

# The Dementia Engagement and Empowerment Project (DEEP)

## What was DEEP about?

The project looked at work that groups of people with dementia have been involved in.

We were looking at UK projects and groups where people with dementia were influencing services and policies.

The project:

- Collected information about the different ways that groups of people with dementia work. Many groups filled in a questionnaire about their work. A small number of groups were interviewed in more detail.
- Ran two national events for people with dementia early in 2012 – one in London and one in Stockport.
- Involved people with dementia in a reference group for the project.
- Made a film about the project that is available at:  
[www.mentalhealth.org.uk/deep](http://www.mentalhealth.org.uk/deep)

## What kind of work were groups involved in?

There are many examples of work around the UK, led by people with dementia. Work includes:

- Lobbying government ministers.
- Talking to the media about dementia.
- Being on an advisory group for dementia projects.
- Speaking at conferences.
- Giving talks to those who work with people with dementia.

## What did DEEP find out?

We identified 17 active groups of people with dementia across the UK. As well as influencing the world around them, most groups provided social support and activities. People with dementia said this was important.

Many groups are just beginning to get established. Many group members were only just coming to terms with their diagnosis of dementia. They are not yet sure that they want to get involved in influencing work.

It is important that there is support to help people come to terms with a diagnosis. This can help people become more confident and get involved. Practical support was helpful, but groups did not want to be 'taken over' by large organisations.

There is not yet an organised, national way in which groups of people with dementia can influence services and policies. Not everyone thought this was a good idea.

DEEP found that it is difficult for groups to find ways to involve 'seldom heard' people with dementia (e.g. people with more advanced dementia, people with dementia from Black, Asian and minority ethnic communities).

## DEEP – next steps

- People with dementia think it important that there is more work to develop national opportunities for groups to network.
- It is planned that DEEP will continue for another three years.
- The Joseph Rowntree Foundation will provide funding to help to support and develop the work of groups of people with dementia.
- DEEP also sets some challenges for dementia organisations to involve people with dementia in their work.

## About the project

DEEP was managed by the Mental Health Foundation, Innovations in Dementia and Alzheimer's Society. DEEP was funded by the Joseph Rowntree Foundation.

The full report, **A stronger collective voice for people with dementia** by Toby Williamson, is available as a free download at [www.jrf.org.uk](http://www.jrf.org.uk)

email: [publications@jrf.org.uk](mailto:publications@jrf.org.uk)

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