

MND Scotland response to Social Security Committee call for views on the Social Security (Scotland) Bill, Stage One - August 2017

Introduction

MND Scotland welcomes the opportunity to submit evidence to the Social Security Committee's call for views on the Social Security (Scotland) Bill.

We have campaigned for improvements to the social security system, and following the transfer of additional powers to the Scottish Parliament we believe there is an opportunity for the Scottish Government to put human rights at the heart of this Social Security Bill.

Our [Let's Get Benefits Right Campaign](#) in 2016 called for people with MND to be automatically entitled to benefits and that these awards should be life-long, avoiding unnecessary reassessments for someone living with a progressive and terminal disease.

A rights-based benefits system cannot be achieved by the Scottish Government alone. Setting up such a complex system to deliver benefits to some of the most vulnerable individuals in society must be done in partnership with the third sector organisations representing those who access the social security system. We welcome the social security experience panels as a method of involving the views of people who have experience of claiming the benefits which will be devolved to the Scottish Parliament. However, MND is a relatively rare illness and to ensure that the voices of all those affected by it are heard, we urge the Scottish Government to continue to engage with charities like ourselves.

Q1. Development of Bill framework

MND Scotland believes that far too much detail has been left out of the Bill to be put in Regulations, which MSPs may only approve or annul.

In addition, there is a real concern that future Scottish governments will have the opportunity to change regulations, and thereby much of the social security system, without the scrutiny of the Parliament.

One of the key things left out of the Bill, which is included in UK primary legislation, is the definition of terminal illness. We would like to see this included in the Bill. We would urge the Scottish Government to work with third sector agencies like ourselves

and Marie Curie when defining terminal illness, which should *not* include anticipated life expectancy.

In addition, we agree with other charities that there are a number of important omissions in the Bill, such as: the purpose of the Bill; a right to independent advocacy; and, a commitment to complaints and redress procedures for those who need them. These should be included in the Bill.

Q2. Seven Principles

We agree with setting out clear principles which outline the vision, purpose and expectations of the Scottish social security system. However, the principles need to be meaningful to those who access the system and therefore person-centred.

We have specific comments on the following principles:

- The Scottish Government has a role in making sure that people are given the social security assistance they are eligible for.
 - 'role' should be replaced with 'duty' or 'responsibility'.
- The Scottish social security system will be designed with the people of Scotland, and based on evidence.
 - We would like to see reference to designing the system 'with' the people of Scotland (including the third sector) reiterated elsewhere in the Bill and the importance of co-production, rather than consultation, highlighted. Clarification on what is meant by 'evidence' is needed. How, and from whom, will 'evidence' be sourced?
- The Scottish social security system should always be trying to improve. Any changes should put the needs of those who require social security first.
 - We welcome a culture of continuous improvement. This should include independent scrutiny of the social security system, which would identify areas where improvement is required. We strongly agree that any changes should put the needs of those who require social security first.
- The Scottish social security system is efficient and delivers value for money
 - The social security system must be efficient for the person claiming benefits and an effective fast-tracking system is essential for people with MND. Greater clarity on 'value for money' is needed, in particular the assurance that this will not impinge on the other principles – specifically, social security being a human right and any changes putting the needs of those who require social security first.

Q3. The Social Security 'Charter'

We welcome the introduction of a charter. However, it must be co-produced with those who have direct experience of the social security apparatus – particularly the social security experience panels and third sector organisations who support people to access the current social security system. This is essential to ensure that the charter can be a positive tool for those administering social security benefits, and those accessing them. Regular reviews of the charter should also be conducted with the experience panels and third sector.

The charter must provide detail on how the system will operate and what claimants can expect from the social security system and the agency. In addition, it should outline the level of service people can expect and where they can go to seek independent support and redress if they do not.

The charter needs to be clear and accessible to all. It must be actively promoted and made widely available, in a range of formats, to all those accessing the social security system.

Q4. Rules for Social Security

If the social security system is to have a rights-based approach in reality, it shouldn't overemphasise the requirements of the individual. There is no mention of the requirements or accountability of the agency and this imbalance needs addressed. It is important that people in Scotland have faith in the system, believing it to be fair and there to assist them when they need it.

The Bill highlights timescales that a person must comply with when applying for benefits and appealing decisions. The Bill should also include timescales and time limits required to be met by the agency when making and communicating decisions on applications, appeals and redeterminations. Short-term assistance available to people awaiting decisions could be helpfully referenced here too.

In terms of detail, we recommend that the social security system gives applicants choice on how to apply for benefits – phone, email, online, paper to avoid any disability being a barrier to accessing benefits easily. Overpayments to people who have died should be written off.

The social security system should be designed in a way which reduces the likelihood of mistakes and overpayments. Lessons should be learned from the DWP and HMRC to ensure that mistakes in the current benefits system are not replicated in Scotland.

Q.5 Notes on Schedules

- **Disability assistance**

The schedule states: 'The regulations are to determine 'terminal illness' for the purpose of determining disability assistance.'

As highlighted in our response to Q1, a definition of terminal illness must be in the Bill, rather than Regulations, with a commitment to a fast tracked system and life-time awards. We urge the Scottish Government to work with ourselves and charities like Marie Curie when establishing how terminal illness should be defined and the system that should follow. Life expectancy should *not* be included in the definition of terminal illness.

Under the current UK 'special rules' system, life expectancy must be 6 months or less. Medical professionals and their patients find predicting life expectancy for people with MND to access benefits extremely problematic and distressing. Many

medical professionals are unwilling to make a life expectancy prediction and when they do, increasing numbers are having their judgement questioned, and sometimes overturned, by ATOS. The effect of this is that fewer medical professionals are willing to complete the required DWP DS1500 form for their patient. This means that some people with MND are therefore prevented from accessing the 'special rules' system and having their benefits 'fast-tracked'. Accessing benefits like PIP outwith the special rules system can currently take up to 9 months. Clearly this is too long for a person with MND, who has an average life expectancy of just 14 months from diagnosis.

- **Carer's Allowance**

Carer's Allowance is currently a 'passport benefit' and only accessible once benefits like PIP are in place for the cared for person. This causes many problems for carers – for example, if receiving PIP is delayed or not reinstated correctly, Carers Allowance stops. Carers Allowance should not be a 'passport benefit' – it should be an independent benefit in its own right.

The Scottish Government should extend Carers Allowance to people aged over 65. The importance and value of all carers should be recognised across society.

Financial support should be available to those who care for less than 35 hours per week, but have perhaps had to reduce hours at work (and income) to do so.

The Scottish Government needs to work closely with National Carers Organisations to ensure that the views of carers are heard.

Carers Allowance should also be increased considerably. See response to Q8.

- **Funeral payments**

We welcome this assistance and recognise the rising cost of funerals and the impact of funeral poverty. This issue alone can be a huge worry for people with MND and their loved ones who are trying to plan ahead, following a devastating diagnosis of MND.

Q6. Short-term assistance

In principle it is important to provide people, who may be challenging a decision to stop or reduce their benefits, with a safety net (for example a crisis loan). It is also important that decisions are made promptly.

Short-term assistance must be extended to people experiencing lengthy delays when applying for benefits. Some people with MND can currently wait up to 9 months before receiving PIP as well as benefits like Carers Allowance which currently depend on PIP being in place.

Q8. Carer's Allowance

Earlier this year, MND Scotland conducted a Carers Survey to find out more about the experiences of people who are caring for loved ones of people with MND. The survey highlights the incredible sacrifice of carers who are forced to give up work or, reduce their hours to commit to caring for their loved one. The emotional, psychological and physical pressures on carers are tremendous.

The proposal to introduce an increase in the rate of Carers' Allowance is welcome, however, this rise does not go far enough. Many carers are forced to give up work to care for their loved one on a full time basis – they are not looking for work. We agree with other charities that Carer's Allowance should be updated in line with increases applied to the National Minimum Wage.

The proposal in the bill to increase Carers Allowance "as soon as possible" needs to be a priority. Carers need the increase now – and more.

Q9. Discretionary Housing Payments

All local authorities should be required to have a scheme. There should be no postcode lottery with Discretionary Housing Payments.

About MND

Motor Neurone Disease (MND) is a rapidly progressing, neurological, terminal illness, which stops signals from the brain reaching the muscles. This may cause someone to lose the ability to walk, talk, eat, drink or breathe unaided. There is currently no cure or effective treatment for MND and the average life expectancy from diagnosis is just 14 months.

There are over 450 people in Scotland currently living with MND. On average over 160 new cases of MND are diagnosed each year. MND is on the increase.

Many of those affected by MND are/or will be in receipt of social security benefits to be devolved to Scotland, primarily Personal Independence Payment (PIP), Attendance Allowance, Carers Allowance and the Funeral Payment.

About MND Scotland

MND Scotland is the only Scottish charity providing equipment, care and support to people affected by Motor Neurone Disease (MND) across Scotland, as well as funding research to find a cure.

For further information, please contact:

Colette McDiarmid
Policy Officer
MND Scotland
2nd Floor, City View
6 Eagle Street
Glasgow, G4 9XA
Tel: 0141 332 3903
Email: colette.mcdiarmid@mndscotland.org.uk
Web: www.mndscotland.org.uk