Scotland Bill

MS Society Scotland

The MS Society is the UK's largest charity supporting people with multiple sclerosis, and as such we have a strong campaigns community and an influential position in the third sector as a leader in welfare policy. MS is the most common, disabling neurological condition affecting young adults in the UK.

Scotland has one of the highest incidence rates of MS in the world, with a population of around 11,000 people living with the disease. We make it our mission to beat it. We raise awareness of MS, make it a priority at political level and provide support and information to people affected by MS around the country.

The MS Society strongly welcomed the principle of further devolution and 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. We believe that scrutiny and control of welfare at a more local level will lead to the development of policy and processes which are more aligned to Scotland's health agenda, and are broadly more supportive of the MS community. We will provide greater detail into our recommendations in our response to the Welfare Reform Committee's consultation.

Our vision for devolved powers

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 fairer 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 through unmanageable assessment processes and short-term awards, but instead shows a greater understanding of the complexity of the condition.

The MS Society recently conducted a survey of over 1,750 people with MS about their experiences of claiming disability benefits. The findings produced some shocking statistics for people with MS in Scotland:

Repeated periods of incapacity due to the condition can unfortunately restrict or determine people's career capability. This can often mean people with MS find themselves in unstable and low-paid jobs – 70% of respondents agreed that MS limits the range of jobs they can do.

On-going welfare reforms have significantly influenced the challenges people with MS face - 50% of survey respondents agreed that changes to disability benefits have had a negative impact on them. A quarter of respondents reported that they had reduced spending on gas and electricity with nearly a third (30%) reporting a reduced spend on food.

Benefits are vital for assisting with the additional costs of MS, which in turn help people to remain independent and in many cases, economically active - 74% of survey respondents agreed that disability benefits help them manage the extra costs of their MS and 65% agreed that without disability benefits they would be unable to afford essential items such as food and heating.

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 stated that they found the process of claiming disability benefits to be stressful.

Across our MS community, there is a growing concern that those involved in welfare reform have created a culture of stereotype and prejudice towards people claiming the necessary benefits to live day-to-day with MS. This stigmatises and marginalises people who rely on disability benefits, when they are in the greatest need of support.

Almost 90% of our survey respondents feel that the public judge people who claim disability benefits. The hidden symptoms of MS are not understood and people are often criticised for claiming benefits whilst not appearing to be obviously disabled or unwell. Fatigue is often perceived as laziness therefore people with MS will hide their symptoms and try to behave as ‘normally’ as possible in company; this can result in severe debilitation.

“Every time changes to the benefits system happen the goal-posts move and my anxiety & depression levels go up massively. I have mental health problems, and the added stress causes my MS to get worse.”

(Quote from a person with MS in MS : Enough Survey, July 2015)

Our ask

The people who are going to be directly affected by the new devolved powers are being left confused and afraid by the apparent lack of progress during the committee stage of the Scotland Bill. 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 its 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 Scotland Office provides greater clarity on the powers of the Scottish Government to set discrete social policy without UK government sign-off.**

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