



MS: Enough

Make welfare
make sense



Foreword

The aspirations of people with MS are no different to anyone else. They want to live, fulfilling, independent lives and participate fully in society. Over 60 years ago, when the MS Society was set up, this was extremely difficult – the condition was poorly understood and there was little in the way of support from the state, often leaving people isolated, afraid and uncertain.



We've come a long way since then, with the welfare system playing a crucial role in supporting people with disabilities such as MS to lead independent lives, stay in work for longer and pay for the extra costs that come with the condition. And of course to allow those who cannot work due to their disability to meet basic living costs and live with dignity.

I meet people all the time who tell me such positive stories about how, thanks to that little extra help, they have been able to afford that taxi that gets them to work, or have been able to pay for the adapted vehicle that allows them to maintain some independence.

But sadly I meet many more people at the moment who tell me much more upsetting stories. Stories of the stress of having to 'prove' their disability to a stranger who does not understand the hidden impact of MS. Stories of being denied the support they need.

People like Sue, who will have been reassessed twice in the Support Group of Employment and Support Allowance in four years. Or Adam, who was asked to be available for work related activity, but who

needs support from carers to dress, shower and move in and out of his wheelchair.

This report is a stark reminder of what this really means for some among our community. There are people with MS who are left with no choice but to cut back on food, heating, clothing or even having to compromise on travelling to medical appointments.

I was particularly shocked to hear that almost half of the people who responded to our survey said that they didn't have enough financial support and that more than a third of those who have undergone face to face assessments reported that the experience had caused their MS to deteriorate or relapse. It's clear that people with MS are having to navigate an unforgiving system of confusing and stressful processes to prove their entitlement to the disability benefits they need.

This is an unacceptable state of affairs. Everyone with MS should be able to access the financial support they need without unnecessary stress or difficulty. This report marks the start of our MS: Enough campaign, calling for the disability benefits system to make sense for people with MS. With a number of common sense changes the system can be improved. I hope the Government will listen to the real experiences of people with MS, like Sue and Anastacia, and ensure the benefits system fully recognises the reality of living with MS.

Living with MS is hard enough. We will continue to raise awareness of the difficulties people with MS face and fight to make sure they have the support they need to lead their lives to the fullest.

Michelle Mitchell,
Chief Executive, MS Society

About MS

Multiple sclerosis (MS) is a chronic, neurodegenerative condition for which there is currently no cure. In MS, the body's immune system attacks myelin, the protective cover around nerve fibres. Damage, which can occur anywhere in the central nervous system, interferes with messages travelling from the brain and spinal cord to other parts of the body. Symptoms are many and varied, but unique to each person. They can include problems with balance, vision, the bladder, bowel, speech, memory, fatigue and painful muscle spasms, among many other things. MS affects over 100,000 people throughout the UK, many of whom experience their first symptoms during the peak of their working lives, in their 20s and 30s.

MS is both a fluctuating and progressive condition. While the progression and symptoms of MS vary from individual to individual, primary progressive MS affects around 10 to 15% of people with MS. This is progressive from the very first symptoms. The remaining 85% of people with MS are initially diagnosed with relapsing forms of MS, where people have distinct attacks of symptoms with the underlying damage building up over time. Most people (around 65%) with relapsing MS will then also go on to develop secondary progressive MS within 15 years of being diagnosed. The progressive and fluctuating nature of MS presents particular challenges for benefit assessment processes.

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Executive summary

Living with a chronic, disabling and degenerative condition such as MS is hard. It is also expensive. There are often substantial extra costs, such as accessible transport, specialist equipment, medication and help with household activities – a neurological condition like MS can cost, on average, an additional £200 a week.ⁱ

A crucial difference to the lives of people with MS

Given that as many as 80% of people with MS are forced to give up work within 15 years of diagnosisⁱⁱ, many rely on the safety net and support provided by disability benefits just to get by week to week. At their best, these benefits can also enable people to work for longer, live independent family lives and participate fully in society.

This summer we surveyed 1,780 people with MS about the role of disability benefits in their lives. Three quarters of respondents (74%) agreed that disability benefits have helped them manage the extra costs of their MS whilst four out of five respondents (83%) said that without the support of disability benefits they would be unable to maintain their current level of independence.

The system is not making sense

But right now, the disability benefits system isn't making sense for people with MS. The claiming process is stressful and assessments and eligibility criteria often fail to capture the complex and unpredictable reality of life with the condition. This has led to too many people living with MS missing out on the support they need and having to make sacrifices many of us cannot imagine in order to get by.

80%

of people with MS are forced to give up work within 15 years of diagnosis.



Almost nine out of 10 (87%) felt the process of claiming benefits is stressful and over half (57%) felt assessments did not accurately determine the impact of their MS. In particular, the hidden symptoms of MS (such as pain, fatigue and cognitive difficulties) are not always adequately captured. 42% of those who had had a Personal Independence Payment (PIP) face-to-face assessment disagreed that the assessor considered their hidden symptoms and 50% of those who had had a Work Capability Assessment (WCA) for Employment and Support Allowance (ESA), disagreed that hidden symptoms were considered.

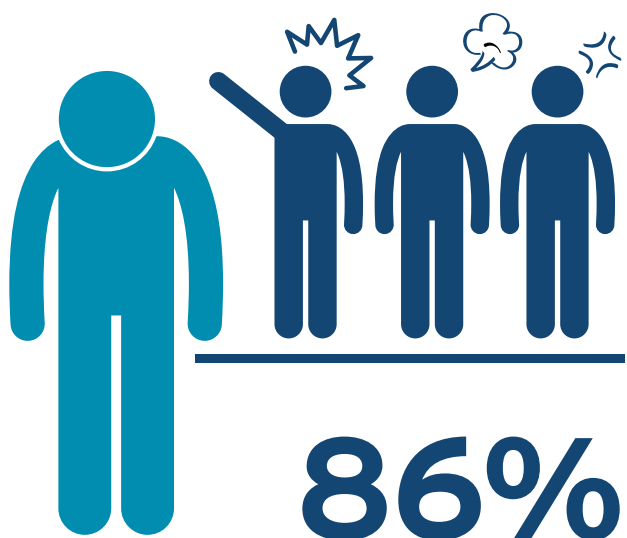
Worryingly, many felt the very process made their MS worse. Almost half (48%) who had had face-to-face assessments for ESA said it caused their MS to deteriorate or relapse. The same was true for over a third (36%) of those who had assessments for PIP.

In response to rising welfare costs, ongoing reforms since 2008 have changed the disability benefits people with MS can receive and how they access them. Further changes to support for disabled people were announced in the Summer Budget 2015, as part of measures which will reduce welfare spending year on year until a reduction of £12 billion is achieved in the year 2019/20.ⁱⁱⁱ The current Government has made an important commitment to continue to support the most vulnerable in our society.^{iv} However, we are concerned that some people with MS are struggling to receive the support they need to live their daily lives.



Over **1/2** said that benefits assessments do not accurately determine the impact of their MS

More than two fifths (41%) of ESA claimants told us that benefits changes had forced them to reduce spending on food and a third (33%) had reduced spending on gas or electricity. The survey also raised concerns that the support provided to those who could return to work is currently inadequate. Two thirds (66%) of claimants placed in the Work Related Activity Group (WRAG) said they received no support to help them find employment and over half (52%) said they were unable to do the actions which were asked of them to take steps towards employment.



of our respondents felt
the public judge people who
claim disability benefits.

Stigma and harassment


These difficulties are compounded by wider societal attitudes which appear to be acting as an additional barrier to people with MS getting the help they need. As many as 86% of our respondents felt the public judge people who claim disability benefits, while a fifth (20%) reported experiencing harassment specifically because they claim benefits. A quarter (25%) even said they don't claim all the benefits they need because of the associated stigma.

Conclusions and recommendations

Having a chronic, neurological condition like MS is difficult enough. The MS Society believes the disability benefits system should work to make life easier not harder. Common sense changes can and should be made to make the system make sense for people with MS and ensure that they can access the support they need to live their lives, participate in society and be as independent as they are able.

To achieve this, this report makes the following recommendations:

- Disability benefits assessments must accurately take into account the fluctuating and hidden symptoms of MS and their impact
- The disability benefits system must take adequate account of evidence provided by experienced professionals who know the person and understand their condition
- Existing criteria which do not reflect the barriers faced by people with MS should be changed
- People with MS must be able to rely on support when they need it, without unnecessary burden or constant fear of having it taken away
- Negative stereotypes must be challenged and greater awareness raised about the crucial impact disability benefits can have on the lives of people with MS
- The Government should undertake a full impact assessment of any further changes they make to disability benefits, including exploring the knock on effects on other areas of public spending such as health and social care
- The Government should work with the Disabled community and disability organisations to ensure that back to work support is adequate and addresses the barriers individuals face



The figures used in
this report are based
on a sample of

1,780

responses from
across the UK.

About the survey

The survey informing this report was distributed via email and promotion through social media to people with MS across the UK. The survey was open for responses between 29 June and 29 July 2015.

The figures used in this report are based on a sample of 1,780 responses from across the UK. This sample is those respondents who had ever made a claim for at least one of the following disability benefits: Disability Living Allowance (DLA), Personal Independence Payment (PIP), Incapacity Benefit (IB), Employment and Support Allowance (ESA) or Access to Work.

While welfare policy is still centrally determined in Westminster, the policy contexts vary across the nations of the UK. In particular, Northern Ireland has not yet passed the Welfare Reform Bill, which would enact the reforms introduced to the rest of the UK by the Welfare Reform Act 2012. As such, PIP does not exist in Northern Ireland; figures relating to PIP therefore only refer to responses from England, Wales and Scotland. Additionally, welfare and disability benefits are administered in Northern Ireland by the Department of Social Development. Any references to Department of Work and Pensions (DWP) policies or statistics in this report also only refer to and affect England, Wales and Scotland.

A crucial difference to the lives of people with MS

The results of our survey demonstrate the significant impact disability benefits can have on the lives of people with MS. Among the impacts, respondents highlighted that disability benefits enabled them to carry out everyday activities, such as getting out and about, participating in social activities with family and friends and carrying out caring responsibilities such as looking after children. For some individuals, disability benefits also play a role in enabling them to stay in or access employment.

Currently the major disability benefits for people with MS are DLA, PIP, and ESA. DLA and PIP are non-means tested benefits intended to help cover the additional costs of an impairment or health condition. ESA replaced IB as the main out of work benefit for disabled people and provides financial assistance for those who can no longer work, as well as employment support for those who may be able to work in the future.

MS can make it very challenging for those affected to maintain financial security. Living with MS can incur substantial additional costs on items such as accessible transport, specialist equipment and help with everyday activities. The Extra Costs Commission estimates that a neurological condition, such as MS, can cost on average an additional £200 per person per week.^v

At the same time, MS impairs individuals' earning potential. Only 37% of people with mild forms of MS are employed^{vi} and up to

80% of people with MS stop working within 15 years of the onset of the condition.^{vii}

Because of this, both disability benefits designed to cover the extra costs of the condition such as DLA and PIP, and those intended to provide security when people are unable to work, play an important role in the lives of people with MS. Over 60% of people with MS in the UK receive either DLA or PIP and from DWP figures, the MS Society estimates that there have been over 25,000 ESA claims by people with MS, including 16,200 reassessments from IB.²



*Extra costs commission interim report

Of total respondents to our survey (n =2,016), 75% had claimed DLA at some point and 19% had made a claim for PIP. 46% had made a claim for ESA and 24% had made a claim for IB. Among those who had claimed benefits (n=1,780), DLA was unsurprisingly the most commonly claimed benefit with 86% of respondents reporting they had made a DLA claim.

Extra cost benefits, DLA and PIP, also act as a gateway to other vital sources of support. These passported benefits include Carer's Allowance, the Disabled Parking Blue Badge Scheme, Disabled Rail Cards and the Motability Scheme. Households where an individual is receiving DLA or PIP are also exempted from the household benefit cap.

Of respondents who had claimed DLA or PIP (n=1,721) 25% indicated that a member of their household had claimed Carer's Allowance and almost half (47%) had a vehicle, scooter or powered wheelchair under the Motability scheme.

Extra costs and financial security

The financial support provided by these benefits not only helps to cover expenditure associated with MS, such as specialist equipment and additional transport costs allowing people to lead more independent lives and participate in society. For many disability benefits are also vital to afford basic essentials and maintain financial security. 74% of respondents agreed that disability benefits have helped them manage the extra costs of their MS, whilst almost two thirds (63%) agreed that without the support of disability benefits they would be unable to afford essential items such as food and heating. A number of respondents highlighted the importance of DLA in particular. (see box)

“I can afford transport such as taxis, a cleaner, and a part time gardener all of which reduce my dependence on the generosity of others and restore my dignity.”

“The benefits help me maintain my independence and contribute to bills as I did when I was able to work. I would be lost without them.”

“I would be lost without it. Although the forms are a minefield and filling them out is a stressful experience, the extra income DLA provides for me is essential to my quality of life. The cost of living has gone up so much in these times of recession and salaries have not risen in keeping. Without this help I would go under and possibly have to lose my home.”

¹Estimate calculated from the most recent published data: Department of Work and Pensions Tabulation Tool. Disability Living Allowance cases in payment caseload, with a main claiming condition of Multiple Sclerosis, as of May 2013. http://tabulation-tool.dwp.gov.uk/100pc/dla/disabled_new/ctdurtn/a_carate_r_disabled_new_c_ctdurtn_may13.html (Accessed July 2015) and Department of Work and Pensions Stat-Xplore Tool, Personal Independence Payment cases in payment caseload, with a main claiming condition of Multiple Sclerosis as of April 2015 <https://sw.stat-xplore.dwp.gov.uk/webapi/jsf/tableView/tableView.xhtml>

²HC Deb 1 September 2014 Written question – 206428. Outcomes of initial and repeat Employment and Support Allowance (ESA) functional assessments and Incapacity Benefits Reassessments (IBR) by disease code: October 2008 – September 2013. Figure calculated by combining total initial claims and Incapacity Benefit Reassessment (IBR) claims



John Parker

John's Motability vehicle enables him to continue his voluntary work

89%

of Motability scheme users said their vehicle, wheelchair or scooter had enabled them to get to all of their medical/hospital appointments.

People with MS have had to reduce spending on basic essentials and socialising as a result of disability benefit changes.



Independence, family and social life

Beyond affording basic essentials, appropriate disability benefits can also allow people with MS to maintain their independence and continue to participate in social and family activities. Four out of five respondents (83%) said that without the support of disability benefits they would be unable to maintain their current level of independence, and over two thirds (67%) agreed that without disability benefits they would be unable to participate in their hobbies.

Those in receipt of passported benefits, and in particular the Motability scheme, highlighted strong positive impacts on social and family activity. The Motability scheme allows those receiving higher rate Mobility component of DLA or PIP to lease a suitable adapted vehicle, powered wheelchair or mobility scooter, in return for their weekly award. Of the respondents who were Motability users (n=802), nine out of 10 (92%) agreed that the scheme had enabled them to maintain their independence and similar numbers (95%) reported that it had enabled them to get out and about.

“DLA is wonderful and has helped so much over these difficult years. It has given access to other benefits, in particular, the Freedom pass with free travel and the Blue Badge.”

“The income I receive from DLA and the access to a Motability vehicle allows me to main[tain] as normal a life as possible, without them I would be housebound and would end up claiming benefits to survive!”

In addition, almost a third (31%) agreed that it had enabled them to continue caring for their children, while 29% said it had enabled them to continue their voluntary/unpaid activity. Motability users also reported positive impacts on employment which are discussed later in the report.

Emotional and physical wellbeing

These results indicate that adequate provision of disability benefits can have

positive impacts on the emotional and physical well being of people with MS through increased financial security and independence.

In addition, some responses suggest there could be a direct link between disability benefits and people with MS being able to manage their condition and access medical services and treatments. 89% of Motability scheme users said their vehicle, wheelchair or scooter had enabled them to get to all of their medical/hospital appointments. This is also borne out by responses to our recent survey about the impact of changes to disability benefits, which are discussed in the next section.

Allowing people to stay in work

It is increasingly recognised that employment has an important positive, therapeutic and economic impact on the life of a person with a long term condition such as MS; providing financial autonomy, dignity, quality of life and a sense of self-worth. Whilst up to 80% of people with MS become unemployed within 15 years of diagnosis,^{viii} disability benefits and support can play a crucial role in helping those who feel they may be able to stay in or return to employment.

12% (219) of respondents indicated that they had made a claim for Access to Work which provides support for disabled people to help them stay in employment. A number of Motability scheme users reported positive outcomes relating to work: one fifth (20%) agreed that it had enabled them to stay in their job and 13% said they would be unable to maintain their job if they lost access to the scheme.

ESA is the main benefit designed to support those who are no longer able to work, as well as help those who could work in the future to take steps towards employment. Whilst some people with MS may be unable to return to the workplace once

their symptoms have become too severe, others may benefit from support to return to employment. For these people and those who wish to stay in employment but may need assistance, adequate support which reflects the barriers people with MS face is crucial.

A number of free text responses highlighted positive impacts of disability benefits on employment.

CASE STUDY

John Parker, 61 Cardiff, Wales

'I was diagnosed with primary progressive MS while I was working as an IT analyst. I applied for DLA, was awarded a lifetime award and applied for a Motability vehicle. It's been brilliant. Without the car I wouldn't have been able to stay in employment.'

Now retired, my vehicle enables me to continue my voluntary work with Age Concern and Tenovus the Cancer Charity. Just as important to us as a family, it allows us to visit our autistic son in Mid Wales.'

‘I was awarded my DLA indefinitely, this enables me to work part-time, I love my job, but have had to change my working days due to my MS...I am really scared that I will lose my DLA completely when I am assessed for PIP, If that happens I will have no choice but to give up my job completely and rely on state benefits.’

People with MS are struggling to access the support they need

Despite the positive impact adequate financial assistance from disability benefits can have for people with MS, currently many people cannot access what they need. The findings of our survey suggest that a significant number of people with MS are falling through the cracks of the welfare system and are struggling as a result.

Almost half of respondents (44%) disagreed that they had enough financial support and less than a fifth (17%) of respondents agreed that disability benefits currently provide appropriate and adequate support to people with MS.

Impact of changes to disability benefits

On-going changes to disability benefits have inadvertently contributed to the difficulties people with MS face. Almost half of the respondents (49%) to our survey agreed that changes to disability benefits have had a negative impact on them.

Changes to disability benefit provision are leading to isolation and financial difficulty. A large number of survey respondents reported having to reduce expenditure in several areas as a result of disability benefit changes. 41% had reduced spending on social interaction with family or friends and 28% had reduced spending on transport. Over a quarter of people (26%) reported

that they had reduced spending on gas and electricity as a result of changes and shockingly, nearly a third (32%) reported reduced expenditure on food.

Our findings also suggest that inadequate financial support is impacting the physical wellbeing of people with MS. In addition to essential items such as food and heating, one in 10 (9%) of respondents said they have had to reduce spending on attending hospital appointments and on medical treatment or prescriptions as a result of benefit changes.

The support provided by disability benefits looks to be particularly falling short for those who find themselves unable to work, either permanently or temporarily. Respondents who had claimed ESA were more likely to have reduced expenditure on essential items as a result of changes to disability benefits. 41% of ESA claimants said they had reduced spending on food compared to 20% who had claimed other benefits, and a third (33%) had reduced spending on gas and electricity compared to 16% of those who had claimed other benefits.

66%

of our respondents felt they had received no support to get back into work.

Personal Independence Payment (PIP)

Since the introduction of PIP, the proportion of people with MS receiving the highest rate of mobility support has fallen significantly. While under DLA, 94% of claimants with MS received the higher rate of the mobility component of the benefits, so far this has only been awarded to 42% of PIP claimants with MS.³ Of respondents to our survey who had claimed PIP, 35% reported being given the enhanced Mobility component.

People with MS are concerned about the potential loss of this level of support, particularly as this component gives them access to a Motability vehicle. Problems with walking, balance and coordination are common symptoms of MS so mobility is often significantly impacted, making this support crucial for many. A number of respondents to our survey had already lost their Motability support following reassessment to PIP.

³Calculated from Department of Work and Pensions Statistics: Tables Disability Living Allowance - cases in payment Caseload (Thousands) : Main Disabling Condition by Mobility Award Type and Stat XPlor tables for PIP awards

⁴Department of Work and Pensions, The Government's response to the consultation on the PIP assessment Moving around activity, October 2013 pp. 46 – Calculated from Table 4: DLA and PIP Mobility Awards for Reassessed Cases

Of those respondents who had a Motability vehicle and were awaiting reassessment for PIP, only 34% felt sure that they would continue to be eligible for the Motability scheme. When asked about the potential impact of losing their Motability vehicle, 79% said that they would no longer be able to get around independently and 68% said their social life would be negatively affected.

Wider impacts were also reported: 18% reported that their partner would have to give up work or reduce their hours to assist them. Significantly, 78% said they would struggle to attend all of their medical/hospital appointments. This suggests reduced support could have negative impacts for condition management and physical and mental wellbeing.

The eligibility criteria for the higher rate of the mobility component was reduced from 50 metres under DLA to 20 metres under PIP. 20 metres is roughly the length of two standard buses. Now, people with a physical disability who can walk over 20 metres, even using aids and adaptations, will no longer qualify for this level of financial assistance. The Government's projections have estimated that around 548,000 DLA recipients will no longer qualify for the enhanced rate mobility component under PIP.⁴ This means it is likely that far fewer people with MS will be able to access the Motability scheme. We strongly believe that people with MS who can walk more than 20 metres (but no more than 50 metres) face many of the same barriers to mobility, and therefore the same additional costs, as those who can mobilise for less than this distance.

Employment and Support Allowance (ESA)

Since the introduction of ESA, a significant number of people with MS have been placed in the Work Related Activity Group (WRAG) or found Fit for Work. Of initial

claims for ESA by people with MS between 2008 and 2013, 27% were placed in the Work Related Activity Group (WRAG), 17% were found Fit for Work and 56% were placed in the Support Group.^{ix}

Many people with MS can and want to work, but for those whose symptoms have become too severe or unpredictable, adequate financial assistance and support is vital. MS can cause both physical and cognitive difficulties such as fatigue, problems with muscle strength and walking and balance. These increase over time as disability accumulates, making employment increasingly difficult.

We are concerned that inadequate safeguards are in place to ensure that people with MS are placed in the correct group of ESA. The distinction between the Support Group and the WRAG is an important one because people in the WRAG receive less money, can be subject to sanctions and have their support limited to a year. We explore the problems with the assessment process for people with MS in the following section of this report.

For those placed in the WRAG, manageable and effective support to overcome barriers to employment is particularly important. However, we are concerned that the support available through ESA is currently inadequate. Of respondents who were placed in the WRAG (n=126), two thirds (66%) reported they had received no support to help them get back to work and 61% disagreed that the support they had received from the JobCentre would help them find a job. Worryingly, 51% said they were not able to do the actions which were asked of them. This is concerning because failure to perform these activities could lead to sanction.

People with MS who find themselves unable to work face the double effect of the extra costs of their condition as well

CASE STUDY

Adam* Powys, Wales

‘I applied for ESA with the help of a local charity as my writing hand is pretty rubbish, thanks to my MS. They put me in the WRAG. I was asked to be available for work for most of the week. They told me I needed to physically visit the Jobcentre and employers to chase vacancies.

‘I felt guilty. Yes I could feed myself, most of the time. But I couldn’t put socks and shoes on. I need carers to shave me, clean me after toileting. Shower, dry and dress me. Hoist me in and out of bed.’

*Surname omitted by request

as a loss of income. Perceived financial insecurity was higher amongst survey respondents who had claimed ESA. 48% of ESA claimants disagreed that they have enough financial support, compared to 38% of those who had not claimed ESA.

For this reason, measures contained within the Summer Budget and the Welfare Reform and Work Bill to reduce the rate of WRAG ESA by almost £30 a week to match Job Seeker’s Allowance will hit people with MS hard. People with MS in the WRAG face substantial barriers to sustained employment as well as additional costs, which are not faced by non-disabled job seekers. The unpredictable nature of MS symptoms poses particular unique challenges for people with MS seeking work. The financial assistance provided in the WRAG is needed to help cover the costs of specialist equipment and higher everyday expenditure on items such as heating and food.

The system is not making sense

Disability benefits should provide a safety net and a helping hand for those dealing with an impairment or health condition. Some people with MS are able to access this with positive effects on their lives. But for too many the system is failing to provide the support they vitally need.

Responses to our survey and previous research by disability organisations – such as the Big Benefits Surveys carried out by the Disability Benefits Consortium (DBC) – suggest that a number of areas within the disability benefits system are causing particular problems. These will be explored in more detail throughout the remainder of this report. Eligibility criteria are failing to consistently reflect the reality of living with MS and assessments do not adequately capture the needs of people with the condition.

The process of claiming is often needlessly complicated and confusing, causing distress and anxiety for people trying to access the support they vitally need. A significant number of respondents reported that an assessment had made their condition worse and this is explored in further detail later in this section.

Surveys have consistently highlighted dissatisfaction with the accuracy of the assessment process amongst people with MS. Over half of respondents (57%) to our survey disagreed that assessments accurately determine the impact of their MS. These findings were also reflected in

responses to individual questions about the PIP face to face assessment and the WCA for ESA.

Knowledge of MS

Of those who had had a face to face assessment for PIP (n=269), 45% disagreed that the assessor understood the impact of their MS and 36% disagreed that the assessor had a good understanding of MS.

Survey respondents also reported issues with the accuracy of PIP assessment reports. Of those who had seen a copy of the report from their PIP assessment (n=112), over half (54%) disagreed that the report accurately reflected the impact of their MS on their life. Only 17% felt it was definitely an accurate reflection of how their MS affects them while 38% did not think it was an accurate reflection.

A similar picture emerged from those who had undergone a WCA. Of respondents who had a WCA (n=248), nearly half (49%) disagreed that the assessor understood their MS and 48% disagreed that it accurately assessed their capability for work.

The inaccurate picture that assessments are capturing of people's daily lives is reflected in the persistently high number of reconsiderations and successful appeals. 20% of PIP Mandatory Reconsiderations have resulted in a different decision⁵ and over half of appealed Fit for Work ESA decisions are overturned.⁶ From our survey, 41% (n= 300) of people disagreed with the initial decision on their PIP claim.



48%

of people who had a WCA disagreed that it accurately assessed their capability for work.

Amy Mackelden

Amy's assessment ignored the hidden and fluctuating symptoms of her MS

“ I openly chatted with the interviewer he struggled to grasp the idea that you don’t have normal days. He clearly thought that remittance meant you were back to normal ”

“ It was little more than a box ticking exercise, the Assessor had little idea of how MS affects people. ”

“ I didn’t feel that the descriptors were assessed in context of reliability/reasonable time/ repeatedly etc.. ”

“ I did not feel that she had sufficient knowledge or experience of MS to make an informed report. On accessing a copy of her report and comparing it to first report I had dropped marks to the extent of it being ridiculous. Had she listened or did she just tick boxes!! ”

“ I would be very surprised if the assessor had any training on MS at all. ”

Consideration of hidden and fluctuating symptoms

Hidden symptoms, such as cognitive difficulties and chronic fatigue, and the fluctuating nature of MS have been a particular source of inaccuracy across PIP and ESA assessments, despite regulations detailing how these should be accounted for.

‘Invisible’ or hidden symptoms can be difficult for other people to understand and frustrating for the person with MS to try to describe or explain the impact they have. MS symptoms can also vary enormously from one day to the next. They might last for a few hours, or for days, weeks or months. No two people with MS will experience the same symptoms in the same way.

Of those who have had a PIP face to face assessment (n=269), 42% disagreed that the assessor considered their hidden symptoms. Of those who had had a WCA for ESA, half (50%) disagreed that it considered hidden symptoms.

Assessors are failing to ask important questions about how people with MS are able to perform activities. Of those who have had a PIP face to face assessment, 37% disagreed that the assessor explored whether they could do activities safely, repeatedly, to an acceptable standard and in a reasonable time despite their being a legal requirement to do so. For fluctuation, problems with the PIP assessment were also highlighted. A quarter of respondents (26%) disagreed that the assessor gave them the opportunity to explain how their MS affects them differently on different days or at different points during the day.

The WCA seemed to perform worse in assessing reliability and fluctuation. Of those who had a WCA for ESA (n =248) 46% disagreed that it took into account

whether they could do activities reliably, repeatedly and in a safe manner and 45% disagreed that the assessment took into account how their symptoms fluctuate.

These statistics suggest that the PIP face to face assessment is performing better in some of these areas than the WCA, albeit with serious concerns remaining.

This is supported by a comparison of the fluctuation regulations developed by the DWP for both benefits as well as the DWP guidance and training materials used by assessment providers. For PIP, extensive reliability criteria have been added to the legislation governing the assessment following calls from disability organisations and charities. These criteria require that assessors consider whether a claimant can carry out an activity ‘reliably’.⁷

CASE STUDY

Amy MacKelden, 31 Isle of Wight, England

‘At my PIP assessment, because I wasn’t in a period of relapse, they thought that I was fine. When I tried to explain my fatigue and how it affects my ability to do things like cooking safely, it was ignored and instead the assessor put down ‘this person can make a meal’ and ‘she doesn’t look tired, she’s well presented, she has a good complexion.

‘The assessor kept pushing me for what had happened in the last two weeks and didn’t want to hear about fluctuations at all. It’s like she didn’t know what fluctuation was.’

In addition, the MS Society and other disability organisations have had extensive input into the training materials for PIP assessors to improve their understanding of hidden symptoms and fluctuating conditions. So far much less oversight of WCA training materials has been provided to external stakeholders and organisations.

The PIP assessment is already much more discussion based than the WCA and this may also account for better success at accounting for hidden symptoms and fluctuation. Dr Litchfield, in his final Independent Review of the WCA, called for a ‘more discussion based approach to be developed rather than the current method of questioning’.^x

However, the MS Society still has concerns about the time period over which fluctuation is considered for both benefits. Under PIP an assessment descriptor will apply if someone is unable to carry out an activity on more than 50% of days in a 12 month period.^{xi}

Similarly, for ESA, functional descriptors are chosen which apply for the majority of days.^{xii} These criteria do not adequately capture the impact of MS relapses.

A severe spike in an individual’s condition over a shorter time period can result in significant increases in mobility needs and additional costs. People with MS impacted by severe relapses still require substantial assistance, even if the severe functional impairment does not impact them for half of the days in a year.

Complicated and confusing processes

These issues are exacerbated by procedural concerns. Accessing disability benefits is often made more difficult by a complicated, confusing and often extremely stressful process. For people already coping with chronic health conditions,

having to navigate these processes can have serious negative impacts.

Overall, 87% of survey respondents agreed that the process of claiming benefits is stressful and 80% agreed that the process of claiming is difficult to understand. People with MS often report that stress impacts on their condition in some way. In a concerning number of cases, respondents felt the assessment process in particular had led to a deterioration in their condition or had negatively impacted on their emotional and mental health.

Of those who had had a work capability assessment for ESA (n= 242), almost half (48%) agreed that the process had caused their MS to deteriorate or relapse, whilst of those who had had a face to face assessment for PIP (n=269), over a third (36%) agreed that it had caused their MS to relapse or deteriorate.

A number of studies have now demonstrated a relationship between stressful life events and disease activity in people with MS.^{xiii}

More recently in 2014, research was published suggesting that major negative stressful events lead to increased risk of brain lesions, while positive stressful events lead to a decreased risk of lesions.^{xv}

A high number of respondents who had been through the assessment processes for the reformed benefits ESA and PIP, also reported a negative impact on their emotional and mental health. Almost two thirds (63%) of respondents who had a PIP

CASE STUDY

Anastasia Dunne Winsford, England

‘This whole process has been very frightening and has made my anxiety worse and caused me to relapse. I experienced severe weakness, pain, mobility problems and vertigo. I have patches of skin all over my body that feel like someone has put a hot iron on my skin.’

‘I was in relapse when I was assessed but assessment escalated symptoms.’

‘My legs are a lot worst now.’

‘Caused numbness fatigue and increase in leg spasms.’

‘Finances are vital, worrying about completing application forms correctly is stressful!’

‘It is so stressful I had a relapse and suffered fatigue during the waiting period.’

42%

disagreed that the assessor considered their hidden symptoms

⁵ Calculated from PIP Statistical Release, June 2015

⁶ Department of Work and Pensions, ESA/WCA stats release, 11th June 2015

⁷ Department of Work and Pensions, Personal Independence Payment handbook, July 2015, pp. 8) Reliably is defined within this handbook as meaning safely, to an acceptable standard, repeatedly – as often as is reasonably required and in a reasonable time period.



CASE STUDY

Jayne Hodges Cirencester, England

'I applied for PIP after being diagnosed last year. I waited 7 months to get a face-to-face assessment. Waiting drove me into debt. I went through all my savings and without help from my family I would have lost my house.

For two weeks before the assessment, I was unable to move. I lived off packets of Cheddars and a chunk of cheese. I am a chef. I would have preferred not to apply for benefits, but I need to be able to keep a roof over my head.'

More than

1/3

said face to face assessments had caused their MS to relapse or deteriorate



face to face assessment agreed that their emotional and mental wellbeing had been negatively affected, while over two thirds (68%) of those who had had a WCA agreed that their emotional and mental wellbeing had been negatively affected.

Unnecessary delays can also add to this stress and anxiety as well as exacerbating any financial difficulties. Our survey found evidence that the waiting periods had negatively impacted people with MS, leaving them without vital support and increasing anxiety and emotional distress.

Of PIP claimants (n= 325), 28% reported not being able to afford some essential items such as food, heating and clothing as a result of experiencing a long wait or delays, while 21% reported being isolated in their home and 15% struggled to attend medical appointments.

Similarly, among ESA claimants, 22% reported facing severe financial difficulties as a result of experiencing a long wait or delays, 20% could not afford some essential items and 10% struggled to attend medical appointments.

Collection and use of evidence

The system is being further complicated by how evidence from care and medical professionals is used and considered. We are concerned that assessors are not obliged to seek and consider further evidence in every case. This means the opinion of care professionals who know the claimants and understand their MS is not always taken into account. Of respondents who had had a WCA, almost four in 10 (39%) disagreed that the assessment took into account additional evidence about their condition.

The Independent Review of the WCA highlighted this issue, with Harrington's Year 3 Review recommending that 'Decision Makers should actively consider the need to seek further documentary evidence in every claimant's case. The final decision must be justified where this is not sought'. As of November 2014, this had been only partially implemented and was the subject of on-going discussion with the assessment provider.^{xvii}

Inadequate consideration of further evidence is compounded by difficulties people have reported in obtaining evidence themselves. 27% of respondents who had claimed PIP said it was difficult to obtain extra evidence.

The most common reasons cited for this difficulty were that they were unclear on who could provide evidence and that their healthcare professionals did not understand what information they needed to provide.

Reassessments

For those people with MS who do successfully manage to navigate the complicated and stressful process, the MS Society is concerned that some may then face frequent reassessment, sometimes shortly after being given an award. People with MS report feeling that they have to constantly prove their difficulties and that they are frustrated by reassessments that seem very unnecessary given the progressive nature of the condition. Not only do unnecessary reassessments cause distress, they are also costly. The administrative cost of a new PIP claim is £182 which includes the cost of a face to face assessment. This compares with an administrative cost of £49 for DLA which in most cases did not require a face to face assessment.^{xviii}

Significantly long term awards are not often available under PIP and ESA. This has increased the frequency of potential reassessment. As of May 2013, shortly before the introduction of PIP, 78% of DLA claimants with MS had awards of 5 years or more. At the time of publication, no official data on the length of PIP awards has been published. However, of respondents to our survey who had been awarded PIP (n=287), over a third (34%) had been given awards of 2 years or less, including 11% who had awards of between 9 and 18 months in length meaning they face reassessment quite soon.

Since the introduction of PIP the DWP has also introduced an additional policy of 'interventions'. This policy means that for PIP awards of more than two years a review

will take place before the award finishes.^{xix} Because of this, people with MS are now also confused to find that they are being reassessed long before their award has come to an end.

The Government's stated intention behind shorter awards, more frequent reassessment and PIP mid-award reviews is to ensure people are receiving adequate support. This is welcome in principle. However, for many people with MS, these measures are unnecessary and putting them through needless stress. As a life-long, progressive, incurable condition, MS is very unlikely to improve significantly

How have the reassessments you have had made you feel?

“Horrible. Very very stressed. Feel it's the last time I can cope with this process. Unsure if I can cope with it again. Made me feel depressed.”

“I was surprised that they wanted a reassessment after only 6 months.”

“I feel angry as it has only been just over a year since I was finally awarded PIP I have been told I need to go for another face to face assessment which is causing me a lot of stress and worry to what the future holds.”

“Their letter said I would receive PIP until 2016. I have just received another assessment form - a year earlier than expected.”



Jackie Mumby

Jackie experienced verbal abuse and harassment for claiming benefits

in the longer term, and an individual's need for support is unlikely to diminish. If people think that their condition has changed or deteriorated they can request a reassessment before their award ends.

Of those respondents who had had a face to face assessment for PIP, 18% had already had a repeat assessment, even though 87% of initial assessments had taken place either this year or during 2014.

However it was respondents who had made claims for ESA in particular who reported feeling that reassessments take place too frequently. Over a third of respondents (34%) who had made a claim for ESA agreed that they were reassessed too frequently. This was somewhat surprising, as due to backlogs, reassessments for ESA have been temporarily halted since January 2014.^{xx} If anything, we would expect respondents to our survey to have experienced fewer reassessments than they will do in the future.

In researching this report, the MS Society requested official data on ESA award lengths for claimants with MS and the number who have had one or multiple reassessments on the same claim via a Freedom of Information Request (FOI). Our request for this information was declined, citing disproportionate cost.^{xxi} However, information gathered through an FOI last year suggests that up to 47% of claimants with MS could be facing reassessment including 40% of people in the Support Group.⁸

Professor Litchfield, within his Year 4 Independent Review of ESA and the WCA, recognised that frequent reassessment was inappropriate and recommended that reassessment, 'of people in the Support Group who have very severe or degenerative brain disorders which will not realistically improve...be extended to 5 years'.^{xxii}

CASE STUDY

Sue* London, England

'I am a power chair user, don't have normal bowel function and have really bad problems with cognition. I've had secondary progressive MS for 47 years, but the DWP doesn't understand that I'm never going to recover.'

'I was put in the ESA Support Group 3 years ago. Two years after being awarded, I was reassessed. I'm scheduled to be reassessed for a second time even though I've only been receiving ESA since 2011.'

'Every time I'm told I will be reassessed, I become so anxious even though I know I should qualify. I'm fearful of losing the support that gives me the ability to see family and access my community. Just the thought makes me feel paranoid.'

*Surname omitted by request

Stigma and harassment

In addition to a system that makes accessing support needlessly stressful and difficult, our survey suggests that some people with MS are facing hostility and harassment due to their condition and that this is acting as an additional barrier to support.

While the majority of the general public are sympathetic to the needs of people with MS, awareness remains an issue. Our research found that people with MS feel there are still negative attitudes among the public towards those who claim disability benefits. 86% of respondents to our survey agreed that they felt the public judge people who claim disability benefits. Data from the 2012 British Social Attitudes Survey similarly found that over 80% of respondents said there was at least a little prejudice against disabled people, including 30% who said they thought there was a lot. ^{xxiii}

In particular, public concern about fraudulent benefit claims remains prominent. The 2007 British Social Attitudes Survey found that respondents felt that on average 34 in every 100 are falsely claiming disability benefits. ^{xxiv} This public perception can inadvertently impact disabled people who are genuinely entitled to the support they receive and rely on to carry out their everyday lives. Over half of the people with MS who responded to our survey (50%) agreed that they felt ashamed of claiming disability benefits.

In some cases, the stigma associated with disability benefits is even limiting the support people were asking for. A quarter (25%) of respondents agreed that they don't claim all the benefits they need because of the stigma associated with claiming.

Of most concern was that a section of respondents reported that they had experienced harassment because of claiming benefits. Over a third of respondents (35%) reported that they had experienced harassment as a result of their condition and a fifth of respondents (21%) said the harassment they had experienced was due to the fact that they claim disability benefits.

25%

said they do not claim all the benefits they need because of the stigma



“ Called a benefit scrounger [and] told to get a f**king job you crippled f**ker’... I have found over the last 12 months the public in general are less tolerant of me. ”

“ I parked for free at a car park and was referred to as “oh you’re one of those scroungers are you! Some of us have to pay our way!”... Just using disability aides is scary sometimes as you feel people are pointing the finger about benefits claimants. ”

“ The words ‘ it’s alright for you, I have to work for a living’ is very hard to hear. It might seem innocent enough to other people but I hear the meaning behind the words. In these times of austerity I feel constantly under the microscope and being judged by all those around me. I hate my disability and am struggling with my depression because of it. ”

In particular, a number of respondents said they had been called a ‘scrounger’ or subjected to verbal abuse which specifically referenced benefit claiming.

Of those who had experienced harassment, almost two thirds (63%) reported experiencing hostile or discriminatory treatment, while 59% reported verbal abuse and 5% said they had experienced physical abuse. A significant number of these encounters appeared to relate to the symptoms of MS being invisible to members of the public and their impact doubted.

Of the free text responses we received to our survey question about the nature of harassment people had experienced

CASE STUDY

Jackie Mumby Goole, England

‘My family members are convinced that there is nothing wrong with me and that I’m a scrounger who is too lazy to work. I have been verbally abused in the street. I have even had a note left on my windscreen while parked in a disabled bay saying that being fat does not make me disabled.

‘I feel ashamed of not being able to support myself through working like every other honest person does, but no one sees me on my bad days. No one sees how I survive on £7k a year, how I pay council tax, bills, prescription charges, and a mortgage just like they do.’

(n=298), 19% concerned incidents involving employment or the workplace, 17% of incidents involved disabled parking and the Blue Badge Scheme and over a quarter (26%) concerned harassment due to the invisible nature of people’s MS.

This reinforces that wider public awareness of the needs of people with MS is needed.

⁸ Department of Work and Pensions Freedom of Information request 2014-3129, September 2014. Total numbers of people with MS initially placed in the WRAG or Support Group who have had at least one reassessment October 2008- September 2012 as shown in table 3a calculated as percentages of total WRAG or Support Group outcomes of initial functional assessments of people with MS October 2008- September 2013 as shown in Table 2

Conclusions

It is clear that when the financial assistance provided through disability benefits is appropriate and adequately addresses the everyday impact of MS, it can have a transformative impact. But too many people with MS are struggling to access what they need to live their lives.

Extra cost and out of work benefits provide a vital lifeline that allows many people with MS to afford basic essentials and maintain their independence. Our survey also found that disability benefits facilitate people with MS participating in family and social activities. Over two thirds (67%) of respondents agreed that without disability benefits they would be unable to participate in their hobbies while almost a third (31%) of Motability users agreed that it had enabled them to continue caring for their children.

For some people with MS, disability benefits and support are also vital to allow them to stay in employment. In particular the employment benefits of schemes such as Access to Work and the Motability scheme for people with MS were highlighted.

System not making sense

Despite this, too often people with MS are struggling to access the support they need. Almost half of respondents (44%) disagreed that they had enough financial support and less than a fifth (17%) of respondents agreed that disability benefits currently provide appropriate and adequate support to people with MS.

The disability benefits system is not making sense for people with MS. In particular, benefit processes are difficult for people with serious, chronic health conditions to navigate and understand, and assessments and eligibility criteria are failing to reflect the reality of daily life for people living with MS.

The face to face assessments for PIP and ESA have so far often failed to consistently capture hidden symptoms and fluctuation. 42% of those who had had a PIP face to face assessment and half (50%) of those who had had a WCA disagreed that the assessor considered their hidden symptoms.

For some claimants, reassessments are occurring too frequently, increasing the stress and anxiety some people with MS are facing. Respondents reported feeling frustrated that they were being required to repeatedly prove the difficulties they face.

These features of the benefits system are reducing the financial assistance and support people with MS are able to access and causing some to struggle. High numbers of respondents to our survey reported having to reduce spending on basic items. Nearly a third (32%) reported reducing spending on food and over a quarter of people (26%) reported reducing spending on gas and electricity as a result of changes to disability benefits.

For those people with MS who find themselves unable to work, the financial assistance provided through disability benefits is especially vital. For those who might be able to return to work in the future, our survey found current provision

of support is inadequate. The majority of people within the WRAG expressed dissatisfaction with the support they received or reported that they had received none at all.

These issues can be resolved. A number of common sense steps need to be undertaken to make the disability benefits system make sense for people with MS. Our recommendations are detailed overleaf.

Impact on health

A number of the survey's findings indicate a potential link between adequate welfare provision and people's ability to effectively manage their MS. Of particular concern is respondents reporting difficulty getting to medical appointments and having to reduce spending on medications and prescriptions. In addition the number of respondents reporting that disability benefits assessments had directly impacted their condition is highly concerning. Almost half (48%) of those who had had a WCA for ESA and over a third (36%) who had had a face to face assessment for PIP agreed that the process had caused their MS to deteriorate or relapse.

This warrants further investigation into how welfare policy can impact health outcomes for people with MS.

Stigma and harassment

Our survey also found that the ability of people with MS to access the support they need is being limited by stigma and harassment. 21% of respondents reported experiencing harassment because they claim benefits and 25% reported that they do not claim all the benefits they need because of the stigma. Policy-makers must take steps to challenge negative public perceptions of disability claimants and work with disability organisations to reduce stigma.

Employment

A complex picture emerged from the survey results in relation to the employment of people with MS. We found that people with MS who felt they may be able to return to work did not feel they were receiving appropriate employment support. However, employment was also one of the major focuses of free text responses to survey questions about harassment and stigma. This suggests there continue to be institutional barriers to employment for people with MS resulting from employer and colleague attitudes.

While our survey results cannot be conclusive on this issue, they warrant further investigation and suggest that an approach which targets the full range of barriers to employment may be needed to adequately support people with MS. The MS Society plans to explore this area further in the future. While it is welcome that the Government have committed an additional £60 million for targeted employment support,^{xxv} they must ensure this addresses the specific barriers faced by people with MS and also target barriers within employment practices and workplace environments.

Recommendations

1 Disability benefits assessments must accurately take into account the fluctuating and hidden symptoms of MS and their impact.

- A more discussion based interview technique should be implemented for the Work Capability Assessment (WCA)
- The DWP and assessment providers should review and revise training materials for PIP and WCA assessors to ensure they adequately address fluctuation and hidden symptoms

2 The disability benefits system must take adequate account of evidence from experienced professionals who understand the person's condition.

- Assessors for disability benefits should be required to refer to further evidence or provide adequate justification for failing to do so.
- Care professionals should be supported to be able to provide evidence to support benefit claims as easily as possible

3 Existing criteria which do not reflect the barriers faced by people with MS should be changed.

- The 20m rule under PIP must be reversed so it accurately reflects restriction on mobility
- Assessments should take into account severity of symptoms not just the length of time affected.

4 People with MS must be able to rely on support when they need it, without unnecessary burden or constant fear of having it taken away.

- The Government should review the policy of time-limiting contributory ESA in the WRAG to 12 months in cases where return to work is unlikely within this time
- Award lengths must be appropriate and not subject people to unnecessary reassessment
- The Government should protect the rate of payment in the (WRAG) of ESA to ensure it reflects the additional barriers and costs faced by people with MS – including amending Clause 13 of the Work and Welfare Bill.

5 Negative stereotypes must be challenged and greater awareness raised about the crucial impact disability benefits can have on the lives of people with MS.

- Leading politicians, other public figures and the MS community need to lead the way in challenging negative stereotypes, so no one entitled to benefits feels ashamed or preventing from claiming them.
- The MS community should continue to raise awareness of the symptoms of MS and champion the vital role played by disability benefits.

6 The Government should undertake a full impact assessment of any further changes they undertake to disability benefits – including exploring the knock on effects on other areas of public spending such as health and social care.

7 The Government should work with the Disabled community and disability organisations to ensure that back to work support is adequate and addresses the barriers individuals face.

Appendix 1:

Glossary of Terms

Disability Living Allowance (DLA):

DLA is an in and out of work, tax-free benefit for disabled children and adults to help with the extra costs of living with a disability. DLA is being replaced by Personal Independence Payment (PIP). DLA has two components, one to help with care costs, and one to help with mobility costs. Each of these components is paid at different rates to people with different levels of need.

Personal Independence Payment (PIP):

PIP began to replace DLA in April 2013 and it is available to those between 16 and 64. The majority of those applying for PIP will have a face to face assessment and all PIP awards will be periodically reviewed. Like DLA, PIP has two components, one to help with care costs and one to help with mobility costs. Each component is paid at two different rates, standard or enhanced, depending on an individual's level of need.

Employment and Support Allowance (ESA):

ESA provides financial support for people who are unable to work or have limited capability to work due to illness or disability. The Work Capability Assessment (WCA) is used to assess eligibility for the benefit (see below). The rate a claimant receives depends on the group they are placed in, and whether they qualify to receive the contribution based amount (based on the number of national insurance contributions they have made) or the income related amount (based on their level of income). The three groups are:

Fit for Work:

Those declared fit for work are not eligible for ESA. People declared fit for work often move on to claim Job Seekers Allowance (JSA).

The Work Related Activity Group

(WRAG): Those in the WRAG are expected to undertake work related activity and can be subject to conditions and sanctions if they fail to do so. Some people in this group will have their payments limited to 12 months depending on their income. Those in the WRAG receive a smaller payment than those in the Support Group.

The Support Group:

Those in the support group receive the highest level of payment and are not expected to undertake work related activity. Payments are not time limited but individuals are reassessed periodically.

Work Capability Assessment (WCA):

The WCA is used to assess eligibility for ESA. It is a points-based assessment that measures a claimant's functionality. For most people the WCA involves a face to face assessment with an assessor from an independent company on behalf of the government.

Job Seekers Allowance (JSA):

JSA is the benefit paid to help people look for work. Claimants must actively demonstrate they have been searching for a job to keep getting payments.

Appendix 2: Methodology

We distributed an online survey via email to the MS Society Research Network and Campaigns Community, and through promotion via Twitter and Facebook. The survey link was also sent out to MS Society local branches in England, Scotland, Wales and Northern Ireland for distribution to local members. The survey was open for responses between 29 June and 29 July 2015.

Those without a confirmed diagnosis of MS, living outside of the UK, or who had never claimed at least one of the relevant disability benefits (Disability Living Allowance, Personal Independence Payment, Incapacity Benefit, Employment and Support Allowance or Access to Work scheme) were excluded from the survey. This resulted in 1,780 completed responses.

Respondent demographics

MS Diagnosis

95% (1,691) of respondents had a diagnosis of MS, while the remaining (5%) were responding on behalf of someone else with MS

Gender

Of those that responded to this question, 72% (1,234) of respondents were female, and 28% were male. 1 respondent indicated that neither of these categories adequately reflected their gender. The MS Society estimates that there are at least 107,000 people with MS in the UK, including around 30,000 (28%) men and 77,000 (72%) women. This means that in relation to gender, our survey responses are largely representative of the wider MS population within the UK.

Age

The largest age group of respondents was 45-54 years which represented 32% (571) responses. This was followed by 55-64 with 30% (532), 19% (336) of respondents were aged between 36-45 years old, 11% (186) were 65 or over, 9% (155) were aged under 36.

Nations of the UK

The breakdown of responses across the four nations of the UK (England, Northern Ireland, Scotland, Wales) was as follows: 76% (1352) of respondents lived in England, 14% (242) in Scotland, 6% (109) in Wales, and 4% (77) in Northern Ireland. The MS Society estimates the distribution of the total population of people with MS, is as follows; 82% in England, 10% in Scotland, 4% in Wales, and 3% in Northern Ireland. From this, it appears that Scotland and England are over represented in our survey while Wales and Northern Ireland are slightly under represented. It is also important to acknowledge that the small size of the samples in Wales and Northern Ireland in particular mean comparisons between UK nations should be treated with caution. While welfare policy is still centrally determined in Westminster, the policy contexts vary across the Nations of the UK. In particular, Northern Ireland has not yet passed the Welfare Reform Bill, which would enact the reforms introduced to the rest of the UK by the Welfare Reform Act 2012. As such, PIP does not exist in Northern Ireland. While, welfare policy is currently uniform across England, Scotland and Wales, Scotland is anticipating receiving power over welfare in the near future.

Type of MS

The most common type of MS among survey respondents was relapsing remitting MS which 44% (791) of respondents had been diagnosed with. 32% (573) reported a diagnosis of secondary progressive MS, including 16% (289) with relapses and 16%

(284) without. 18% (313) of respondents had been diagnosed with primary progressive MS. 6% (103) of respondents did not know what type of MS they had been diagnosed with.

Length of diagnosis

26% (525) of respondents had had MS for 11-20 years. A further 25% (450) had had MS for 5-10 years. 15% of respondents reported that they had had MS for 2-5 years (278) and 21-30 years (272). Only 7% of respondents had had MS for two years or less and a further 2% (33) had had MS for over 40 years.

ⁱ Extra Costs Commission, Driving down the costs disabled people face : Final report, June 2015, pp. 13

ⁱⁱ The Work Foundation, Ready to Work? Meeting the Employment and Career Aspirations of People with Multiple Sclerosis, pp. 4

ⁱⁱⁱ HM Treasury, A country that lives within its means Spending Review 2015, July 2015, pp. 7

^{iv} HM Treasury, Summer Budget 2015, July 2015, pp. 26

^v The Extra Costs Commission, Final report: Investigating costs faced by disabled people, pp. 13

^{vi} The Work Foundation, Ready to Work? Meeting the Employment and Career Aspirations of People with Multiple Sclerosis, pp. 4

^{vii} Ibid.

^{viii} The Work Foundation, Ready to Work? Meeting the Employment and Career Aspirations of People with Multiple Sclerosis, pp. 4

^{ix} HC Deb 1 September 2014 Written question – 206428. Outcomes of initial Employment and Support Allowance (ESA) functional assessments by disease code: October 2008 – September 2013.

^x Dr Paul Litchfield, Year 5 Independent Review of the Work Capability Assessment

^{xi} Department of Work and Pensions, PIP Handbook, pp 8

^{xii} Department of Work and Pensions, Training and Development, Revised WCA Handbook, Version 7 Final, February 2015, pp 69

^{xiii} Mohr et al., 'Association between stressful life events and exacerbation in multiple sclerosis: a meta-analysis', BMJ. 2004 Mar 27; 328(7442): 731.

^{xiv} Mohr et al., 'A randomized trial of stress management for the prevention of new brain lesions in MS', Neurology. 2012 Jul 31; 79(5): 412–419

^{xv} Burns et al., 'Do positive or negative stressful events predict the development of new brain lesions in people with Multiple Sclerosis?', Psychol Med. 2014 Jan; 44(2): 349–359.

^{xvi} Professor Harrington, Independent Review of the Work Capability Assessment – year 3, November 2012 pp.63

^{xvii} Dr Litchfield, Independent Review of the Work Capability Assessment – year five, November 2014 pp. 91

^{xviii} National Audit Office (NAO), Personal Independence Payment: early progress, February 2014, pp.13

^{xix} Paul Grey, An Independent Review of the Personal Independence Payment Assessment, pp.50

^{xx} The Independent, 'Atos quietly dropped from carrying out repeat reassessments by DWP, internal memo shows', 25 February 2014

^{xxi} Department of Work and Pensions Freedom of Information request 2015-2515, June 2015

^{xxii} Dr Litchfield, The Year 4 Independent Review of Employment and Support Allowance and the Work Capability Assessment,

^{xxiii} NatCen, British Social Attitudes survey 2012

^{xxiv} NatCen, British Social Attitudes survey 2007

^{xxv} Department of Work and Pensions, Welfare Reform and Work Bill: Impact Assessment to remove the ESA Work-Related Activity Component and the UC Limited Capability for Work Element for new claims, July 2015, pp. 1

^{xxvi} Calculated from figures from The MS Society, MS in the UK, April 2014, pp. 2

Notes

Notes

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