

Social Security Committee

Social Security (Scotland) Bill Consultation

Response from Parkinson's UK in Scotland

Introduction: About Parkinson's

There are more than 11,000 people with Parkinson's in Scotland.

Our response is informed by our work with people who have Parkinson's and their unpaid carers, families and friends. Our team of Information and Support Workers covers the whole of Scotland, and provides free, confidential support and advice to anyone affected by Parkinson's. A significant amount of their time is spent supporting people affected by Parkinson's to understand and claim the financial benefits to which they are entitled.

Parkinson's affects adults of all ages, including around 2,000 people of working age in Scotland. The majority of people living Parkinson's are aged over 65.

Parkinson's is a progressive, fluctuating neurological disorder, which affects all aspects of daily living including talking, walking, swallowing and writing. People with Parkinson's often find it hard to move freely. There are also other issues such as tiredness, pain, depression, dementia, compulsive behaviours and continence problems which can have a huge impact. The severity of symptoms can fluctuate, both from day to day and with rapid changes in functionality during the course of the day, including sudden 'freezing'. There is no cure.

1. The proposed Bill as a general framework with rules about the new benefits in Regulations

Q. Do you have any views on this approach?

Parkinson's UK is concerned about the lack of detail that has been included in primary legislation, and the implications for scrutiny of how the new benefits will actually work.

Simply placing documents in Parliament for approval does not constitute scrutiny. The Scottish Parliament webpage notes that "it is extremely rare for the Parliament to have any scope to amend or change subordinate legislation."¹ With so much of the detail of the new system being covered in regulations, the Scottish Parliament will not be able to amend the Scottish Government's proposals about how the system will work in practice, including many areas that have proved to be highly contentious in the UK benefits system, including criteria and assessment processes. These areas are too important to be left for MSPs only to have powers to accept or reject proposals in full.

There is very minimal detail contained in the schedules relating to each type of assistance, and although the policy memorandum promises "illustrative, draft

regulations which will explain how the powers in the Bill will be used), then the detailed benefit rules in each set of regulations” these are not yet available.

Placing the operational detail in regulations also makes them easier to change in the future. While Scottish Government argues that “rules will have to change from time to time to reflect changes in economic and social conditions”, social security systems are also highly likely to change in response to the political climate, as has been seen in the UK benefits system changes which have disproportionately affected disabled people. Parkinson’s UK believes that people who use the social security system need robust legal protections, so that they are not made more vulnerable if the political climate changes and so that when necessary changes are proposed, they are subject to appropriate scrutiny.

2. The proposed principles underlying the Scottish social security system

Q. What are your views on these principles and this approach?

Parkinson’s UK is broadly supportive of the seven principles, but we would like to see them go further.

In particular, we welcome the fact than the Bill defines social security as a human right in itself, and essential to the realisation of other human rights, but we share concerns expressed by the Alliance that this may not go far enough. Human rights should not only be mentioned, but the legislation as a whole needs to recognise rights as legally enforceable entitlements and linked to international human rights law, or the commitment to human rights risks remaining a laudable aspiration, while being essentially unmonitored and unenforceable.

We believe that the legislation should explicitly reference the internationally recognised PANEL principles of

- participation
- accountability
- non-discrimination and equality
- empowerment and
- legality.

We welcome the explicit protection of “respect for the dignity of individuals” but note that this term is not subject to further definition. This means that it may be difficult for a person to argue that their dignity has not been respected within the system. We believe a definition is needed to give force to this principle.

Parkinson’s UK welcomes the Principle that the system will be “designed with the people of Scotland”, but believes that it would be helpful to strengthen this principle throughout the document to make clear that the expectation is that the system will be co-produced with people who will use it.

Q. Are there other principles you would like to see included?

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3. The proposed social security ‘charter’.

Q. Do you agree with the idea of the charter?

Parkinson's UK supports the idea of a charter, where it supports principles that are enacted in the primary legislation. We welcome the decision to call it a social security charter, rather than a claimant's charter. This suggests a degree of reciprocity between the person and the agencies.

We believe that a charter will be helpful to provide more detail about the legislation and to lay out the rights and responsibilities both of those using the system and those administering it. It will be particularly helpful because the administration of benefits can be complex and difficult to understand.

We are concerned that the Scottish Government proposes to use the charter to "constitute peoples' rights in relation to social security in Scotland". We believe that peoples' rights should be defined in primary legislation, rather than in a document that has no formal legal standing.

Q. Is there anything specific you would like to see in this charter?

Parkinson's UK believes that the charter must lay out clear duties for the agencies and individuals that will administer the social security system as well as for those who use it.

4. Proposed rules for social security

Q. Do you have any comments on these rules?

Parkinson's UK notes that these rules appear to be specific and binding on the person receiving social security (eg specifying prison sentences and fines for fraudulent claims), while the duties of the Social Security Agency and its staff to act within set timescales is not specific.

Parkinson's UK believes that maximum timescales for assessment and decisions making should be set in law. Under the current system, delays are a major source of stress for claimants with a major impact on household income and quality of life when decisions are delayed. People are currently left in limbo for many months waiting for assessments, decisions and appeals.

5. Proposed schedules for Scottish Government to take over current benefits.

Q. What are your thoughts on the schedules in the bill in regard to these benefits?

Parkinson's UK does not feel able to comment on the content of these schedules as they provide very little detail about the Scottish Government's plans for future benefits.

6. Proposed short-term assistance.

Q. What are your views on this proposal?

Parkinson's UK supports this measure. The Policy Memorandum suggests that the short term assistance system will only relate to issues arising in relation to the Scottish social security system. There may be a need to consider how claiming

systems can be streamlined if a person is also applying to the Scottish Welfare Fund.

7. Proposed powers to top up reserved benefits and create new benefits

Q. Do you agree with these proposals?

Yes.

8. Proposed increase in carer's allowance

Q. What are your thoughts on this proposal?

Parkinson's UK strongly supports the proposal to increase the level of Carer's Allowance, as increasing the level of support sends a strong message that carers are valued. We are not completely convinced that it is relevant to tie the Carer's Allowance rate to that of Job Seeker's Allowance (JSA), and note that even at the increased rate of £73.10 per week, it does not reflect the time that is spent caring.

We are disappointed that the Bill and Policy Memorandum do not make provision for extending carer's allowance to people aged over 65. It is estimated that informal carers provide up to 80% of the costs of care for people living with Parkinson's. Carers typically have very high levels of involvement over many years, as the needs of the person they care for increase over time. In a recent survey, nearly two thirds of carers of people with Parkinson's in Scotland were providing care for more than 50 hours a week, yet fewer than one in five people who care for someone with Parkinson's in the UK say they receive Carers Allowance.

One reason for the lack of take up of Carers Allowance is that people who claim the state pension are not eligible. This is major inequality and should be addressed. Older carers of people with Parkinson's tell us that they cannot understand why they are expected to provide care without their contribution being recognised. It sends a strong message that this care is not valued, despite the money that it saves in care costs.

9. Proposed continuation of discretionary housing payments system

Q. Do you agree that discretionary housing payments should continue largely as they are?

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Q. Do you have any other views on the proposals for discretionary housing payments?

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10. Q. Is there anything else you want to tell us about this Bill?

Independent Advocacy

Parkinson's UK is concerned that the Bill does not include a right to access to independent advice and advocacy. There is a clear need for this, yet existing legislation does not entitle people with neurological conditions to access an independent advocate, and many services restrict access to certain client groups.

Our Local Advisors report that many people with Parkinson's find benefits forms extremely challenging to complete without support. In our local advisors' experience, it is common for people to understate the impact that Parkinson's has on them, because it is difficult to face up to the real impact of the condition.

It can be difficult for people to understand what details they need to supply without support from people who know the benefits system.

Accountability

We do not believe that the requirement for Scottish Government to produce an annual report on the social security system and lay it in Parliament is sufficient to monitor the progress of the social security system. We would like to see provision for independent review.

About Parkinson's UK in Scotland

We're the Parkinson's charity that drives better care, treatments and quality of life. Together we can bring forward the day when no one fears Parkinson's.

Find out more about us at www.parkinsons.org.uk

For more information, please contact our Parliamentary and Campaigns Manager, Tanith Muller - email: tmuller@parkinsons.org.uk, telephone 0344 225 3726.

¹ <http://www.parliament.scot/visitandlearn/60169.aspx>