

Alzheimer Scotland

Health and Sport Committee – Budget Call for Evidence

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) and our wide range of publications.

Alzheimer Scotland's response will address the questions set out in the call for evidence, however, we have structured our response to reflect what we consider to be the some of the key areas which the committee should examine when scrutinising the budget:

- The Gap Between Policy and Practice in Scotland.
 - Dementia Post-Diagnostic Support.
 - Self-Directed Support.
- Policy, Delivery and Ongoing Challenges.
 - Delivery of Services in Line With LDP Standards, National Health and Wellbeing Outcomes, National Performance Framework.
 - Social Care Funding.
- Scotland's Third National Dementia Strategy.

The Policy/Practice Gap in Scotland

In Scotland, there are a number of policies for health and social care which have set out ambitious and commendable visions for a rights-based, person-centred system which is delivered seamlessly from the point of view of people using services. Condition specific strategies such as Scotland's National Dementia Strategies, legislation such as the Social Care (Self-Directed Support) (Scotland) Act 2013 and the new National Health and Social Care Standards, have all taken a rights based approach grounded in the PANEL (Participation, Accountability, Non-Discrimination, Empowerment and Legality) principles, seeking to uphold people's rights and improve their overall health and wellbeing. However, Alzheimer Scotland's experience of working with people with dementia, their families and carers suggests the policies are not always being realised in practice.

It is our experience that transformational system change and service redesign has not taken place across health and social care settings; in some instances, temporary funding has allowed for pilots of new ways of working, however, services often revert back to the status quo once the funding concludes. Alzheimer Scotland is aware of this having taken place in relation to funding through Reshaping Care for Older People, the Integrated Care Fund and improvement programmes under the second National Dementia Strategy. Whilst appreciating that these short term funding streams were an effort to act as a catalyst for system redesign, they came during a period of wider change and structural reorganisation for health and social care. As a result, the intended outcome of delivering and embedding new ways of working in health and social care services has not occurred. The committee should give consideration to how the budget can encourage long-term planning and redesign, moving away from short-term funding approaches, to embed new ways of working.

Dementia Post-Diagnostic Support

An example of the gap between policy and practice in Scotland was highlighted in the NHS National Support Services Information Services Division report 'Dementia Post Diagnostic Support: NHS Board Performance 2014/15'¹ report which looked at delivery against the Scottish Government's LDP standard for Dementia Post-Diagnostic Support². The report indicated that for the year 2014/15 (the latest available data), only 2 out of 5 people who were diagnosed with dementia and eligible for Post-Diagnostic Support received it. Additionally, Alzheimer Scotland is aware that in many IJB areas across Scotland, there are waiting lists developing for people who are referred to Link Workers.

People with dementia and their carers [tell us time and again how important having a high-quality Post-Diagnostic Support from a named Link Worker is to them](#). Despite the Post-Diagnostic Support guarantee made by the Scottish Government and the LDP standard being in place, many areas have not mainstream-funded Post-Diagnostic Support Link Workers to deliver the Standard, leaving the future of such vital services at risk. The importance of this work in building resilience in people, allowing them to plan for their future care and delaying the need for formal interventions cannot be underestimated. This is also true of similar social supports which, despite being the services which people interact with most frequently and acting as the foundation of support for people living in the community, remain undervalued as they are seen as 'secondary' to clinical interventions.

The committee should examine how the budget can ensure that social interventions are valued as much as clinical interventions, including their potential as preventative interventions and look at how resources can be shifted into community settings, where an increasing number of people are being supported.

Self-Directed Support

Self-Directed Support (SDS) legislation was passed to improve the lives of people who use services by embedding a human-rights based approach, to give people greater choice and control over the supports and services they access.

In a recent report, *Self-Directed Support: Your Choice, Your Right*³ written by John Dalrymple of In Control, Donald MacAskill of Scottish Care and Henry Simmons of Alzheimer Scotland, a number of disparities are identified between the intentions of the legislation and the experience of individuals across Scotland who access social care. The report indicates that the delivery of this system is undermined by poor understanding of both public and professionals, inconsistent delivery between Local Authorities, difficulty in accessing support and no discernible change in the power dynamic between professionals and the individual seeking support.

The report makes a number of recommendations, several which the committee should consider as part of its scrutiny of the budget. These include ensuring the accountability of organisations with responsibility for the implementation of SDS, moving away from the time-allocation method of care assessment and providing a shift towards allowing greater autonomy and decision-making to frontline workers rather than commissioners and contract managers.

¹ '[Dementia Post Diagnostic Support: NHS Board Performance 2014/15](#)' (NHS NSS ISD, 2017).

² '[LDP Standard – Dementia](#)' (Scottish Government, 2016).

³ '[Self-Directed Support: Your Choice, Your Right](#)' (In Control, Scottish Care and Alzheimer Scotland, 2017).

Policy, Delivery and Ongoing Challenges

Alzheimer Scotland will develop the point about the gap between policy and practice, specifically addressing the need for greater preventative spend and a fundamental shift in the way in which services are delivered. The committee should, in this context, examine challenges in relation to the LDP Standards, the new National Health and Care Standards, the National Health and Wellbeing Outcomes (NHWOs) and the National Performance Framework (NPF).

Delivery of Services in Line with LDP Standards, NHWOs and NPF

Many of the aims of the NHWOs and NPF overlap; the considerations of both are concerned with the delivery of high quality care and support for people, to keep them in their communities for as long as possible, and ensure they are treated with dignity and respect.

Whilst the LDP Standard for Dementia Post-Diagnostic Support is consistent with this approach, it sits within a context of the majority of LDP Standards which refer to measures specifically targeted at acute settings. Despite there being a decreasing number of beds in acute settings and more people being cared for or supported in community settings, it is not evident that there has been a substantial shift in resources to allow for greater spending on community supports and services. Whilst this will in part reflect the nature of the more resource intensive needs of patients admitted to acute settings, a significant factor will be in resources being directed to meet the targets set nationally. Despite health boards and IJBs commissioning and delivering services in response to the local context of their area, this high rate of spending in acute settings is consistent across Scotland.

Alzheimer Scotland does not suggest that social care under the new integrated arrangements should have equivalent LDP standards or further reporting measurements. However, we believe the committee should examine this inequity in resource allocation to ensure that, as with some aspects of health delivery, the allocation of the budget allows for a strong line of accountability so that national policy drivers are delivered locally.

Social Care and Free Personal Care Extension (for under 65s)

The provision of free personal care is a good example of preventative spend which can reduce the likelihood of an unplanned admission to care, reduce the need for crisis-driven interventions and, where a person has a degenerative condition, may delay the need for a person to move into a residential care setting. Whilst requiring initial investment, the cost savings from avoiding more costly interventions or supports make this a more efficient and effective use of resources. However, as eligibility criteria are tightened and fewer people are eligible for support, there is a risk that this will lead to poorer outcomes for people and inhibit professionals from being able to carry out preventative interventions.

Whilst we understand the need for local flexibility, there is considerable variation across local authority areas in the charging and delivery of care services, creating an inequity of access across Scotland. The reasons for differences in charges are multifaceted, however, the confusion and poor understanding of care charging by those seeking to access services in Scotland is made worse by a lack of transparency and information about the way in which contributions are calculated.

Additionally, given the context of Amanda Kopel's campaign for Frank's Law, the Scottish Government feasibility study into providing care for under 65s and the consultation launched by Miles Briggs on a potential Members' Bill, the committee should give consideration to the challenges

and opportunities which arise around the proposed expansion of free personal care to include people aged under 65.

Alzheimer Scotland believes that as people over 65 receive free personal care to assist them are to be supported to realise their rights and live well in society through the provision of various supports and provisions, it is that people under 65 are excluded from the same level of support based solely on their age.

However, Alzheimer Scotland believes that the expansion of free personal care should not be an end in itself and cannot solely be an extension of current provision. There is a significant risk that if adequate resource is not made available to local authorities/integrated joint boards, introducing this policy risks simply increasing the number of people eligible for free personal care, without addressing some of the key problems of the present. These include 15 minute visits, time and task approaches and high staff turnover rates. A simplistic extension of Free Personal Care may result in the expanded provision of low quality provision which doesn't meaningfully support people.

Scotland's Third National Dementia Strategy

In June, the Scottish Government published Scotland's third National Dementia Strategy 2017-2020⁴, demonstrating their ongoing commitment to improving the lives of people with dementia, their families and carers. The strategy is progressive and ambitious, building on and strengthening existing guarantees including:

- A commitment to go beyond the initial guaranteed minimum of one year's post diagnostic support, offering individuals diagnosed early in the illness with a named Link Worker who will continue to use Alzheimer Scotland's '5 Pillars Model of Post-Diagnostic Support'⁵ beyond the initial 12 months if necessary, until formal health or social care supports are needed. This step enhances a progressive dementia policy which is already world-leading.
- A commitment to ensure that individuals diagnosed later and whose needs are more appropriately delivered using the Alzheimer's Scotland '8 Pillars Model of Community Support'⁶ receive their Post-Diagnostic Support from a named Dementia Practice Coordinator from that point and through the advanced illness.
- Testing how best to provide earlier support to people within a primary care environment and working to ensure communities in Scotland are as dementia friendly as possible.
- Additionally, there is a commitment to test Alzheimer Scotland's 'Advanced Dementia Practice Model'⁷ and focus on end of life care

If the aspirations of this strategy are to become reality for people with dementia, their families and carers, it will require significant local investment in community-based, social supports. Not only will these returns offer significant improvements in the quality of life for people with dementia and their carers, the potential benefit to the system includes delaying admission to residential and formal care services, avoiding unnecessary admission to hospitals and preventing crisis-driven service responses, building capacity across our communities. As noted earlier in this response, there are existing challenges with delivering dementia Post-Diagnostic Support in its current form; whilst the

⁴ ['Scotland's National Dementia Strategy: 2017-2020'](#) (Scottish Government, 2017).

⁵ ['5 Pillars Model of Post Diagnostic Support'](#) (Alzheimer Scotland, 2011)

⁶ ['8 Pillars Model of Community Support'](#) (Alzheimer Scotland, 2012)

⁷ ['Advanced Dementia Practice Model'](#) (Alzheimer Scotland, 2015)

commitment to strengthen the PDS Guarantee is welcome, it will require further work and investment to ensure it is delivered to every person in Scotland who is entitled to it.

Conclusion

When scrutinising the Scottish Government's budget, the Health and Sport Committee should give consideration to policy/practice gap in Scotland. Whilst many of the policy drivers in Scotland are positive, there is a need for further work and investment to ensure that these become the reality for people living with dementia, their families and carers. Whilst appreciating that the commissioning, decision-making and delivery of services is the responsibility of Integrated Joint Boards, there needs to be a stronger accountability for these boards to ensure that they do so in line with national policies, not only those underpinned by an LDP Standard.

Alzheimer Scotland will continue to work with national and local partners to deliver on the National Dementia Strategy and make sure that the collective voice of people with dementia, their families, carers and our members are as strong and as engaged as possible throughout Scotland.

Alzheimer Scotland is happy for this submission to be made publicly available. A copy will also be placed on Alzheimer Scotland's website.

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