Integration of health and social care

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 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 contribute to the evidence session on 13 March 2012.

Integration of health and social care

Most support for people with dementia is provided by informal carers, typically a family member. Alzheimer Scotland believe that a key objective of health and social care services must be to assist people with dementia to continue living their normal lives in the community for as long as possible. The needs of people with dementia and their carers do not fit neatly into health or social care defined parameters; the current system does not allow for these needs to be addressed in a coordinated way.

In practice there are three approaches to service integration:

- **Full integration** the integrated organisation is responsible for all services either under one structure or by contracting some services with other organisations.

- **Linkage** organisations may develop protocols to facilitate referral or collaboration; however, organisations continue to function within their respective jurisdictions, responsibilities and operating roles.

- **Coordination** the development and implementation of defined structures and mechanisms to manage complex and evolving needs of patients in a coordinated fashion. Each organisation keeps its own structures but agrees to participate in an umbrella system and to adapt its operations and resources to the agreed requirements and processes.

We consider there is an inherent danger in focusing attention on the structural reorganisation essential to create full integration; this would be a hugely costly process. It would also be the main focus of attention for the next couple of

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1 Leutz W (1999) Five laws for integrating medical and social services: lessons from the United States and the United Kingdom. *The Milbank Quarterly* 77 (1) 77-110
http://www.milbank.org/770103.html
years, at a time when it is essential to concentrate efforts on demographic changes.

We believe the focus should be on ensuring organisational practices to facilitate the coordination of health and social care needs of the individual.

**Way forward**

The demographic challenges 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 cultural 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.

People with dementia and their families already do much for themselves; the state would benefit greatly from harnessing the natural supports that exist in people's lives during the early stages of the illness and supporting families to plan for future care needs.

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.

There must be a new partnership between the state and the individual that will ensures state resources are used far more effectively alongside individual natural supports. It is essential we do not focus our efforts on structural changes to the organisations, but systematic transformation in the organisation and control of state resources, driven by the fundamental principles of human rights.

**Good practice examples**

**Self-directed support**

Alzheimer Scotland received funding from the Scottish Government in 2009 to run a two year pilot project with the aim to demonstrate that self-directed support is a practical, cost-effective approach to providing more personalised services which better support both the person with dementia and the carer and family and which allow the person to stay in their own home, when that is what they and their families choose. The pilot worked with people with moderate/severe dementia who had been assessed as needing significant levels of support, in some cases 24 hours per day, to remain safe in their own homes or for whom care home admission was being considered.
The average cost of a self-directed support package was £208.10$^2$ per week; this is £266.06 **less** than the cost of a standard care home placement and £342.71 **less** than a care home placement which includes nursing care under the National Care Home Contract framework.

**Post-diagnostic support**

We have asked the Scottish Government to provide a one-year guarantee of post-diagnostic support for every person diagnosed with dementia and their family. We have also proposed a model for post-diagnostic support – one which we know is effective and works for people. It was the basis of our post-diagnostic pilot project funded by the Scottish Government.

We believe that if every person in the first year after diagnosis receives this support, they will be empowered to take control of their lives and live well with dementia; they will be connected to peer support and community support; they will have their legal and financial arrangements sorted out; and at the end of that year, have developed a plan for how they want their future care and support to be delivered.

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$^2$ These figures are based on an average direct payment rate of £11 per hour. It does not include any financial contribution made by the individual or their families to the cost of the care package. The direct payment also does not include services that some people chose to maintain that were provided by their council, such as day care and sometimes respite services. There were no cost breakdowns available for these elements of provision.