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 with dementia and carers in getting their views and experiences heard. We provide specialist and personalised services to people with dementia and 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. We welcome the opportunity to respond to the consultation on the integration of adult health and social care.

The case for change

Alzheimer Scotland believe that a key objective of health and social care must be to assist people with dementia and their carers to continue living their normal lives in the community for as long as possible.

The interventions required to support people with dementia in the community cover a range of health and social care needs. However, there is currently no coordinated approach to bringing the strengths of health and social care together to treat the symptoms of the illness. Crucially, there is no integrated practice direction when people start to decline.

The integration of health and social care presents an opportunity to provide a coordinated approach to enhancing the coping and resilience of people with dementia and their carers living in the community, in a manner that promotes their human rights.

Outline of proposed reforms

Alzheimer Scotland welcomes the intention to improve outcomes through better integration of health and social care. We believe the focus of attention should be on ensuring organisational practices to facilitate the coordination of health and social care needs of the individual. There must also be a clear link with Self-directed support.

The demographic changes we face in Scotland are huge; we require a corresponding change in the way we organise and use our public funds. We require a change in culture as well as a change in practice. Our health and social care system lacks any current clear guiding principles. The 1968 Social Work Scotland Act is still the primary social care legislation; however, it has been amended so many times the sound core principles have been lost and are now out of date. The most significant amendment from the NHS and Community Care Act 1990 created a purchaser and provider split, which we have never recovered from - our most important care systems lack any coherent values.

Professionally led locality planning and commissioning

It will be essential that a dementia strategy is set at the partnership level as part of the national agreed outcomes in order to avoid local divergence in the scale and quality of dementia support.

Integrated budgets and resources

We are concerned that there is a risk of funding for dementia of being consumed in adult health and social care budgets. There is a potential danger of increased large scale commissioning of generic services, to the detriment of dementia-specific support. When provided in this way, we fail to recognise community support as a potential resource to facilitate resilience and promote independence; inappropriate services can exacerbate the challenges of living with dementia.

Demographic changes and financial challenges mean that current models of care are not sustainable in the longer term. An estimated 40% if people with dementia live in some form of institutional care; people with dementia are also thought to account for 70% to 90% of the care home population[1].

Health and social care regeneration is the major public policy issue at this time; no other issue will have the same impact on the public purse. We now have the opportunity to use the principles of human rights legislation to turn around this void in values and create a vision for care that will unlock us from the restricting snare of commissioning and contracting.

People with dementia and their families already do so much for themselves. There must be a new partnership between the state and the individual that will ensure state resources are used far more effectively alongside individual natural supports. It is essential we do not focus on structural changes to the organisations, but systematic transformation in the organisation and control of state resources, driven by fundamental principles of human rights.

Delivering integrated dementia care

Dementia is the interrelationship of neurological and psychosocial factors; the experience of the illness is subjective and unique to each individual. A bio-psychosocial model of dementia provides a framework for understanding the range of factors that determine the nature of dementia, progression of the illness and appropriate interventions.

Alzheimer Scotland's 8 Pillars Model of Community Support for Dementia follows a bio-psychosocial understanding of the illness. It provides an integrated and comprehensive evidence-based approach to supporting people with dementia in the moderate to severe stages of the illness living in the community.

Supporting quality of life and independence and building resilience in the community requires a combination of all 8 Pillars. It builds on key developments in relation to post-diagnostic support and will ensure the impact of the investment in early intervention is not lost.

The 8 Pillars Model provides local authorities and NHS boards with a blueprint for restructuring integrated dementia care so that resources are used to greatest effect.

[1] Care Commission & Mental Welfare Commission (2009) *Remember I am still me* Edinburgh and Lithgow S, Jackson GA & Browne D (2012) Estimating the prevalence of dementia: cognitive screening in Glasgow nursing homes *International Journal of Geriatric Psychiatry* 27:785-791

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