

Measure of Activity and Participation (MAP): Participation and ageing: the experience of people on the NPSDD



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Background

The National Physical and Sensory Disability Database Committee (NPSDDC) was set up in 1998 by the Department of Health and Children (DoHC) with the task of developing a national database that would collect information on the specialised health and social service needs of people with physical or sensory disability. Implementation of the NPSDD on a nationwide basis began in 2002.

As signatories to the International Classification of Functioning, Disability and Health (ICF), the DoHC recognised the value of expanding data collection efforts to include indicators of participation based on the ICF, and established the Measure of Activity and Participation (MAP) subgroup to oversee the piloting of new survey questions in 2003. The MAP consists of three sections (barriers, participation, WHODAS II) and was introduced in 2004.

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Introduction

The 2006 Census figures show that persons with disabilities represent 9.3% of the total population with 35.1% of those with disability aged 65 years or over (CSO, 2007). The recent National Disability Survey provides estimates of disability at 18.5% with 30.0% of this group aged 65 years or over (CSO, 2008). The difference in disability estimates is due to the expanded definition of disability used in the National Disability Survey. In terms of the profile of the general population it is widely accepted that we are an ageing population, with projections by the CSO estimating that by 2036 older people will make up 20% to 23% of the population (ESRI, 2007). This is in part due to advances in medicine and technical innovations which are enabling people to live longer and survive diseases and accidents which would previously have been fatal. "The substantial increases in life expectancy at birth achieved over the previous century, combined with medical advances, escalating health and social care costs, and higher expectations for older age, have led to international interest in how to promote a healthier old age and how to age 'successfully'" (Bowling, 2005: 1548).

Increasingly there is an emphasis on "successful ageing" or "positive ageing". In fact, the Government has committed to engaging with agencies that represent older people to develop a national positive ageing strategy (www.olderandbolder.ie). Definitions of successful ageing are many and varied (Bowling et. al. 2006) with Rowe et. al (1997: 433) defining it as "multidimensional, encompassing the avoidance of disease and disability, the maintenance of high physical and cognitive function, and sustained engagement in social and productive activities". Absence of disability is an inappropriate indicator of successful ageing for people who have disability from an early age. The distinction between those ageing with disability and those acquiring disability with age would need to be considered with a more holistic view of disability and ageing incorporated in any definition of positive ageing.

At present the cut-off point for registration on the NPSDD is age 65 years. The NPSDD is a national information system that informs service planning and delivery for people with physical, sensory and speech and language disabilities. Once a person turns 66 years of age his/her service needs are met by Older People's services in the DoHC. Thus the structure of the Database is reflective of how the funding system is organised. This has been contested by the National Council on Ageing and Older People (NCAOP) in their 2007 report on quality of life and older people where they called for "the age limit of 65 years for the National Physical and Sensory Disability Database (NPSDD) [to be] removed as a matter of priority" (p18). Discussions continue at national level on this issue.

Despite the current structure and criteria, it is recognised that an understanding of how age and disability interact is essential to informing effective service planning and policy. As Zarb and Oliver (1993) state, "...it is impossible to develop appropriate policies and support services without an awareness of, and sensitivity to people's subjective experiences of ageing with a disability". Although specifically referring to people over 65 years of age, the ESRI report on social inclusion of older people states that, "Access to services can play a crucial role in older people's quality of life. Problems in relation to access, as might happen more in rural areas, could undermine that quality of life" (2007: 26). Access to services as a determinant of quality of life could be said to be relevant to all people with disabilities regardless of age.

This bulletin is based on 10,696 people who completed the MAP section of the NPSDD by end 2008. In interpreting the data some caveats must be borne in mind:

- Information on onset of disability is not captured on NPSDD. Thus we can compare across age groups but it is not possible to distinguish between those who are ageing with disability and those who have acquired disability with age.
- Information is only recorded on people up to and including age 65 years. Thus the cut-off point for analysis is 65 years of age.

In light of this there are two main aims of this bulletin:

- To explore the experience of participation across age groups and diagnostic categories;
- To explore the interaction between service need and participation experience.

Profile

This sample is divided almost equally between male and females. The gender/age breakdown is shown in Table 1 and highlights that the majority of people are in the 45-65 years age group.

Table 1: Gender by age group

Age groups	Female		Male		Total	
	n	%	n	%	n	%
16-24 years	460	8.4	573	10.9	1033	9.7
25-44 years	1480	27.1	1415	27.0	2895	27.1
45-65 years	3521	64.5	3247	62.0	6768	63.3
Total	5461	100.0	5235	100.0	10696	100

The highest numbers of records that have completed the MAP section of the form are in the former HSE south west area with 20.2% of the total. Overall, the majority of people have physical disability (7551, 70.6%) followed by multiple disabilities (2114, 19.8%).

The top three diagnostic categories within each age group are as follows:

- 16-24 years: Cerebral palsy, cystic fibrosis, congenital deafness
- 25-44 years: Multiple sclerosis, cerebral palsy, head injury,
- 45-65 years: Multiple sclerosis, diabetes¹, stroke/hemiplegia

¹In 2007 the NPSDDC took the decision that diabetes should be recorded as secondary diagnosis for all new registrations and reviews of existing registrations in the future. Diabetes is not in itself a disabling condition and is no longer recorded as a primary diagnosis; only the disabling effects of diabetic complications, e.g. amputation or visual loss, are now recorded as the primary diagnosis on the NPSDD.

The majority of people (67.1%) were living in accommodation that was not adapted or altered for physical/sensory needs. Living arrangements are shown in Table 2.

Table 2: Type of living arrangements

Living arrangement	n	%
Alone	1647	15.4
With husband/wife or partner and no children	1794	16.8
With husband/wife or partner and children	3251	30.4
With one or both parent	1144	10.7
With parent(s) and sibling(s)	1306	12.2
With sibling(s)	264	2.5
With son/daughter(s)	575	5.4
In full-time residential service	411	3.8
Other	303	2.8
Refused	1	0.0
Total	10696	100.0

Of the 4,021 people who had a primary carer, 56.8% were in the 45-65 years age group. The majority of people (89.6%) in this age group lived with their primary carer. Almost 72% of these primary carers are husbands, wives, or partners. Forty two percent of these primary carers were in the 50-59 years age group while 17.7% were in the 60-69 years age group. The ageing of carers over time will also have implications for service provision.

Participation restriction

Participation restriction is measured on a scale of 'mild', 'moderate', 'severe', 'complete'. However, for ease of interpretation, the graph below illustrates the extent to which people with disabilities have experienced participation restriction to 'some extent' which combines all four response categories. In addition, individuals were asked to what extent the restriction bothered them. The percentage of people who experienced restriction compared to those that experienced restriction and were bothered by the restriction is shown in Figure 1.

Figure 1: % of people who experienced some restriction compared to % of people who experienced some restriction & who were bothered by this restriction

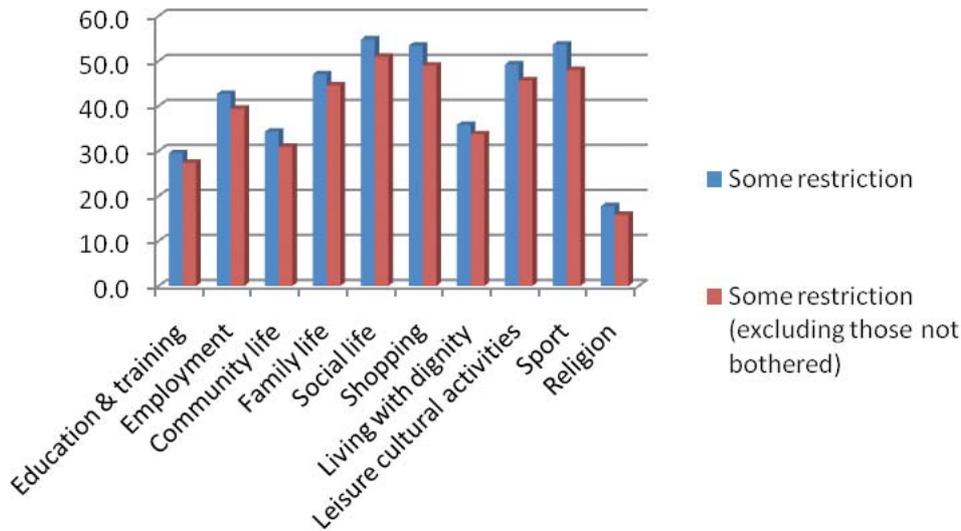
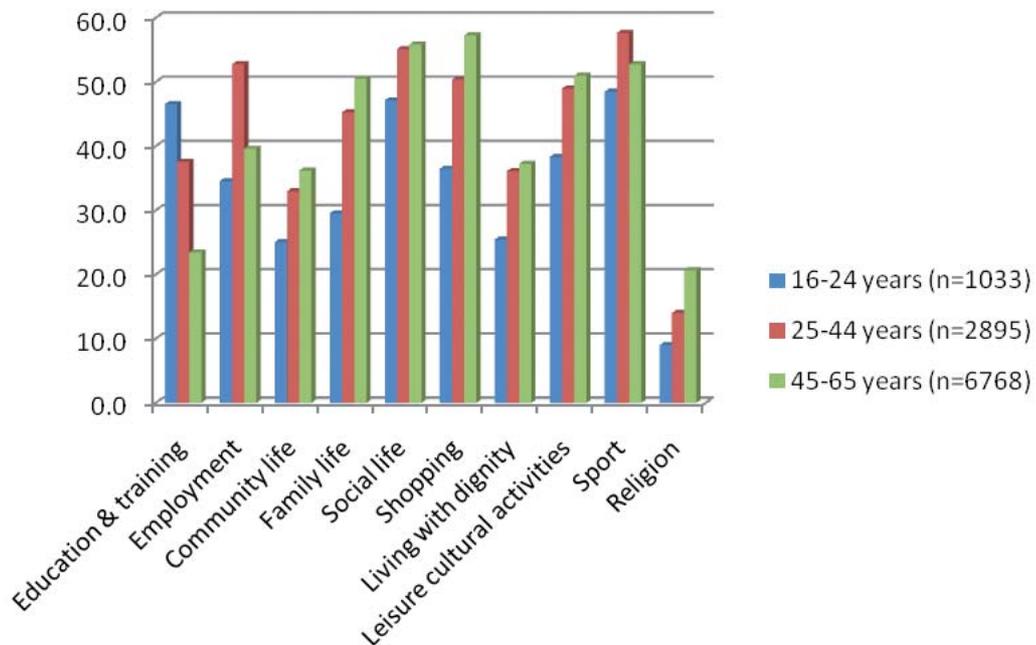


Figure 2: % of people who experienced some participation restriction by age group



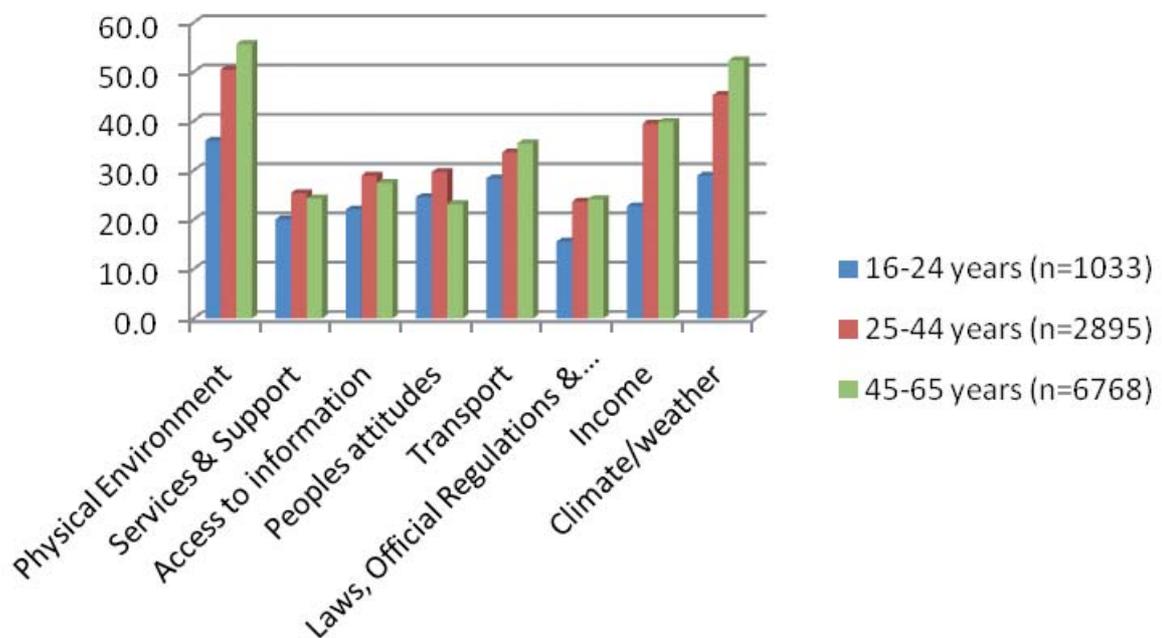
Sport was the main area of restriction for those in the lower (48.5%) and middle (57.7%) age groups while shopping was the main area of restriction for those in the older age group (57.3%). Taking into account to what extent this restriction bothered them, sport and shopping remain the greatest areas of restriction for the middle and older age groups but for the 16-24 year olds the highest area of restriction changes from sport to socialising. This indicates that although more people are restricted in participating in sport, not everyone is bothered by this restriction and in fact more people are bothered by their restriction in socialising in this younger age group.

The highest level of complete restriction was in sports and physical recreation in the 45-65 years age group with 23.5% being completely restricted in participating in this area in the year prior to their interview. Of these, 66.4% were bothered 'a lot' by this restriction while 19.6% were bothered 'a little'. This was also a high area of restriction for the 25-44 years age group as was employment and job seeking. In fact, 19.4% of people in the middle age group and 19.2% of people in the older age group were completely restricted from participating in employment and job seeking. Those in the 16-24 years age group consistently experienced lower levels of complete restriction across all areas compared with the other age groups.

Barriers

Overall, the physical environment represented a barrier for the majority of people across each age group with the percentage of people experiencing this barrier increasing with age (36.0% in the 16-24 years group, 50.5% in the 25-44 years group, 55.7% in the 45-65 years) (see Figure 3). This is consistent with findings from an Enable Ireland study on participation which found that 70% of adults with disabilities surveyed stated physical barriers as the main barrier in accessing social and leisure activities (Enable Ireland, 2009).

Figure 3: % of people experiencing barriers to participation by age group

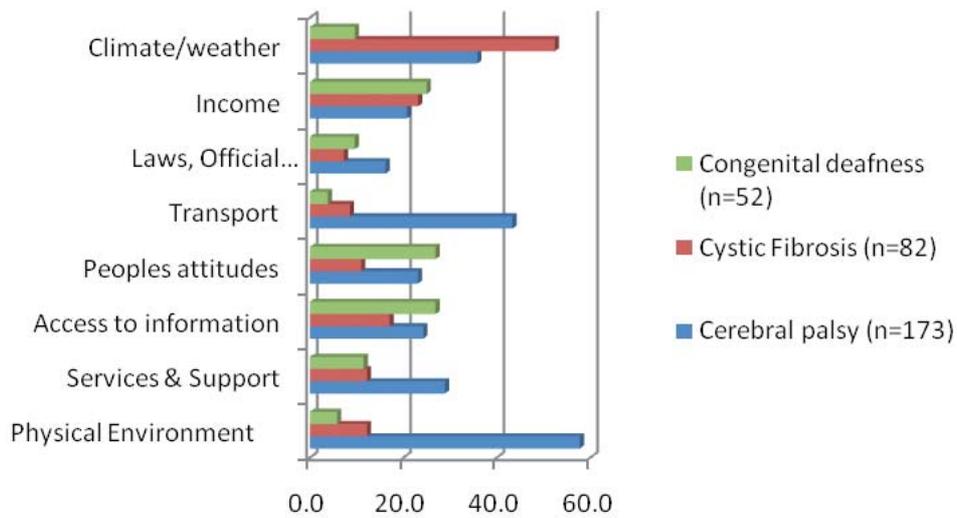


However, in examining the MAP data taking into consideration diagnostic condition as well as age, the barriers and challenges that proved to be most dominant differed. Figures 4, 5 and 6 show the barriers encountered by those in the top three diagnostic groups within each age group in the 12 months prior to completing their NPSDD interview.

16-24 years

In the 16-24 year age group (Figure 4), the physical environment was the greatest barrier for those with cerebral palsy whereas climate/weather was the barrier recorded most frequently by people with cystic fibrosis. Although transport was a major issue for people with cerebral palsy, it did not feature so highly for the other condition groups. Attitudes and access to information were the greatest barriers for people with congenital deafness followed closely by income. Income featured as a prominent barrier for 22.7% of the 16-24 year age group, 39.5% of the 25-44 year age group and 39.8% of the 45-65 year age group.

Figure 4: Barriers by top 3 diagnosis for those in the 16-24 year age group

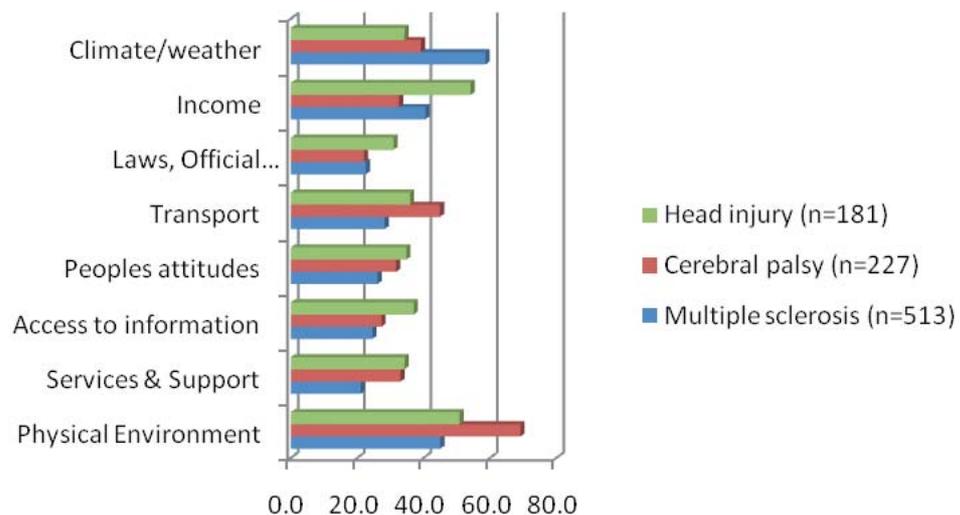


25-44 years

There were a higher percentage of people with cerebral palsy in the 25-44 year age group experiencing barriers in each area than those with cerebral palsy in the lower age band (Figure 5). However, the physical environment (69.2%) was still the most dominant barrier for this condition group, followed again by transport (44.9%). Thus, even as people with cerebral palsy age, the main barriers to their participation are found to be the physical environment and transport.

Although the physical environment represented a barrier for those in the other condition groups, it was found that climate/weather was the greatest barrier for people with multiple sclerosis (58.7%) while income was the greatest barrier for people with head injury in this age group (54.1%).

Figure 5: Barriers by top 3 diagnosis for people in the 25-44 year age group

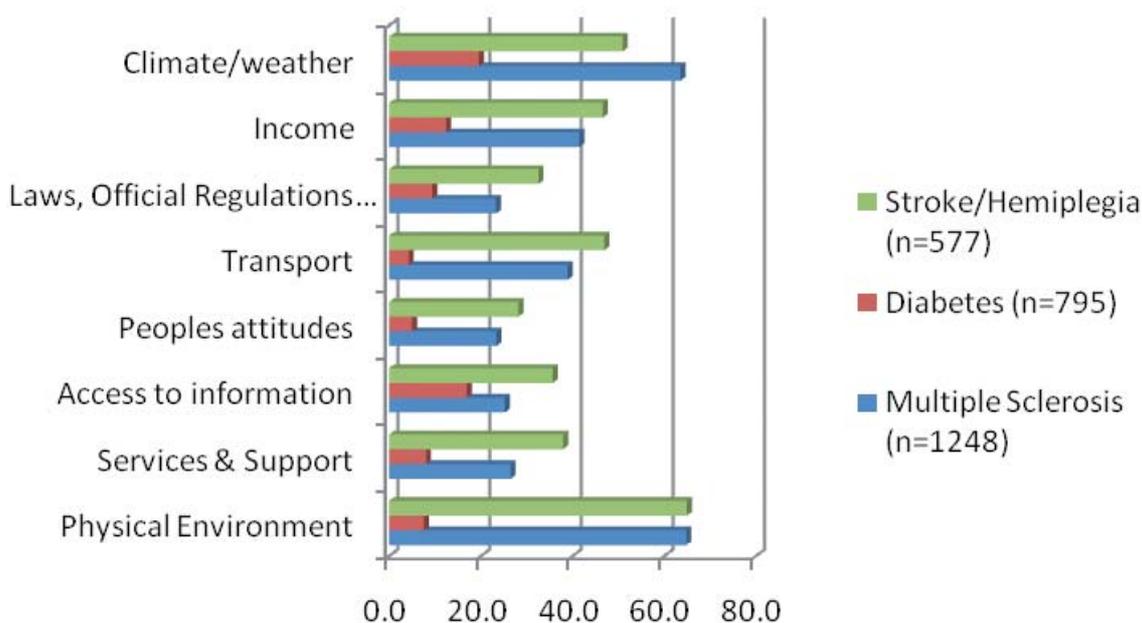


45-65 years

Figure 6 illustrates the barriers experienced by the top three condition groups in the older age band, 45-65 years. Diabetes is the second most dominant diagnostic condition in this age group although a very low percentage of people in this group experienced barriers to participation. This is not surprising given the nature of diabetes and the fact that many people with this condition can manage its effects through medication without a resultant disabling condition.

For people with multiple sclerosis and stroke/hemiplegia in this age group, the physical environment was the greatest barrier. Climate/weather was the second greatest barrier for these condition groups and the greatest barrier for people with diabetes.

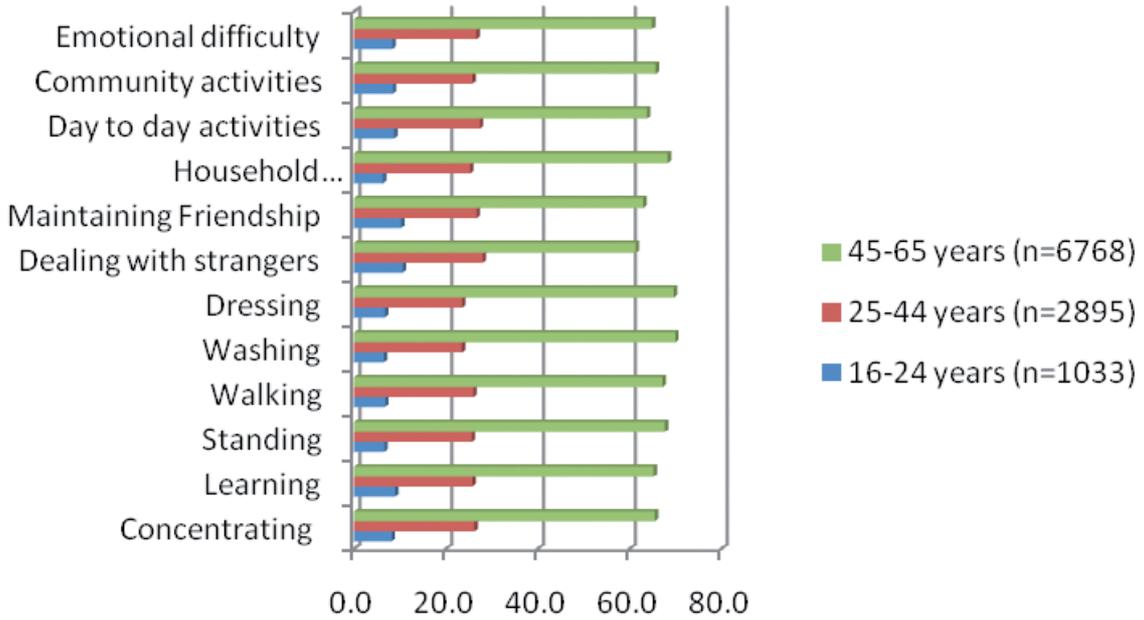
Figure 6: Barriers by top 3 diagnosis for people in the 45-65 years age group



Difficulties with daily activities

Without taking diagnosis or age into account, overall the greatest difficulty people experienced in the 30 days prior to their NPSDD interview was the emotional affect of their disability (72.1%). This was followed by difficulty standing for long periods of time and walking long distances. Zarb and Oliver (1993) found that "several people emphasised that their physical and emotional well-being were inextricably linked and that this had always been the case throughout their experience of living with a disability". In addition, Cardol et. al. (2002:33) found "of all the factors included in the regression analysis, emotional distress was the most important variable explaining restrictions in participation".

Figure 7: % of people who experienced difficulty with daily activities by age group



The emotional impact of disability should not be underestimated but is a more prevalent experience for the older age group (Figure 7). There was a larger percent of people (64.9%) in the 45-65 year age group who have been emotionally affected by their disability than those in the two lower age bands (16-24 years, 8.4%; 25-44 years, 26.7%). Overall a greater percentage of people in the 45-65 years age group experienced difficulty with daily activities than the other two age groups.

In the 16-24 year age group, dealing with strangers (10.6%) and maintaining a friendship (10.3%) were the highest areas of difficulty experienced. Dealing with strangers was the area where most people (28.0%) in the 25-44 year age group experienced difficulty followed by day to day activities in work or school (27.4%). Whereas washing oneself (70.0%) and dressing (69.7%) were the top two areas of difficulty for the 45-65 year age group. Figures 8, 9 and 10 show the difficulty experienced by the top three diagnostic groups in each age group.

Figure 8: Some difficulty with daily activities by top three diagnosis for people in 16-24 age group

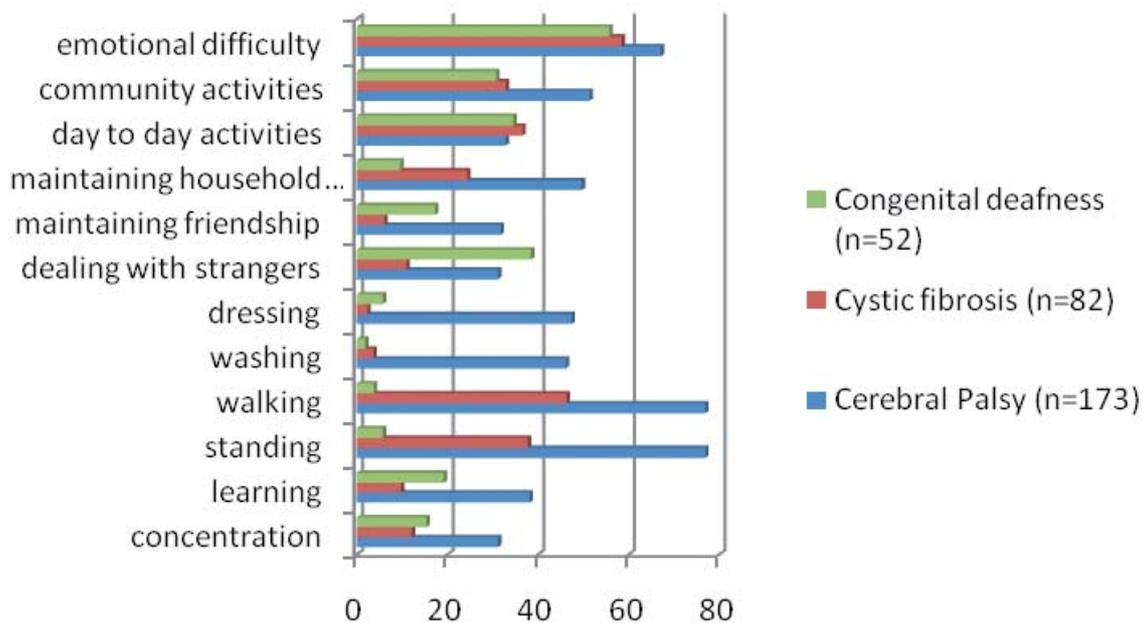


Figure 9: Some difficulty with daily activities by top three diagnosis for people in 25-44 age group

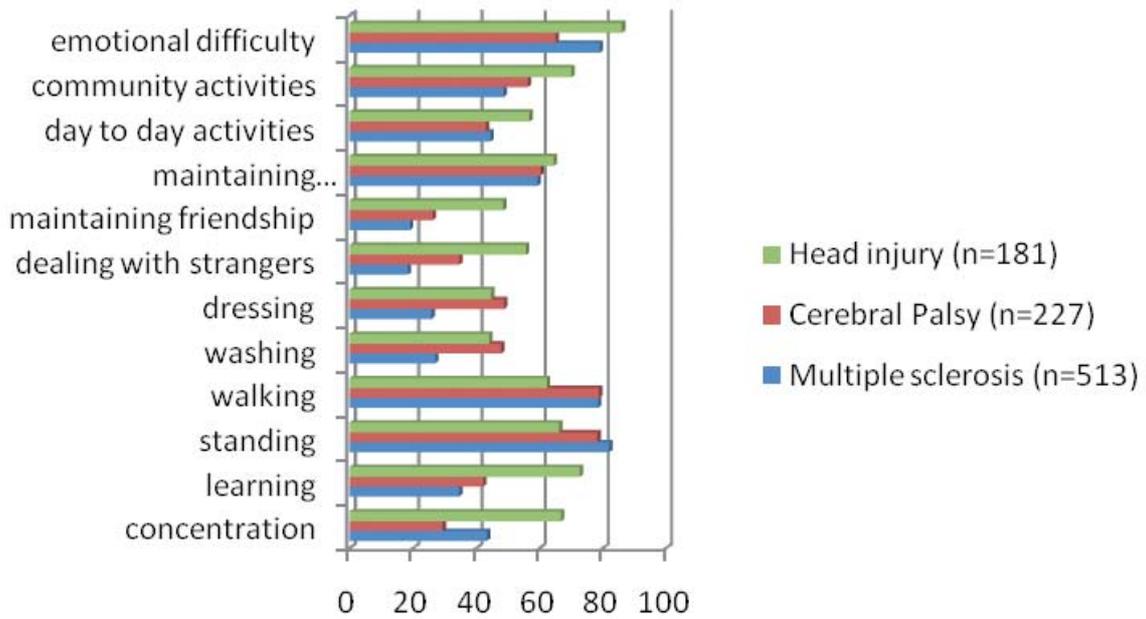
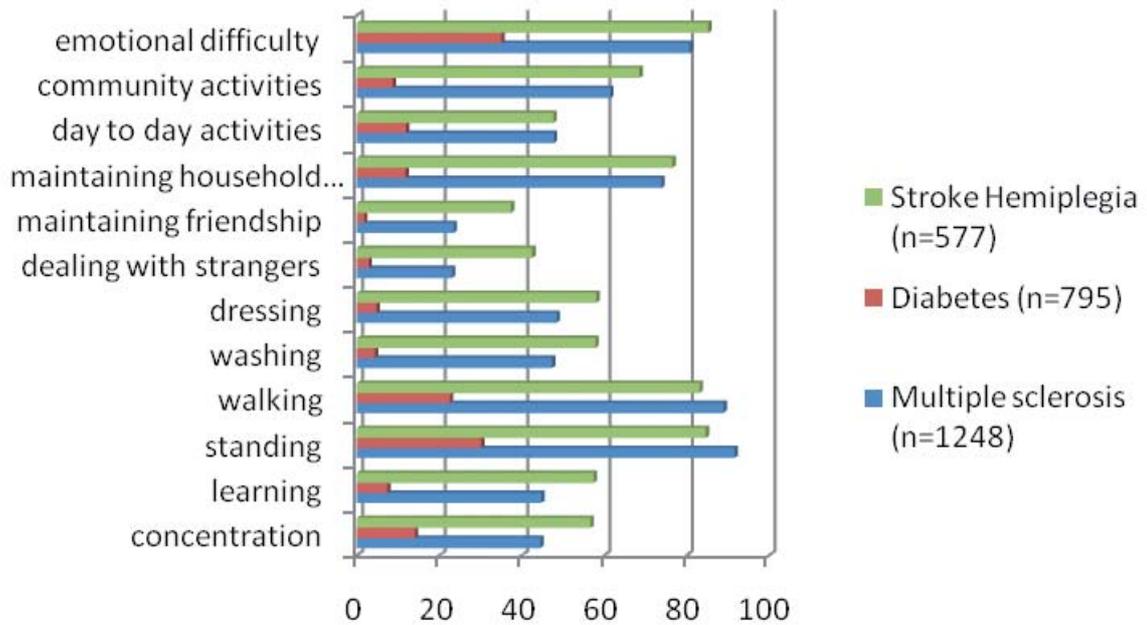


Figure 10: Some difficulty with daily activities by top three diagnosis for people in 45-65 age group



Service use and requirements

Overall, physiotherapy was the service most frequently used (31.3%) and simultaneously, it was the service that had the greatest need for future assessment regardless of age; 13.8% of people in the 16-24 years age group, 21.6% of people in the 25-44 years age group and 22.4% in the 45-65 years age group indicated a need for assessment for this service. This was followed closely by the use and need for assessment for occupational therapy (OT). However, for the 45-65 year age group chiropody was the second highest (17.3%) need (with OT third). While chiropody was third on the list of services needed for the 25-44 year age group, eight percent of people in the 16-24 year age group requested a need for assessment for a driving instructor for an adapted car, with a much lower percentage of need for this service recorded for the remaining age groups. This indicates that the service needs are similar for those in the middle and older age groups with more differences between them and the lower age group (see Tables 3 and 4).

Table 3: Top five services currently used by age group

Ranking	16-24 years	25-44 years	45-65 year
1	Physiotherapy	Occupational therapy	Physiotherapy
2	Occupational therapy	Physiotherapy	Occupational therapy
3	Peer support	Public health nurse	Public health nurse
4	Orthotist/prosthetist	Community resource worker	Clinical nutritionist
5	Clinical nutritionist	Peer support	Home help

Table 4: Top five services for which assessment is required by age group

Ranking	16-24 years	25-44 years	45-65 year
1	Physiotherapy	Physiotherapy	Physiotherapy
2	Occupational therapy	Occupational therapy	Chiropody
3	Driving instructor (<i>adapted car</i>)	Chiropody	Occupational therapy
4	Counsellor	Complementary therapy	Home help
5	Chiropody	Personal assistant	Complementary therapy

A higher percentage of people in the 45-65 year age group (16.2%) currently access a home help service than those people in the younger age groups. However, personal assistant (PA) services were used by more people in the 16-24 year age group (10.3%) than the 25-44 year age group (9.9%) or the 45-65 year age group (7.0%).

The greatest need for PA services was in the 25-44 year age group, with 8.9% of this group recording a need for an assessment. Assessment for home help was needed by more people in the older age band with 11.6% of this group indicating this need.

Almost 11% of those in the 25-44 year age group and 10.1% of the 45-65 years age group required an assessment for complementary therapy while only 5.3% of the 16-24 year age group indicated a need for an assessment for complementary therapy.

Services and participation

Overall the top three areas of restriction were socialising, sport and shopping. It was found that the top five services required did not differ across these areas of restriction with physiotherapy, occupational therapy, chiropody, home help and complementary therapy the most required (see Table 5).

Table 5: Percentage of people who experienced some restriction by top five services for which assessment is required

	Socialising	Sport	Shopping
Physiotherapy	23.8	26.2	24.9
Occupational therapy	18.2	19.5	19.3
Chiropody	15.8	16.1	16.1
Home help	13.3	12.9	13.9
Complementary therapy	11.8	12.9	12.7

If we take one area of restriction (socialising) and the services needed by each age group differences in need are identified (Table 6). In addition, when compared with overall service need by age group in Table 4 the introduction of experience of restriction results in changes in the services identified. Most notable of these changes are the inclusion of need for peer support for people in the 16-24 year age group and the need for personal assistant moving from 5th to 4th most needed service in the 25-44 years age group.

Table 6: Top five services for which assessment is required by those in each age group who have experienced some restriction in socialising

Ranking	16-24 years	25-44 years	45-65 years
1	Physiotherapy	Physiotherapy	Physiotherapy
2	Occupational therapy	Occupational therapy	Occupational therapy
3	Counsellor	Complementary therapy	Chiropody
4	Driving instructor	Personal assistant	Home help
5	Peer support	Chiropody	Complementary therapy

Conclusion

This bulletin illustrates that experience of barriers, participation restriction and difficulties with daily activities differ when different age groups are examined. In addition, it was found that diagnosis was also a factor in type of barriers and areas of restriction experienced.

The data above are illustrative of the change in service needs when experience of restriction is considered however it is difficult to fully explore the impact of service interventions on participation at one point in time. To fully examine the impact of services on participation it would be useful to look at the full gamut of services currently used and needed by an individual, the experience of participation when accessing and using these services and then to track any differences in the participation experience over time as services change or in some cases as services remain constant. Differences in the experience of ageing and disability should also be considered as the data have shown that the participation experience and service needs differ across age groups. Future trend analysis would be most beneficial to inform service planning and to improve its effectiveness.

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