

**Social Security Committee -  
Call for Evidence on the Social Security  
(Scotland) Bill**

**MS Society Scotland Response  
23 August 2017**



The MS Society is here for people with MS, through the highs, lows and everything in between. Across Scotland more than 11,000 people live with Multiple Sclerosis. MS is often painful and exhausting and can cause problems with how we walk, move, see, think and feel. Once diagnosed, MS stays with you for life, but treatments and specialists can help you to manage the condition and its symptoms.

The below response is informed by input from people affected by MS including responses to a survey carried out with our supporters in August 2017.

**Question 1:**

The MS Society has concerns about the approach being adopted. The approach is understandable, as from the Scottish Government's perspective it makes it easier to create flexibility and adapt rules depending on how the system develops. However, it raises significant and legitimate concerns about scrutiny and accountability.

The Policy Memorandum accompanying the Bill states "*taking this approach should improve Parliament's ability to scrutinise executive action*" this seems entirely counter intuitive. In leaving the Bill as an enabling framework it means a significantly reduced opportunity for Parliamentary scrutiny of the actions and structures that the legislation will enable. This is concerning. Whilst we don't doubt the commitment of the Scottish Government to create a system which meets the expectations raised by the rhetoric used, we do have concerns that by not placing provisions in primary legislation that this could be eroded over time. As the question above states "Parliament cannot change regulations, only approve or reject them." It is unclear therefore how this increases transparency or scrutiny.

Understandably, expectations have been raised about the opportunities and possibilities presented by the devolution of elements of social security. Across Scotland many people with MS have been impacted by recent benefits changes, in particular the transfer from DLA to PIP. The expectation amongst the MS community is that in Scotland we will be able to create something fairer, more respectful and accessible. Much of what will make this a reality and help tackle the perceived inequities in the current system, such as rules around assessments, are not addressed in the Bill. This could lead to a certain amount of scepticism from people who are expecting to see reasonably radical change from the legislation. It may also lead to a loss of interest in the process due to the positioning of changes within regulations. The impetus for engagement may be lost, and with it crucial voices needed to create a system which meets the needs of the people of Scotland.

We welcome assurances from the Scottish Government that draft guidance and regulations will be produced at an early stage and hope that Parliamentarians will be able to see these whilst scrutinising the legislation from Stage 1 onwards.

#### Question 2:

The seven proposed principles that will guide the social security system rightly focus on the needs of the individuals who rely on it. The MS Society welcomes the focus on dignity and human rights, part of which is the focus on the Scottish Government's role in making sure that people are given the social security assistance that they are eligible for. At present many people do not claim all the benefits they are entitled to, partly due to stigma. In 2015 we surveyed people with MS on the experience of the disability benefits system and found that nearly 1 in 3 respondents didn't claim the benefits they are entitled to due to stigma. We welcome the use of principles to underpin the Bill and believe this brings it into line with similar approaches used in other recent legislation

While these principles go some way to ensuring that people with MS do not lose out on the vital support they need, it stops short at a guarantee that the financial support people with MS will receive is adequate. The seven principles promote the notion that people living with a disability should receive the benefits that they are eligible for. However we believe there are additional measures needed in order for the Scottish Government to meet their aspirations of adhering to human rights provisions as it relates to disabled people. Article 28 of the UN Convention on the Rights of People with Disabilities (CRPD) states that disabled people have the right to an adequate standard of living and social protection. This article is the bedrock of the guarantee by signatory countries ensuring that disabled people are able to enjoy their right to life on an equal basis with others. The MS Society therefore calls on the Scottish Government to take a further step towards securing the equality of disabled people as envisaged by the CRPD, by including a further principle in its Social Security framework:

'The Scottish social security system will ensure that levels of financial support are adequate and allow people to live independently and with dignity'.

Principle 4 encompasses eligibility. We would welcome the extension of this beyond eligibility to include 'entitled to' and would be keen to see an amendment to this effect.

Principle 7 talks about "value for money". One respondent to our survey commented that *"(it is) difficult to measure value for money when helping disabled people. Value to the individual is more important."* Wording around value for money may need to be tightened up to clarify that it means that the administration side of the system provides value of money to the people of Scotland, not at the expense of people accessing the system.

#### Question 3:

In our response to the Scottish Government's consultation last year we supported the idea of having both a set of principles and a charter. We are pleased to see both of these included in the Bill. The language used in the charter must be accessible and we are keen to see it promote inclusion, fairness and transparency. It is our understanding that the charter will be co-produced with people on the experience panels. We support this

approach and would like to see further opportunities for others to contribute to the drafting of the charter, including those with fluctuating conditions such as MS.

#### Question 4:

##### Accountability and Liability

At present the rules focus on the liabilities of the citizens accessing the system rather than on the accountability of the state. We feel there is an imbalance here and that the Bill needs to be clearer on the measurable liabilities of the state and expectations citizens should have of it to deliver social security.

##### Timescales

Presently the rules don't outline timescales within which people can expect action when engaging with the system. The concern being that if these are not on the face of the Bill then they become more difficult to enforce and can be changed more readily which could be to the detriment of people using the service. The nature of fluctuating conditions like MS mean that the impact of the condition can be very suddenly and keenly felt meaning that reliance and need for access to the social security system can change rapidly if they suffer a relapse. Legally enforceable timescales can help to manage expectations and allow for people to make adequate arrangements. In instances such as relapses, where need changes rapidly, there could be improved provisions for a fast tracked access. This could be added within section 18 covering short-term assistance.

##### Improvement and Review

The policy memorandum states "*The Scottish Government is committed to continuously improving the delivery of social security*". The Bill places a duty on Ministers to review the charter after five years but little beyond that in terms of reviewing the system itself. We would welcome an amendment placing a duty on Ministers to review the system as a whole after a set period of time. The committee may also wish to consider whether such a duty should go further and ask the Scottish Government to create an independent body, or expand the function of a current body such as the Disability and Carers Benefits Expert Advisory Group, to continuously review elements of the legislation and its implementation. Any ongoing review should engage with a wide range of voices including those with fluctuating conditions such as MS whose condition can lead to particular challenges for the system to manage.

#### Question 5:

The areas that are of most interest to our supporters are those of disability assistance and carers allowance. The schedules on these tell us nothing of how the system will operate for people with MS. It is therefore difficult for us to comment further on this section. We would welcome further dialogue when more information becomes available and would call for further details about the operation of these benefits to be published as a priority.

#### Question 6:

The proposal for short-term assistance is welcome. Under the present system the impact of having your benefit removed whilst going through the appeal process can have a devastating effect on the life of the individual.

The case of our supporter David Trotter gives an example of the impact this can have. David has MS and saw his benefits drastically reduced during the transfer from DLA to PIP. This led to him losing his motability car, despite him having a long term condition that impacts upon on his mobility. Losing his motability car meant that David had to significantly reduce his hours at work and pushed him into financial difficulties. The stress of the situation saw his MS deteriorate leading to increased disability. The appeal process lasted 5 months and ultimately a short hearing overturned the decision and reinstated David's benefits at the higher level he had received on DLA. The effects of the incorrect original award are still being keenly felt by David, financially, emotionally and physically.

We hope that what is proposed in the Bill will ensure the situation David experienced can be consigned to history, we would be happy to provide further information on this area.

#### Question 7:

Respondents to our supporter's survey were overwhelmingly in agreement with these proposals and were keen to see them utilised.

#### Question 8:

Carers play a vitally important role in supporting people with MS. In a recent study carried out by the MS Society of people with MS that identified themselves as having a care need we found that 89.7% said that in the past 12 months they had received unpaid care and support from family or friends. This demonstrates the breadth of the impact of carers.

We welcome the proposals to increase the level of Carers Allowance to the level of Jobseeker's Allowance. We see this as the first step in improving the financial settlement for carers and recognise that the Scottish Government intends to develop a Scottish carers benefit in the long term.

The issue of uprating is not addressed on the face of the bill and we would reiterate the point raised by a number of other charities that this should done in line with percentage increases applied to the National Minimum Wage. Added to this we would like to see steps taken to ensure that people do not fall into a 'carers benefit trap' whereby they need to make stark choices between working additional hours and losing carers benefits. The work of carers removes a significant burden from formal health and social care services and needs to be supported and respected accordingly.

Finally, we welcome the commitment by the Scottish Government to actively consider the introduction of a Young Carers Allowance.

#### Question 9:

| No response

## Question 10:

Inclusion within the Bill of measures to ensure the new system endeavours to understand the needs of people with lifelong and fluctuating conditions would be welcome and provide reassurance to people with MS. We would encourage the Scottish Government to provide further information on what steps it intends to take to learn from the problems in the current system to understand the often unique issues faced by people with fluctuating conditions in accessing the benefits they need to live independent lives.

An important area which is not covered within the Bill is that of support and advocacy. On a number of occasions our supporters have noted the difficulties they have faced accessing disability benefits in the past and that they lacked the adequate knowledge and support to do so in a timely manner. By making support available to someone as they look to enter the system for the first time there is an increased likelihood they will receive the award they are entitled to and the opportunity to reduce the stress that the individual may experience when applying to the system. This should be a central tenet of accessibility, along with making sure the people are able to enter the system in a manner which is most appropriate to an individual, i.e. options to access via phone, online, face to face, via a conduit.

Further to this, the Bill should make provisions for improved advocacy support for people going through the appeals process to ensure that people are receiving the award they are entitled to and not missing out due to a lack of knowledge of the system. We would refer the committee to the response from our colleagues at the ALLIANCE into the importance of independent advocacy.

Finally, we would ask the committee to consider whether what is on the face of the Bill at present meets the aspirations of the parliament for a fairer, more respectful and accessible system of social security? Does the Bill rely too much on the present system of welfare support as a systematic starting point on which to place adaptations? Or will the structure of the Bill allow for the fundamental change which many in Scotland are keen to see? Does the Bill create a system that will fully meet the needs of people with an often fluctuating and complex condition such as MS?

We look forward to continuing to engage with the Scottish Government and the Scottish Parliament to ensure this important piece of legislation creates a system that meets the needs of people with MS.

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### **About multiple sclerosis**

- MS affects more than 11,000 of in Scotland
- MS is often painful and exhausting and can cause problems with how we walk, move, see, think and feel
- MS is unpredictable and different for everyone
- Multiple sclerosis (MS) is a condition of the central nervous system.
- In MS, the coating around nerve fibres (called myelin) is damaged, causing a range of symptoms.

- Symptoms usually start in your 20s and 30s and it affects almost three times as many women as men.
- Once diagnosed, MS stays with you for life, but treatments and specialists can help you to manage the condition and its symptoms.
- We don't know the cause and we haven't yet found a cure, but research is progressing fast.

### **About the MS Society**

- The MS Society is here for people with MS, through the highs, lows and everything in between
- We have a free helpline - 0808 800 8000 and information can be found on our website [www.mssociety.org.uk](http://www.mssociety.org.uk)
- We're driving research into more – and better – treatments for everyone
- Together we're strong enough to stop MS

### **Contact**

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