

# **Alzheimer Scotland**

## **Social Security Committee – Social Security Bill**

### **Introduction**

Alzheimer Scotland is Scotland's leading dementia voluntary organisation. We work to improve the lives of everyone affected by dementia through our campaigning work nationally and locally, including facilitating the involvement of people living with dementia in getting their views and experiences heard. We provide specialist and personalised services to people living with dementia, their families and carers in over 60 locations and offer information and support through our 24 hour freephone Dementia Helpline, our website ([www.alzscot.org](http://www.alzscot.org)) and our wide range of publications.

Alzheimer Scotland welcomes the opportunity to contribute to the Social Security Committee's scrutiny of the Social Security of the Bill.

We note that many of the key factors which will determine the success of the social security system in Scotland, and ultimately determine how well people are supported, are not included on the face of the Bill. Whilst our response will address the Bill as presented, we will reiterate points from our pre-legislative consultation response which remain pertinent.

This response is broken down under the following headings:

- Approach to Legislation
- Rights, Principles and Charter
- Devolved Benefits
- Other Considerations
- Conclusion

### **Approach to Legislation**

Alzheimer Scotland welcomes the publication of this Bill for a new Social Security System in Scotland. We welcome the intention of the Scottish Government to create a system which has dignity and respect at its heart and understand the approach to set out a legislative framework for administration in primary legislation, whilst reserving many of the details about the specific benefits themselves for secondary legislation. This approach may avoid unnecessary complexity. However, it will require thorough scrutiny of the regulations (as well as other policy and operational documents) to ensure that the intention behind the legislation is realised.

The legal framework will not, in itself, deliver the culture of dignity and respect aspired too. This will require a significant change in operational policy, new ways of working and a more open and transparent system; the Social Security Charter represents an opportunity to help define this, however, the operational culture, political leadership and transparency of procedures will ultimately determine to what extent it is delivered.

A recent Freedom of Information (FOI) request highlighted that Department of Work and Pension (DWP) employees had been set an internal target to uphold 80% of original decisions (at 'mandatory reconsideration' stage), demonstrating how operational policy and political pressure can radically impact upon the experience of those using the system. This reinforces the point that legislation alone cannot drive improvements in the experience of claimants and must be part of a wider shift in culture and practice.

The Scottish Government must ensure that there is a strong line of accountability to ensure that people who use the system can hold it to account where they disagree with decisions or where the system falls below the standards expected. Furthermore, social security must be responsive to the changing needs of people receiving support and the population as a whole. It is essential that if Ministers are to be able to set the details of benefits in regulations (which will be laid regulations before parliament), there must be processes in place to ensure that the regulations and any decisions made in relation to the system are informed by relevant expertise, including people with experience receiving support and professionals with specialist knowledge.

As part of this, if the Scottish Government wishes to deliver a system which is truly rights-based, a key component must be open and transparency. The current UK system has been criticised for its lack of transparency, particularly in relation to criteria used by medical assessors to determine fitness to work or how illness or disability impact on a person's life. The weighting given to medical assessment and other evidence must be made clear. Similarly, we believe that medical assessment of an individual must be distinct and separate from the decision-making process, to ensure that a fair and impartial decision is taken.

### Independent advice and scrutiny

Within the pre-legislative consultation, the Scottish Government raised the possibility of the establishment of specific body (or bodies) with responsibility for providing specialist input to the Scottish Government about the social security system, including asking whether this should be embedded in statute. Alzheimer Scotland supported this proposal, suggesting that an independent body/committee should be established within statute with responsibility for both informing and scrutinising the effectiveness of the social security system in Scotland. We believed (and continue to believe) that this would provide clear lines of accountability and responsibility, whilst ensuring Ministers were informed by a range of stakeholders and able to respond to issues within the system. Furthermore, we believe that statute (whether primary or secondary) must set out the operation of the body, with the remit and scope clearly defined.

Alzheimer Scotland also proposed that reports produced by the should body laid before parliament, with a specific role for the Social Security Committee to consider the reports in detail and question members of the panel (potentially in a similar manner to that of the Auditor General and the Public Audit Committee).

In addition, Alzheimer Scotland believes that regardless of the make-up of the scrutiny and/or advisory body, there should be a formal requirement for it, in addition to involving civic society groups and public consultation, to meaningfully involve and engage with the

Experience Panels to ensure that the views of people with experience of the system are central in driving improvements. We further proposed that this relationship should be clearly explained as part of the Social Security Charter.

## **Rights, Principles and Charter**

Alzheimer Scotland welcomes the inclusion of the principles on the face of the Bill and believes they are comprehensive as a framework for some of the key elements which will be integral to the success of the new social security system. However, we believe there should be a principle included articulating the need for services across health, social care, housing and other relevant bodies to work together to ensure that people's experience of receiving support is co-ordinated and not unduly burdensome or duplicative.

### Rights-based approach

Alzheimer Scotland welcomes the Scottish Government's approach in establishing a social security system in Scotland which treats people in need of support with dignity and respect. In particular, we are pleased to see the reference to rights in the second principle and its recognition of social security as a key part of people exercising their rights.

However, the inclusion of rights in the legislation is not sufficient in itself; there must be a clear line of accountability and an accessible process for appeals, to remedy situations where a person's rights have not been upheld. This is necessary as the Social Care (Self Directed Support) (Scotland) Act 2013 has demonstrated that embedding a rights-based approach within legislation does not guarantee that this will transfer into practice and improve the experience of people receiving support from the system.

### Social Security Charter

Alzheimer Scotland has previously articulated our belief that that the principles included in the Bill should be expanded upon in the 'Social Security Charter', demonstrating how these are to be achieved in practice and setting out how people may ensure these are upheld. One way of setting out how a rights-based approach should work in practice is to include the PANEL principles (promoted and endorsed by the Scottish Human Rights Commission) to set out how a rights-based approach can be achieved in practice:

- **Participation** – The consultation document recognises the importance of people's experiences in shaping and informing improvements of the social security system, including through 'user panels'.
- **Accountability** – The new social security system must be easily navigable and transparent, including a clear process for appeals.
- **Non-Discrimination** – The Scottish Government has made clear its intention for the foundation of the new system to treat people applying for support through social security with dignity and respect.

- **Empowerment** – Creating flexibility within the system, including the proposals on lump sum payments, preferential energy tariffs etc.
- **Legality** – Creating a legal basis on which the rights of people can be upheld, through the principles in legislation and clear structures for appeal.

The Charter must also act as a definitive statement of how the social security system should operate in practice and should therefore:

- Provide additional information on the principles based in statute, detailing how these are to be applied in practice.
- Include information on how the appeals process works and where people should address complaints.
- Set out which specific benefits are under the remit of the Scottish Social Security Agency (SSSA) and where people can get further information on each benefit.
- The support a person can receive to help them through the application, assessment and appeals processes.
- How the process of accountability and involvement work through the ‘user panels’ and how people may go about being involved in these panels.

In its pre-legislative consultation, the Scottish Government indicated there would be a duty to treat people with dignity and respect. This is not explicit in the Bill as published. Alzheimer Scotland supported this proposal and for all people involved in the delivery of social security in Scotland being subject to this duty, including frontline staff, managers and directors, as well as any external organisation contracted to work on behalf of the SSSA, e.g. medical assessors. In addition, we suggested that the duty to uphold and deliver all of the principles should be explicitly embedded within the legislation. This could be achieved with a specific duty requiring adherence to the Act’s principles in applying the provisions of the Act or any subsequent subordinate legislation.

The Scottish Government must seek to co-produce the Charter through a process which is accessible and meaningful to people who are likely to be affected by its content. Alzheimer Scotland would welcome the opportunity to work with the Government to ensure that people with dementia and their carers are involved in this process and can inform the development of the Charter.

## **Devolved Benefits**

### Existing Benefits Inc. Carers benefit

Alzheimer Scotland welcomes the Scottish Government’s intention to increase the rate of Carer’s Allowance in Scotland, as well as the intention to have introduce this as quickly as is possible with the new legislation. However, the Scottish Government proposals with regard to this benefit have not addressed a number of the concerns we raised as part of our response to the pre-legislative consultation.

Alzheimer Scotland has established and continuing concerns with the status and delivery of Carer's Allowance, grouped within "earnings replacement benefits" intended to provide financial support for people who have given up work or reduced their hours of work to care for another person. Even with the proposed increase, this amount cannot reasonably be considered as a meaningful replacement of earnings for a carer who is providing "regular and substantial care" (defined in statute as 35+ hours per week); especially where the carer has had to give up employment to care for someone else.

The Scottish Government must therefore consider in what regard they wish Carer's Allowance to be held as part of the social security system. If it is to continue as an "earnings replacement benefit" as is currently the case, Alzheimer Scotland believes that the benefit should be commensurate with the "regular and substantial" criterion and recognise the contribution that informal caring makes within Scotland. If this is not deemed financially viable, the inherent problems of the existing carer allowance rules must be addressed, including:

- The weekly earnings limit of £110 – a person cannot be "gainfully employed", restricting their ability and choice to work, or take on even modest extra hours to supplement their income and take the opportunities for social inclusion which employment affords.
- The lack of an income taper creates an unfair cliff edge – a person may have an income of £109 per week and be entitled to full Carer's Allowance, whilst a person with an income of £111 is not entitled to any amount of Carer's Allowance despite there being no significant difference in income.
- A carer may not be in "full time education" – the Scottish Government has identified carer employment and education as a key issue, but only within its medium-long term goals. We believe this should be a higher priority for the Scottish Government as carers this issue affects carers long after their caring responsibilities have ended.
- Underlying Entitlement/Overlapping rules – This rule prevents Carer's Allowance from being paid if the person is in receipt of another "earnings replacement benefit" e.g. state pension. In such cases, the claimant has an "underlying entitlement" to Carer's Allowance but cannot be paid any amount of the benefit which is overlapped by another earnings replacement benefit. Overlapping benefit rules affect about 42% of claimants. However, they must still make the claim in order to qualify for a Carer's Premium or Carer's addition in means-tested benefits.

This latter point, and more generally the complexity of eligibility for Carer's Allowance and its relationship to means tested benefits, is the source of much confusion, stress and anxiety for many carers, who have told us that they want to see a streamlined and simplified process which is easier to understand and apply for.

Alzheimer Scotland believes the new social security system must recognise and respect the individuality, distinct identity and needs of each person. However, at present, eligibility for Carer's Allowance is dependent on the cared-for person being in receipt of a "qualifying

benefit” linking the two benefits together; in cases where the cared-for person may not be eligible or may choose not to claim a qualifying benefit, the carer is left without monetary support, even if they otherwise meet the eligibility criteria for Carer’s Allowance.

It is our view that the rules relating to the severe disability premium or severe disability addition, paid as part of certain means tested benefits, are unfair. A cared-for person is not entitled to this additional payment for severe disability where a carer is paid any amount of Carer’s Allowance in respect of the claimant. This links the cared for person and carer financially and means that they are not considered as individuals in their own right. It forces carers and the person they care for to make a choice which will inevitably have a negative financial impact on either person. The carer would need the permission of the cared-for person to claim Carer’s Allowance, which the person may be reluctant to accept, knowing that they will likely lose the severe disability premium or addition.

We understand that these issues go beyond the scope of the Bill as published, however, resolving these is crucial to realising a social security system which meaningfully supports people, upholds their rights and reduces the complexity of the process.

#### Appeals, Overpayments and Redeterminations

The Scottish Government must ensure that provisions for late requests for ‘redeterminations’ reflect the recent ruling of Upper Tribunal Administrative Appeal Chamber (SG v Secretary of State for Work and Pensions (Appeal CE/766/2016) and R (CJ) v Secretary of State for Work and Pensions (JR/3861/2016).

Since 2013, there has been a requirement for claimants, who wish to challenge a decision about their entitlement to benefit, to apply for a ‘mandatory reconsideration’ before appealing to an independent tribunal. Where the Department for Work and Pensions (DWP) decides a mandatory reconsideration application has been made too late, it has asserted that no right of appeal arises. This aforementioned ruling concludes that that position is unlawful and sets out that where a claimant makes a mandatory reconsideration request at any time within 13 months of the original decision, the claimant is entitled to pursue an appeal to the tribunal if he/she is dissatisfied with the decision.

Alzheimer Scotland is concerned about the provision for overpayments and the new ‘reconsideration’ of decisions as both sets of provisions do little to alter the existing mechanisms in these areas.

For the reclaiming of overpayments, Alzheimer Scotland believes that this is a demonstrable example of where legislation, policy and practice is divergent and has the potential to disproportionately penalise people with dementia. As dementia is a progressive condition which gradually will reduce a person’s functional capacity, diminishing their ability to carry out tasks such as paperwork and management of money, requirements around informing relevant authorities about material changes of circumstance become increasingly challenging. Similarly, for carers who may be supporting a person in difficult and unfamiliar circumstances, understanding the complexity of the system and what they are expected to do may prove difficult, particularly for those with no prior experience of the system. Staff

working within the new social security system must, when reviewing such cases, give consideration to the circumstances of people, particularly where progressive conditions, such as dementia, may significantly impact on a person's ability to carry out such tasks.

Whilst existing UK legislation and the proposed Bill distinguish between overpayments made as a result of genuine error and those made as the result of fraudulent claiming, the process for reclaiming this money is often stigmatising and intimidating for people, with the tone and language of correspondence often being accusatory and intimidating. This a demonstrable example of where legislative intent and practical implication can differ significantly.

Alzheimer Scotland recognises and welcomes the Scottish Government's aim of establishing and delivering a system that is distinct from that of existing UK system. However, it is our view that changing terminology, for processes which remain similar to the existing system, does not in itself create that distinction and may have the unintended consequence of introducing unnecessary complexity and confusion for people claiming social security benefits from both the UK and Scottish systems. An example is the change of 'mandatory reconsiderations' to 'redeterminations'. These processes need to be materially different from the existing processes to warrant any changes in terminology. The Scottish system will inevitably be distinguishable from the existing UK system if it can deliver the principles of the Bill and ultimately a better experience for the people it supports. It is imperative that as far as possible, the new system does not unintentionally introduce further, or unnecessary, complexity for those who use it.

### **Other Considerations**

The new social security system provides an opportunity to create and embed a bespoke system which links into existing supports and services, providing a more streamlined and co-ordinated support. As part of this, accessibility to other parts of the system should also be improved, including reserved benefits, social care and housing support. At the moment, the system is highly fragmented requiring often duplicative and repetitive processes to access any form of supports or services.

It is inevitable and unavoidable that the new Scottish Social Security system will add another some additional level of bureaucracy. The challenge this presents is how to ensure that the new system works seamlessly with the existing UK system. There is real opportunity to create a fairer Scottish Social Security system which delivers an enhanced experience for the people of Scotland. However, achieving this aspiration will be undermined if it does not operate seamlessly. Therefore, the Scottish Government must, as soon as possible, set out details about the practical implementation of the system and how the process can be co-ordinated to ensure that existing recipients do not experience any disruption to their support and that future applicants know how and where to apply, without being subject to duplicative processes. We would welcome further information on:

- The method of face to face contact for information, application and/or assessment – will this be in new social security centres or run from existing Department of Work and Pensions (DWP) centres?

- The way in which the system can better provide joined up support to meet the needs of an individual, without the need for visits to multiple services to provide the same information. E.g. better information sharing between different institutions when accessing different supports.

Related to this, people with dementia and carers have previously indicated that if the sharing of information between institutions across health and social care (and any other relevant organisation) would help to streamline and simplify the process, they would welcome the option to consent to this.

Furthermore, Alzheimer Scotland understands that the skill sets across professions and the different domain of each support necessitates multi-agency involvement. However, from the point of view of people with dementia and their carers, the repetitive and burdensome process of providing the same information repeatedly is time consuming, emotionally draining to the person and unnecessary. The Scottish Government should look at how organisations involved in the support and care of people receiving social security can better work in partnership to share information (where appropriate) and meet a person's needs in a coordinated way.

Specifically for carers, there is an opportunity to tie systems together with forthcoming 'Adult Carer Support Plans' (ACSP) considering a caregivers needs and desired outcomes, linked to different sources of support, including Carer's Allowance or Self-Directed Support. When applying for an ACSP, a person should be provided with information about Carer's Allowance and vice versa to ensure that the person is, at the very least, aware that they may be eligible to additional support.

## **Conclusion**

Alzheimer Scotland broadly supports much of the Bill as presented, however, we recognise that at this stage, it is largely technical and procedural in nature. The most important elements, i.e. those which will have the biggest impact on people receiving support, will come about through the regulations and operational delivery of the system. Whilst this is an ongoing process, the committee must not scrutinise the Bill as an isolated piece of legislation in its own right and must consider how the Scottish Government can ensure that the new system delivers a meaningfully improved experience for the people it supports.

Alzheimer Scotland is happy for this evidence submission to be published on the committee's website. A copy will also be placed on Alzheimer Scotland's website.

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