

Including People with Dementia - Shaping Generic Services

A project report by Steve Milton, Innovations in Dementia (CIC)

Funded by Department of Health Strategic Partners Programme

Introduction

Innovations in Dementia (IID) was commissioned by Age UK as part of the Department of Health Strategic Partners Programme in August 2012 to work with fifteen local AGE UKs to support them in making their mainstream services more accessible to people with dementia. The intended outputs of the project were:

- to involve people with dementia and carers in looking at current services and what could change to make them more accessible
- to develop an action plan for those changes
- to share action plan and other good practice
- to collate findings and produce a report appropriate for the wider Voluntary and Community Sector, including Dementia Action Alliance members

Participating local Age UKs

| | |
|-------------------------|----------------|
| Blackburn with Darwen | Lancashire |
| Blackpool | Norfolk |
| Calderdale and Kirklees | North Tyneside |
| Coventry | Solihull |
| Doncaster | West Cumbria |
| East London | Wigan |
| Gloucestershire | Wirral |
| Isle of Wight | |

What we did

Initial meetings in London

Participating local Age UKs attended meetings in London in September 2012. The purpose of these meetings was to introduce participants to each other and to the consultant, and to share existing practice and ideas for making mainstream services more accessible to people with dementia.

Initial service audits - October to November 2012

Innovations in Dementia (IID) visited each participating local Age UK and met with relevant staff to run through an initial audit of services, focusing on the extent to which they were accessible to people with dementia. We focused on five “domains” which our previous work had identified as being particularly relevant to the dementia-friendliness of organisations.

- The engagement of people with dementia- specifically - the ways in which people with dementia had a say in the services being provided.

- The Place - This focused on the physical environment in which services were delivered, as well as the accessibility of published materials to people with dementia.
- The People - We looked at the level of awareness about dementia among staff, volunteers, and in some cases, existing service users.
- The Networks - We looked at local networks and partner organisations that may be able to support AGE UKs locally in making their services more accessible.
- The Resources - We looked at the internal resources that might be available to support the engagement of people with dementia in mainstream services.

Having discussed these domains - we then identified key areas for action and drew up action plans for each local AgeUK.

Progress meetings - December 2012

Participating Age UKs attended a second set of meetings at which we shared learning from the audits and discussed how the action plans were to be taken forward.

Delivery support - January to February 2013

Innovations in Dementia worked with participating Age UKs providing additional support to enable them to implement or refine their action plans, including:

- Conducting an environmental audit of Age UK premises.
- Meeting with representatives of the Older People's Reference Group to help them make their meetings and processes more accessible to people with dementia.
- Delivering 2-hour awareness sessions for staff and volunteers - including staff who will cascade the sessions to others.
- Meeting with staff to help refine their dementia training strategy
- Meeting with staff to help refine their action plan.
- Meeting with staff to help plan an engagement session with people with dementia.

Way ahead meetings - February 2013

At the final meetings in London, participants shared their action plans, discussed learning from the project, and shared ideas for taking the work forward in the future.

Sharing resources and learning

In support of the project, we adapted a range of Innovations in Dementia resources to support the rollout of action plans. These included:

- An environmental check-list
- Guidelines for consulting with people with dementia and carers
- A guide to producing dementia-friendly written material for people with dementia
- A help-pack for customer facing staff
- Guidelines for managers using the SCIE e-learning for staff and volunteers
- A two-hour awareness session for staff and volunteer induction

These resources can be downloaded at www.ageuk.org.uk/dementiafriendly.

What we learned

In our work with the fifteen Age UKs we encountered a range of creative and innovative approaches to supporting people with dementia. However, most identified clear room for improvement in the accessibility of mainstream services. Given the changing demographic, and the fact that people are being diagnosed with dementia at much earlier stages, this resonates very clearly with the potential of Age UK nationally to respond to the need to make our communities and organisations dementia-friendly.

Most people now being diagnosed with dementia will not need or want specialist services at the time they are diagnosis - they want to remain part of their communities, and Age UK is uniquely placed to make this happen.

The action plans that emerged from the initial audits focused heavily on “the People”, and to a lesser extent on “the Place”.

The people

Most Age UKs identified that resources could best be used raising the level of dementia - awareness of staff and volunteers. This chimed with earlier work with people with dementia who identified “the people” as the most important factor in determining whether a community, or organisation was dementia-friendly.

We learned that awareness-raising need not be resource-heavy, but does need to be targeted at the right people. We worked with Age UKs to produce matrices matching specific roles with existing training resources, so that the right people were targeted for training relevant to their role, making the training more effective.

The place

Audits of premises and written materials showed that very small changes can result in significant improvements to accessibility for people with dementia.

Partners felt that brand bank guidelines from national Age UK should reflect a dementia-friendly approach to design and production.

Examples of ongoing work

Most local Age UKs are rolling out training to staff and volunteers, and many are in the process of auditing premises. Here is a flavour of the range of actions which local Age UKs are now taking to make their mainstream services more accessible and responsive to people with dementia.

Age UK Blackburn with Darwen

is providing support to enable partner organisations to become more dementia-friendly

Age UK Blackpool

is making a film with a service user with dementia to use in training staff and volunteers

Age UK Coventry

has conducted a major audit of premises and written materials

Age UK Doncaster

is developing an access group of people with dementia

Age UK East London

is to conduct a major review of all premises and written materials, and “handypersons” are to given uniforms with name badges!

Age UK Gloucestershire

is reviewing all buildings and published materials

Age UK Isle of Wight

is focusing on making its Good Neighbour scheme dementia-friendly

Age UK Kirklees and Calderdale

is supporting dementia “champions” in each service and engagement events are planned

Age UK Lancashire

will be piloting circles of support for people with dementia

Age UK Norfolk

has produced a comprehensive training package for all staff and volunteers

Age UK Solihull

has made training mandatory for all new staff and volunteers

Age UK West Cumbria

is working with people with dementia to make Cockermouth the first dementia-friendly town in the area

Age UK Wigan

is teaming up with the Alzheimer's Society for engagement work with people with dementia.

Age UK Wirral

has put in a large scale bid to completely remodel their communal areas, and is writing a "statement of rights for service users" to ensure that people with dementia are treated with dignity and respect.

We hope you have found this report useful. We intend to continue to share and develop amongst Partners the best practice which is already taking place in local Age UKs, and to begin to incorporate and embed the work in Age UK nationally.

For more information about Age UK's work on dementia please visit www.ageuk.org.uk/dementiafriendly.