

Measure of Activity and Participation (MAP): the experience of people with neurological conditions



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Introduction

Issue 3 in the 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. In addition, it illustrates the link between this experience and the impact of service interventions.

Neurological conditions are disorders of the nervous system, including the brain, spinal cord, peripheral nerves and muscles (The Association of British Neurologists, 2003). Neurological conditions affect approximately 500,000 people in Ireland (Neurological Alliance of Ireland website, 2008) and this figure is thought to be greatly underestimated with a forthcoming Health Service Executive (HSE) report estimating nearer 800,000 people affected (HSE, 2007, forthcoming).

Profile

In the period up to June 2007, 7,562 people aged 16-65 years, had completed the MAP section of the NPSDD. Of these, 3,293 (43.0%) reported a neurological condition as their primary diagnosis. This bulletin is based on these 3,293 people.

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ISSN: 2009-1303

CONTENTS

Introduction	1
Profile	1
Barriers & Challenges	2
Participation Restriction	3
WHODAS II	6
Service Information	10
Conclusion	13
Appendix	14
References	15

Gender

Gender was evenly distributed with 1,673 (50.8%) females and 1,620 (49.2%) males. Table 1 provides a breakdown of gender and age.

Table 1 Gender and age group of those with a neurological condition						
	Female		Male		Total	
Age group	n	%	n	%	n	%
16*-24 years	111	6.6	146	9.0	257	7.8
25-39 years	373	22.3	369	22.8	742	22.5
40-59 years	904	54.0	805	49.7	1709	51.9
60-65 years	285	17.0	300	18.5	585	17.8
Total	1673	100.0	1620	100.0	3293	100.0

* Map information is only collected on those aged 16 years and over

Specific Diagnoses

The top five neurological conditions reported were:

1. Multiple sclerosis (1,124, 34.1%)
2. Stroke hemiplegia (461, 14.0%)
3. Cerebral palsy (274, 8.3%)
4. Head injury (212, 6.4%)
5. Epilepsy (201, 6.1%)

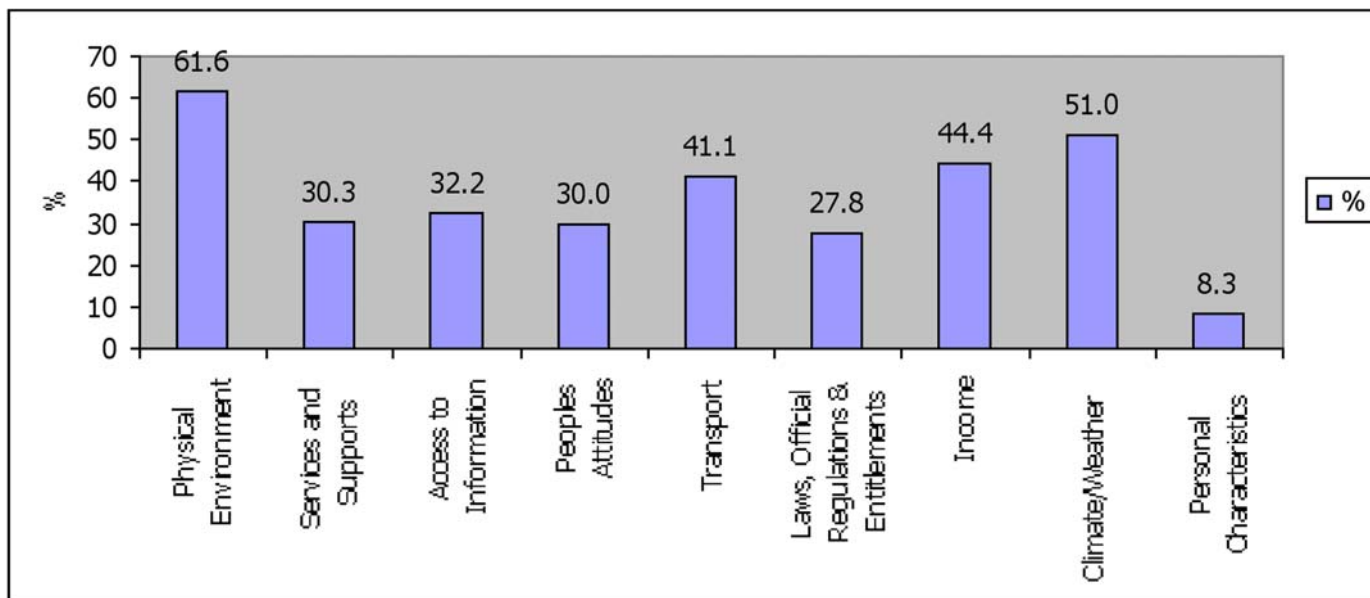
These top five account for over two thirds of all of the neurological conditions. A complete breakdown of all of the conditions within the neurological group is provided in the Appendix.

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: 2,030, 61.6%
- Climate/weather: 1,679, 51.0%
- Income: 1,462, 44.4%

These are also the top three barriers identified for the entire group who have completed the MAP section.

Figure 1: Barriers & challenges

Participation Restriction

Respondents are asked to state the level of difficulty they have experienced in participating in major life areas such as education, employment and socialising. As Kischka (2004) notes, participation refers to '*changes in patients' social roles within their environment as a consequence of their illness*'. It was found that those with a neurological diagnosis experienced the most restriction in participating in the following areas:

- **Sports or physical recreation (1,997, 60.6%)** (examples of sports or physical recreation include going to the gym, walking the dog or doing exercises at home)
- **Socialising (1,990, 60.4%)** (Socialising can include one-to-one encounters including informal conversations and basic human contact)
- **Shopping (1,950, 59.2%)** (examples of shopping include physical access to stores, carrying bags, reaching items on shelves, dealing in financial transactions)
- **Leisure/cultural activities (1,855, 56.3%)** (leisure and/or cultural activities are generally more formal and focussed on specific events, performances and in many cases involve a group of people with shared interests)
- **Family life (1,718, 52.2%)** (examples of family life include taking care of children, participating in family outings, preparing and eating meals together, helping with homework)

Table 2 illustrates the number and percentage of those who reported some participation restriction (mild/moderate/severe/complete). The extent to which this restriction bothered the individual is also captured in Table 2.

Table 2 Participation restriction and extent of bother of this restriction								
Areas of participation restriction	Number & % that experienced participation restriction		Extent to which those who experienced participation restriction were bothered by the restriction*					
	n	%	Not at all bothered		Bothered a little		Bothered a lot	
n			%	n	%	n	%	n
Education & training	1078	32.7	109	10.1	315	29.2	647	60.0
Employment & job Seeking	1555	47.2	138	8.9	348	22.4	1050	67.5
Community life	1308	39.7	173	13.2	456	34.9	662	50.6
Family life	1718	52.2	106	6.2	520	30.3	1074	62.5
Socialising	1990	60.4	163	8.2	674	33.9	1116	56.1
Shopping	1950	59.2	192	9.8	704	36.1	1031	52.9
Living with dignity	1422	43.2	99	7.0	479	33.7	821	57.7
Leisure/cultural activities	1855	56.3	141	7.6	633	34.1	1050	56.6
Sports or physical recreation	1997	60.6	232	11.6	574	28.7	1160	58.1
Religion	672	20.4	96	14.3	260	38.7	309	46.0

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

Of those experiencing restriction participating in:

- **sports and recreation activities:** 1,734 people (86.8%) were bothered somewhat by this restriction
- **socialising:** 1,790 people (89.9%) indicated that they were bothered to some extent by this experience
- **shopping:** 1,735 people (89.0%) were bothered to some extent by this restriction.

The top five neurological conditions were examined to ascertain differences (if any) in the experience of participation. **Socialising** features as the top area for restriction for people with epilepsy (84, 41.8%), cerebral palsy¹ (133, 48.5%) and stroke hemiplegia (312, 65.9%).

Sports and physical recreation was the area in which the most difficulty was encountered for people with cerebral palsy (133, 48.5%) and head injury (145, 68.4%).

Shopping was the area in which most difficulty was encountered for people with multiple sclerosis (718, 63.9%).

¹ People with cerebral palsy had a joint top area of participation restriction in socialising and sports/physical recreation

When the level of participation was ranked across all groups and domains, it was found that overall, socialising was the most frequent area of participation difficulty, with sports and physical recreation in second place. Table 3 provides a breakdown of the percentages across the five neurological conditions who experienced restriction, in addition to the complete ranking. Ranking was achieved by identifying the areas of the most participation restriction for each condition and a rating of 1-10 was assigned to each domain. These ratings were then combined across each domain to get overall rank order.

Table 3 Rank order of participation restriction based on top 5 diagnoses in neurological conditions

	Cerebral palsy n=274	Epilepsy n=201	Head injury n=212	Multiple sclerosis n=1124	Stroke hemiplegia n=461
	%	%	%	%	%
1. Socialising	48.5	41.8	67.5	60.4	67.7
2. Sports or physical recreation	48.5	39.3	68.4	62.8	59.7
3. Leisure/cultural activities	44.2	35.3	65.1	57.2	60.7
4. Shopping	42.7	31.3	63.2	63.9	65.9
5. Family life	29.6	34.8	64.6	54.7	62.3
6. Employment or job seeking	39.8	39.3	62.3	44.4	51.8
7. Living with dignity	34.3	24.9	55.2	39.1	52.7
8. Education & training	31.4	32.3	52.4	28.4	30.2
9. Community life	29.9	24.4	56.6	38.3	47.3
10. Religion	10.2	10.0	25.0	20.3	26.7

The high level of participation restriction faced by people with head injury may have implications for service planning. In this regard, acquired conditions such as head injury, multiple sclerosis and stroke appear to have a greater restriction pattern than cerebral palsy or epilepsy.

The five most common neurological groups were further examined (Table 4) in terms of their experience of *complete* participation restriction in various areas. Table 4 shows that employment and job seeking was the highest area of *complete* restriction for people with head injury (80, 37.7% of all those with head injury), for people with stroke hemiplegia (153, 33.2%) and for people with epilepsy (18, 9.0%).

For people with cerebral palsy and multiple sclerosis, sports and physical recreation was the area where complete restriction was encountered to the greatest extent (46, 16.8%; 303, 27.0%).

Table 4 Complete Participation restriction by top 5 diagnoses in neurological conditions

	Cerebral palsy n=274	Epilepsy n=201	Head injury n=212	Multiple sclerosis n=1124	Stroke hemiplegia n=461
	%	%	%	%	%
Education & training	7.7	6.0	22.2	9.6	13.9
Employment or job seeking	12.0	9.0	37.7	2.3	33.2
Community life	8.4	5.0	25.5	11.7	21.9
Family life	1.8	2.5	19.8	6.3	13.2
Socialising	7.7	3.5	25.0	9.3	19.3
Shopping	4.7	5.0	17.5	11.0	21.5
Living with dignity	4.4	3.0	16.0	5.6	9.3
Leisure/cultural activities	8.4	5.0	25.5	12.3	22.1
Sports or physical recreation	16.8	8.5	34.0	27.0	31.2
Religion	0.7	1.0	8.0	3.6	7.2

WHODAS II

The World Health Organization's Disability Assessment Schedule, (WHODAS II) assesses the extent of difficulty an individual has in performing daily activities such as washing oneself, communicating with strangers, maintaining household responsibilities. Table 5 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 the NPSDD dataform. The majority of respondents stated that the difficulties listed under the WHODAS II section of the dataform had an overall interference in their lives (2,932, 89.0%). The three areas that individuals experienced the most difficulty in were:

- Standing for long periods such as 30 minutes (2,669, 81.1%)
- Walking a long distance such as a kilometre (2,646, 80.4%)
- Taking care of household responsibilities (2,163, 65.7%)

Similar information is captured in the Census 2006 and the Survey of Lifestyles, Attitudes and Nutrition (SLÁN, 2003). 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, the Census and SLÁN data refer to a much wider population.

Census data found that 28.7% of people with disabilities experienced difficulty in learning, remembering or concentrating, 22.4% had difficulty in getting dressed and 35.8% had difficulty in working or attending school/college. The WHODAS II data found that 41.8% of people with a neurological condition who completed the MAP data reported that they 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 a greater experience of difficulty than those identified with disability in the census.

Figure 2 WHODAS II - % with neurological condition that experienced *some* difficulty



Emotional effect of disability

Respondents are also asked how much they have been emotionally affected by their disability. It was found that 77.8% of those with a neurological condition (2,561 people) were emotionally affected by their disability.

Overall interference with life

2,932 people (89.0%) found that the listed WHODAS II domains had to some extent interfered with their lives. Of these:

- 522 people (17.8%) reported that the difficulties interfered '*mildly*' with their lives.
- 742 people (25.3%) reported that the difficulties interfered '*moderately*' with their lives.
- 824 people (25.0%) reported that the difficulties interfered '*severely*' with their lives.
- 844 people (25.6%) reported that the difficulties interfered '*extremely*' with their lives.

Table 5 also illustrates the extent of difficulty experienced by people in the top 5 neurological diagnostic groups. It is interesting to note the differences across diagnostic groups in the difficulties experienced with every day activities. This shows that:

- For those with cerebral palsy, walking long distances (219, 79.9%) and standing for long periods (211, 77.0%) represented the greatest difficulties.
- For those with epilepsy, the emotional effect of their disability (121, 60.2%) and concentrating on doing something for 10 minutes (75, 37.3%) represented their greatest difficulties.
- For those with head injury, the emotional effect of their disability (192, 90.6%) was their greatest difficulty, followed by learning a new task (152, 71.7%).
- For those with multiple sclerosis, standing for long periods (981, 87.3%) and walking long distances (959, 85.3%) represented the greatest difficulties.
- Finally, for those with stroke hemiplegia, the emotional effect of their disability (396, 85.9%) and walking long distances (378, 82.0%) were the areas where they experienced greatest difficulty.

Table 5 Top 5 diagnoses of those who experienced any difficulty in WHODAS II domains

WHODAS II domains	All neurological conditions (n=3293)	Cerebral palsy (n=274)	Epilepsy (n=201)	Head injury (n=212)	Multiple sclerosis (n=1124)	Stroke hemiplegia (n=461)
	%	%	%	%	%	%
Concentrating on doing something for 10 minutes	41.8	32.8	37.3	66.5	42.8	54.4
Learning a new task	39.6	36.9	32.8	71.7	37.0	53.1
Standing for long periods such as 30 minutes	81.1	77.0	28.9	68.4	87.3	80.9
Walking a long distance such as a kilometre	80.4	79.9	24.4	66.0	85.3	82.0
Washing your whole body	45.7	44.9	9.5	48.6	42.1	56.2
Getting dressed	46.3	46.7	8.0	47.6	42.4	56.2
Dealing with strangers	27.8	31.0	18.9	50.9	20.4	42.1
Maintaining a friendship	24.8	24.1	15.9	53.3	19.7	33.4
Taking care of household responsibilities	65.7	54.7	28.9	69.3	68.4	73.8
Day to day work/school	49.3	44.2	31.3	59.4	50.1	53.8
Joining in community activities	56.7	51.5	34.3	70.3	54.7	66.6
Emotional effect of disability	77.8	63.1	60.2	90.6	80.5	85.9
Overall interference of difficulties with life	89.0	80.3	71.6	93.4	90.4	95.0

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 and/or sensory disability (NPSDD Committee Annual Report, 2007). The current service use and future service requirement of specialised health and personal social services of those with neurological conditions are summarised below. Following this, service usage is examined in relation to the barriers, participation restriction and functioning experienced by individuals.

Current specialised health and personal social service use

Of the people who completed the MAP section of the NPSDD dataform and who have a primary diagnostic category that is neurological in nature, the following service use was captured:

- **Therapeutic intervention and rehabilitation service:** 2,759 people (83.8%)
- **Personal assistance and support service:** 1,373 (41.7%)
- **Day service or activity:** 1,332 (40.4%)
- **Residential service:** 298 (9.0%)
- **Respite service:** 555 (16.9%) and 65 people (2.0%) had used emergency respite services in the 12-month period prior to their NPSDD interview.
- **Technical aids/appliances:** 2,402 (72.9%). The most frequently used technical aids and appliances were:
 - Walking stick/canes/crutches (496, 20.6%)
 - Manual regular wheelchair (447, 18.6%)
 - Powered wheelchair (313, 13.0%)
 - Manual specialised wheelchair (249, 10.4%)

Future specialised health and personal social service requirements

The service requirements of those with a neurological condition who completed the MAP section of the data form highlighted that respondents were awaiting assessment, on a waiting list for receipt of this service or were unable to avail of the service as follows:

- **Therapeutic intervention and rehabilitation services:** 2,186 people (66.4%)
- **Personal assistance and support services:** 1,119 people (34.0%)
- **Day service or activities:** 968 people (29.4%)
- **Residential services:** 258 people (7.8%)
- **Respite services:** 656 people (19.9%)
- **Technical aids/appliances:** 1,412 people (42.9%) requested at least one technical aid or appliance.
 - The most common requests were for special furniture and other aids to personal care (969, 29.4%), aids to mobility (735, 22.3%) and other aids (123, 3.7%).

The MAP data also captures information on the restrictions people with disabilities experience when accessing general health services as follows:

Mainstream hospital services

825 people (25.1%) with a neurological condition indicated that they were restricted in accessing mainstream hospital services and 54.3% of this group (448 people) were 'bothered a lot' by this restriction.

Community based services

738 people (22.4%) with a neurological condition indicated that they were restricted in accessing community based services and 45.9% of this group (339 people) were 'bothered a lot' by this restriction.

Mental health services

135 people (4.1%) with a neurological condition indicated that they were restricted in accessing mental health services and the majority of this group (81 people, 60.0%) were 'bothered a lot' by this restriction.

Experience accessing services and impact of interventions on participation/functioning

The link between accessing services and the experience of participation and functioning can be explored further through examples. It should be noted that these are purely illustrative and the services selected have not been given any priority. Rather, the purpose is to highlight how the information can be used to inform service planning and delivery into the future.

Previous research has shown that people with neurological conditions face difficulties accessing both services and information (Joule, 2006, Neurological Alliance, UK, 2001). Of those with a neurological condition who completed the MAP section of the NPSDD form, 1,061 people (32.2%) reported facing a barrier in accessing information (e.g. about entitlements, services or nature of condition).

Taking an example of the use and requirement of the services of a personal assistant (PA), Table 6 compares the participation restriction of those who are accessing a PA to those who currently do not have a PA but who require such services. This data were tested for significance and found to be highly significant.

Table 6 Participation and use of personal assistance services				
	% of people who stated that they experienced participation restriction			
	Those currently accessing PA services (346)		Those not currently accessing PA services but requiring these services (399)	
	n	%	n	%
Socialising	239	69.1	306	76.7
Shopping	230	66.5	298	74.7
Leisure/Cultural Activities	221	63.9	292	73.2

Further examples below explore the barriers and challenges, the participation restriction and the WHODAS II measure in relation to service use and requirements.

- Of the 30.0% of people (989) who stated that people's attitudes represented a barrier to their participation, 10.2% (101 people) are currently accessing the services of a counsellor and 14.4% (142 people) require the services of a counsellor over the next five years.
- Of the 52.2% of people (1,718) who experienced difficulties with their family life, 9.0% (154 people) are currently accessing the services of a counsellor and 14.3% (246 people) require the services of a counsellor in the next five years.
- Of the 77.8% of people (2,561) who stated that they were emotionally affected by their disability, 8.1% (208 people) are currently accessing the services of a counsellor and 12.5% (320 people) require the services of a counsellor.

Conclusion

This bulletin explores the difficulties in participating experienced by people with a neurological condition. The basic premise behind the MAP tool is to provide information on the services to people with disabilities in order to improve their level of participation in those areas of life from which they feel wholly or partially excluded. It is beneficial to identify the areas, barriers and the services that prove effective in bringing about an improvement. The data has shown that the impact of PA services is clearly significant. Going forward, it will be useful to compare the data year on year, examining the appropriateness of the services currently in use and their impact on individuals' participation. This longer term analysis will help to understand the real impact of service provision for individuals.

Previous bulletins in the MAP series

- Issue 1: Measuring Activity and Participation of people with disabilities – An overview
- Issue 2: Measure of Activity and Participation (MAP) World Health Organization's Disability Assessment Schedule (WHODAS II).

Both issues are available to download from the HRB website

(www.hrb.ie).

Appendix

Table A below provides a breakdown of the conditions reported under the neurological conditions.

Table A Conditions within the nervous system diagnostic category		
Primary Diagnostic Category	n	%
Progressive disorders		
Multiple sclerosis	1124	34.1
Parkinson's Disease and related disorders	123	3.7
Muscular dystrophy	71	2.2
Friedreich's Ataxia or Cerebellar Ataxia	59	1.8
Motor Neurone Disease	46	1.4
Alzheimer's Disease and other cerebral degenerations	13	0.4
Other demyelinating diseases of the central nervous system	11	0.3
Huntington's Chorea	7	0.2
Myasthenia Gravis	7	0.2
Myelopathies	<5	-
Non-progressive disorders		
Stroke hemiplegia	461	14.0
Cerebral palsy	274	8.3
Head injury	212	6.4
Epilepsy	201	6.1
Spinal Injury	144	4.4
Spina Bifida	115	3.5
Paralytic Syndromes Paraplegia	84	2.6
Spina Bifida and Hydrocephalus	80	2.4
Unspecified nervous system diagnostic category	65	2.0
Paralytic Syndromes Quadriplegia	43	1.3
Neuropathy	40	1.2
Hydrocephalus	17	0.5
Dystonia	14	0.4
Meningitis	14	0.4
Guillain-Barre Syndrome	13	0.4
Myopathy	12	0.4
Myalgic Encephalomyelitis	10	0.3
Encephalitis	8	0.2
Myelitis	6	0.2
Paralytic Syndromes Monoplegia	5	0.2
Mononeuritis	<5	-
Paralytic Syndromes Diplegia	<5	-
Paralytic Syndromes Erbs Palsy	<5	-
Migraine	<5	-
Total	3293	100.0

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ISSN: 2009-1303