



The Dementia Engagement
and Empowerment Project

DEEP (dementia engagement and empowerment project) – helping to connect involvement groups of people with dementia

September 2015

Dear All

We are coming to the end of this current phase of DEEP. Not much will change in the next phase (from October onwards). However, whilst Rachael is on maternity leave, Steve and Nada, will be your main contacts. This is until the new co-ordinators are in post (early 2016) :

A report about DEEP

A report about DEEP (from 2012-2015) has just been published by Joseph Rowntree Foundation. This report was written by Rachael.

The report includes:

- Details about DEEP and its impact
- Case studies of DEEP groups
- The issues that have arisen
- Outcomes for people with dementia
- A suggested model for a DEEP group

You can read the full report here: <https://www.jrf.org.uk/report/developing-national-user-movement-people-dementia>

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DEVELOPING A NATIONAL USER MOVEMENT OF PEOPLE WITH DEMENTIA – LEARNING FROM THE DEMENTIA ENGAGEMENT AND EMPOWERMENT PROJECT (DEEP)

What's the issue?

Although the voices of people with dementia are increasingly heard, the user movement is still in its infancy. By connecting local groups and individual activists through a national network (DEEP) that engages and empowers people with dementia, people are beginning to work together to set priorities about dementia and to shape political agendas.

Ways forward

• Involvement is not just about consulting people with dementia, but about providing and responding to opportunities for them to shape their own agendas.

• Local groups are where most people with dementia get support to find their voices.

• Health, social and political bodies should involve people with dementia in setting priorities.

• Appropriate funding of local groups is essential to broker the relationship between people with dementia and decision-makers.

• Local organisations, commissioners and decision-makers are key allies for groups.

• People with dementia often feel they have a 'window of opportunity' to be involved, and therefore need to see results from the energies they put into being involved.

• There is a need for mechanisms that support people with dementia to carry on contributing as their needs change, and to ensure that a range of people with dementia, including those with more advanced dementia, can have their voices heard.

Author
Rachael Listerland, Director of
Involvement in Dementia

SEPTEMBER 2015

FIT group (Bradford) included in a report

Joseph Rowntree Foundation have published another report. This is about work in Bradford and York - to create dementia friendly cities.

The FIT group from Bradford have been involved in a lot of this work. FIT stands for Face it Together.

You can read the full report here:

<https://www.jrf.org.uk/report/how-can-we-make-our-cities-dementia-friendly>

HOW CAN WE MAKE OUR CITIES DEMENTIA FRIENDLY? SHARING THE LEARNING FROM BRADFORD AND YORK

What's the issue?

Dementia friendly communities (DFCs) aim to be accessible, inclusive, welcoming and supportive to those affected by dementia, enabling them to contribute to, and participate in, mainstream society. More than 80 places across the UK are now working towards becoming more dementia friendly, with similar movements gaining ground overseas.

York and Bradford – two very different Yorkshire cities – are among those leading the field. This paper contributes to the emerging evidence base by drawing out the key messages from independent evaluations of their DFC programmes.

Ways forward

- The active, meaningful engagement of people with dementia and their families is fundamental
- DFCs must engage with, and achieve equity for, all people with dementia, whatever their circumstances.
- Practical barriers to inclusion must be addressed if normal lives are to be continued
- The human rights of people with dementia and carers must be recognised and promoted
- DFCs must be underpinned by ongoing awareness raising, training and positive media coverage.
- Connections and networks, within and beyond the community, are at the heart of DFCs.
- Local grassroots community activity is the bedrock of DFCs.
- This activity must be supported by strong strategic planning, commissioning and leadership.
- Both primary and secondary health providers have a vital role to play in supporting social inclusion
- There is no simple – each community must develop its own approach.

Authors
Philip Hains, JRF and Anna Owen,
Dear Health Partnership Ltd

SEPTEMBER 2015

EDUCATE have a new website

EDUCATE are a very active member of DEEP. They are based in Stockport. Their aim is to inspire others to live well with dementia, and to involve people with dementia in the lives of their communities.



You can visit their new website here: <http://www.educatestockport.org.uk>

Film about the SURF group from Liverpool

The SURF group from Liverpool have made a film with Joseph Rowntree Foundation.

SURF stands for Service Users Reference Forum. It includes people with dementia, family carers and professionals working together.

The film is called “*Window of Opportunity*”.

In this film Tommy Dunne and Gina Shaw describe the achievements of the group and their ambitions to transform Liverpool into a city that enables people living with dementia to live full and active lives independently for as long as possible.



You can watch their film here: <https://vimeo.com/137476446>

New DEEP group in Wales

The Memory Team and Nexus have been awarded funding by DEEP to establish a new service user involvement group. The area has a strong group of carers who inform services and policies. However, the voices of people with dementia have been missing.

Since March, this exciting new group have met twice and have a third meeting planned for September. At our next meeting, members are looking forward to a visit from EDUCATE. EDUCATE is an established service user involvement group from Stockport. We are pleased to be able to learn from their experiences.

Already the group have provided feedback on national targets for Memory Assessment Services in Wales. And, at the last meeting information leaflets given to people with dementia were reviewed and discussed. A collated response was then passed onto the University Health Board who are currently revising their literature.

Dementia Congress 2016 - make your point

We are really pleased that DEEP will be part of the opening session again at Dementia Congress 2015. Dementia Congress is a large national conference that showcases work around dementia. There will be two speakers from DEEP groups as part of the opening session. DEEP groups are also involved in a range of workshops.

As part of the opening session we would like to include many more views by people with dementia. We would love as many people as possible to respond to the following question:

What does a 'good life?' look like for you. Please tell us in one sentence or in one picture! Please email your response to [**steve@myid.org.uk**](mailto:steve@myid.org.uk)

Issues facing younger people with dementia

DEEP is working with Young Dementia UK to make a film. This will share the issues faced by younger people with dementia (under the age of 65). **If you are a younger person with dementia, what would you like others to know about your experience?**

We would like to hear your views about:

- family
- work
- money and financial issues
- the support/services you want
- the psychological impact of being a younger person

Again, it would be great if you could tell us in one sentence or one picture! Please email any comments to Kate Fallows at Young Dementia UK. Email: katefallows@youngdementiauk.org

DEEP celebration event

Please hold the **10th November 2015** in your diaries. The event will **showcase** all the work of DEEP groups, including those who received DEEP involvement grants. It will be a chance to **meet people** from other DEEP groups. And an opportunity to **influence** the next phase of DEEP.

The meeting will be a one day event in **Birmingham**. There will be limited numbers - 70 people maximum. We will therefore need to restrict the numbers of people who can attend per group.

Information about how to register for the celebration event was sent to your group in mid-September. If you have not received this, please contact: nada@myid.org.uk

Keep in touch

Let us know about your work. It is great to share it through the DEEP update. Here are the contact details for Steve and Nada.



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