Alzheimer Scotland

Scottish Government – Mental Health Strategy

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 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 has responded to the aspects of the consultation paper which may affect people with dementia, their families and carers. As such, this response does not address the proposals related to CAMHS.

General Comments

Alzheimer Scotland welcomes the opportunity to consult on this consultation and broadly welcome the development of a Mental Health Strategy which has the opportunity to complement the third National Dementia Strategy, due for publication in later 2016, and the wider dementia agenda in Scotland.

Alzheimer Scotland is concerned with the Scottish Government's move to a 10 year Mental Health Strategy. We understand the desire to develop a strategic and sustainable approach to support the planning, development, commissioning and delivery of services, including the need for workforce development to transform the way in which services for people with mental health issues is delivered. However, the changing demographics in Scotland, along with a continuously evolving policy landscape requires continuous monitoring and responsiveness to changing needs within a population. Whilst this is not impossible under a strategy, the long term nature of the strategy may result in certain sections becoming obsolete or irrelevant. If the Scottish Government is minded to extend the Mental Health Strategy to 10 years, we believe there must be key milestones throughout the course of the strategy which demonstrate the implementation and progress made against commitments within the strategy.

Although appreciating that this is an early consultation document and that a number of the proposals are related, we believe that in addition to people with dementia, a specific focus of the final strategy must address the impact that undertaking a caregiving role can have on carers. The emotional and psychological impact on carers is considerable and whilst some support is provided by way of respite services, short breaks or day-care services, these are variable across Scotland and are not, in isolation, sufficient to ensure the good mental health of Scotland's carers. We believe there is merit in the Scottish Government, in tandem with the implementation of the Carers (Scotland) Act 2016, ensuring that this strategy

acknowledges the potentially detrimental impact of a caregiving role on a person and details how health and social care professionals can ensure their mental (and physical) health needs are fully met.

Framework

Alzheimer Scotland broadly welcomes creating a 'whole life' approach which recognises the importance of good Mental Health throughout the entirety of a person's life. We would propose that 'Age Well' be reworded to say that:

- A person is supported to remain at home for as long that is the wish of the person.
- People are able to continue to access a full range of mental health supports and interventions regardless of the setting they are in.

It is essential that the Scottish Government sets out the distinction between the generalist link workers and specialist Dementia Link Workers who support people with a diagnosis of dementia in line with the Post Diagnostic Support guarantee¹ and HEAT Target². Although there is some overlap in terms of the outcomes which the two roles seek to achieve, the Dementia Link Worker role requires more specialist training and knowledge of people with dementia and a specific period of support for the person with dementia and their carer. There needs to be clear understanding across health and social care professionals about how the roles differ and to which professional a person with dementia should be referred once a diagnosis has been made.

Priority Areas Three and Four

Alzheimer Scotland is interested in the third 'priority statement' and how this will complement and relate to the Scottish Government's expected piloting of Dementia Post Diagnostic Support services in primary care settings as part of the next National Dementia Strategy³. Similarly, we welcome the fourth priority statement about supporting people to manage their own mental health. This approach has been advocated by Alzheimer Scotland as part of our approach to post-diagnostic support and enabling supported self-management for people with dementia and their carers.

This approach is underpinned by the support for the person with dementia and their carer, through <u>Alzheimer Scotland's 5 Pillars Model</u>⁴, delivered by a trained specialist dementia

¹ P.6, Second National Dementia Strategy (2013-16), Scottish Government – <u>http://www.gov.scot/Resource/0042/00423472.pdf</u>

² Dementia HEAT target, Scottish Government – <u>http://www.gov.scot/About/Performance/scotPerforms/partnerstories/NHSScotlandperformance/Dementia</u>

³ P2-3, Proposals for Scotland's National Dementia Strategy 2016-19, Scottish Government – <u>http://www.gov.scot/Resource/0049/00497716.pdf</u>

⁴ 5 Pillars Model of Post-Diagnostic Support, Alzheimer Scotland – <u>http://www.alzscot.org/campaigning/five_pillars</u>

link worker, helping the person to understand their condition and symptoms, explore local community connections and how to access further support and information. The success of the approach, where fully resourced and delivered by skilled professional, is demonstrated the positive impact that an approach which builds resilience and confidence in the person to self-manage can have. Success is reliant upon investment in early preventative work to support the person, and avoid crisis interventions.

Within Annex A, 'priority statement' three makes reference to increase the use of care plans to identify issues and solutions for people and to prepare them for if something goes wrong. Again, this is in line with the 5 Pillars Model and the development of a Personal Outcome Plan which contains similar information, both for the person and for the professionals who come into contact with the person with dementia. Such plans are also important as dementia progresses and should be reviewed and adapted regularly to make sure they reflect changing circumstances. However, we know from our experience of working with people that both formal care plans and the Personal Outcome Plans are not always accessible by the full range of health and social care professionals supporting the person or transferrable as a result of incompatible IT systems between different health and social care organisations. If this aspect is not addressed across Scotland, the increase of care plans will not, in isolation, improve outcomes for people.

Priority Areas Six and Seven

Alzheimer Scotland supports 'priority statements' six and seven as we believe they align with the biopsychosocial approach which underpins Alzheimer Scotland's 8 Pillar Model of Community Based Support⁵ and our Advanced Dementia Practice Model⁶. The 8 Pillars Model provides a framework to support people with dementia and their carers to enable them to live in the community for as long as possible, ensuring the impact of early intervention investment is not lost and that crisis interventions are avoided. It recognises that a change in the illness, social situation, setting etc are all interconnected to the person's health and wellbeing and that a change in one aspect invariably affects all other elements and ultimately impacts on the overall health and wellbeing of the individual and their carer.

Excess disability is created when people with dementia do not receive appropriate care and treatment for the symptoms of the illness. Without the right support, there is a gap between how people actually function and how they could potentially function. The 8 Pillars Model provides a blueprint for restructuring integrated dementia care so that resources are used to greatest effect. This approach also fits with 'priority statement' five.

It is welcome that in Annex A, 'priority statement' seven notes the importance of employment and welfare programmes taking account of mental health conditions. This

⁵ 8 Pillars Model of Community Support, Alzheimer Scotland – <u>http://www.alzscot.org/campaigning/eight_pillars_model_of_community_support</u>

⁶ Advanced Dementia Practice Model, Alzheimer Scotland – <u>http://www.alzscot.org/campaigning/advanced_dementia_model</u>

should be extended to include other elements of support such as housing and social care, including Self-Directed Support (SDS). From our experience of working with people with dementia, the potential for SDS to improve people's lives and use money innovatively to improve their health and wellbeing is not being realised.

Rights-Based Approach (Priority Statement 8)

Alzheimer Scotland strongly welcomes the rights-based approach proposed within the consultation document for the next Mental Health Strategy and in particular, the inclusion of the PANEL principles. We have long argued that a rights based approach must be the basis on which policy, legislation and practice is developed and delivered. Working with the Scottish Government and partners in health and social care, the following developments have helped to deliver a shift towards the embedding of this approach.

- Scotland's National Dementia Strategies⁷.
- The Charter of Rights for people with dementia⁸.
- Standards of Care for Dementia in Scotland⁹.
- Promoting Excellence Framework¹⁰.

A key factor in the move towards a rights-based approach for people with dementia and their carers has been through the support and training for health and social care workforce, including upskilling staff through the Promoting Excellence Framework, training of Dementia Champions to drive improvement in acute settings and ongoing work to maximise the contribution of the Allied Health Professional workforce across Scotland.

It is therefore essential that the Scottish Government ensure there is a clear approach set out within the Mental Health Strategy for its implementation and specifically, how health and social care professionals will be supported and trained to deliver the aims and outcomes as set out in the strategy.

Alzheimer Scotland welcomes the Scottish Government's intention to review the definition of 'mental disorder' within mental health legislation and how dementia relates to this, and offer our support and participation in this review.

We also welcome the Scottish Government's commitment to reviewing the current incapacity legislation at some point between 2016-18. Alzheimer Scotland, in line with other consultation responses, believes this should include reviewing the Adults with Incapacity Act

⁷ Scotland's National Dementia Strategies, Scottish Government –

http://www.gov.scot/Topics/Health/Policy/Adult-Health-SocialCare-Integration/Dementia ⁸ Charter of Rights for People with Dementia, Alzheimer Scotland – http://www.alzscot.org/assets/0000/2678/Charter of Rights.pdf

⁹ Standards of Care for Dementia in Scotland, Scottish Government – <u>http://www.gov.scot/Resource/Doc/350188/0117212.pdf</u>

¹⁰ Promoting Excellence Framework, Scottish Government – <u>http://www.gov.scot/resource/doc/350174/0117211.pdf</u>

(Scotland) 2000, Mental Health (Care and Treatment) (Scotland) Act 2003 (including the amendments through the Mental Health (Scotland) Act 2015) and the Adult Support and Protection (Scotland) Act 2007.

It would be helpful for the Scottish Government to set out timescales for the review of the legislation and to provide detail on the scope and approach of the review, as early as possible. Alzheimer Scotland would welcome the opportunity to contribute to this review as may be helpful, including ensuring that people with dementia and carers with lived experience of the effects of the legislation have their voices heard.

Conclusion

Alzheimer Scotland believes that the approach and framework outlined for the next Mental Health Strategy are broadly positive. We strongly support the Scottish Government's decision to take a rights-based approach to the strategy, utilising the PANEL principles.

However, we have some concerns which must be addressed in subsequent work to develop the next Mental Health Strategy. Whilst acknowledging that the consultation document was not intended as a comprehensive overview of all of the strands of work, we believe there would be merit in looking at the mental health of carers as a specific area of work.

If helpful, Alzheimer Scotland is willing to contribute further to the development of any proposals within the next Mental Health Strategy which may impact on people with dementia or their carers.

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