

Department of Health Policy Research

Programme Project

HEALTHBRIDGE

The National Evaluation of Peer Support

Networks and Dementia Advisers

in implementation of the

National Dementia Strategy for England

[Ref: 025/0058]

Lay Summary*

*This lay summary has been written for people with dementia, carers and others wishing to access a summary of the evaluation. The brief report (aimed at commissioners and service providers) and full report are also available. See contact details on page 5.

The Healthbridge evaluation

The Healthbridge evaluation was an evaluation of 40 services supporting people living with dementia (this means people who had been diagnosed with dementia and people who care for them day-to-day).

The services were set up by the Department of Health in 2010 as part of the National Dementia Strategy for England (Department of Health 2009).

Twenty-two **Dementia Adviser Services** were set up. Dementia Advisers are an adviser or team of advisers who support people living with dementia with information and advice that help them to get the support they need. Eighteen **Peer Support Networks** were also set up. Peer Support Networks involve group or individual support by people living with dementia for other people in the same or a similar position. Some peer support groups involved activities, such as music or gardening, while other groups involved discussion about experiences of dementia.

The services were organised in many different ways, involving the NHS, Social Services and Voluntary Sector organisations such as the Alzheimer's Society or Age UK, often within partnerships between the organisations.

What we did.....

There were three main parts to the evaluation:

1. We monitored what went on within all 40 services, including gathering information about people using the services (how many people, and information such as gender, age and ethnic origin). We also found out about the well-being of people using the services through questionnaires which they completed and returned to us.
2. We worked with staff and managers from all 40 services to find out about how they were set up and run. This was done through postal surveys as well as discussions at national meetings.
3. We selected eight of the 40 services (four Peer Support Network and four Dementia Adviser) to study in much more detail. We interviewed people living with dementia as well as staff, managers, volunteers, and other professionals who had come into contact with the eight services about their views and experiences.

Involvement of people with dementia and carers in the evaluation

There were lots of ways in which people with dementia and those who care for them were involved in the evaluation:

- ◆ Everybody who had been supported by any of the Peer Support Network or Dementia Adviser services was asked to complete Well-being Questionnaires and return them to us.
- ◆ A total of 101 people living with dementia who were being supported by the eight services that we studied in detail took part in individual interviews. They were asked about their general well-being and daily life as well as ways in which they had been supported by the Dementia Adviser or Peer Support Network services. These interviews took place in people's homes or places they chose. We met with each person two or three times so that we could get to know each other. Sometimes people with dementia and carers preferred to be interviewed together, other times on their own.

Here, Suzanne, a carer who had accessed support from a Dementia Adviser talks about support from the adviser as well as from peers. She began by describing some of the isolation and stigma she and her husband who had a diagnosis of dementia had experienced:

Suzanne: And you forbade me to talk to anyone didn't you? About it; because you felt there was a great shame about it didn't you? You were very embarrassed.

Suzanne went on to talk about how important support from the Dementia Adviser had been:

Suzanne: It was a pivotal part of that [post-diagnostic] journey that she [Dementia Adviser] should be there because without her we would have fallen through that net, we would have fallen through the black hole, I'm convinced. Because we would not have known which direction to go in...

Suzanne also talked about support from peers, within a group to which the Dementia Adviser had signposted her and her husband:

Suzanne: We're all thrown in the same boat and, you know, sink or swim... but quite often though, you're in a situation where you can, sort of, help other people and having a social life with the kind of people that we do now, you can help share their worries and woes.

The Healthbridge evaluation: what we found out

Here are some of the things that worked well in the Peer Support Network and Dementia Adviser services:

- * The support that people received was specific to their needs and circumstances. For example, people were getting the right information and advice at the right time for them.
- * People were very positive about support from people who were in the same position as they were (peer support). It helped them to feel more confident and to be more independent.
- * Support from Peer Support Networks and Dementia Advisers helped people to find new meaning and purpose. Their lives were not the same as before dementia, but with support from the services they could still find ways to enjoy life, build new relationships and get the support they needed.
- * Peer Support Network and Dementia Adviser services helped people with dementia and their carers to access other services and support through information about services and advice about day-to-day life.
- * Peer Support Networks and Dementia Advisers provided new friendships, and also gave people more confidence in socialising with other people.
- * The services helped to raise awareness about dementia, tackling stigma. This meant that people living with dementia felt more part of their wider communities.

There were instances of confusion between Peer Support Network or Dementia Adviser services and services or organisations that were already providing support for people living with dementia. It was important that all services worked in partnership, including in defining boundaries within and between organisations.

What can those who support people with dementia and carers learn from the Peer Support Network and Dementia Adviser services?

Timing and flexibility of information and signposting that ensures each individual has the support they need at the right time for them is important.

There is a unique quality to support by and for people living with dementia. It is important to acknowledge and nurture this.

Services such as those evaluated are in a good position to understand the needs of people living with dementia and their communities.

It is important to focus on individuals and relationships so that people living with dementia can find purpose and meaning in life after their diagnosis.

There is lots to be learned about how organisations can tackle stigma and discrimination from the services that were evaluated.

What can people who run organisations for people living with dementia learn?

It is important that up-to-date advice and information about all local services and support is available to people with dementia and carers.

Peer support, information and advice can support people living with dementia to be more independent for longer.

When setting up new services it is important to work in partnership with existing services. This includes thinking carefully about overlaps and boundaries between organisations.

Work needs to be done to make sure that people who are not accessing services are able to do so, for example people from ethnic minorities and LGBT communities.

In order to understand the needs of communities, it is important to make use of knowledge and experience within those communities.

Services such as Peer Support Networks and Dementia Advisers can help raise awareness about dementia and tackle stigma.

What can people in local and national government who make decisions learn?

Peer support, information and advice are very important in supporting people living with dementia and wider communities. This needs to be recognised in future policy.

Dementia should be seen as a public health concern, and dementia care should be developed alongside other work on public health.

It is important that dementia is not just seen as a health issue; it affects people's social situation too, and therefore services from health, social care and the voluntary sector need to work together to develop support for every area of life for people living with dementia.

It is important to plan the future of services in order to make sure that changes in staffing and funding do not impact on support received by people with dementia and carers.

The Healthbridge evaluation

Thanks.....

A huge thank you to all of the people with dementia, carers, staff, volunteers and other stakeholders who took the time to be involved in the evaluation. Your input was invaluable and we appreciate you sharing your views and experiences.

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Reference

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