Multiple Sclerosis Ireland

1. Financial In-work supports

We want to know what works best and is attractive for people with disabilities when considering a return to or taking up work in terms of financial supports

How important are the following when considering taking up or returning to employment?

	Very Important	**Moderate Importance**	**Neutral**	**Slightly Important**	**Low**
Disability Allowance Earnings Disregards (up to €120, €120-350)	O	Y	O	O	O
Partial Capacity Scheme (on Illness Benefit, Invalidity Pension)	O	Y	O	O	O
Retention of Medical Card for 3 years	Y	O	O	O	O
Secondary Benefits: (Rent Supplement/Free Travel/Fuel Allowance)	Y	O	O	O	O
Household Benefits Package (Electricity/Gas Allowance/Free TV Licence)	O	Y	O	O	O
Family Income Supplement	Y	O	O	O	O
Tax Credits and reliefs	Y	O	O	O	O

How well do you think the following are understood by people with a disability or their advocates?

	Well Understood	**Moderately Understood**	**Neutral**	**Slightly Understood**	**Not**
Disability Allowance Earnings Disregards (up to €120, €120-350)	O	O	O	Y	O
Partial Capacity Scheme (on Illness Benefit, Invalidity Pension)	O	O	O	Y	O
Retention of Medical Card for 3 years	O	Y	O	O	O
Secondary Benefits: (Rent Supplement, Free Travel, Fuel Allowance)	O	Y	O	O	O
Household Benefits Package (Electricity/Gas Allowance, Free TV Licence)	O	Y	O	O	O
Family Income Supplement	O	Y	O	O	O
Tax Credits and reliefs	O	O	O	Y	O

Comments

According to the Disability Federation of Ireland, on average a person with a disability/long term illness will spend one third of their weekly disposable income to cover disability associated costs. These disability associated costs still affect people who are working and therefore the loss of means tested payments and benefits can result in a situation of in-work poverty for many. This is explained further in the Pre-Budget Submission for 2017 from the Disability Federation of Ireland: http://www.disability-federation.ie/index.php?uniqueID=11149

Furthermore, it should be noted that MS is an unpredictable illness with approximately 80-85% of those affected experiencing a relapsing-remitting form. This means that people with MS will often be faced with sudden and unpredictable financial burdens when they experience relapses, whereby they experience sudden sharp increases in the costs associated with living with their condition. Evidence for the financial burden associated with MS relapses can be found in O'Connell et al, 2014 *Economic costs associated with an MS relapse.* O'Connell et al concluded that even a mild relapse can have a significant financial impact on the individual, with more severe relapses being associated with steeper costs. This relapsing element of MS also means that an individual's ability to work will vary and fluctuate in an unpredictable manner.

Life expectancy for people with MS is not significantly less than that of the general population, so a person with MS could expect to live with additional costs and with the financial burdens associated with relapses for between 40-60 years. Furthermore, MS is a progressive condition, with approximately 65% of those initially diagnosed with relapsing-remitting MS in time entering the secondary progressive phase of the disease. Secondary progressive MS is characterised by increasing levels of disability and therefore also increasing direct and indirect medical costs. More information and data on this can be found in MS Ireland's report 'The Societal Costs of Multiple Sclerosis in Ireland 2015' - http://bit.ly/2b7xTgr

Therefore any governmental initiatives to make work pay for people with disabilities will need to account for the substantial additional daily costs of living with a disability or long term illness, as well as the episodic and unpredictable nature of conditions like MS. It will also be necessary to allow for easy and rapid transitioning between social welfare payments and in-work financial supports, because, as noted above, in the case of fluctuating conditions like MS an individual's level of fitness for work is not fixed and constant.

2. Financial Barriers

Please rank the following in importance 1 – 6 (according to the scale of barrier) when considering taking up or returning to work: (1 = most important)

Loss of DSP Payment	4
Loss of Secondary Benefits (Rent Supplement, Free Travel, Fuel Allowance)	3
Loss of Household Benefits Package (Electricity/Gas Allowance, Free TV Licence)	5
Perceived difficulty obtaining DSP payment/benefits again (e.g. If work ceases)	2
Loss of Medical Card after 3 years	1
Other (please specify) _____	O

It is recognised that the needs and issues arising for people with disabilities vary, and that different circumstances arise for different people at different times. If there are circumstances that are particularly relevant, please indicate:

As noted above, MS is an unpredictable and episodic condition whereby an individual's ability to work can fluctuate. MS is also associated with considerable additional out-of-pocket medical expenses, as noted in MS Ireland's recent submission to the Clinical Advisory Group for Discretionary Medical Cards: http://bit.ly/2d7AXIW

The Medical Card is therefore an absolutely vital support for people with MS. MS Ireland conducted a survey of 850 people with MS in July 2014 which found that:

- 71% of our respondents deemed access to GP services as essential to enable them to remain well
- 63% thought access to medicines under the medical card were essential
- 64% thought that the medial card was critical in access in therapy services in the community
- 68% of respondents thought the medical card was critical in accessing specialist equipment e.g. walking aids, wheelchairs, continence equipment etc.
- 56% of respondents thought that access to hospital services for in-patient treatment was important
- 70% of respondents said that the medical card was critical in sourcing affordable respite

These findings clearly illustrate how the Medical Card is viewed as a lifeline by many people with MS and therefore the prospect of it being withdrawn after three years of working (at which point the person will still be living with increased out of pocket medical expenses and the financial burdens associated with relapses, as outlined in the response to the previous question) is a major disincentive to re-entering the workforce.

The perceived difficulty of obtaining DSP payments/benefits again if work ceases must also be addressed as a matter of priority. An individual must be able to easily and smoothly resume any DSP payments/benefits if they are forced to withdraw from the workforce suddenly as will often be the case with MS relapses. The perception among many people with disabilities and long term illnesses is that these payments/benefits are hugely difficult to access in the first place, so the idea of giving them up and then having to go through the application process again (with no guarantee of success) is a major disincentive to re-entering the workforce.

In general, do people with a disability feel that they would be better off financially by taking up work?

Yes	**No**
O	Y

Please elaborate:

MS Ireland would like to note the considerable differences between employment rates of people with MS in Ireland compared to Europe, as highlighted in a recent report 'MS and Employment: Facts and Figures': http://bit.ly/2dBUtMC

The general population employment rate in Ireland is 68.8% compared to the European rate of 70%. For people with MS, the employment rate in Ireland is 43% compared to 60% in the EU. This means people with MS in Ireland are 28% less likely to be in employment than EU counterparts.

Whilst there are no doubt social and other factors at play in accounting for these stark differences, it seems likely that the net income gains in employment are less in Ireland than in the EU and this is a driving factor.

3. Length of time out of workforce

Are there particular financial barriers to resumption of work for PWD if out longer term, i.e. 2 yrs or more?

What suggestions would you have to overcome barriers for PWD who have been out of the workforce long term?

It should be noted that the needs of re-entering the workforce for someone who has acquired a disability or long term illness during their working life are different from those who have a life-long condition. Existing employment support services appear to be designed more with those with congenital disabilities in mind, who may have a very low or non-existent employment and education record. Many people with conditions like MS, which is typically diagnosed between the ages of 20 and 40, will have a substantial record of work in high-skilled roles. If their previous employment has become untenable, they will want to explore meaningful and positive alternative employment and education options that will make use of the knowledge, skills and experience they have acquired.

Models to consider would be paid internships, such as the Believe and Achieve programme by the European Multiple Sclerosis Platform: http://www.emsp.org/projects/believe-and-achieve/

Programmes such as this give people with illnesses such as MS the chance to redeploy knowledge and skills acquired in previous employment into meaningful and challenging roles. Another successful programme operating in Ireland at the moment is the Willing Able Mentoring (WAM) programme operated by AHEAD (Association of Higher Education Access and Disability). This paid work placement programme aims to promote access to the labour market for graduates with disabilities and build the capacity of employers to integrate disability into the mainstream workplace. It could be proposed that a programme such as this would be of benefit to people who have had to withdraw from the workforce due to an illness or disability, as well as recent graduates.

Do you feel there are particular financial barriers that apply more to men than women, or to women than men?

MS affects three times as many women as men. Therefore it should be considered that the complications associated with employment and MS will be compounded by the factors that impact on the general participation of women in the labour market, such as childcare.

4. Communication

Please rank the following sources of information people with disabilities use to research the financial aspects of taking up or returning to work:

	Always	**Often**	**Sometimes**	**Rarely**	**Never**
Department of Social Protection website	O	O	O	Y	O
Intreo office/Local DSP office	O	O	Y	O	O
Citizens Information Office	O	O	Y	O	O
Citizens Information Website	O	Y	O	O	O
Representative groups for PwD	Y	O	O	O	O
Friends and family	O	Y	O	O	O
Media (TV/Radio/Newspapers)	O	Y	O	0	O
Other (please specify)	O	O	O	O	O

Do you think people worry about asking for information from the Department of Social Protection when considering returning to work – e.g. applying for Partial Capacity Benefit, or the Disability Allowance Earnings Disregard?

Yes	No
Y	O

If yes, why?

People in this situation may well be deterred by worry that benefits and entitlements will be withdrawn or they will be subjected to a higher level of scrutiny if they are seen as fit to work.

5. Experience of PWD who ARE working

Approximately 21% *of PWD are in the workforce; in your view what are the financial and other factors which have supported these people to:*

A) Transition successfully from education/training to employment:

Paid internships such as WAM (referenced in response to question 3) are examples of supports that enable transitions from education to employment.

Appropriate career guidance during education and training that empowers people to think about what accommodations and adjustments they might need in the workplace, and advice on disclosure and how to discuss a disability/workplace adjustments with an employer could also have huge value.

B) Remain in employment:

A 2016 report by the Multiple Sclerosis International Federation (MSIF) on international trends in MS and employment listed to top five key factors that emerged from the study as being most helpful in helping people with MS remain in the workplace. They are: 1. Stable disease activity, 2. Supportive employers and colleagues, 3. Seated work, 4. Flexible work hours, 5. Computer adjustments. This report is available here: https://www.msif.org/about-us/advocacy/employment-and-ms/

Stable disease activity: Recent research now strongly suggests that long-term outcomes for people with MS are improved by early identification, early treatment with disease modifying therapies (DMTs) and regular monitoring. However, this is difficult to achieve in Ireland currently due to serious deficits in resources and staffing for neurology services and issues with the way some MS medications are funded. For further information and references please refer to MS Ireland's Pre-Budget Submission 2017 and our recent submission to the Minister for Health regarding funding arrangements for MS medications, both of which are available here: http://www.ms-society.ie/pages/community/advocacy/our-submissions

Flexible working hours: According to the report 'MS and Employment: Facts and Figures': http://bit.ly/2dBUtMC, 31.7% percent of respondents were working full time and only 11.1 % were working part time. In comparison to Europe, the report notes that people with MS in Ireland who are working are more likely to be doing so in a full time capacity than European counterparts; however the proportion of people in Ireland with MS who are employed on a part time basis is much lower. This could be suggestive of a difficulty achieving more flexible working hours arrangements for people with MS in Ireland, relative to the EU.

Seated work/computer adjustments: There is currently a gap as regards appropriate and timely workplace assessment services from specialists who have a detailed understanding of particular illnesses and conditions, so as to determine what workplace adjustments are needed. Such specialists may be occupational therapists or organisational psychologists who have received training in particular disability or illness areas, or professionals from relevant support organisations who have received training in undertaking assessments. Any workplace assessment should always be conducted in consultation with the multi-disciplinary team of healthcare professionals who are working with the employee.

Low uptake rates of the Workplace Equipment Adaptation Grants and Retention Grants also suggest that these schemes and their application processes require review.

Supportive employers and colleagues: A review should be conducted of the Disability Awareness Training Support Scheme – what is the uptake of this scheme and are employers aware of it? Platforms like Ibec's Diversity Forums could also have a crucial role in raising awareness and understanding among employers of disabilities and long term illnesses. Closer engagement between governmental organisations, employer organisations such as Ibec and disability representative/support organisations could also help facilitate this.

6. How do you see the role of the Intreo centre evolving to meet the needs of PwD?

The Department of Social Protection is expanding the role of the Intreo centres as an employment and recruitment service for pwd who wish to take up work.

What do you think PwD need from their Intreo centre in terms of assisting them to search for work?

It should be noted that the employment needs of people with disabilities and long term health conditions can be very different to those of the general job-seeking population, and should therefore be treated differently by these services. For example, there may be a need for specific Intreo services with specialism around long term illness and disability. These services should be staffed by people with a professional understanding of illness and disability, i.e. people from health and caring professions.

Intreo services should also play a role in employment retention – a person with an acquired disability or long term illness should be able to seek advice and support on retaining employment, and returning to work after a period of absence. Supports offered might be referrals to appropriate workplace assessment services which can advise on reasonable adjustments (in consultation with the employer and any healthcare professionals who are already working with the individual), referral to vocational rehabilitation, advice about in-work financial supports available from the government, advice about retraining and redeployment, and arrangements of in-work supports (e.g., training to use new equipment or software that has been implemented as part of a workplace adjustment agreement).

How do you think the Intreo centre can best engage with PwD? e.g.

- Communication – social media, email/letters from intreo, telephone?
- Promotion of services via disability representative bodies/media?
- Named case worker

A named case worker for consistency would be important, i.e. removing the stress of having to repeatedly explain a situation/circumstances and reproduce evidence and paperwork.
Closer engagement with disability representative bodies/support organisations would be important, i.e. organising seminars or training to inform workers on new developments and changes in policy and practice, so that this information can then be disseminated by these organisations to the people they represent and support.

Accompaniment of family/friend/advocate at Intreo:

	Yes	No
▪ Is this important to PwD?	Y	O

- Yes for some and important to have the option available but not everybody with a disability would want to avail of this.