

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.

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BACKGROUND

The Dementia Engagement and Empowerment Programme (DEEP) is a growing user movement across the UK. It connects involvement/influencing groups of people with dementia – groups where people with dementia are working together to raise awareness about dementia – to policy-makers and decision-makers, to influence local dementia practice and strategy, and to challenge the existing narrative about what it is like to live with dementia.

This paper describes the growth of DEEP over a three-year period (2012–2015). This was preceded by a scoping study in 2011–2012 that mapped the groups and projects involving people with dementia across the UK and explored what these groups and projects needed to support the further development of their work (Williamson, 2012). Twelve groups (and four time-limited projects) across the UK were identified. They agreed that they would like opportunities to network and connect together, share ideas and sometimes work collectively on national dementia issues. Out of this the DEEP network was born. The network is managed by Innovations in Dementia in partnership with the Mental Health Foundation. The Joseph Rowntree Foundation funded this three-year phase of the work, joined by Comic Relief for the final two years.

At the time of writing there are 50 groups in the DEEP network, translating as 1,000 voices of people with dementia, as well as a number of individuals with dementia who work as activists/influencers independently rather than as part of a group. This has been a rapid rate of increase from the 12 groups that joined the new network following the scoping investigation of 2012. Groups operate in a variety of ways. Some are campaigning groups, some are awareness-raising and training groups, some work on consultations and local practice or policy development, some are working to create dementia friendly communities, while others get involved in opportunities as they arise, such as making films. Some are large (the Scottish Dementia Working Group has more than 150 members), some work on a country-wide basis (e.g. the Northern Ireland Dementia Action Group). Most, however, are smaller, local groups, varying between 10 and 30 members. What connects them is the notion of people with dementia being engaged in discussions, decisions and interesting work, which for many people ultimately leads to a sense of empowerment. Groups are supported and 'housed' by a variety of organisations including the NHS, local authorities and local charities including the Alzheimer's Society, while some groups exist within service settings (e.g. day centres). A small number of groups have set themselves up independently, with a constitution and bank account, and are led by people with dementia. Most of the groups have paid staff members who provide practical support to the running of the group, as well as volunteer support.

The costs of running a group are variable and a lot of staff members absorb their support of the group into their day jobs. In-kind support is often provided via free meeting rooms and refreshments. Independent groups often seek out grant or other funding to cover their costs, including the hire of staff support.

Case study: EDUCATE (Stockport)

Early Dementia Users Co-operative Aiming to Educate

EDUCATE is a DEEP group supported by the NHS. It has 18 members who take an active role in delivering training to professionals across Stockport (and sometimes nationwide) alongside dementia training staff. Members share their individual stories of living with dementia and also highlight their expectations of how professionals should engage with and support people with dementia. You can find out more about EDUCATE at www.educatestockport.org.uk.

Case study: The Forget Me Nots, Swindon

The Forget Me Nots are members of a day care service in Swindon. The service provides care and support to up to 40 people with dementia each week. The ethos of the service is about engagement, participation and maintaining people's sense of role, contribution and purpose in life. The Forget Me Nots have been involved in a range of influencing work including redeveloping the Social Care Institute for Excellence (SCIE) Dementia Gateway (www.scie.org.uk/publications/dementia/index.asp), making films about dementia (www.innovationsindementia.org.uk/videos_walkinggroup.htm) and providing a user perspective to a European grant-making process.

Case study: SURF group (Liverpool)

The Service Users Reference Forum is a large involvement group made up of people with dementia and carers, sitting alongside a range of commissioners, dementia leads, and members of the Liverpool Dementia Action Alliance. The group is co-chaired by two people with dementia. They work on a range of issues including creating a dementia friendly Liverpool, raising awareness with school children, and working on innovative product development.

Why is DEEP important?

The involvement of people with dementia has become an explicit expectation in health and social policy and practice over the last few years. We have seen similar transformations in other social movements where the rights of people to have their voices heard have become embedded e.g. the civil and gay rights movements. People with learning disabilities and people with mental health issues are also increasingly involved in the issues that are important to them and are setting agendas about services, policy and practice in many areas, as well as working to shape societal responses and overcome prejudice and discrimination (e.g. the Time to Change programme www.time-to-change.org.uk)

The National Dementia Strategy (2009) states that the person with dementia (and their carer) should be placed centre stage in terms of saying what was important in their lives and what a good life with dementia looks like. The more recent Care Act (Department of Health, 2014) places obligations on local authorities to ensure that people can exercise individual control and choice, with particular attention to the individual's views, wishes, feelings and beliefs.

Yet although these and other policy documents commit organisations to involving people with dementia, it is only now that a new social movement among people with dementia, based on the mantra 'nothing about us without us', is beginning to build. For many years, carers were the proxy voice for people with dementia, speaking on their behalf. People with dementia tended to be diagnosed at a late stage of their illness, with delivery of care being considered more of a priority than involvement. Within this context, people with dementia have had an uphill struggle to find their voices, and then to have them heard.

Things are changing though. Earlier diagnosis, an increased discussion of people's rights to be involved, and more empowered people with dementia (for example through the DEEP network) are all contributing to the increased involvement of people with dementia. More confident and empowered people with dementia are beginning to set their own agendas about the issues they want to shape and to have stronger expectations about how others will engage with them.

What has been the role of DEEP?

"DEEP is part of our identity now. We feel part of a bigger voice, a movement, that we're stronger together."

Member of a DEEP group

DEEP is the network of involvement groups. It also supports groups within the network (through member groups, Innovations in Dementia and the Mental Health Foundation). This essential support includes:

- building connections between groups, mapping interests and skills
- brokering national opportunities for people with dementia to be involved and influential;
- collating and developing good practice about involvement groups or involvement approaches;
- being a central repository of the work, ideas and solutions of groups and keeping groups updated about each other's work;
- funding local groups and initiatives who have ideas about increasing the involvement of people with dementia;
- setting expectations about how others will engage with and involve people with dementia effectively and supportively.

Building connections between involvement groups

"You can start to think that you are the only ones doing it – DEEP helps you to see you are not alone."

Member of a DEEP group

A lot of work has taken place to encourage groups to feel part of something bigger, and to make links with other groups across the network. Networking events have brought groups in close geographical proximity together, forging relationships between them and a sense of solidarity as people with dementia realised that groups often had shared agendas. Groups have travelled to visit each other, met up at conferences and used Skype to share ideas, inspiration and knowledge. In this way groups have started to identify and talk about themselves as a member of DEEP as well as of their own local groups.

Case study: Residential meeting for people with dementia

This three-day event, held in March 2015, brought together people with dementia who have been doing work on the national dementia scene. This includes speaking at conferences, being members of national advisory groups, and using social media to promote dementia awareness worldwide. The event focused on drawing together previous contributors to the national dementia scene and new dementia activists. Residential meetings have the advantage of people being able to spend good quality time together as well as 'work'. This makes for a more relaxed meeting, where lots of good ideas come forward in the social time as well as the working time. Discussion and debate resulted in a set of collective views and actions for DEEP.

Case study: mentoring to new groups by more established groups

Members of the Scottish Dementia Working Group (SDWG) travelled to Belfast to talk with a group of 10 people with dementia about setting up a country-wide influencing group. The SDWG shared its 12 years of experience of developing and running a large membership group and has kept in touch with the new Northern Ireland group as a sounding board. Similarly the EDUCATE group met with the Face it Together (FIT) group from Shipley, Bradford, to help them think about group structures. The FIT group hosted a network event for other groups in Yorkshire.

Brokering national opportunities

"We need DEEP if people with dementia are to have any chance of having a voice that is heard nationally, and it we are going to make strides in changing attitudes and perceptions".

Member of a DEEP group (*Brightpurpose, in press*)

Over the past three years DEEP groups have participated in a range of national and international involvement opportunities. This includes input into British Psychological Society guidance on psychosocial interventions for people with dementia (2014), a House of Lords Select Committee Review on the Mental Capacity Act (in 2013), designing (and participating in) dementia friendly conferences including for Alzheimer's Europe, relationships with the Department of Health, and regular participation in national meetings of the Dementia Action Alliance.

Groups have felt that these opportunities are important in raising awareness about their work, but also have gained confidence from working on national dementia platforms. National organisations and bodies are beginning to look to the DEEP network as a more appropriate and representative way of involving people with dementia in national discussions.

This work has run alongside the local influencing work that all groups are involved in.

'What it means to get involved' by Keith Oliver, Forget Me Not group member, East Kent

As I always say, the two best things about service user involvement for me is that you meet some wonderful people affected by dementia and professionals supporting us, alongside a real genuine sense that together we are starting to achieve significant progress around raising awareness of what to live with dementia is like and how this can be enhanced further.

This has for me been realised over the past year with a number of projects including:

- Sharing our views from the Forget Me Not group with a House of Lords select committee which was seeking to improve the Mental Capacity Act. We were the first group of people with dementia they had met to listen to, and like other members I felt our words were taken on board
- It was a great honour to be asked by DEEP to present an opening talk at the 2014 UK Dementia Congress to try and unite the voices of those with a diagnosis and those caring for us.

With one voice the message is so much stronger.

Collating and developing good practice

“As a group we want to be at the cutting edge– being part of DEEP is vital to this.”

Member of a DEEP group (*Brightpurpose, in press*)

Groups are continuously testing out the best ways of supporting people with dementia. They are working out the best ways of running meetings, sharing decision-making, making a local noise, writing up notes of meetings, using technology to aid communication and connections, identifying the local decision-makers they need to influence, managing group dynamics, increasing diversity within the group and charting new territory as they try to keep people involved as their condition changes.

These experiences are especially valuable for new groups and prevent them having to reinvent the wheel. They also make the network alive in terms of learning, shared knowledge and a feeling of fellowship.

Case study: Cornwall Dementia Leadership Group

Local health and social care professionals regularly approach this group asking for its perspective on various initiatives, leaflets, policies, and service specifications. The group asks visiting professionals to provide them with some background information before the visit, in an accessible format using a template that the group has designed. Professionals are encouraged to present their ideas with visual information at the meetings to back up the discussion and are explicitly asked to keep the group informed about what happened because of the group's involvement.

Being a central repository

“It means we're not re-inventing the wheel, we can draw on the experiences of other groups. It gives us heart that someone is trying to pull it all together.”

Member of a DEEP group (*Brightpurpose, in press*)

DEEP groups are busy, with huge demands on their expertise and unique perspectives. The staff supporting groups are also busy, often working beyond their job roles to sustain groups. DEEP can pull together all the learning, good practice, news and impacts and share this around the network through monthly updates, the Dementia Voices website (www.dementiavoices.org.uk) and ongoing contact with groups.

Funding local groups and initiatives

“The funding has given the group such energy and focus. It's really wonderful to see so many people with dementia working together and creating something positive right here in the heart of the community.”

Facilitator of a DEEP group (*Brightpurpose, in press*)

Small grants have made all the difference to groups being able to further their own agendas. Grants of between £400 and £5,000 have been distributed throughout the network resulting in 30 projects. These include the setting up of new groups (e.g. involvement groups for younger people with dementia) supporting existing groups, work to develop a lesbian, gay, bisexual, transgender network, films, buying iPads to connect group members, and leaflets. The grants have empowered groups to design their own projects and to share their outcomes with the rest of the network.

Setting expectations

“I see the power of DEEP acting as a lever for change locally and nationally in the future.”

Facilitator of a DEEP group (*Brightpurpose, in press*)

Connecting together creates power in numbers. The network of groups has become stronger at setting expectations about how other organisations should engage with groups. People with dementia want to be listened to and have their views taken into account by decision-makers. But often this can

be at the instruction of others – professionals and organisational bodies – and in a manner that is more about traditional consultation than genuine involvement.

DEEP groups have become stronger at saying ‘work with us on our terms and in ways that are meaningful and supportive’, and organisations and professionals have listened.

See also DEEP guidance notes Collecting the views of people with dementia at <http://dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Collecting-views.pdf>

What has been the impact of DEEP?

DEEP has been about inspiration, shared ambitions for wide social change and inordinate local successes in influencing services, strategies, community developments and raising awareness. People with dementia talk about being part of their local involvement group as a job, a role, something that gives them a sense of purpose. People with dementia support each other to gain confidence within their group, and groups are gaining confidence in their influencing work as they connect with other like minded groups.

“Being part of a network gave our members the confidence that they have a right to have their voices heard.”

Facilitator of a DEEP group (*Brightpurpose, in press*)

On the national stage, organisations and bodies have seen the relevance of DEEP in increasing the diversity of views and voices that they include in their involvement processes. Outcomes include:

Tangible changes/influences on guidance and national policy, e.g. the House of Lords review of the Mental Capacity Act, contributions to the British Psychological Society papers on the dementia care pathway and psychosocial interventions for people with dementia, creating more dementia friendly conferences and a position on the editorial board of the Journal of Dementia Care.

Changes in culture at national events, e.g. at dementia conferences, such as those run by Hawker Publications and Alzheimer’s Europe. People with dementia have been much more visible as delegates and presenters, with many adjustments being made to improve the experience. This includes guidance to other presenters and delegates on the appropriate use of language, signage, quiet spaces, reserved seating and easy access to refreshments and food.

Outputs from DEEP have been well received and used to promote awareness and improve practice. For example there is a range of DEEP guidance notes on issues such as ways of involving people with dementia, including in staff recruitment, working with the media, running a DEEP group, setting up a focus group and running conferences. The National Institute for Clinical Excellence (NICE) cites DEEP as a valuable resource in terms of service development (see www.nice.org.uk/About/NICE-communities/Social-care/Tailored-resources/Dementia/Statement-8)

The voices of people with dementia are being heard louder and with more of a range than ever before. In March 2015, people with dementia, with the support of the Red Nose team at Comic Relief, took over Twitter for a day, posting viewpoints via the hashtag #dementiadiaries, which trended. There were simultaneous broadcasts on national TV and radio by people with dementia raising awareness about living with dementia. The film *Make a Point About Dementia* (www.youtube.com/watch?v=mf8Z4Qsjxzk&feature=youtu.be) was launched by DEEP members at the national Dementia Congress in November 2014, relaying viewpoints from people with dementia and carers about their priorities around dementia. Following this, a meeting was held with Norman Lamb, Minister of State for Care and Support, where he committed to ongoing engagement with the DEEP network.

A forthcoming independent evaluation of DEEP commissioned by Comic Relief will include a more detailed assessment of impact.

Case study: Dementia Words Matter – a call to action

“Words are very powerful – they can build you up or put you down. When you are talking about dementia remember this.”

Agnes Houston, person with dementia

In Spring 2015 a Call to Action was launched through the member organisation Dementia Action Alliance, setting challenges about the use of language and words to describe dementia, particularly in the media.

Dementia Words Matter (<http://dementivoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf>) is a DEEP guide that sets out the words that people with dementia would prefer avoided in media reporting, organisational documents and conference presentations about dementia. They include words such as ‘sufferer’, ‘demented’, ‘senile’ and ‘living death’ – words which people with dementia describe as the ‘curl up and die words’. These are words that make people physically flinch when they hear them, that create stereotypes and are negatively attached to the person not to the condition. The Call to Action asks organisations to sign up to using the Dementia Words Matter guide in their work, and to commit to the 3Cs:

- check words and descriptions used in your printed materials against the DEEP guide
- change any words and descriptions that people with dementia have identified as ones to avoid
- challenge words which you recognise as the ‘curl up and die’ words whenever you see or hear them – in newspapers, on TV, on websites and in conferences and meetings. And pass on the challenge to others to take forward in their own settings.

At the time of writing, 115 organisations have signed up their commitment to this call to action.

Reflections on the issues that have arisen during the development of DEEP

This three-year phase of DEEP has been a development phase, aiming to establish a functioning network or user movement, create the ‘feel’ of a network between groups, test out ways of working, and set up a framework for the future. Inevitably this has meant that much of the work has been bespoke in nature, and responsive to groups coming forward, positive local situations, national opportunities that have arisen and based on action learning. It has been a mixture of proactive and reactive work.

Rapid growth of an evolving network

The steep rise in groups joining the DEEP network has been a surprise. Existing groups of people with dementia have been finding out about DEEP, identifying themselves as influencing groups and wanting to become part of the network. There has also been some focused development work in geographical locations where there was an absence of influencing groups e.g. Northern Ireland, Wales and Yorkshire. A number of new groups also set up as the result of the small involvement grants distributed by DEEP.

In 2012, the 12 identified groups were not operating as any kind of network. A primary focus of this phase therefore has been to provide opportunities for networking, to create links and forge relationships. The vision has been that DEEP is perceived and experienced as a functioning network that belongs to the groups and is owned by them – reinforced but also challenged by another 38 groups wanting to be part of this emerging network.

Member groups of the network continue to request a central hub that holds the network together. This hub (currently hosted by Innovations in Dementia) does not manage the groups of the network

nor determine the work they do. But it weaves the threads of connectedness and amplifies the dementia voices that emerge.

Looking to the future: one of the challenges is how to embed systems and approaches that allow this rapidly growing network to flourish and measure impact and influence, while avoiding the creation of hierarchies and bureaucracy that people with dementia clearly do not want.

Fragility of groups

Most DEEP member groups are early in their development, with 27 of the groups being less than two years old. They have often been set up by motivated professionals and a small group of people with dementia who are interested in getting involved. They are reliant on precarious local funding, with staff support to the group often going beyond any job description or funded hours. At a time of economic austerity, the funding of user involvement can be one of the first things to go. Membership of the group can be variable, often depending on good and early diagnosis in the local area. A small involvement group can suddenly find itself bereft of members as people's needs or circumstances can quickly change, or without a pivotal staff supporter whose personal drive sustains the group.

Looking to the future: the business case for involvement groups needs to be developed. There is a mass of anecdotal evidence from within the DEEP network that staying connected, and having a role and a sense of purpose has long-term health and wellbeing outcomes for people with dementia. The British Psychological Society has listed involvement groups for people with dementia as an evidence based psychosocial intervention (<http://bps.org.uk/networks-and-communities/member-microsite/dcp-faculty-psychology-older-people-fpop/news/launch-clinical-psychology-early-stage-d>). Involvement groups are not costly and yet, for many, their status and long-term preservation is insecure. Energies are expended on sustaining the group, potentially limiting the work that the group is able to do. However, the nature of the condition means that it is unlikely that the local groups, and indeed the DEEP network, will ever be wholly self-sustaining. This is especially true if a range of voices – not only those of people in the earlier stages – are to be included in the network. Funders and policy-makers need to recognise this, and be prepared to commit long term to the maintenance and growth of this social movement.

Special and specialised support to groups

Very special people provide very special support to DEEP and DEEP groups. It takes a lot of skill to empower people with dementia who arrive at groups, often feeling knocked sideways by their diagnosis, having lost confidence and living with a deteriorating condition which affects their cognition. Supporters include professionals such as nurses, psychologists, social workers and community workers but also volunteers, buddies and students. Family carers also provide a lot of back-up practical and emotional support to many group members.

"When I arrived at EDUCATE - I thought 'I could never do that', seeing people talking openly to each other about dementia. I was still shocked about my diagnosis, crying and feeling very sorry for myself. But now, look at me! I'm giving talks, I've been on the telly and the radio, I'm having a good life – and all because of this group."

Member of the EDUCATE group.

Looking to the future: it is essential that group structures are established (and written down) to support the group to continue to operate in the event of any staff changes that occur. The evolution of many groups has been quite organic, with positive staff and individual activists with dementia often leading the way. Groups are coming of age now, and pinning down the way that they work will ensure their survival as members and supporters change.

Whose involvement agenda is it?

Organisations are beginning to access the DEEP network to find out the views of people with dementia. There is a danger that they 'use' the network to further their own goals, without reflecting on adapting their own processes, or thinking about engagement beyond consultation. DEEP guidance notes make recommendations about ways of engaging with groups of people with dementia. However, DEEP does not provide a monitoring role on local engagement, even though it works hard to ensure national influencing opportunities are well planned and executed.

Looking to the future: As the DEEP identity grows, member groups are empowered to be more explicit about their expectations of how others will engage with them. They can draw on the DEEP guidance notes to encourage others to engage with the group on its own terms. Centrally organised DEEP events can ensure appropriate changes are made for a good involvement process, and can provide back-up to groups to make improvements to local involvement processes. People with dementia have described this as 'strength in numbers'.

Involvement is not just consultation

The dictionary defines involvement as: to engage, to connect, to participate and to influence.

In the context of services, involvement is often confused with consultation. Consultations are usually led by a manager or decision-maker who wants to find out what people think about a particular issue. But consultation alone is just one part of the continuum of involvement, is often one-off and limits the ways in which people are involved in decisions, planning, and shaping the future. Involvement should be seen as an ongoing process where people are supported to engage, connect, participate and influence at many points and in many ways.

This is at the heart of how the DEEP groups operate but it doesn't always translate to how external organisations and bodies want to engage with the DEEP network. Inviting one person with dementia to sit on a national advisory group, for example, is often the fallback position of organisations looking to involve people with dementia. It takes a lot more hard work and commitment to change existing organisational structures so that a diverse range of people with dementia can be supportively involved in a way that goes far beyond the tokenistic.

Case study: House of Lords review of the Mental Capacity Act

In October 2013, members of a Select Committee at the House of Lords were reviewing the Mental Capacity Act. They wanted to ensure that the views of people with dementia were included in their review process. Rather than invite representatives to attend a formal review committee, members of the committee did the leg work by travelling out to meet a DEEP group – the Forget Me Nots in east Kent. The group met in a familiar venue, with their regular staff and student supporters on hand. The committee had already provided the group with the questions that they were interested in discussing, giving the group time to consider and prepare their responses. People known to the group helped to facilitate small group discussions, while members of the select committee observed and listened to the issues that people with dementia raised. Following the focus group discussions, the select committee stayed for lunch. A thank you letter and a copy of the transcript was sent to The Forget Me Nots who were included in the review paper, and the entire transcript of the discussion was included as an appendix to the main report (www.parliament.uk/business/committees/committees-a-z/lords-select/mental-capacity-act-2005/).

Additionally, groups do not just want to be consulted reactively about their views but also want to proactively set their own agendas for social change. They also want to work on interesting and innovative projects – not just dementia strategy and policy documents – that challenge the way that dementia is perceived.

Case study: Dementia Diaries

In January 2015, On Our Radar launched the Dementia Diaries project in partnership with DEEP and Comic Relief. The project is a series of audio diaries, which you can hear at www.dementiadiaries.org.

Members from five DEEP groups across the UK have been trained to share their experiences using a simple handset. This is Gina from the SURF group in Liverpool, with her audio recorder.

"I just push 'report' and everything you need to know comes out."

People can record short audio diary entries and capture their thoughts and experiences as they occur. Each diary entry is automatically sent via the internet to a dedicated team who listen to it, transcribe it and add it to the Dementia Diaries website.

Ongoing training and support is provided for every participant via the telephone.

"It's a great project, helpful staff – especially when I go into a haze."

So far, the Dementia Diaries participants have submitted more than 450 diary entries. The project has been featured on BBC radio and television, and in national and local newspapers. More than 3.8 million people have seen it on Twitter.

Looking to the future: A strong network of well-resourced groups of people with dementia would change the predominant narrative of what it means to live with dementia. The energy of the groups should be directed on their own priorities rather than on survival. Groups say they want to co-produce projects as consultants on issues such as:

- taking an active role in dementia friendly communities;
- challenging the portrayal of people with dementia and working with the media;
- exploring citizenship rights and advocacy;
- testing post-diagnostic support opportunities;
- participatory research;
- consumer testing;
- supporting people with more advanced dementia.

Diversity and increasing the range of voices

"We are reaching voices less easy to hear."

There is a range of different voices and lived experiences within the DEEP network. The purpose of the network is not for people with dementia to speak as 'one voice' but to increase the reach and amplify their unique experiences. This includes people with dementia from black, minority and Asian communities, people who are lesbian, gay, bisexual and transgender (LGBT), and people who have more advanced dementia. A report about accessing the voices of people with dementia from LGBT communities is available to read at <http://dementiavoices.org.uk/2015/03/over-the-rainbow-report-about-lgbt-people-and-dementia>.

Many groups are grappling with how to best support people to remain involved as their condition changes. Technology has been one way of connecting with people for whom group participation is difficult (e.g. the Scottish Dementia Working Group has taught many group members to use Skype).



Rachel Litherland and Jo Bennett



Chris Roberts



Keith Oliver, Peter Ashley and Chris Roberts

Case study: Using iPads to connect

The Scottish Dementia Working Group (SDWG) has used its DEEP involvement grant to buy iPads to connect individuals and help communication.

Nancy, a group member who does not live near any other group members, was able to use the iPad to connect with group members meeting in Glasgow.

During the meeting, the iPads were passed around the room so that Nancy could see people as they were speaking. Nancy described the experience as 'fantastic' and 'just wonderful'.

Using the FaceTime app members of the SDWG can now 'attend' meetings without travelling great distances.

Agnes Houston (member and former chair of SDWG) also used her iPad to connect with a meeting in Luxembourg while sitting at her kitchen table (she is now vice chair of the European Dementia Working Group). The meeting in Luxembourg raised ideas about how people with dementia from across Europe can connect and take part in conferences and events using technology.

Other groups have introduced 'transition' groups such as a reading group at EDUCATE, where members continue to meet and have a role but don't have to take part in the business meetings.

Looking to the future: Although there is already a wide range of individual voices within the network, there is space to bring more diverse groups of people with dementia into the DEEP network, for example, through DEEP groups in care homes or hospital settings. DEEP members feel strongly that they have been 'lucky' to have found an involvement group at a stage of their life when they can still fully engage, and are concerned about people with dementia in other settings who do not have a chance to articulate or share their perspectives. There is a sense that most people with dementia need to be empowered before they can engage, and that DEEP groups could act as mentors to support and inspire.

Is DEEP relevant to everyone?

Being part of an involvement group is not for everyone. Following diagnosis, a local influencing group may be offered as one type of support alongside other services such as memory cafés, peer support groups or day centres. The idea of 'getting involved' may not be a priority for many people with dementia.

Having said this, there are many anecdotal examples from within groups where people with dementia have joined a group and then gained rapid confidence and inspiration from others, and have started to get involved in ways they never thought they would. Also, some of the DEEP groups are not set up as formal influencing or campaigning groups but sometimes adopt this role a bit later, as group members support each other and gain confidence.

Looking to the future: The strength of the network is that it can accommodate a wide range of groups and people. Being part of an active involvement group may not be for everyone, but can channels be created to ensure that all people with dementia have opportunities to share views that the DEEP network can action on their behalf?

Discussions of power and control – decision-making within groups and DEEP

"Blimey, that's the first time I've ever thought about that!"

Members of EDUCATE when asked about power and control in DEEP groups

When people with dementia connect to each other they begin to experience increased power and more opportunity to shape services and the world around them, rather than just being recipients of care (or consultations!). When asked about 'power and control' DEEP groups said:

- it's important that power and control is with people with dementia – that they are the leaders;
- paid staff and volunteers are there for support and facilitation to help group members;

- people with dementia should be the ones who lay down the mandate;
- respect is important;
- we should write guidelines about people with dementia as leaders within groups.

The central hub of DEEP is currently run on the basis of trust – groups feed in views and news, while Innovations in Dementia consults, collates and checks out positions with groups, acting as the representative or broker on behalf of all DEEP groups. Within groups, it is usual for staff supporters to manage the operational running of groups while empowering members of the groups to take the lead in making decisions and prioritising work and group objectives.

During this phase of DEEP there has not been the desire from groups to move away from a centrally managed hub that holds and supports the DEEP groups to work together as a network. There has been the sense that without such a hub, this fledgling network would not have emerged.

Looking to the future: mechanisms for devolving decision-making away from a central hub should be explored. However, any approaches need to avoid setting up hierarchies of groups or creating situations where people with dementia who are very able and active are seen as spokespeople for the entire network. This would carry the risk that others are not heard, including people with more advanced dementia, with communication problems, in smaller groups, in more rural areas or without access to good one-to-one support.

Alliances with family carers

DEEP is primarily a network of people with dementia. There are a small number of groups that consist of both people with dementia and carers, but they are distinguished by the fact that both people's viewpoints are prioritised within the group (rather than carers speaking on behalf of people with dementia). In many of the other groups, family carers are in the background providing emotional and practical support to group members to enable them to participate. This might be by taking people to meetings, helping people to prepare, or accompanying them to events and conferences. Sometimes family members will provide early practical support and then take more of a back seat as people with dementia gain confidence and the group takes over the support role.

There have been opportunities in this phase of DEEP for people with dementia and carers to take to public platforms together, each sharing their unique perspective.

Looking to the future: At the time of writing, the National Involvement Network for Family Carers of People with Dementia is taking shape, hosted by the Life Story Network. This presents opportunities for continuing alliances where both perspectives need to be heard.

Outcomes for people who are part of DEEP groups

Members of DEEP groups describe the benefits they derive from being involved and having an influencing role as:

- creating a sense of solidarity, building confidence, empowerment and increased self-esteem;
- improving health and wellbeing;
- enabling people to 'give back', to leave a legacy;
- improving services, helping to spend money on the services that people need and want;
- using people's skills and experience and their unique expertise from the 'lived experience';
- seeing and hearing 'real people' can challenge stereotypes;

- people have a role, are occupied and maintain a sense of value and purpose.

There are also some costs or barriers for people who get involved:

- it can be tiring to maintain involvement and people can sometimes be 'overused' by others who want to engage people with dementia in their work (although this is where being part of a group is helpful, as opportunities can be shared around the group);
- organisations may not be willing to make the adjustments that make it easier for people with dementia to get involved;
- there are financial costs to involvement e.g. venue hire, transport costs, supporter costs and refreshments that organisations may not recognise as important;
- people often feel they have a short window for involvement and therefore have a sense of urgency to see change happen, which may be difficult for large organisations to achieve.

"Health-wise, I get very tired, so it does cost me a wee bit in extra tiredness, but as long as I get a clear day without a meeting the next day and I can relax...but it does take it out of me in terms of strength, and again, we are getting that wee bit older. I think the benefits to myself of being invigorated by the involvement outweigh the fatigue."

Agnes Houston, Chair, SDWG (Weeks et al, 2012)

A model for a DEEP group

DEEP groups are all shapes and sizes. They are set up for different reasons and are shaped by group members and local issues and variances. It is not possible (or desirable) to define what a DEEP group should look like or how it should operate. However, there are certain features that work well in the groups and that could be used as the basis for building a new involvement group.

These include:

- Terms of reference or a constitution as well as agreed ways of working, including ground rules. People want to be clear about the purpose of the group and their role in it.
- Having interesting things to work on. Many groups begin by focusing on health and social care issues, but often branch out into other areas that group members find important e.g. accessible transport, dementia friendly communities and product development.
- Being clear about how other people and organisations will engage with the group. Asking for accessibly written documents, straightforward engagement processes and feedback after people have been involved.
- Strong support in the form of paid group co-ordinators and/or volunteer support. Their role should be to take care of the practicalities of involvement (e.g. diary co-ordination, booking venues and transport) as well as maintaining positive group dynamics.
- Approaches that enable all group members to contribute to the work and discussions of the group. This will often be built into ground rules and may include turn taking, using props such as a red card to indicate when a person wants to speak, or a person with dementia acting as chair. Many groups break from business discussions during meetings to share news, or take part in a different kind of activity such as poetry reading. This can give people who find it difficult to contribute to the business part of the meeting a chance to join in.
- Different ways for people who are not comfortable speaking out in larger groups to contribute their views, e.g. small group discussions, sticky notes to write down ideas, individual support from a volunteer.

- Reviewing processes to ensure that all members of the group are being appropriately supported and still feel that the group is relevant to them

Relationships with key local commissioners and decision-makers – in terms of achieving change it really helps to have direct access to local professionals who can help to take forward the goals of the group

Some practical things that groups do to support people with dementia to be involved

- Give a lot of attention to the practicalities e.g. transport (booking taxis etc), choosing venue, time of day, refreshments, support, reminders. This can be expensive and needs time and patience. It also requires the building and sustaining of a close relationship with each individual.
- Use a range of methods to help people with dementia to understand the issue or the engagement activity. This might include visual prompts to reinforce the discussion (e.g. discussing menus in a dining room or kitchen), using photos and pictures, using flipcharts and posters to record ideas and summarising discussions at regular intervals so that people can re-connect to the ideas.
- Check and double check people's viewpoint. It may be that your own expectations or feelings colour what you think you are hearing people say or communicate.
- Think about the words you use to talk about dementia (see DEEP guidance note Dementia Words Matter <http://dementivoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf>).
- Give enough time to any specific involvement activity. Give people the space to communicate their ideas, and ensure people who need it receive support so they can contribute.
- Be aware that involvement can be challenging – inviting people to think about tricky issues may raise emotions and cause people to be cross or anxious. This doesn't mean that you should avoid these tricky issues, but pre-empt them as much as possible and ensure you have thought through how you might respond.
- Make any involvement experience as accessible as possible, but without being patronizing. Ensure any written materials are accessible, that straightforward language is used without any acronyms, that events and meetings are structured well, with restricted agendas and good approaches to allow a range of people with dementia to participate fully.
- Involving people with dementia can feel challenging. It needs time, creativity, flexibility, strong listening skills, and often a real drive to keep it a priority within stretched organisational settings. Create your own support by linking with those who are working to support people with dementia to be more involved.
- Ensure that people with dementia are consenting to be involved and engaged; involvement isn't something that should be done to people. Follow an appropriate consent procedure that is accessible for people with dementia. Avoid assuming that people lack capacity to be involved which often results automatically in excluding people with more advanced dementia.
- Remember, it is not just about work. Build in some fun and social time – often the best ideas come out in these moments

On the shoulders of giants

"Listen to us. Hear us. We are here."

People with dementia using a day care service in 2000.

These striking words were spoken to the author by a group of people with dementia in west Kent in 2000. They clearly felt that they were not listened to, that their unique perspective was not valued and that society had very low expectations about just what it meant to live with dementia.

15 years on, and the world is beginning to take notice of people with dementia. Dementia strategies and social movements promote a society in which people should be supported to live well with dementia and continue to take part as citizens in local communities. Individuals with dementia are increasingly involved in advisory groups, policy discussions, service developments, awareness-raising campaigns, research and national and international alliances. Through the DEEP network more than 1,000 voices of people with dementia are connected together, amplified, and harder to ignore. And these are not just the voices that are confident and practised public speakers, but a diverse collection of people who are gaining strength from each other to speak out.

15 years is a relatively short time for a user movement to take wing, especially when people are living with a deteriorating cognitive condition with variable diagnostic rates, combined with society's low expectations about what is possible when living with dementia. For the DEEP network there is still a lot of growing to do.

In the story of the increasing involvement of people with dementia, we should remember the pioneering contribution of individuals with dementia over the last two decades, some of who have died and some of who DEEP is privileged to still work with. Without their willingness to speak out, to challenge, to take part, to encourage, to inspire, to make demands and to carry with them this story of change, the DEEP network would not have the same strong basis on which to evolve

Conclusion

People with dementia are gathering strength in numbers by making connections through the DEEP network. Through engagement and empowerment, shared working, a range of involvement opportunities, and organisations and professionals who are willing to shift the balance of power, the voices of people with dementia are beginning to take centre stage, alongside those of their carers. The mechanisms are now in place for a strong user movement of people with dementia, which will continue to build on the shoulders of pioneering people with dementia who give their time and energy freely to change the way that dementia is experienced and understood.

About this paper

This paper sets out the work and achievements of DEEP over the past three years, and the priorities for developing this network into a strong user movement of people with dementia. It provides reflections on the process of creating a national network of people with dementia as well as some practical suggestions about setting up local involvement groups.

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FOR FURTHER INFORMATION

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