

WELFARE REFORM COMMITTEE

THE FUTURE DELIVERY OF SOCIAL SECURITY IN SCOTLAND

WRITTEN SUBMISSION RECEIVED FROM ALZHEIMER SCOTLAND

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 and through 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) and our wide range of publications.

Alzheimer Scotland welcomes the opportunity to contribute to the Welfare Reform Committee's call for evidence as part of its inquiry into the future of social security in Scotland. Alzheimer Scotland has involved people with dementia and carers, including both the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN), our membership and colleagues, using their experiences and views to inform our submission.

Alzheimer Scotland believes that the devolution of benefits to the Scottish Parliament represents a real opportunity to make improvements to a system which people with dementia and their carers tell us is difficult to navigate, does not treat them with respect or compassion and does not meet their needs.

However, we are concerned that the scope to amend and shape the proposed devolved benefits will be severely constrained by the Scotland Bill in its current form. If the devolution of these benefits does not allow for meaningful changes to be made to the way in which they are delivered, this would represent a missed opportunity for improvement within the welfare system.

Culture and Stigma of the Current System

Receiving a diagnosis of dementia has a profound impact on the individual diagnosed and their families, usually requiring the person and a carer to give up employment. This period of time is experienced with considerable stress, anxiety and uncertainty as people adapt to changes in income, routine and lifestyle. It is therefore crucial that the social security system responds in such a way as to support people during this difficult transition period and as the illness progresses.

However, people with dementia, their families and carers have told us that, at present, there is a stigma attached to claiming benefits, characterised by distrust, disempowerment and a deficit-model of provision from a system which focuses on what a person cannot do, rather than what they are able to do. In particular, we are aware of such an approach being taken where a person's need for support is assessed, including for Personal Independence Payments (PIP) and Attendance Allowance. In addition, people we have supported have told us that the current system can treat claimants with suspicion, challenging the legitimacy of their claim.

This is coupled with underlying messages which remind people that sanctions or punitive measures will be applied if claimants are believed to have provided inaccurate information, causing people to feel more vulnerable and disempowered.

Alzheimer Scotland is aware of growing public hostility and negativity towards the provision of welfare benefits, which is exacerbated by rhetoric within the popular press and some politicians. This has a consequence of attaching stigma to benefits resulting in people who require financial support, including people with dementia and carers, feeling further excluded from the societies in which they live. For some people, this acts as a disincentive to come forward to claim the support for which they are eligible.

The committee must also take into consideration that many people with dementia will have co-morbid conditions and that carers often have underlying health problems, which add to the complexity of the support which they are eligible to receive. Many people with dementia and their carers find themselves unable to continue work and where they wish to continue, are constrained by a system which does little to support them to do so. This is a shortcoming within the system which the devolution of some elements of the welfare system should seek to address.

Application Process

People with dementia and their carers shared with us that the most difficult aspect of the benefits system is the application process, with a multitude of difficult problems arising. In many cases, people are supported through a combination of welfare benefits and local authority support, resulting in people with dementia and carers facing a landscape of support which is complex and extremely difficult to navigate.

Both carers and people with dementia have indicated that:

- Whilst they were aware of the names of different benefits, they were unsure what they were for or if they could claim them.
- They have found it very difficult to find accessible information and advice about the range of benefits and other sources of financial support available and to them.
- When they had identified that they may be entitled to benefit(s), it was difficult to find the correct person to contact regarding this.
- The provision of information and advice about welfare benefits varies across Scotland. As a result many people do not know where to get advice about potential entitlement.
- Many of them experienced a considerable delay between their initial claim and the commencement date of the benefit coming into effect; the process as a whole takes too long.

Forms and Paperwork

The process of applying for support requires considerable levels of form filling (much of which is duplicative and overlapping), at different sites, often with limited or no support through the process. This results in a process which is repetitive, time intensive and potentially distressing for the person with dementia and their carers, particularly where issues of a personal nature must be discussed.

In addition, in instances where applications have been fully or partially moved online, people with dementia and their carers have told us that this can present a barrier to them applying as some lack confidence, access or ability to complete the process. Similarly, the necessity of phoning to begin a Personal Independence Payment (PIP) claim can be difficult; these processes are seen as 'faceless', not providing the reassurance and support people may need for an unfamiliar and complex process. This is especially true in instances where a person with dementia has communication difficulties and may not be able to provide the information required. Despite this, we are aware that it is common for carers or family to be told that, if they are not recognised as an appointee, the person with dementia must speak to them on the phone. In this instance, it would therefore be useful for an alternative hard-copy application to be made available.

Furthermore, people with dementia and their carers have indicated that the forms are not person-centred, are not written in 'plain English' and do not provide the necessary flexibility to account for a person's unique circumstances.

Assessment/Eligibility/Medical Evidence

Alzheimer Scotland believes strongly that there is a need for greater recognition and accommodation within the welfare system about the nature of dementia as a progressive neurological condition. Specifically, evidence of a medical diagnosis of dementia should be accepted without the need for repeated assessment, which can place undue stress on the person with dementia and their carer. Alzheimer Scotland is aware of this taking place for some applicants of Personal Independence Payment (PIP), with people with a diagnosis of dementia having their claim approved without the need for follow-up assessment. In addition, Alzheimer Scotland is aware of one example where, an assessor contacted our services, with the knowledge and permission of the person with dementia, to clarify details of the person's needs, thus avoiding a delay in the progress of the claim.

However, we have broad range of concerns about the current process of assessment which accompanies both Personal Independence Payment (PIP) and Attendance Allowance. We believe that the requirements for regular face-to-face assessments are inappropriate for a person with dementia and do not provide an accurate picture of the level of support to which the person requires. We believe the process should be revised for a number of reasons, including:

- The requirement to travel to assessment centres can be difficult for people with dementia, particularly for those in rural areas for whom travelling may be difficult.

- Being in an unfamiliar environment and speaking with assessors whom they do not know and who may not have a sufficient understanding of dementia, has the potential to be distressing for a person with dementia, particularly where questions are of a sensitive and personal nature.
- Dementia is an illness which continues to be surrounded by stigma and negative perceptions. As a result it is common for people with a diagnosis of dementia to try to hide their symptoms and to refuse to acknowledge or discuss their diagnosis. As a result, the assessment may not accurately assess the person's needs: the person may not have insight into their condition or, in response to the personal nature of the questions asked in these assessments, may hide the extent to which they need support. Similarly, we are aware of instances of 'follow-up' phone calls where the person with dementia denies that they need support, despite carer and professional statements to the contrary.

It would therefore be more appropriate that proof of a medical diagnosis for a progressive and degenerative condition, such as dementia, exempted individuals from these ongoing assessments. If no exemption is applied then it will be crucial that the best supporting evidence is used to make decisions about entitlement. Evidence gained from a medical assessment or interview with the person with dementia may not always be the best way to establish the facts. Evidence from a range of sources including those who know the person best, such as the person's family, carers or health and social care professionals, is more effective approach. Any face-to-face assessments must be undertaken by staff who have an appropriate level of knowledge of the condition, as well as in a format which is suitable for the person with dementia and in an environment in which they are familiar.

In addition, it is difficult to understand the rationale behind the administration Personal Independence Payments (PIP) which, when a person is over-65, allows for a re-assessment of the daily living component but not of a person's mobility, despite the cause of the increased need for support for daily living also likely to impact on the mobility of the individual. This should be reviewed as part of the devolution of this benefit.

'One-stop shop' – Information, Support and Advice

People with dementia and carers have explicitly stated that there is a need for a 'one-stop shop' service, where they can go for information, advice to maximise their income and support to complete their claims, covering local authority, devolved and reserved benefits. This would require a collaborative approach between national and local government, the third sector, all levels of health and social care, and housing, providing a dual-purpose service where people receive welfare-rights advice, as well as financial and housing advice, whilst being able to apply for all relevant supports through a single advisor.

These sites would have staff with an understanding of progressive illnesses, such as dementia, and about how the illness may progress, understanding that the person is likely to need increasing levels of support, accordingly helping them apply for

relevant benefits to which they are entitled. This would deliver person-centred support for people with dementia and their carers, creating a single point of contact for advice and support, which is felt to be lacking in the current system.

Alzheimer Scotland has is aware of similar systems which have worked well, including the Long Term Conditions Financial Inclusion Partnership which operates in Glasgow, involving Glasgow City Council; Chest, Heart and Stroke Scotland; Glasgow Housing Association; NHS Greater Glasgow and Clyde; The Pensions Service; Jobcentre Plus; and Glasgow's Advice and Information Network. This partnership programme received the Chair's Award from the Convention of Scottish Local Authorities (COSLA) in 2012. Similarly, there are existing services in Renfrewshire and Falkirk which offer a single service offering support to people to access financial support across different sectors.

Alzheimer Scotland, from our experience of supporting people with dementia and their carers through the application process, is aware that there is an inconsistency in the level of support across Scotland. A similar level of support must be available and actively promoted across the country to ensure a consistent level of support for people with dementia and their carers to access the full range of welfare supports to which they are entitled.

Administration of Benefits

As noted elsewhere within this response, there is a need for a fundamental change in how benefits are considered and delivered, including at a political level. At present it is unclear if the devolution of these benefits will see decision making centres moved to Scotland or whether a Service Level Agreement will be reached to continue provision in its current form; if the latter, it is difficult to envisage how a meaningful shift in approach can be achieved.

We further note that only the housing benefit element of the Universal Credit system is due to be devolved, again raising questions about the ability for the delivery and administration of the benefit to be meaningfully improved.

Payment of benefits

Alzheimer Scotland believes that the devolution of certain welfare benefits should not change the present system whereby payments are made directly to the individual. We believe that the only way to ensure that people with dementia and their carers maintain their independence and resilience is to have the flexibility and freedom to use the monetary support they receive to meet their needs however they choose.

Appeals process

One of the strengths of the current system is the clear and defined process in relation to challenging decisions through the mandatory reconsideration and Her Majesty's Courts and Tribunals Service. It is imperative that the new system maintains a similar level of clarity and transparency around the decision-making

process, how appeals are handled, with accessible and detailed information accessible to individuals making a welfare claim.

Capacity/ DWP Appointeeship

As many people with dementia lack capacity to manage their own financial affairs and claim the support to which they are entitled, many carers will have Department of Work and Pensions (DWP) appointeeship which allows the carer to act on the person's behalf. Alzheimer Scotland believes that if a new system is established for devolved benefits, not only must a similar provision be made for those seeking to act on behalf a person who lacks capacity, but any existing appointeeships must continue as before, with no negative consequence or disruption for carers.

Additional Concerns

Carer's Allowance

Alzheimer Scotland has established and continuing concerns with the status and delivery of Carer's Allowance. Carers Allowance is one of a group of benefits known as "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. However, the amount (£62.10 per week) 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 and Scottish Parliament 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 viable, the inherent problems must be addressed, including:

- The weekly earnings limit of £110 – a person cannot be "gainfully employed", restricting their ability and choice to work, supplement their income and take the opportunities for social inclusion which employment affords.
- The lack of an income taper – 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 no significant difference in income.
- A carer may not be in "full time education".
- 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 claim for Carer's Premium on their pension.

Alzheimer Scotland is aware of instances where a person's earnings have increased above the threshold, resulting in the DWP retrospectively removing the entitlement to the benefit, requiring the carer to pay back the full amount, including an additional civil penalty.

The individuality and distinct identity and needs of each person must be recognised and respected. 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 entitled or may choose not to claim a qualifying benefit, the carer is left without monetary support, even if they otherwise meet the eligibility criteria.

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. 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.

Definition of a Carer

Furthermore, both must consider the definition of carers in relation to support. As set out in Section 16 Paragraph 4(a) of the Scotland Bill 2015:

"Carer's benefit" means a benefit which is normally payable in respect of the regular and substantial provision of care by a relevant carer to a disabled person; and for this purpose—

- (a) *"relevant carer" means a person who—*
- (i) is 16 or over,*
 - (ii) is not in full-time education, and*
 - (iii) is not gainfully employed;*

This is inconsistent with the definition as set out in the current Carers (Scotland) Bill, and is the source of other restrictions on financial support, including exemption/discounts on council tax. We believe that the definition of carer must be amended to create consistency across all legislation and policy, with eligibility criteria for benefits set out separately. Doing so represents an opportunity to tie systems together with forthcoming 'adult carer and support plans' considering a caregivers needs and desired outcomes, linked to different sources of support, including Carer's Allowance or Self-Directed Support.

Gender impact

The majority of people living with dementia are women, as are the majority of carers of people with dementia. Accordingly, the decisions taken in relation to the future of social security in Scotland will have a disproportionate impact on women across Scotland. Of the benefit due to be devolved, the following are those which will have the greatest impact on people with dementia and their carers; broken down by percentage, women account for:

- 51% of Disability Living Allowance claims.
- 54% of Personal Independence Payment claims.
- 65% of Attendance Allowance claims.
- 69% of Carer's Allowance claims.

In addition, Alzheimer Scotland is particularly aware that as a result of generational differences in working practices, many older women are not entitled to a full state pension, having not earned enough throughout their working lives to reach the contribution thresholds for full state pension or contribute to an occupational/personal pension. This can leave many older women at a significant economic disadvantage, invariably impacting on their ability to stay active and involved in their local communities.

It is therefore crucial that when making changes to the delivery of social security in Scotland, both the Scottish Government and the Scottish Parliament give make sure that the structures they create help to mitigate this imbalance. This represents a significant opportunity to improve women's experiences across a number of areas including employment, social and child care and anti-poverty strategies, all underpinned by a human rights-based approach in legislation, policies and services.

Conclusion

Alzheimer Scotland strongly welcomes this inquiry into the future of welfare and benefits in Scotland. However, this inquiry must be the start of a process and a wider discussion about the type of Scotland in which we wish to live and how we care for people in our society, including people with dementia and their carers.

We believe that this inquiry is timely given the Fairer Scotland engagement process currently underway by the Scottish Government. In addition, we believe that the devolution of the benefits affords an opportunity to re-establish the principles of social security system as one which supports people during difficult circumstances, when they may be vulnerable and treats them with compassion, dignity and respect.

Alzheimer Scotland consents to this submission being made publicly available on the Welfare Reform Committee's section of the Scottish Parliament website. A copy will also be available at: www.alzscot.org/campaigning/consultation_responses

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