

## **WELFARE REFORM COMMITTEE**

### **THE FUTURE DELIVERY OF SOCIAL SECURITY IN SCOTLAND**

#### **WRITTEN SUBMISSION FROM THE MS SOCIETY SCOTLAND**

##### **Introduction**

We are in a time of unique opportunity for Scotland, but we must carefully consider the impact of devolved welfare negotiations on vulnerable people in our society, who are watching and waiting for clarity on decisions that could change their lives.

We have a strong message for the Scottish Government as it plans for the further transfer of powers under the Scotland Bill:

- People with MS must be at the heart of shaping a new welfare system.
- Decision makers must look at how Scotland's approach to welfare can mitigate some of the damage being done by current austerity approaches and tackle inequalities.
- The welfare system in Scotland must not threaten the financial security of people affected by MS through unmanageable assessment processes and short-term awards, but instead show a greater understanding of the complexity of the condition.

We recently conducted a MS: Enough survey of 1,780 people with MS across the UK about their experiences of claiming disability benefits.

Key findings based on the 242 responses from people with MS living in Scotland demonstrated:

- 65% agreed that without disability benefits they would be unable to afford essential items such as food and heating.
- 85% agreed that, without disability benefits, their independence would be negatively impacted.
- 91% found the process of claiming disability benefits stressful.
- Almost 90% feel that the public judge people who claim disability benefits.

We need the Scottish Government to work with the MS community. To listen to the issues they face. To push for reform and to protect people with MS under a new devolved Scottish benefits system.

##### **A crucial difference to the lives of people with MS**

Disability benefits enable those who rely on them to carry out everyday activities that many people take for granted, like attending medical appointments, caring for family and socialising with friends. For some individuals disability benefits also play a vital role in enabling them to stay in or access employment.

Repeated periods of incapacity can unfortunately restrict or determine someone's career capability. Up to 80% of people with MS stop working within 15 years of the onset of the condition [1]. Others find themselves in unstable and low-paid jobs –

70% of our Scottish survey respondents agreed that MS limits the range of jobs they can do and the support they have received in the WRAG reflects this.

Further to impacting on ability to work, MS can have substantial associated costs for example the need for accessible transport, specialist equipment and domestic help. The Extra Costs Commission estimates that a neurological condition, such as MS, can cost on average an additional £200 per week [2].

Benefits are a lifeline for people facing these additional costs. They help them to remain independent and in many cases, financially stable.

74% of survey respondents agreed that disability benefits help them manage the extra costs of their MS, 65% agreed that without disability benefits they would be unable to afford essential items such as food and heating and 85% agreed that, without disability benefits, their independence would be negatively impacted.

### **People with MS are struggling to access the support they need**

When people with MS cannot access the benefits they need, they must make difficult decisions. Some people cannot access essential items and support. Life with MS should not mean doing without the necessities.

“When I got my Motability car I went from working 12 -16 hours a week to working full-time because of my car. I’m really worried I will lose it.”

A Scottish participant in MS Society Scotland Voices for Change 2014

Our helpline is now taking an increased number of calls about benefits, the impact of changes already introduced to disability benefits and concerns about the wider welfare reforms [3].

### **The system is not making sense**

Life for a person with MS is unpredictable. Some experience periods of relapse and remission, for others it follows a progressive pattern from onset. Even those with relapsing remitting MS typically experience increasing disability and morbidity.

The process of assessing eligibility for Employment and Support Allowance (ESA) and Personal Independence Payment (PIP) currently relies heavily on face-to-face assessments.

Assessments are often problematic in evaluating people with fluctuating conditions and frequently fail to recognise the barriers created by hidden symptoms. These symptoms are often distressing and debilitating and can include intense pain, problems with mobility and co-ordination, depression, fatigue, incontinence and loss of vision.

“With conditions like MS that have no cure, and don’t just go away, there must be a fairer way for people to be treated throughout the benefit process.

To be assessed less than a year since my original assessment makes me feel like a benefit scrounger, a cheat, as if they are trying to catch me out.

Living with MS on a day to day basis is hard enough without being scrutinised by the DWP/Atos.”

An MS: Enough Scottish survey respondent describes their experience, July 2015

The current welfare system is fraught with bureaucratic obstacles and delays and people with MS experience confusion and stress as a result of the benefits claim process. In Scotland, an incredible 91% of survey respondents found the process of claiming disability benefits stressful. A number of studies have now demonstrated a relationship between stressful life events and disease activity in people with MS [4] and this is repeatedly reflected in feedback from our MS community.

“The process pushed me to the limit of my resilience. My feelings were as close as I have ever been to suicidal. Feelings of low self-esteem completely took over my life and it took a great deal of effort to get back to coping with my MS.”

An MS: Enough Scottish survey respondent describes their experience, July 2015

“I suffered a relapse during the process of claiming, which I put down to the stress. I was initially awarded 0 points at assessment and the decision-maker overturned it, but put me into the WRAG.”

An MS: Enough Scottish survey respondent describes their experience, July 2015

Many people with MS are assessed too often. They can be put under pressure to repeatedly prove they need support even when they have medical evidence that their condition will only get worse. As MS is a progressive condition reassessments are often unnecessary and disproportionately burdensome for claimants.

### **Stigma and harassment**

Respondents to our survey reported a perceived culture of stereotype and prejudice towards people claiming the benefits they need to live day-to-day. Participants in our ‘Voices for Change’ programme in 2014 [3] also stated how the welfare reform changes and negative media portrayal of people on benefits has exacerbated their experience of stigmatism.

“We want to work. We’re not the same as people abusing the system but you’re lumped together. No employer wants to take you on because of your unpredictability.”

“Being on benefits is stigmatising. I feel I’m on the scrapheap of life.”

“I am too embarrassed to tell my own family that I am receiving DLA because of the stigma being on benefits brings.”

Three quotes from Scottish participants in MS Society Scotland Voices for Change 2014

The hidden symptoms of MS are not understood and people are often criticised for claiming benefits while not appearing to be obviously disabled or unwell. Fatigue is often perceived as laziness [5].

“My daughter looks alright but some days she can’t walk or brush her hair. How do you expect people like that to get up and go to work? The assessors don’t see what a person with MS goes through, what it’s like living with MS on a daily basis.”

A Scottish participant in MS Society Scotland Voices for Change 2014

Almost 90% of our survey respondents feel that the public judge people who claim disability benefits. Of further concern, nearly a third (28%) of respondents do not claim all the benefits they need because of the associated stigma.

## **Our part in a fairer Scotland**

The MS Society wants to see Scotland create a more level playing field for people affected by MS where the welfare system is fairer and people can live free from discrimination and stigma. We want the system to be based on the principles for public services identified by the Christie Commission:

- Built around people, communities and their needs, aspirations and skills.
- Services working together to effectively achieve outcomes – integrated services to help secure improvements in quality of life and wellbeing.
- Services which focus on prevention, reducing inequalities and promoting equality.
- Constant improvement with services that are open, transparent and accountable.

We have been dismayed by the lack of consensus and collaboration between the UK and Scottish Governments during the committee stages of the Scotland Bill. We are concerned that political and administrative differences between the two governments could shift the focus of the Bill away from the true spirit of Lord Smith’s recommendations. There is a risk people who are going to be directly affected by the new devolved powers will be left confused and afraid by the apparent lack of progress.

In designing a welfare system following further devolution of powers, the Scottish Government must recognise:

- The important role of the third sector in designing the delivery and determining the outcomes of devolved welfare and employment services for our MS Community.
- The reality of living with MS and engage the MS community in the creation of a Scottish Welfare system that makes sense for people with the condition to end the struggle for welfare support people face.

## **Recommendations**

The findings from the MS: Enough survey builds on our existing evidence to drive for welfare reform.

Devolution of welfare budgets will give the Scottish Government greater autonomy to set the rules over a range of benefits which affect carers, people with disabilities and

the elderly. These proposals, along with many others, may see the welfare landscape in Scotland developing quite differently from the rest of the UK.

The changes we want to see to the benefits system in Scotland for people with MS include:

**The MS Society wants people with MS to be at the heart of shaping the new powers.** We urge the Scottish Government to recognise the reality of living with MS and to make the system make sense for people with the condition to end the struggle for welfare support people with MS face.

**The Scotland Bill must legislate for the transfer of powers from the UK Government to Scottish Parliament.** The Bill should not be used to devolve power directly to local government, bypassing the Scottish Parliament [6].

**The MS Society wants to see a Scotland which creates a more level playing field for people affected by MS; where the welfare system is appropriate and people can live free from discrimination and stigma.** Many people with MS want to remain in work as long as possible, so we strongly support the development of an employability programme that is tailored to this outcome, but does not penalise those for whom the barriers to work are too great.

We know that the extra costs of living with MS are considerable, leaving many families vulnerable to financial exclusion. **We want to see a welfare system in Scotland which does not threaten the financial security of people affected by MS.** This means an end to unmanageable assessment processes and unnecessarily short-term awards, but instead shows a greater understanding of the complexity of the condition. This must include adequate recognition of fluctuating and hidden symptoms such as pain and fatigue.

**We welcome the Smith Commission recommendations related to welfare and employability.** The link between financial security and health outcomes is well established, and Scotland's current journey towards more integrated health and social care services can only be enhanced by the inclusion of these two vital elements.

People with MS and their families and carers need to understand what is going to happen to welfare and specialist employability services in Scotland. **The MS Society asks that the Scottish Government provides a detailed framework and a clear timetable of the proposals for new policy as a matter of urgency.** This will allow the MS community in Scotland to contribute to consultations in a meaningful and informed way and will ensure there is adequate preparation ahead of the delivery of these benefits. **We also ask that the UK Government provides greater clarity on the freedom and powers of the Scottish Government to set discrete social policy without UK government sign-off.**

## **About MS**

Multiple sclerosis (MS) is a chronic, neurodegenerative condition for which there is currently no cure. 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.

Scotland has one of the highest incidence rates of MS in the world, and 11,000 people in Scotland live with the life-long condition.

MS is both a fluctuating and progressive condition. The progressive and fluctuating nature of MS presents particular challenges for benefit assessment processes.

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## References

[1] The Work Foundation, Ready to Work? Meeting the Employment and Career Aspirations of People with Multiple Sclerosis

[2] Extra Costs Commission, Driving down the costs disabled people face: Final Report June 2015 pp13

<http://www.scope.org.uk/Scope/media/Interim-report/Extra-Costs-Commission-Final-Report.pdf>

[3] 'Voices for Change: What impact are welfare reforms having on people living with MS in Scotland and how can this impact be mitigated?' MS Society 2014

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

[5] MS Essentials, Third Edition August 2014, MS Society

[6] SCVO Response to Devolution Committee call for written evidence on the Scotland Bill

[www.scvo.org.uk](http://www.scvo.org.uk)