, NPSDD 2016

	Currently using		Required	
	n	%	n	%
Therapeutic intervention & rehabilitation service	4,143	86.5	1,842	38.5
Personal assistance and support service	1,949	40.7	713	14.9
Day service or activity	2,148	44.9	587	12.3
Residential service	341	7.1	124	2.6
Respite service	647	13.5	452	9.2
Emergency respite services	44	0.9	n/a	n/a
Assistive products	3,517	73.4	768	16.0

Assistive products

The most frequently used assistive products were:

- Shower aids (1,309 items)
- Walking stick/canes/crutches (1,114 items)
- Manual regular wheelchair (1,111 items)
- Bathroom grab rails and bars (886 items)

The most common requests were for special furniture and other aids to personal care (304 items), aids to mobility (125 items) and other aids (29 items).

Conclusion

This bulletin updates a previous bulletin (Doyle & O'Donovan, 2008) exploring the restrictions and difficulties in participation experienced by people with a neurological condition. 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. The results show that the same areas of restriction continue to exist for

those with a neurological condition compared to 2008. Improvements were seen in all areas of participation when compared to 2008, of note, employment and job seeking, leisure/cultural activities and community life.

Further investigation is required to clearly demonstrate which of the services are having a positive impact and to examine the appropriateness of the services currently in use and their impact on individuals' participation.

Appendix

Table A provides a breakdown of the neurological conditions reported.

Table A Conditions within the nervous system diagnostic category, NPSDD 2016		
Primary diagnostic category	n	%
Multiple sclerosis	1,833	38.3
Cerebral palsy	698	14.6
Head injury	438	9.1
Stroke hemiplegia	314	6.6
Spinal injury	208	4.3
Spina bifida	184	3.8
Spina bifida and hydrocephalus	158	3.3
Epilepsy	142	3.0
Muscular dystrophy	130	2.7
Paralytic syndromes paraplegia	113	2.4
Friedreich’s ataxia or cerebellar ataxia	84	1.8
Parkinson’s disease and related disorders	84	1.8
Other nervous system diagnostic category	68	1.4
Paralytic syndromes quadriplegia	61	1.3
Hydrocephalus	42	0.9
Neuropathy	40	0.8
Dystonia	30	0.6
Motor neurone disease	23	0.5
Huntington’s chorea	20	0.4
Paralytic syndromes Erb’s palsy	16	0.3
Other demyelinating diseases of the central nervous system	13	0.3
Guillain-Barre syndrome	12	0.3
Myalgic encephalomyelitis	11	0.2
Meningitis	10	0.2
Encephalitis	10	0.2
Myasthenia gravis	9	0.2
Myelitis	9	0.2
Myopathy	8	0.2
Paralytic syndromes diplegia	7	0.1
Alzheimer’s disease and other cerebral degenerations	5	0.1
Paralytic syndromes monoplegia	~	0.1
Mononeuritis	~	0.1
Migraine	~	0.0
Myelopathies	~	0.0
Total	4,789	100.0

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ISSN: 2009-1303

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