

A STRONGER COLLECTIVE VOICE FOR PEOPLE WITH DEMENTIA

What's the Issue?

A growing number of people with dementia in the UK have become actively involved in groups to try to influence services and policies affecting the lives of people with dementia. The Dementia Engagement & Empowerment Project (DEEP) aimed to investigate, support, promote and celebrate these groups.

Ways Forward

- Groups led by or actively involving people with dementia need to identify how they want to develop their influencing activities, and how they want a network to engage with them, including people with dementia from 'seldom heard' groups, and the support they need to do this.
- Governments and the Department of Health need to ensure that all dementia policy initiatives have clear plans for involving people with dementia, offer support and resources and promote positive stories to the national media. Specialist health and social care media need to incorporate regular features and comments written by people with dementia, and promote positive stories of involvement to the wider media.
- National and local organisations providing services or working with people with dementia need to develop and implement involvement plans, allocating resources to develop new groups, link groups together and help them share resources.
- Event organisers need to incorporate sessions at dementia-related events for groups of people with dementia to talk about their involvement work, and provide support and resources to enable people with dementia to attend these events. Trainers and educators need to build in regular sessions led by people with dementia in the training of students and staff.
- Researchers and research networks need to involve groups of people with dementia in helping to identify research topics, advise on research findings and undertake research on topics identified as important by people with dementia.

Authors

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BACKGROUND

There are around 800,000 people with dementia in the UK and this figure is set to increase dramatically because of our ageing population; the risk of developing the most common forms of dementia such as Alzheimer's disease increases with age. In recent years, dementia has attracted much more public and political attention. All four UK nations either have, or plan to have, national dementia strategies in place to address the challenge that dementia poses.

There is widespread recognition of the benefits of 'service user' or 'citizen involvement' in public policy, both at an individual and collective level. Although the language of involvement has not been so widely used in the field of dementia the activities of a number of groups and projects involving people with dementia have been similar to those undertaken by groups of people with other disabilities and diagnoses. However, these activities have only begun to develop in the last 10 years involving people with dementia. They are much less widespread and there has been no systematic attempt to map out these groups and activities, or explore what the various groups and projects might want in the future.

The Dementia Engagement & Empowerment Project (DEEP) aimed to explore, support, promote and celebrate groups and projects led by or actively involving people with dementia across the UK that were influencing services and policies, affecting the lives of people with dementia. DEEP was a one-year project which finished in Summer 2012. It found that:

- There are only a small number of groups led by or actively involving people with dementia that are influencing services and policies. A 'service user movement' of people with dementia, though growing, is still at an early stage.
- 'Influencing' type work included national lobbying and meeting with government ministers and officials, local lobbying of services, media work, training and education, participating on advisory groups, awareness-raising work, and speaking at events.
- Most groups undertook a mixture of both influencing type work together with peer support and social activities. Most groups and projects were supported by organisations or services with staff and carers involved. The way that people with dementia decided on the groups or project varied but was usually done through informal structures and processes.
- Most groups were local in their geographical scope and relatively informal in terms of their membership and wanted to remain that way. Some groups faced practical difficulties in terms of funding and most groups found it challenging to include people with more severe dementia or from other 'seldom heard' groups.
- The idea of a UK-wide network of groups and projects led by or actively involving people with dementia doing this kind of work was welcomed. It was felt that a network should primarily support the development of new and existing local groups but could also have a national influencing role. It would need to be supported by a national organisation, providing people with dementia could stay in control.

Overview of DEEP

DEEP aimed to draw a comprehensive picture of leadership, participation and empowerment involving groups and projects of people with dementia. It also aimed to explore what those groups and projects wanted or needed to support the further development of leadership and participation involving people with dementia, including the possibility of a national network. The project had several components:

- A mapping survey involving a literature review, questionnaire (that was sent to 162 organisations who were encouraged to ‘cascade’ it on through their own networks and contacts) and follow-up interviews to collect as much information about all the groups and projects across the UK led by or actively involving people with dementia, influencing services and policies;
- A national event to bring groups of people with dementia together to discuss the findings of the survey and the possibility of a national network;
- A published report and film that would capture the activities, learning and information gathered by the survey and the event; and
- An extended reference group network of people with dementia to ensure that the key components of DEEP were relevant, meaningful and, as far as possible, shaped by people with dementia.

The project was managed through a collaborative partnership led by the Mental Health Foundation, a UK research and development charity, working with Innovations in Dementia, a community interest company, and the Alzheimer’s Society.

The mapping survey

Data was collected between summer 2011 and spring 2012. There were 85 responses to the questionnaire from groups and projects, and 22 responses from individuals with dementia. The majority of responses came from England but there were groups identified who were operating in Scotland and Wales. No responses were received from Northern Ireland. Participation in the survey was open access and a number of groups and projects that responded appeared to have misunderstood the survey as their involvement focused primarily on carers of people with dementia or the involvement of individuals in their own care and treatment (which though important, was not the focus of the project).

Thirteen telephone interviews were undertaken and three face-to-face group interviews.

There were two types of questionnaire that could be completed (a short one and a more detailed one). Table 1 summarises the breakdown of respondents from the analysis of the more detailed questionnaire and information obtained through the follow-up interviews.

Table 1

Please note: groups and projects were placed in one category only although all ten of the groups/projects where there was leadership by people with dementia also had active involvement of people with dementia.

Leadership and/or active involvement of people with dementia in the group/project?	Number of groups/projects
Yes, leadership	10
Yes, active involvement in ‘influencing’ type activities	7
Yes, leadership/active involvement but focused only on the service that people were using or time limited to a specific project	7
No	6
Not clear	10
Others (making plans for future leadership)	3

The national event

The original plan had been to hold one national event, and this took place in February 2012 in London. However, thanks to the offer of support from a group in the north west and an NHS foundation trust

a second event was held in Stockport in March 2012. In total, the two events involved ten groups and 46 people with dementia attending.

Discussions at the events explored in more detail the findings from the survey as well as the idea of a national network of groups and projects, for which there was considerable support.

The extended reference group network

In keeping with the underlying principles of DEEP it was essential that the project should involve and include people with dementia in how it developed. This was done through establishing a network of groups and individuals with dementia. The network was supported by Innovations in Dementia who ensured its members were properly involved. It included a number of individuals and groups already known to DEEP but it also expanded as the project progressed. By the end of the project the network had over 30 individuals and groups. The network played a key role in developing the mapping survey and shaping the national events.

Reflections on the current context

It is only in the last 15 years that a public discourse about dementia has emerged in the UK. However, until very recently people with dementia were 'talked about' in this discourse, but rarely 'talked with'. And when they were talked about it wasn't often they were talked about as people, but usually just as a container for the more important issue, dementia itself. The dementia 'discourse' ticked all the boxes of a medical model dominating conceptualisation of a much more complex issue. And whether it was professionals, charities, media or politicians the 'd' of dementia seemed to be reflected in the vocabulary used to describe the condition – 'a devastating disease', 'deficit', 'a living death' (though virtually never 'disability'). In the absence of cures or universally effective treatments people were frequently ignored, at the receiving end of stigma, or 'therapeutic nihilism' – the view that it is pointless helping people with dementia. If attention was paid to them, the focus was almost entirely on controlling symptoms and finding causes or a cure. It was almost entirely bio-medicalised as an illness. The person, their life – past, present and future – sense of self, agency, and subjective experience, was treated as almost irrelevant so corrosive was the effect of a dementia diagnosis on personhood.

Much of this discourse is still evident in 2012. And few would argue that people with dementia should not have the right to expect professionals and scientists to make as much effort as possible to find and apply effective treatments as has been done with other long term conditions that are equally as severe in their disabling symptoms. But in the same way that it is correct not to contest this, so too should the discourse about participation, empowerment, citizenship and social justice that is present with other long-term conditions be applied to, with, and by people with dementia.

The last 10 years have seen remarkable developments in the awareness, understanding, and public profile of dementia and this has made significant inroads into the negative discourse of therapeutic hopelessness, stigmatisation, and almost total 'disabilisation' of people with dementia. In the same period there have been an enormous number of dementia-related policy announcements and many of these have not only challenged that discourse but have tried to do this with the active involvement of people with dementia. This has not always been easy or worked smoothly but it is nevertheless a very significant change. People with dementia have become visible, as "real" people able to express their views, experiences, hopes, fears, frustrations and many other things, not just about their dementia but about their lives in general. Agency, self, subjective experience, empowerment, personhood, participation, citizenship, leadership, have all been shown to be viable, credible, achievable concepts that can be made real and meaningful by individuals and groups of people with dementia, just as they have been for people with other illnesses, conditions and disabilities. DEEP found this to be happening at a national level, but just as importantly, at a local level too.

On the basis of what people with dementia have said as part of DEEP it also seems reasonable to assert that the recent 'challenges' on dementia announced by the Prime Minister cannot be addressed and overcome without the active involvement of people with dementia in both the methods used

and evaluation of success. Ensuring health and social care services are meeting the needs of people with dementia, that communities are becoming truly 'dementia-friendly', and that research addressing topics important to people with dementia must involve people with dementia (as well as families and professionals) in the process as well as in measuring outcomes and success. Groups of people with dementia at both local and national levels are well placed to become involved in this work if they so wish and are invited to do so. If they are not invited, but want to be involved, then they should be supported to make their voice heard and responded to positively.

However, it should also be recognised that a 'dementia service user involvement movement' or 'dementia rights movement' still barely exists as compared to many other disability groups, and for lots of people with dementia involved in groups and projects those phrases are not ones that they would recognise or accept. DEEP found that most groups and projects are small, local, relatively recently established, and involve partnerships and support from mainstream health, social care or third sector organisations. They tend to combine activities focused solely on their members, such as social events and peer support, with more outward-facing 'influencing' activities that may not involve all members or be such a regular part of their day-to-day functioning.

Collective 'activism' involving people is still small scale and in its early days (perhaps with the exception of the SDWG) and this may be frustrating for those eager to develop a national movement (or network) and achieve objectives which will make a real difference to the lives of people with dementia through influencing at a national level, research, services, policies, communities and society. The fact that dementia is a progressive and terminal condition should not be underestimated when recognising the frustration that many people with dementia feel, who have these aspirations. Enabling people with dementia to come together, share experiences and learning, and plan these kinds of activities was an important theme that emerged from DEEP. Arnstein's concept of 'citizen control' is clearly the type of goal that some individuals and groups with dementia are aiming for.

Yet it is also important to give just as much recognition and support to local groups doing local activities to influence at local levels. The very fact that these groups are grassroots, provide peer support and social activities for members, as well as opportunities to influence, makes them accessible and inclusive of people with dementia who may get involved for a wide variety of reasons. These groups, and individuals involved with them, may participate at all sorts of different levels of Arnstein's ladder because this is what they choose to do and feel comfortable with – over time they may aspire to 'citizen control' but this should not be something imposed upon them or required of them to 'prove' they are led by or actively involving people with dementia. This is where Marsh & Macalpine's work is much more useful in understanding where the different groups that engaged with DEEP were 'at'. Enabling these kinds of groups to come together and share their experiences and learning was also an important theme that emerged from DEEP.

There was virtually a unanimous consensus that there would be real benefits in a national network that can connect groups involved in the activities identified through DEEP. By making this an inclusive network which includes groups and projects led by or actively involving people with dementia choosing to operate anywhere, or in a multiplicity of places on Marsh & Macalpine's 'continuum', groups can learn and develop from each other, stay connected with grassroots local activity as well as potentially become more involved in national influencing work. At one of the events the phrase '*think locally, act nationally*' was suggested as a way of conceptualising a possible network (although a group like the SDWG are clearly thinking and acting nationally), but the findings from DEEP indicate a slightly more nuanced version of this is more appropriate along the lines of '*think locally, act locally, network nationally*'.

Despite the more positive dementia discourse and political attention that is being paid to it the current ideological and economic climate does not generate optimism that there will be a significant increase in resources from the public sector for dementia. Furthermore, initiatives to support the involvement and empowerment of people with dementia are seen by many to be luxury 'add-ons' which can be ill-afforded compared to the resource demands of direct health and social care provision, and research. But DEEP found that collective involvement and empowerment has real value not only for people with dementia but the services they use, the communities they live in, and the policies that affect their lives. For this value to be sustained and built upon commitment and resources are needed to support and develop existing groups as well as building capacity by supporting new groups to be set up and develop.

DEEP was a snapshot in time of a new, emerging movement in the field of disability. The next section summarises the main themes, next steps, and recommendations but it is hoped that this report and the associated films will be an important record not only of the project but of that movement more broadly. The moment in time is well encapsulated by Professor Murna Downs from the Bradford Dementia Group, a university initiative that is committed to the active involvement of people with dementia, in her title for a recent conference presentation, 'From invisible patient to citizen and activist – dementia comes of age' (*British Society of Gerontologists Annual Conference, July 2012*). But time moves on and it seems therefore fitting to conclude with a quote from one of the groups, that captures the sense of change and impact that has occurred and will take place in the future – “it’s the ripple on the pond effect”.

Next steps

The vision underpinning JRF’s proposed new programme on dementia ‘Dementia without Walls’ (2012–2015) is that the UK is a good place for people who have dementia to live, and live well. The difference JRF wants to help make is: people living with dementia are more understood, *more heard, more included, more connected and more supported* – with and by each other, their local communities and society as a whole.

JRF will be supporting a continuation project which will build on DEEP, involving the organisations that collaborated on DEEP (Innovations in Dementia, The Mental Health Foundation, the Alzheimer’s Society, and the groups led or actively involving people with dementia).

The goal is to support the development of a collective voice of people with dementia through investing in emerging and established groups. ‘DEEP2’ will support the more established and ambitious groups in sharing their knowledge and expertise, building capacity around the UK (e.g. ways of harnessing social media and other new technologies for empowerment and influence). It will also seek to demonstrate the value of supporting networks led by people with dementia to actual and potential funders by collecting evidence of the impact of this on policy and practice. The project will build capacity in groups that are at an earlier stage and in parts of the country where there are no groups genuinely led by people with dementia that have been identified, and consider how to sustain itself beyond current JRF funding.

DEEP2 will use the expertise of the existing involvement groups to build capacity elsewhere and to support the development of a network of groups of people with dementia. People with dementia will be supported to be co-producers at every stage of the project, and to be fully engaged in the project from the outset. Groups, and individuals within groups, will be recruited to formally participate in the DEEP2. Roles and approaches to enable people to participate in a range of ways, depending on their individual circumstances, will be defined. People with more advanced dementia will be enabled to participate by routinely using a range of engagement methods. Groups will be helped to share knowledge and ideas with each other to enable capacity building, with the aim of setting up a functioning network that is sustainable and able to grow, and that reflects the wishes of people with dementia.

The project will be working proactively with individuals within groups, and groups as a whole, to become more confident, learn new skills and have opportunities for engagement, at a local and national level (where this is desired). It will link with any other emerging networks of people with dementia, including individuals not connected to groups, who feel the DEEP project is of relevance to them. The project may also produce resources to assist other organisations to further their engagement with people with dementia.

The project will keep abreast of, and link groups of people with dementia to, relevant initiatives, including work on dementia-friendly communities, the implementation of the national dementia strategies, and dementia action alliances.

The main outcomes will be:

- 1 A stronger collective voice of people with dementia, with more confidence and capacity to influence attitudes, policies and provision;

- 2 Empowered individuals within groups who feel more confident and aware of engagement and influencing opportunities, and what they can achieve;
- 3 Empowered groups who are having influence at a local, regional or national level.

Conclusion

On the basis of DEEP's findings a number of recommendations can be made for groups, projects, services, and organisations in contact with people with dementia. Involvement and empowerment of people with dementia should not be regarded as something that is done solely as a discrete piece of work or a particular project (although this may be necessary as well) but as integral to the work of any organisation that is seeking to improve the lives of people with dementia. Not all of these organisations will necessarily have the skills, knowledge or experience to know how to involve people with dementia but the groups and projects identified through DEEP, and the organisations that have been involved with DEEP can provide advice and guidance to help them to do this. The success of future involvement and empowerment work depends as much on the support of other organisations as it does on the commitment and hard work of the groups themselves.

Here are our specific recommendations as to how this support and commitment can be demonstrated:

For groups led by/actively involving people with dementia or groups planning to do this in the future, that want to participate in a network:

- Discuss and identify how they would like to develop their influencing activities and what support they would want from a network to do this. Also discuss and identify their achievements, experiences, and expertise in this type of work which they could share with others through a network.
- Discuss and agree how they would want a network to engage with them and be accountable to them for its work.
- Be supported to engage people with dementia from 'seldom heard' groups e.g. Black, Asian and minority ethnic groups, people with learning disabilities, people with more severe dementia, etc.
- Be supported to engage effectively with organisations and services, work collaboratively, share learning, and develop tools to measure impact.
- Where desired, to be supported to build alliances with involvement and empowerment initiatives involving people with other disabilities and illnesses, as well as carers' groups.

For governments/Department of Health:

- Ensure that all dementia policy initiatives have clear plans for the proper involvement of people with dementia in their design, implementation and evaluation.
- Ensure that this involvement includes active engagement with local groups and projects for people with dementia, as well as high profile, prominent campaigners.
- Offer support and resources (including 'in kind' e.g. venues, access to training, etc.) for the proper involvement of people with dementia in ongoing implementation of national dementia strategies, and the PM's challenge, in the design, development and evaluation of initiatives addressing the challenge.
- Promote positive stories of involvement and empowerment to the national media.

For national and local organisations providing services and/or working with people with dementia:

- Clinical commissioning groups, health boards, local authorities, service provider organisations (third sector and 'for profit') - develop and implement involvement plans for people with dementia, with the required support and resources.
- Allocate resources to capacity-build local groups and projects and support the development of a national network to link groups together.
- Avoid cuts in funding for groups and projects wherever possible but work in partnership with other organisations to share resources (including 'in kind', e.g. venues) to enable groups under threat of closure to continue.
- Implement practical guidance to be developed by DEEP partners on involving people living with dementia in meetings, events, etc.
- Invite groups to contribute to staff training, design and evaluation of services, etc.

- Signpost individuals with dementia following diagnosis to local involvement groups where the person is expressing an interest in this kind of activity.

For dementia action alliances:

- Develop and implement involvement plans for people with dementia, with the required support, resources and reporting on implementation of those plans.
- Ensure that a commitment to involvement and empowerment is expressed in strategies and public declarations.
- Support groups with resources and 'in kind' support e.g. paying expenses, facilitating participation, etc.
- Promote positive stories of involvement and empowerment to the national media.

For specialist health and social care media, and media sections in relevant organisations:

- Incorporate regular features and comments written by people with dementia and reflecting the work of groups and projects involving people with dementia.
- Promote positive stories of involvement and empowerment to the wider media.

For event organisers:

- Incorporate sessions at dementia-related events for groups of people with dementia to talk about their involvement and empowerment activities and work.
- Provide support and resources to enable people with dementia to attend these events.

For trainers and educators:

- Build in regular sessions led by people with dementia in the training and education of students and staff on professional training or dementia-related courses.

For researchers and research networks:

- Involve groups of people with dementia in helping to identify research topics, advising on research findings, discussion and dissemination of findings (recognising this can also help demonstrate research "impact").
- Undertake research on topics identified as important by people with dementia.

For organisations planning to make themselves and their communities more 'dementia friendly':

- Involve groups of people with dementia in developing and evaluating their plans, and providing resources and support to enable their participation to do this.

For health and social care organisations (including third sector organisations) working with 'seldom heard' groups:

- Support people with dementia who wish to be involved in influencing activities to participate in existing groups or projects, or to use learning from these groups to develop new groups reflecting the particular needs and issues of those involved.

Information about Groups

Leadership and active involvement groups

ACE Club - Rhyl, North Wales

The ACE Club raises awareness and educates professionals and communities about the experience of living with young onset dementia; it also provides peer support and activities for people living with a diagnosis of young onset dementia in the local community.

Contact: Vivienne Davies-Quarrell

Telephone: 01745 345369

Email: vivienne@ace-alzheimers.com

Website: <http://ace.glendevon-care.com/>

Doncaster Dementia Forum – Yorkshire

The Forum lobbies and influences local service development and holds the local Older People's Mental Strategy Group to account.

Contact: Wayne Goddard

Telephone: 01302 566500

Email: Wayne.goddard@doncasterpct.nhs.uk

Website: n/a

EDUCATE (Early Dementia Users Co-operative Aiming To Educate) – Stockport

EDUCATE looks to give people living in the Stockport area with dementia a voice through involvement in training, or speaking to others about their experiences of having dementia.

Contact: Mark Perry

Telephone: 0161 419 6016

Email: markperry@nhs.net

Website: n/a

Forget Me Not - Swindon

Forget Me Not is a group of people with dementia under the age of 65 who come together for peer support and social activities as well as raising awareness about dementia with professionals and in their communities.

Contact: Lynda Hughes

Telephone: 01793 436775

Email: Lynda.hughes@awp.nhs.uk

Website: n/a

Hope Group - Brighton

HOPE is a group of people living with dementia who aim to increase the knowledge of all staff and students in health and social care by sharing experiences of living with dementia, improve the situation of people with dementia and their carers by raising awareness through training and work in partnership with professionals to promote better working relationships for the benefit of professionals and people living with dementia.

Contact: Kirsty Jones

Telephone: 07702 096264

Email: kirsty.jones@westsussex.gov.uk

Website: n/a

Living with Dementia Group - England

The Living With Dementia Group (LWDG) has been part of the Alzheimer's National Living With Dementia Programme which has involved people with dementia sharing their experiences and knowledge, and raising awareness of dementia at local and national levels through a wide range of activities including giving presentations, media work, influencing policymakers and acting as a consultative body for the Society. The Society is currently reviewing its approach to involvement as the first stage of a new five-year development programme.

Contact: Gaynor Smith

Telephone: 0207 423 5158

Email: gaynor.smith@alzheimers.org.uk

Website: www.alzheimers.org.uk/involvement

Open Doors Project - Salford, Greater Manchester

The Open Doors Project employs a person with dementia and leads on the development of a range of initiatives across Salford, including a dementia cafe providing post-diagnostic education and support (in conjunction with memory services), a friendship and support network for individuals newly diagnosed, participates in steering groups in relation to key service redesign, provides education to professionals in relation to dementia, and supports and disseminates research and development in dementia in conjunction with Manchester University.

Contact: Gillian Drummond

Telephone: 07771972628

Email: gillian.drummond@gmw.nhs.uk

Website: n/a

Positive Dementia Group - Aberdeen

The group has been involved in awareness raising through giving talks to students, chaplains, social workers etc. They have also been involved in media work (e.g. radio interviews, TV, newspaper articles & 'Through Our Eyes' DVD). Some members have spoken at conferences about their experience. They have also been involved in consultation by the local authority/NHS to use their experiences and comments in influencing policies/strategies including more recently the Scottish Dementia Strategy. Some are involved in research too.

Contact: Sarah Geoghegan

Telephone: 01224 644627

Email: sgeoghegan@alzscot.org

Website: www.alzscot.org

Scottish Dementia Working Group (SDWG) - Scotland

The SDWG is a national campaigning and awareness-raising group made up of over 100 people with dementia.

Contact: Martin Sewell

Telephone: 0141 418 3939

Email: sdwg@alzscot.org

Website: www.sdwg.org.uk

Torbay Dementia Leadership Group - Devon

This is an Empowerment Group of people with an early diagnosis of dementia which provides some peer support, discusses matters and services concerning people with dementia, and is active in influencing local services and organisations.

Contact: Norms McNamara

Telephone: 01803 669216

Email: norrms@gmail.com

Website: n/a

Active involvement groups

Alzheimer's Society Research Network - England

Alzheimer's Society Research Network is a team of over 200 carers and people with dementia who are involved in setting the Society's research priorities, prioritising and commenting on grant applications, sitting on grant selection panels, monitoring ongoing projects funded by Alzheimer's Society and telling others about the results of the research.

Contact: Matt Murray

Telephone: 0207 423 3603

Email: matt.murray@alzheimers.org.uk

Website: www.alzheimers.org.uk/researchnetwork

Alzheimer's Society Service User Research Panels (SURPS) - England

SURPS are small groups of people with dementia who use existing Alzheimer's Society services and who meet regularly to review organisational tools such as evaluation questionnaires, materials such as information leaflets, and processes such as service development. They also respond to requests from external organisations to discuss issues or developments relevant to dementia. SURPS are facilitated by a member of Alzheimer's Society staff but in a way that prioritises the needs, choices and views of panel members. In this way SURPS act as a way for people with dementia to make their voices heard.

Contact: Jane Tooke

Telephone: 0207 423 5135

Email: jane.tooke@alzheimers.org.uk

Website: n/a

Bay Tree Voices - Bradford

People with dementia involved in making film clips which are used in educating care practitioners.

Contact: Andrea Capstick

Telephone: 01274 235192

Email: a.j.capstick@bradford.ac.uk

Website: n/a

Circles of Support for People with Dementia - England

A project to develop circles of support for people with dementia – people with dementia are actively involved in advising on the project.

Contact: Alison Macadam

Telephone: 01202 471423

Email: alison.macadam@ndti.org.uk

Website: www.ndti.org.uk

Involvement Project - Involving people living with Dementia - South West England

The project worked in partnership across health, primary, social care and voluntary organisations, to strengthen and enable engagement and involvement with those living with dementia in the south west. This has included developing 'what works for involvement' resource cards; measuring and monitoring the improvements that have been made as a consequence of engaging and involving those people living with dementia to inform the implementation of the National Dementia Strategy; and building a network of involvement opportunities for people with dementia across the South West that offers a coordinated approach through which they can communicate their views in shaping what help and support is needed now and in the future.

Contact: Anne Rollings

Telephone: 0117 9672992

Email: anne.rollings@alzheimers.org.uk

Website: n/a

Memory Services National Accreditation Programme (MSNAP) - England

MSNAP works with services to assure and improve the quality of memory services for people with memory problems/dementia and their carers. Involving service users and carers in MSNAP is a priority, and people with first hand experience of using memory services are encouraged to get involved in all stages of the accreditation process.

Contact: Emily Doncaster

Telephone: 020 7977 6644

Email: edoncaster@cru.rcpsych.ac.uk

Website: www.rcpsych.ac.uk/memory-network

West Berkshire Empowerment Group - Berkshire

The Empowerment Group, all of whom have memory problems, meet on a monthly basis. This is followed by a meeting to discuss steering the work of the local Alzheimer's Society, GPs, Memory Clinics, NHS services etc.

Contact: Claire Garley

Telephone: 01635 500869

Email: claire.garley@alzheimers.org.uk

Website: n/a

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About this paper

The purpose of this paper is to describe the Dementia Engagement & Empowerment Project (DEEP). DEEP was initially a one-year project that finished in 2012 and aimed to investigate support, promote and celebrate groups of people with a dementia diagnosis across the UK that were trying to influence services and policies affecting the lives of people with dementia. It was a multi-faceted project involving a mapping survey, events, films and a reference group made up of people with dementia. The paper summarises the findings and outcomes from the main report about these activities, reflects on the involvement of people with dementia in influencing services and policies, and makes recommendations for how to build on this work in the future.

FOR FURTHER INFORMATION

This summary is part of JRF's research and development programme. The views are those of the authors and not necessarily those of the JRF.

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

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ISSN 0958-3084
ISBN 978 1 85935 944 0

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