

Measure of Activity and Participation (MAP): Personal assistance and support services



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Executive Summary

The purpose of this bulletin is to document the results from the Measure of Activity and Participation (MAP) section of the National Physical and Sensory Disability Database (NPSDD), an International Classification of Functioning (ICF) based measure that captures data on participation restrictions for people with a disability. This bulletin focuses on those registered on the NPSDD who have completed the MAP section of the form and who have stated that they require the services of a Personal Assistant (PA) and/or home help. As the objective of the NPSDD is service planning, this bulletin profiles those who have a continuing unmet need for the services and the potential impact that this has on their participation in a range of day to day activities.

The findings illustrate that this group of people experience challenges in their day-to-day living. They identify specific barriers in their environment including the physical infrastructure and climate/weather. For the cohort of people covered in this bulletin, there are also participation restrictions in activities that many would take for granted, such as shopping, socialising and involvement in family life. One in four people requiring PA and/or home help services reported that they were completely restricted from participating in sports and/or recreation activities and employment and/or job seeking.

Using the WHO's Disability Assessment Schedule (WHODAS 2.0) the results showed that ninety per cent of those requiring PA and/or home help services experienced difficulty when standing for long periods and walking long distances. Similarly, nine-tenths of those who require PA and/or home help services reported that their disability caused an overall interference with their lives and over three-quarters reported experiencing emotional effects of their disability.

The bulletin highlights the unmet needs of those that require PA/home help and their levels of restriction in everyday living.

This is Issue 8 in the MAP Bulletin Series. The series is listed at the back of this publication. All issues can be found at www.hrb.ie.

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Background

MAP data from the NPSDD gives an insight into the experiences of restriction and participation barriers reported by people with disabilities. Previous MAP bulletins examined functional difficulties experienced by those receiving PA services (O'Donovan & Doyle, 2007) and participation issues for those with neurological conditions and having or needing PA services (Doyle & O'Donovan, 2008). This bulletin examines, in more detail, the role of home help and/or PA services as they have been shown to contribute positively to the lives of people with disabilities by facilitating more independent living.

A Health Service Executive (HSE) report on services for people with disabilities highlighted the need for a more 'person-centred' approach, moving from congregated settings towards a social model of disability, placing a premium on community inclusion (HSE, 2012). For many people with disabilities, the availability of a PA or home help service equips them to be active, independent members of their community, to make choices and decisions which affect their lives and to achieve personal goals and aspirations (HSE, 2012).

A recently published report by the Disability Federation of Ireland (DFI) looked in depth at the PA service in Ireland and concludes that it is a much valued service by those who use it and that it supports independent living (DFI, 2014). The report suggests that, in light of recent budgetary austerity measures in Ireland, it is vital that the government remain committed to strategies that support the right to independent living (DFI, 2014). Having access to the services of a PA and/or home help has advantages for people with disabilities and this bulletin highlights the difficulties faced by those who are awaiting such services.

Overview

This bulletin investigates requirements for personal assistance and support services (specifically PA and home help services) as recorded on the NPSDD and examines the relationship between these service requirements and social-environmental participation, participation restrictions in life activities, and difficulties with daily activities.

The NPSDD defines a PA as '*a [person] assigned to the person with a disability to enable them to live an independent life. The PA provides assistance at the discretion and direction of the person with the disability thus promoting choice and control for the person with the disability to live independently*'.

Home help is defined on the NPSDD as a service to '*provide domestic type support e.g. cooking/cleaning etc. but in many cases where home care assistants are not available the home help may also provide support of a personal nature e.g. washing or dressing*'.

PAs and home help services play a key role in enabling independent living for people with a disability by empowering these individuals to go about their daily lives. In 2007, Ireland became a signatory to the United Nations (UN) Convention on the Rights of Persons with Disabilities under which, Article 19 specifies that 'persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community' (United Nations, 2007). For the person with a disability, the services of a PA and/or home help are invaluable and their availability has been shown to lead to improved quality of life and fuller participation in society (DFI, 2014).

Methods

The MAP is an International Classification of Functioning, Disability and Health (ICF) based set of measures which was introduced on to the NPSDD in 2004. The MAP section of the NPSDD includes three components:

- Barriers and challenges – highlights the social-environmental factors that potentially serve to exclude or restrict participation of people with disabilities in society.
- Participation restriction – looks at the extent of restriction experienced in participating in particular life areas.
- WHODAS 2.0 – World Health Organization Disability Assessment Schedule which is a standardized measure capturing the level of difficulty with daily activities experienced by those with a disability.

The MAP section of the NPSDD data form is completed only by those aged 16 years and over. The data presented in this bulletin are based on the official dataset for 2013 and includes only those on the NPSDD who have had their information entered or reviewed in the past 5 years.

Results

Profile

In 2013, 9,928 people aged 16-65 years were registered on the NPSDD and had completed MAP. In total 1,289 people required PA and/or home help services; of these, 570 people required a PA service and 719 people required home help services (Table 1). These figures include those who had no service, and those who had a service but required an enhancement to that service, such as additional hours.

Table 1 PA/home help service status, 2013				
	PA		Home help	
	n	%	n	%
In receipt of service(s), no modifications required	979	63.2	993	58.0
Needing service(s) or service enhancement	570	36.2	719	42.0
Total	1,549	100.0	1,713	100.0

Of the 570 people requiring a PA service, 144 people (25.3%) already had a PA service but required an enhancement to their service (i.e. more hours) (Table 2). Of the 719 people requiring a home help service, 113 people (15.7%) were already in receipt of home help but required additional hours. The majority of those who require a PA and/or home help are recorded on the NPSDD as awaiting formal assessment for these services.

Table 2 PA/home help requirements, 2013				
	PA		Home help	
	n	%	n	%
Currently receiving service(s) but require enhanced/alternative service required	144	25.3	113	15.7
Required, yet to receive service(s)	426	74.7	606	84.3
Total	570	100.0	719	100.0

Age group and gender

Slightly more females (53.2%) than males (46.8%) required PA services; most were in the 40-59 years age group. For those who required home help services, most were female (469, 65.2%) and were in the 40-59 years age group.

Table 3 Gender and age group, 2013												
Age group	Require PA services						Require home help services					
	Female		Male		Total		Female		Male		Total	
	n	%	n	%	n	%	n	%	n	%	n	%
16-24 years	22	7.3	32	12.0	49	8.6	11	2.3	11	4.4	22	3.1
25-39 years	72	23.8	51	19.1	123	21.6	49	10.4	29	11.6	78	10.8
40-59 years	153	50.5	138	51.7	291	51.1	278	59.3	146	58.4	424	59.0
60-65 years	56	18.5	46	17.2	102	17.9	131	27.9	64	25.6	195	27.1
Total	303	100.0	267	100.0	570	100.0	469	100.0	250	100.0	719	100.0

Type of disability

The main disability categories of those who require PA and/or home help services are shown in Table 4. The top three categories are neurological, combined disabilities and physical disability.

Table 4 Type of disability of those requiring PA/Home help, 2013				
Disability type	Require PA		Require home help	
	n	%	n	%
Neurological	277	48.6	341	47.4
Combined disabilities	167	29.3	193	26.8
Physical	85	14.9	160	22.3
Hearing loss/deafness	3	0.5	3	0.4
Visual	36	6.3	22	3.1
Speech and/or language	2	0.4	0	0.0
Total	570	100.0	719	100.0

Primary diagnostic category

The top primary diagnostic categories of the 570 people who require PA services were as follows:

1. Multiple sclerosis (102, 17.9%)
2. Cerebral palsy (63, 11.1%)
3. Head injury (45, 7.9%)
4. Stroke hemiplegia (38, 6.7%)
5. Spina bifida and hydrocephalus (30, 5.3%).

The top primary diagnostic categories of the 719 people who require home help services were as follows:

1. Multiple sclerosis (183, 25.5%)
2. Stroke hemiplegia (53, 7.4%)
3. Cerebral palsy (49, 6.8%)
4. Head injury (34, 4.7%)
5. Rheumatoid arthritis (31, 4.3%).

Primary carer

Just over half of those requiring a PA service (304 people, 53.3%) reported having a primary carer. The majority of

primary carers were family members (298, 98.0%) and 90.1% (274) lived with their primary carer. More than 40% of those requiring home help services reported having a primary carer (310 people, 43.1%). The majority of primary carers were family members (290, 93.5%). Nine in every ten people (90.3%, 280 people) lived with their primary carer.

Living arrangements and living accommodation

The majority of those who reported requiring PA services lived with family members (393, 68.9%), 101 people (17.7%) lived alone and the remainder (76, 13.3%) lived with 'non-family' (e.g. friends or neighbours etc.) or in 'other' arrangements (e.g. residential settings). A similar pattern occurs for those who require home help services; the majority live with family members (518, 72.0%) but a higher proportion of those who require home help (176, 24.5%) live alone (Table 5).

Of the 570 people who require PA services, 398 (69.8%) stated that they live in private accommodation, 103 (18.1%) in rented accommodation and 69 (12.1%) were in residential services or 'other' accommodation. The majority of those who require home help services live in private accommodation (554 people, 77.1%), 143 (19.9%) live in rented accommodation and 22 (3.0%) live in full-time residential services or 'other' accommodation.

Table 5 Type of living arrangements, 2013				
	Require PA		Require home help	
	n	%	n	%
Living alone	101	17.7	176	24.5
Living with family	393	68.9	518	72.0
Living with non-family	73	12.8	20	2.8
Other	3	0.5	5	0.7
Total	570	100.0	719	100.0

Barriers and challenges

The main barriers and challenges reported by those requiring PA services and home help services are shown in Figure 1.

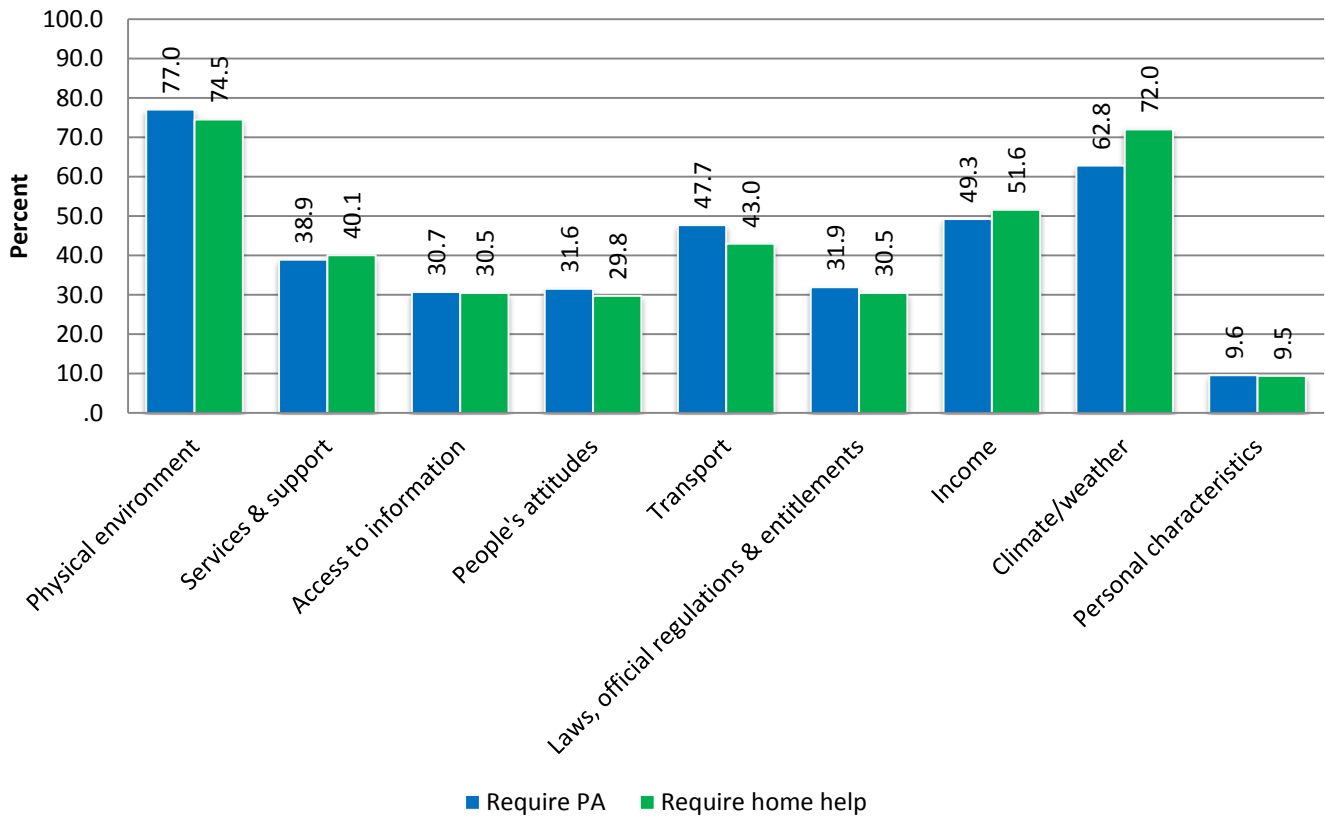


Figure 1 Barriers and challenges of those requiring PA/home help services

The top barriers and challenges reported by those requiring a PA service were:

- Physical environment (439, 77.0%)
- Climate/weather (358, 62.8%)
- Income (281, 49.3%).

The top barriers and challenges reported by those requiring home help services were:

- Physical environment (536, 74.5%)
- Climate/weather (518, 72.0%)
- Income (371, 51.6%).

Participation restriction

The MAP data on participation highlights the major life areas where participation restriction was experienced and to what extent this restriction has bothered the individual. The extent of participation restriction can be 'mild', 'moderate', 'severe' or 'complete'. In addition, an individual can be recorded as bothered 'a little', bothered 'a lot' or not bothered at all by his/her participation restriction. Shopping, socialising and family life were the three main areas of participation restriction experienced by those requiring a PA service (Table 6). Most people reported that they were 'bothered' by their participation restrictions in these areas. Of those who reported shopping as an area of participation restriction, 76 people (19.0%) were 'completely restricted', 61 people (15.0%) were 'completely restricted' in socialising and 37 people (10.1%) were 'completely restricted' in family life activities.

As with those requiring a PA service, those requiring home help services reported the same top three areas of participation restriction; shopping, of which 96 people (17.6%) were ‘completely restricted’, 79 people (15.2%) were ‘completely restricted’ in socialising and 54 people (11.1%) reported being ‘completely restricted’ in participating in family life (Table 7).

Table 6 Participation restriction for those requiring PA services								
Area of participation restriction			Participation - extent restrictions bothered you*					
	N	%	Not at all		A little		A lot	
			n	%	n	%	n	%
Education & training	170	29.8	13	7.6	53	31.2	103	60.6
Employment or job seeking	250	43.9	23	9.2	60	24.0	166	66.4
Community life	256	44.9	20	7.8	77	30.1	157	61.3
Family life	366	64.2	18	4.9	105	28.7	239	65.3
Socialising	407	71.4	21	5.2	138	33.9	244	60.0
Shopping	399	70.0	28	7.0	154	38.6	213	53.4
Living with dignity	320	56.1	16	5.0	97	30.3	205	64.1
Leisure/cultural activities	360	63.2	20	5.6	122	33.9	214	59.4
Sports or physical recreation	331	58.1	34	10.3	97	29.3	195	58.9
Religion	287	25.7	37	12.9	100	34.8	148	51.6
Hospital services	360	32.3	34	9.4	110	30.6	210	58.3
Mental health services	69	6.2	2	2.9	23	33.3	43	62.3
Community based health services	297	26.6	31	10.4	104	35.0	158	53.2

*a number of people did not provide responses for the extent to which they were ‘bothered’ by their restriction

Table 7 Participation restriction for those requiring home help services								
Area of participation restriction			Participation - extent restrictions bothered you*					
	n	%	Not at all		A little		A lot	
			n	%	n	%	n	%
Education & training	200	27.8	15	7.5	63	31.5	121	60.5
Employment or job seeking	327	45.5	26	8	76	23.2	224	68.5
Community life	344	47.8	32	9.3	133	38.7	178	51.7
Family life	488	67.9	27	5.5	151	30.9	308	63.1
Socialising	520	72.3	41	7.9	185	35.6	291	56
Shopping	546	75.9	40	7.3	190	34.8	315	57.7
Living with dignity	368	51.2	9	2.4	118	32.1	240	65.2
Leisure/cultural activities	474	65.9	26	5.5	173	36.5	272	57.4
Sports or physical recreation	460	64	43	9.3	145	31.5	270	58.7
Religion	181	25.2	26	14.4	55	30.4	99	54.7
Hospital services	225	31.3	22	9.8	67	29.8	133	59.1
Mental health services	37	5.1	1	2.7	14	37.8	22	59.5
Community based health services	175	24.3	18	10.3	60	34.3	93	53.1

*a number of people did not provide responses for the extent to which they were ‘bothered’ by their restriction

Complete participation restriction

Other areas where participation is 'completely restricted', that is, life areas where individuals are unable to participate at all include sports/recreation and employment/job-seeking. Among those requiring a PA service, 27.2% (155 people) indicated that their participation in sports/recreation had been completely restricted in the past twelve months while 23.7% (135 people) were completely unable to participate in employment or job seeking. Among those requiring a home help service, 28.9% (208 people) and 24.2% (174 people) reported being 'completely restricted' from participating in sports/recreation and employment or job seeking respectively.

WHODAS 2.0

The WHODAS II (World Health Organisation's Disability Assessment Schedule) is a measure of the difficulty the individual has had with performing particular daily activities over a period of 30 days. The main areas of difficulty for those requiring the services of a PA and/or home help were standing for long periods of time, walking long distances and household responsibilities (Figure 2).

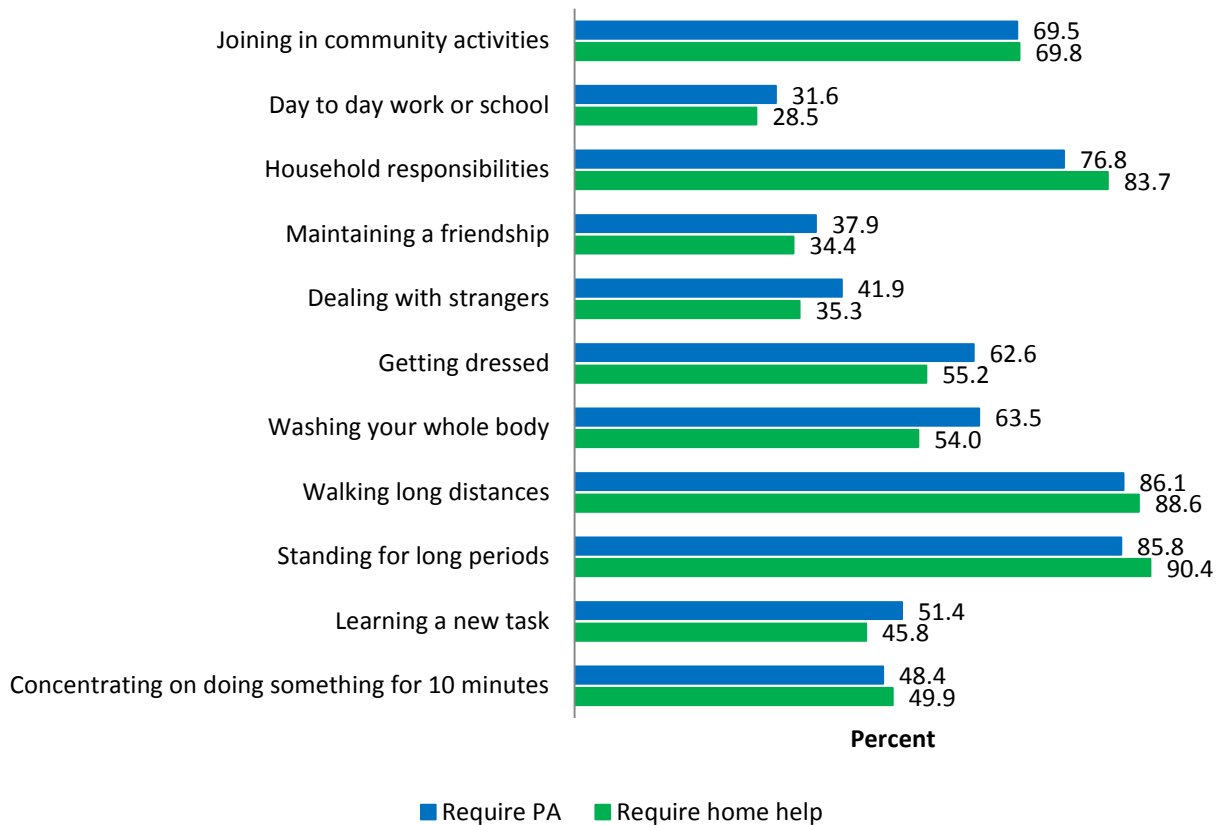


Figure 2 WHODAS 2.0 results for those requiring PA/home help services

The top daily activities representing difficulties for those requiring PA service were:

- Walking long distances (491 (86.1%))
- Standing for long periods (489, 85.8%)
- Household responsibilities (438, 76.8%).

The top daily activities representing difficulties for those requiring home help service were:

- Standing for long periods (650, 90.4%)
- Walking long distances (637, 88.6%)
- Household responsibilities (602, 83.7%).

Service users were also asked to appraise the emotional effect of their disability and how much the difficulties experienced interfered with their life overall. Both ranked highly among those requiring PA and/or home help services (Figure 3). The findings show that almost 95% of those who require home help and 91% of those who require a PA service experience an overall interference in their lives because of their disability. In relation to the reported emotional effects of their disability, 81.2% of those requiring home help experience some emotional effects while 76.7% of those requiring a PA service reported this.

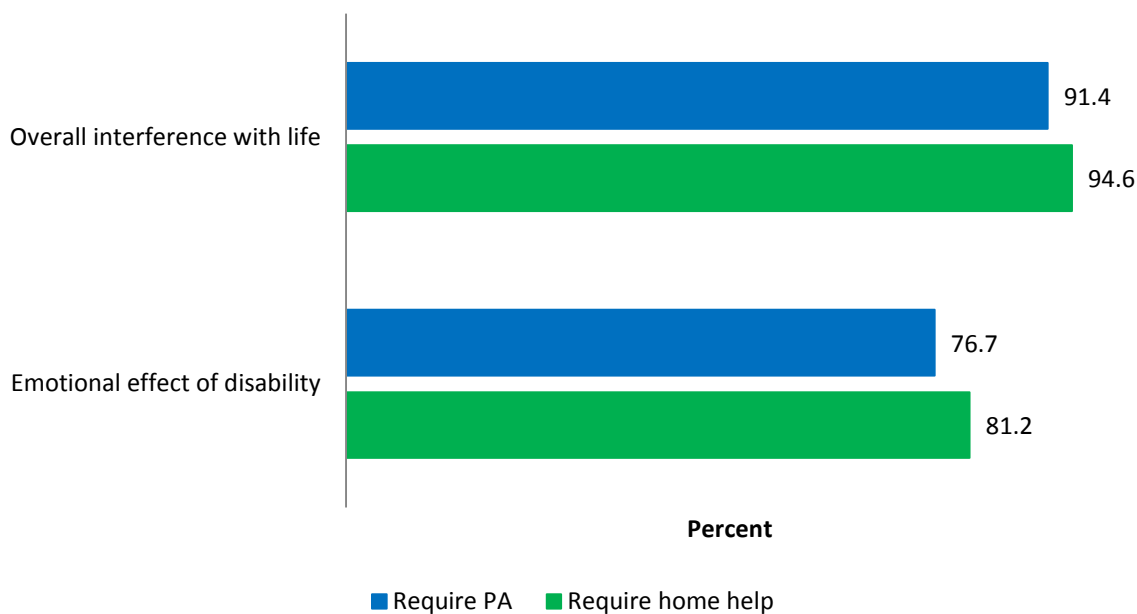


Figure 3 Overall interference and emotional affect of disability for those requiring PA/home help services

Conclusion

This bulletin explores the difficulties experienced by people requiring PA and/or home help services. The findings illustrate that this group of people experience barriers such as the physical environment and climate/weather and report specific participation restriction in activities that many would take for granted such as shopping, socialising and involvement in family life. One in four people requiring PA and/or home help services were completely restricted from participating in sports/recreation activities and employment or job seeking. The WHODAS 2.0 measure revealed that nine out of ten people requiring PA and/or home help services experienced difficulty when standing for long periods, walking long distances and in household responsibilities. Similar amounts of people reported that their disability caused an overall interference with their lives and about 80% reported emotional effects of their disability. The provision of a PA and/or home help service has been recognised as of significant benefit to these individuals in their daily lives in order to participate fully in society as set out in the UN Convention on the Rights of Persons with Disabilities (United Nations, 2007). This bulletin presents the reported restrictions and difficulties experienced by people who do not have the required level of these supports in place.

References

Doyle A & O'Donovan MA (2008) *Measure of Activity and Participation (MAP): the experience of people with neurological conditions*. MAP Bulletin 3. Dublin: Health Research Board.

Disability Federation of Ireland (2014) *Access to Life: Personal Assistant Services in Ireland and Independent Living by People with Physical and Sensory Disabilities*. Dublin: DFI.

Health Service Executive (2012) *'New Directions: Review of HSE day services and implementation plan 2012-2016: personal support services for adults with disabilities'*, Naas: HSE.

O'Donovan MA & Doyle A (2007) *Measure of Activity and Participation (MAP) World Health Organization's Disability Assessment Schedule (WHODAS II)*. MAP Bulletin 2. Dublin: Health Research Board.

United Nations (2007) *Convention on the Rights of Persons with Disabilities (UNCRPD)*. Geneva: United Nations.

Map Bulletin Series

O'Donovan MA & Doyle A (2006) *Measuring Activity and Participation of people with disabilities – An overview*, MAP Bulletin 1, Dublin Health Research Board.

O'Donovan MA & Doyle A (2007) *Measure of Activity and Participation (MAP) World Health Organization's Disability Assessment Schedule (WHODAS II)*. MAP Bulletin 2. Dublin: Health Research Board.

Doyle, A & O'Donovan, MA (2008) *Measure of Activity and Participation (MAP): The experience of people with neurological conditions*, MAP Bulletin 3. Dublin: Health Research Board.

O'Donovan MA & Doyle A (2009) *Measure of Activity and Participation (MAP): Participation and ageing: the experience of people on the NPSDD*, MAP Bulletin 4. Dublin: Health Research Board.

O'Donovan MA (2011) *Measure of Activity and Participation (MAP): Disability data sources in Ireland*, MAP Bulletin 5. Dublin: Health Research Board.

Carew, AM & Doyle A (2012) *Activity, participation and assistive technology*, MAP Bulletin 6. Dublin: Health Research Board.

Doyle A & Carew AM (2013) *MAP: Origins and potential uses*, MAP Bulletin 7. Dublin: Health Research Board.

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