

# Measuring Activity and Participation of people with disabilities – An overview



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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 National Physical and Sensory Disability Database (NPSDD) on a nation-wide basis began in 2002.

At this time, the Department of Health and Children became signatories to a new classification of disability, the World Health Organisation's (WHO) International Classification of Functioning, Disability and Health (ICF) and subsequently attempted to broaden data collection efforts in line with this classification. The ICF provides a holistic framework which views disability as the interaction between the individual (reduced functioning and activity limitation) and his/her environment. This holistic or multi-dimensional approach is reflective of the recognition that disability is not simply a condition of the body or the mind, but is, in fact, a multi-dimensional phenomenon that incorporates body function, activity limitations, participation restrictions and environmental factors.

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The DoHC recognised the value of expanding data collection efforts to include indicators of participation based on the ICF, and this is evident through the establishment of a subcommittee to explore the inclusion of such indicators on the NPSDD. The Measuring Activity and Participation (MAP) subgroup oversaw the pilot of new survey questions on these indicators in 2003. The new questions were introduced into the NPSDD tool in the three MAP sections (detailed below) in 2004. The inclusion of the three sections provides an opportunity to capture a more holistic picture of the experience of disability and the service needs of the person with a disability.

There are a number of major benefits to collecting this additional information. Firstly, the services required can be related to an individual's level of functioning and his/her every-day experience of barriers to activity and restricted participation. This in turn should lead to more effective prioritisation of interventions. Secondly, the information should help identify the actual benefit or otherwise of receiving such services on the broader ability of a service user to participate more fully in society. As Gallagher and Mulvany (2004: 507) state:

*According to WHO, disability assessment is important because medical diagnosis alone fails to predict such aspects as service needs, level of care, work performance and social integration. Disability assessment is useful for health care and policy decisions such as identifying needs, matching treatments and interventions, measuring outcomes and effectiveness, setting priorities and allocating resources.*

In addition to benefiting service planning, introduction of the MAP data provides the individual with the opportunity to describe his/her overall experience more fully. The MAP section of the NPSDD data form consists of 3 main elements:

- The **Participation** section identifies the extent that the individual's participation has been restricted in certain life areas such as education, employment, socialising, shopping and family life. Respondents are also asked to indicate the extent to which this experience of restriction has bothered them.

- The **Barriers and challenges** section highlights the social-environmental factors that potentially serve to exclude or restrict participation of people with disabilities in society. It also attempts to ascertain whether these identified factors act as barriers or challenges to the participation of the people included in the NPSDD over a period of twelve months (from date of data form completion).
- 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 (from date of data form completion). The extent to which these difficulties have interfered with his/her life is also captured in this section.

At June 2006, a total of 5,191 people completed the MAP section of the data form. This bulletin presents an overview of the key findings in relation to activity limitations and participation restrictions of this group and will demonstrate the relevance of capturing such information to inform service planning and provision. The impact of services on participation will be explored, with preliminary findings indicating that accessing particular services positively impacts on an individual's participation.

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## KEY FINDINGS

- Transport was identified as a major barrier for people with visual disability in particular.
  - Participation restriction was experienced most prominently in the areas of sports and physical recreation; employment and job seeking; socialising; and shopping.
  - 25.7% and 27.3% of people were completely restricted from participating in sports and physical recreation and employment respectively.
  - 68.7% of people were emotionally affected by their physical and/or sensory disability to some extent (in the 30 days prior to interview/registration).
  - Climate/weather, physical environment, and income were the main barriers to participation.
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## PROFILE

The information reported in this bulletin refers only to those 5,191 people who have completed the MAP section of the NPSDD data form. Females accounted for 49.8% of this group (2,585 people) and males accounted for 50.2% (2,606 people). It should be noted that the MAP section of the data form is only completed by people aged sixteen years and over. The majority of people (52.5%) who have completed this section were within the 40-59 years age group.

The breakdown by type of disability is presented in Table 1 below. This illustrates that the majority of this subgroup of people reported a physical disability only, accounting for 73.7% of females and 71.9% of males. The profile of people included in the MAP section is consistent with the entire NPSDD registrations in terms of gender and type of disability. However, a much lower percentage of people were in the under 18 age bracket for the MAP group than for the entire NPSDD. This is due to the fact that only people aged 16 years and over complete the MAP section of the data form.

<b>Table 1 Type of disability and gender</b>						
	<b>Female</b>		<b>Male</b>		<b>Total</b>	
	<b>n</b>	<b>%</b>	<b>n</b>	<b>%</b>	<b>n</b>	<b>%</b>
Physical	1905	73.7	1875	71.9	3780	72.8
Hearing loss/deafness	125	4.8	87	3.3	212	4.1
Visual	72	2.8	91	3.5	163	3.1
Primary speech & language	9	0.3	12	0.5	21	0.4
Multiple disabilities	474	18.3	541	20.8	1015	19.6
<b>Total</b>	<b>2585</b>	<b>100.0</b>	<b>2606</b>	<b>100.0</b>	<b>5191</b>	<b>100.0</b>

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A total of 2,075 people (40.0%) reported having a primary carer. Of this group, 55.3% had a primary carer that is a husband/wife or partner while 28.0% indicated that a parent is their primary carer.

The three main primary diagnostic categories were:

- Nervous System (38.6%)
- Endocrine & Metabolic (20.7%)
- Musculo skeletal System (16.4%)

The top three conditions within each of these diagnostic categories were:

- Nervous System
    - ◇ Multiple Sclerosis (13.1%)
    - ◇ Stroke Hemiplegia (5.6%)
    - ◇ Cerebral Palsy (2.9%)
  
  - Endocrine & Metabolic
    - ◇ Diabetes (20.2%)
    - ◇ Metabolic Disorders (0.2%)
    - ◇ Other endocrine disorders (0.1%)
  
  - Musculo Skeletal System
    - ◇ Rheumatoid Arthritis (4.0%)
    - ◇ Osteo-arthritis (2.9%)
    - ◇ Back Problems (1.8%)
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## **PARTICIPATION**

The section 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. The decision was taken to use language that is easy to understand and hence inclusion of the term 'bothered' to ascertain an individual's feelings on his/her participation restriction.

Key life areas included in this section are:

- education and training
- employment or job seeking
- community life
- family life
- socialising
- shopping
- living with dignity
- leisure/cultural activities
- sports or physical recreation
- religion.

General health services are also included and refer to hospital services, mental health services and community based health services.

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## Participation Restriction

Overall, it was found that the most prominent life areas where participation restriction was experienced (excluding those people who stated that these areas were not applicable to them; for example, education may not be applicable to someone who is past school-leaving age) are:

- Sports and physical recreation (58.5%)
- Employment and job seeking (57.1%)
- Shopping (48.3%)
- Socialising (47.8%)

Of the 58.5% of people who experienced participation restriction in sports and physical recreation, 88.8% indicated that they were bothered by this experience. In addition, 92.4% of people who experienced difficulties in participating in employment or job seeking stated that they were bothered by this. In terms of education and training, it was found that 42.6% of people experienced restriction with 92.2% of these bothered by the restriction. Of the 48.3% and 47.8% of people who experienced restriction in shopping and socialising, 91.1% were bothered by this restriction.

The following table illustrates the percentage of people in each disability group who indicated that they had experienced participation restriction to some extent across these major life areas. The figures highlighted in blue indicate the top three areas in each disability group where the highest percentage of participation restriction was experienced in the previous 12 months (from date of completion of the data form). Once again the figures provided are overall figures that illustrate the percentage of people who have experienced participation restriction.

<b>Table 2 Participation restriction and type of disability across major life areas</b>					
	<b>Physical Disability</b>	<b>Hearing Loss/ Deafness</b>	<b>Visual Disability</b>	<b>Primary Speech &amp; Language</b>	<b>Multiple Disabilities</b>
Education & training	38.1	<b>48.2</b>	<b>58.3</b>	<b>38.9</b>	55.4
Employment or job seeking	<b>54.7</b>	<b>55.2</b>	<b>61.3</b>	<b>46.7</b>	<b>66.2</b>
Community life	35.8	41.2	35.6	26.7	52.7
Family life	41.0	35.7	24.8	30.0	53.7
Socialising	44.9	<b>50.5</b>	39.2	<b>55.0</b>	<b>59.5</b>
Shopping	<b>47.3</b>	22.3	<b>55.3</b>	21.1	56.5
Living with dignity	28.7	19.5	27.2	10.5	40.9
Leisure/cultural activities	44.8	38.2	48.7	31.6	56.7
Sports or physical recreation	<b>58.6</b>	25.5	54.4	31.3	<b>65.8</b>
Religion	14.1	19.7	10.1	0.0	21.7
Hospital services	18.6	20.7	20.3	5.0	23.1
Mental health services	11.5	3.6	4.3	12.5	16.2
Community based health services	13.9	14.6	12.1	5.6	17.7



The figures in Table 2 show that:

- Employment or job seeking, sports and physical recreation and shopping were the most prominent life areas where participation restriction is experienced by people with physical disability.
  - Employment or job seeking socialising, and education and training were three life areas where many people with visual disability have experienced participation restriction in the past twelve months.
  - For people with primary speech and language disability, it was found that socialising, education and training and employment or job seeking were the three areas where many of this group experienced difficulties.
  - Finally, people in the hearing loss/deafness group indicated highest participation restriction in employment or job seeking, socialising and education and training.
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The following table illustrates the number and percentage of people across disability type who have experienced participation restriction and were bothered by this experience. The extent to which they were bothered could be reported as either 'a little' or 'a lot'. A decision was made by the subgroup to use colloquial terms such as 'bothered by', 'a little', 'a lot' in constructing the questions for the MAP section so as to make the questions more accessible. It should be noted that the percentages in this table are calculated based on the total number of people recorded within each disability group. Therefore, the temptation to compare Table 2 and Table 3 directly should be resisted, as the figures in Table 2 are based on an analysis that removes people for whom these services were not applicable and are not based on the total number of people in each disability group.

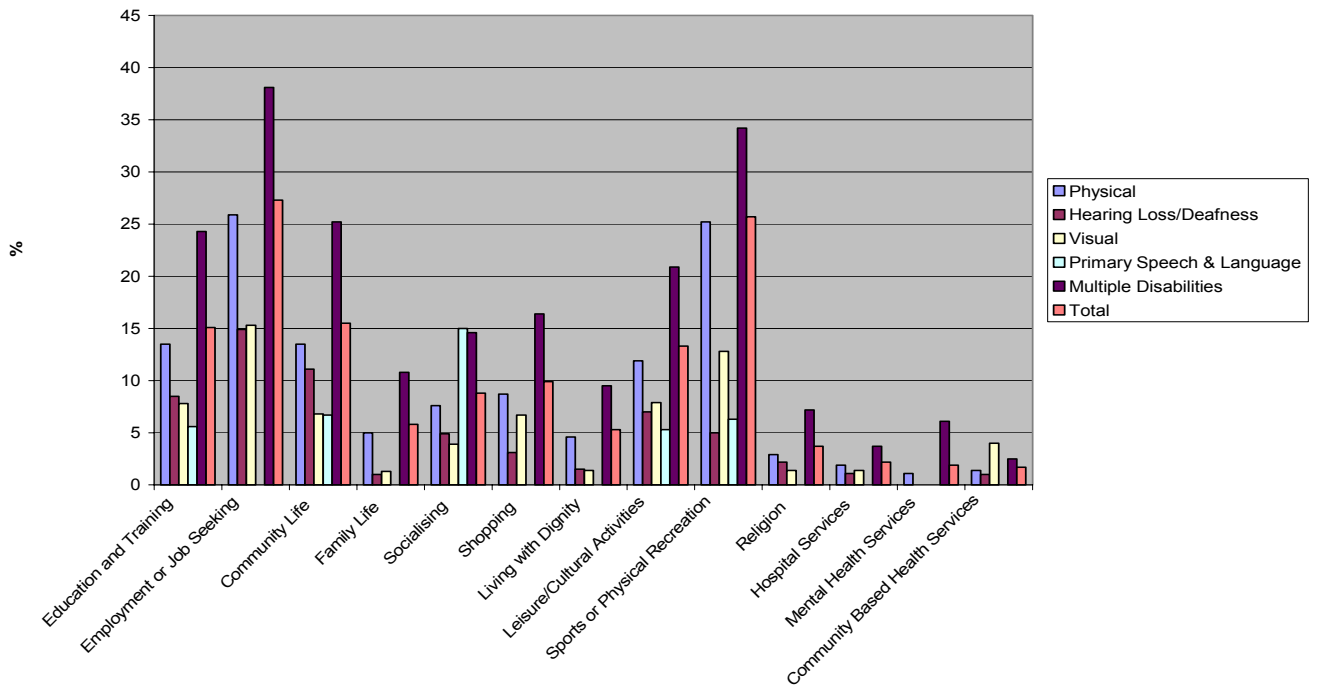
<b>Table 3 Percentage of people bothered by their participation restriction</b>						
	<b>Physical Disability</b>	<b>Hearing Loss/ Deafness</b>	<b>Visual Disability</b>	<b>Primary Speech &amp; Language</b>	<b>Multiple Disabilities</b>	<b>Total</b>
	<b>n=3780</b>	<b>n=212</b>	<b>n=163</b>	<b>n=21</b>	<b>n=1015</b>	<b>n=5191</b>
<b>Education &amp; Training</b>	20.6	28.8	38.7	33.3	29.7	23.3
<b>Employment &amp; Job Seeking</b>	34.8	36.8	38.0	33.3	40.4	36.1
<b>Community Life</b>	22.2	25.0	23.3	14.3	33.5	24.5
<b>Family Life</b>	37.0	29.7	22.7	28.6	47.6	38.3
<b>Socialising</b>	39.6	42.5	34.4	38.1	52.4	42.1
<b>Shopping</b>	40.8	19.8	46.6	9.5	48.4	41.5
<b>Living with Dignity</b>	25.3	17.0	23.3	9.5	36.2	27.0
<b>Leisure/ Cultural Activities</b>	38.4	30.7	41.7	28.6	47.7	40.0
<b>Sports or Physical Recreation</b>	42.1	17.0	39.9	23.8	46.4	41.8
<b>Religion</b>	10.6	14.2	8.6	0.0	16.3	11.7
<b>Hospital Services</b>	16.5	15.1	16.0	4.8	19.2	16.9
<b>Mental Health Services</b>	2.4	0.9	1.2	4.8	3.0	2.4
<b>Community Based Services</b>	12.0	12.3	9.2	4.8	14.0	12.3

- Of the people who reported having a physical disability only, 42.1% (1,592 people) of these have experienced participation restriction in the area of sports and physical recreation and were bothered by this to some extent.
- Of the people with hearing loss/deafness, 42.5% (90 people) have experienced participation restriction in the area of socialising and were bothered by this experience.
- Almost 47% (76 people) with a visual disability only have been restricted in participating in shopping and were bothered by this restriction.
- Of the people who have multiple disabilities, 52.4% (532 people) have experienced participation restriction in socialising and were bothered by this.

### **Complete Participation Restriction**

In looking at the figures more closely it is interesting to highlight the areas where participation is 'completely' restricted, that is, life areas where people are unable to participate at all. For example, 25.7% (1,074 people) indicated that their participation in sports/recreation had been completely restricted in the past twelve months while 27.3% (970 people) were completely unable to participate in employment or job seeking. In addition, 15.5% and 15.1% of people were completely restricted from participating in community life and education and training respectively. Just over 13% of people were completely restricted from participating in leisure and cultural activities. The graph below illustrates the extent of complete participation restriction across each life area by each disability group.

**Figure 1: Complete participation restriction and type of disability**



The graph highlights that 25.9% of people with physical disability were completely unable to participate in employment or job seeking, while 25.2% were completely unable to participate in sports and physical recreation. In addition, 15.0% of people with primary speech and language disability were completely unable to participate in socialising.

## Impact of Services on Participation

It is anticipated that the information collected on participation combined with service information will provide an indication of the types of service that impact on participation, with the hope that the provision of services will result in improved/increased participation. For example, it was found that accessing the services of a personal assistant had a positive impact on participation for people registered on the NPSDD as compared to those that do not currently access personal assistant services (See Table 4 below).

<b>Table 4 Participation and use of personal assistance services</b>		
	<b>% of people who stated that they did not experience participation restriction</b>	
	<b>Those currently accessing PA services</b>	<b>Those <i>not</i> currently accessing PA services</b>
Community Life	41.0	28.9
Socialising	34.2	21.0
Shopping	32.1	21.5

It is clear from the table above that access to personal assistance services impacted positively on participation, with people who were accessing this service more likely to state that they have not experienced participation restriction.

It is anticipated that the impact of various services on participation will be explored in greater detail in future MAP bulletins.

## **BARRIERS AND CHALLENGES**

The section on barriers and challenges focuses on social and environmental factors that potentially contribute to the participation restriction discussed previously. These barriers and challenges include:

- Physical environment
- Services and supports
- Access to information
- People's attitudes
- Transport
- Laws, official regulations and entitlements
- Income
- Climate/weather.

For example, inaccessible transport may prevent a person with a disability from participating in leisure activities, education or employment. Subsequently, if a person with a disability is prevented from participating in employment this will have an adverse impact on overall household income which in turn can be disabling.

Based on the data collected in the MAP section of the NPSDD (and illustrated in Table 5 overleaf) it was found that climate/weather (45.0%), the physical environment (44.9%), and income (36.4%) represent the main barriers to participation for people with physical and sensory disability included in the database. Transport (29.1%) and access to information (27.1%) also presented significant barriers to participation for this group.

<b>Table 5 Barriers and challenges and type of disability</b>						
	<b>Physical Disability</b>	<b>Hearing Loss/ Deafness</b>	<b>Visual</b>	<b>Primary Speech &amp; Language</b>	<b>Multiple Disabilities</b>	<b>Total</b>
Climate/weather	46.7	20.8	33.7	4.8	46.3	45.0
Physical environment	43.9	10.4	62.6	9.5	53.7	44.9
Income	35.3	35.4	39.9	14.3	40.6	36.4
Transport	28.0	6.6	46.0	14.3	35.8	29.1
Access to information	25.6	28.8	26.4	23.8	32.2	27.1
People's attitudes	22.0	32.1	30.1	19.0	30.1	24.2
Laws, official regulations & entitlements	22.5	19.3	18.4	23.8	28.3	23.4
Services & supports	21.9	11.4	14.7	28.6	24.7	21.8

When these barriers and challenges were examined in relation to type of disability, it was found that climate/weather, physical environment and income were among the greatest barriers for people with physical disability. The physical environment was found to be the greatest challenge to people with visual disability, with 62.6% of this group stating that this was a barrier to them. In particular, transport was highlighted as a barrier for 46.0% of people with visual disability.

For individuals with hearing loss/deafness and primary speech and language disability, access to information was identified as a major challenge to their participation. People with primary speech and language disability also indicated that supports and services (28.6%) and laws, official regulations and entitlements (23.8%) restricted their participation.

In addition, it was found that income was consistently a barrier to participation for a large percentage of people regardless of type of disability. For example, 35.3% of people with physical disability, 35.4% of people with hearing loss/deafness and 39.9% of people with visual disability indicated that income was a barrier to their participation in the previous twelve

## WHODAS II

WHODAS II ascertains the extent to which an individual encounters difficulties in performing daily activities. These daily activities include:

- concentrating on doing something for ten minutes
- learning a new task
- standing for long periods such as 30 minutes
- walking a long distance such as a kilometre or equivalent
- washing your whole body
- getting dressed
- dealing with people you do not know
- maintaining a friendship
- taking care of your household responsibilities
- your day-to-day work/school
- joining in community activities.

In addition, respondents are asked to indicate the extent to which they have been emotionally affected by their physical/sensory disability and how much these difficulties have interfered with their life overall. Details on the number of days these difficulties have been present and the number of days the difficulties impacted on daily activities over a 30-day period are also captured.

It was found that 68.7% of people who completed this section of the form had been emotionally affected by their physical and/or sensory disability to some extent in the last thirty days. In addition, 79.3% stated that the difficulties encountered have interfered with their life to some extent with 42.2% stating that this interference was severe or extreme.

Difficulty was experienced in the following areas:

- 61.5% have had some difficulty standing for long periods of time
  - 59.6% have had some difficulty walking long distances
  - 26.9% of people had some difficulty learning a new task
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- 15.3% and 19.7% have had some difficulty maintaining a friendship or dealing with strangers respectively
  - 29.1% of people have had some difficulty washing their whole body or getting dressed
  - 13.5% have experienced extreme difficulty in joining in community activities
  - 14.0% of people were totally unable to carry out their usual activities or work for each of the past 30 days because of their physical or sensory disability.
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## **FUTURE**

The upcoming Annual Report of the NPSDDC (2006) will provide detailed information regarding current and future service needs of people with physical and/or sensory disability. This bulletin serves to complement the service information reported in the Annual Report by illustrating the extent of information captured on the database and highlighting the usefulness of this information to service planning.

All future registrations aged 16 years and over will complete the MAP section of the data form and all those who were registered prior to the introduction of the MAP section will complete this section at the time of their update/review.

In addition, it is anticipated that future MAP bulletins will be published providing more detailed analysis and discussion of particular areas of interest. Potential special bulletins include:

- Detailed exploration of WHODAS II data
  - Exploration of the relationship between participation restriction and access to services across various types of services
  - Regional exploration of data
  - Examination of the MAP data across various condition groups
  - Examination of the MAP data across age groups
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This bulletin has also highlighted particular areas where further research is required. For example, it would be useful to examine why some people are bothered by their participation restriction while others are not.

In addition, the MAP data is a potential source of information for agencies/service providers who deal with people with physical/sensory disability. Much insight will be provided into the impact of services on participation, across various regions and for various conditions that agencies are specifically interested in.

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## REFERENCES

Gallagher, P and Mulvany, F; (2004) Levels of Ability and functioning: using the WHODAS II in an Irish Context, *Disability and Rehabilitation*, 26 (9), 506-517.

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<b>G: WHODAS II</b> (for 16 years of age and over)					
This section asks about <u>difficulties due to your physical/sensory disability</u> . Think back over the last 30 days and answer these questions, thinking about how much difficulty you had doing the following activities. For each question, please provide only one response.					
108. In the last 30 days, how much difficulty did you have in doing the following activities					
	None	Mild	Moderate	Severe	Extreme/ Cannot do
108a. Concentrating on doing something for ten minutes?					
108b. Learning a new task (e.g. learning how to get to a new place)?					
108c. Standing for long periods of time such as 30 minutes?					
108d. Walking a long distance such as a kilometre (or equivalent)?					
108e. Washing your whole body?					
108f. Getting dressed?					
108g. Dealing with people you do not know?					
108h. Maintaining a friendship?					
108i. Taking care of your household responsibilities?					
108j. Your day-to-day work/school?					
108k. How much of a problem did you have in joining in community activities (e.g. festivities, religious or other activities) in the same way as anyone else can?					
108l. How much have you been emotionally affected by your physical/sensory disability?					

Not at all   Mildly   Moderately   Severely   Extremely

108m. Overall how much did these difficulties interfere with your life?              

Record Number of Days

108n. Overall, in the past 30 days, how many days were these difficulties present?.....

108o. In the past 30 days, for how many days were you totally unable to carry out your usual activities or work because of your physical/sensory disability?.....

108p. In the past 30 days, not counting the days that you were totally unable, for how many days did you cut back or reduce your usual activities or work because of your physical/sensory disability?.....