

Inclusion of People with Dementia in the Design of Services

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On behalf of Genio
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1. Background and Introduction

1.1 Background

In 2011 the HSE & Genio Dementia programme began its work in developing a community supports model for people with dementia. The high level aim of the programme is to develop and test a range of personalised, flexible and responsive supports and services and to demonstrate how these supports enable people with dementia to live full lives in their community for as long as possible. Each of the twelve demonstration sites involved in this programme is led by a dementia consortium made up of key stakeholders who work collaboratively to create an integrated range of services and supports that are determined by the needs and preferences of people with dementia. Consortium members include people who are living with dementia, family members who are supporting those with dementia, representation from primary health care, acute care, community health and social care, mainstream service agencies such as Garda, public services such as County Council, community and voluntary groups and organisations.

Creating responses that support people with dementia, should be informed by people with dementia, as their insight and perspective of living with dementia and the challenges it presents is a contribution that has obvious value. Projects involved with the HSE & Genio Dementia Programme have sought to gain the perspective of people with dementia through the course of their work. People with dementia were provided with real opportunity to contribute to the design of initiatives at development stage, and throughout the lifetime of the project as initiatives were

planned and implemented. How this engagement can occur and be effective when seeking the input of people with dementia at varying stages of the dementia journey is the focus for this paper.

In 2015 project representatives from the HSE & Genio Dementia Programme came together in a one day workshop titled “Inclusion of the Person with Dementia”. This workshop, facilitated by Innovations in Dementia, provided an opportunity to share learning through collective exploration of experiences in involving people with dementia in their project’s design and development. They considered what worked well, what was challenging, how were these challenges overcome? Innovations in Dementia supported this learning opportunity by providing input from their learning in the United Kingdom working with over 60 groups of people with dementia.

This paper has been informed by the discussions that took place at this workshop.

1.2 Recent developments in involving people with dementia

“Nothing about us without us” is a slogan which is increasingly being articulated by people with dementia.

It is increasingly recognised that people with dementia should have the right to a say in decisions that affect them and a sense of ownership, investment, responsibility and of connectedness to the services which are available to them.

Nationally and internationally we are seeing an increased movement of people with dementia coming together to represent, support and empower people with dementia, contribute to research and influence policy and decision makers. Some

local examples include the Irish Dementia Working Group and the D.R.E.A.M. (Dementia Research Education Advocacy in Motion). Further information on these groups is available at: www.alzheimer.ie/get-involved/campaigning/advocacy.aspx and www.mydementia.ie.

In the UK, there is a growing user movement of people with dementia emerging through the DEEP programme. DEEP stands for the Dementia Engagement and Empowerment Project. It connects involvement/influencing groups of people with dementia - groups where people with dementia are working together to raise awareness about dementia, to provide viewpoints to policy makers and decision makers, to influence local dementia practice, strategy and service/project design, and to challenge the existing narrative about what it is like to live with dementia. There are currently 60 groups that are part of the network as well as connected individuals with dementia. DEEP is funded by Joseph Rowntree Foundation, Comic Relief and Life Changes Trust, and led by Innovations in Dementia in partnership with the Mental Health Foundation. www.dementiavoices.org.uk provides details of the DEEP groups and the work they do, as well as the full range of DEEP guidance notes.

1.3 Why involve people with dementia?

The benefits of involving people with dementia are many and varied, not least for the person with dementia themselves.

A recent report on the work of DEEP (www.jrf.org.uk/report/developing-national-user-movement-people-dementia) highlighted a range of benefits, stating that increased involvement:

- Creates a sense of purpose, builds confidence, empowerment and increased self esteem.
- Improves health and wellbeing.
- Enables people to 'give back', to leave a legacy.
- Recognises people's skills and experience and their unique expertise from the 'lived experience'.
- People have a role, are occupied and maintain a sense of value and purpose.

The benefits also extend to services and those working within them:

- Most importantly - it focuses the services on what people actually want.
- Seeing and hearing 'real people' can challenge stereotypes and help the entire organisation see people with dementia differently.
- It sends out a very important message to those working with the service and to your strategic partners about the values of your organisation.

There are also significant drivers from national policy which support the need to listen more effectively to people with dementia. The Irish National Dementia Strategy emphasises the need for people with dementia to have a voice in decisions and for services to be responsive to their needs. See health.gov.ie/blog/publications/the-irish-national-dementia-strategy for further details. The Assisted Decision Making Capacity Bill 2015 provides added impetus and a new framework for amplifying the voices of people with dementia. See www.thirdageireland.ie/sage and www.inclusionireland.ie/capacity for some useful resources and examples of the law in action.

2. Involvement of people with dementia

Involving people with dementia in the design and delivery of projects can bring positive benefits for all stakeholders, and so it is not surprising that it is increasingly common practice to ensure that people with dementia are involved in the design of services and supports and in research and projects which are informing service development.

This section considers the different levels at which engagement can take place, and a range of methods for engaging and involving people.

2.1 What does involvement look like?

For some, involving people means questionnaires or focus groups. These are important tools of course - but there is a lot more to it than that, and it is likely that you are already engaging people with dementia in decisions that affect their lives.....

➔ By offering choice

Some organisations probably feel that they don't involve people with dementia at all and to be fair they are perhaps being too hard on themselves, as most organisations that work with people with dementia are already doing so at the most basic level of all – which is by offering choice.

This might seem obvious, but choice can be a powerful thing, especially for people for whom it is routinely denied. Many people with dementia still tell us that they are often 'talked over' or questions are directed at their carer. Most people mean well of course,

but some still believe that almost by definition, people with dementia are unable to exercise choice.

A simple choice, for example of "tea or coffee?" can be the first important step in involving people with dementia in decisions that affect their lives.

If you feel that this doesn't routinely happen in your organisation - then start here.

➔ By asking people what they think of what you do already

This is probably what most people think involvement is about - using questionnaires, interviews, focus groups, comments or complaints forms to find out what people think of a service. This is important of course and we will be looking later at ways to make sure that as many people as possible can make use of these ways of getting their voices heard.

➔ By asking people what they want and need

At this next level we are asking people to tell us more about what they want, what they need, and what their aspirations are. We might also be asking them broader questions about what we do and how we do it and what we should be doing.

The tools will often be the same as above but the scope is broader and can require a more imaginative approach as you are often asking about things which are more abstract than "what do you think of the food?" This is also different to a formal needs assessment which is usually a health professional's assessment of what the person's needs are.

It is the best starting point for any organisation that wants to get a true picture of what people need to live well.

➔ **By supporting people to have a say outside of your organisation**

Many organisations are asked to represent or articulate the views of a particular client group on a range of issues from policy development to product testing. Supporting people with dementia to engage in these processes supports their individual “agency” and gives them a recognised valued role. It also adds credibility to your message and sends out an important message to your strategic partners.

➔ **By giving people with dementia an active role within your organisation**

This can mean involving people with dementia in the design and/or delivery of what your organisation does. A few organisations have started to employ people with dementia, others have people with dementia on boards of trustees, others work with people with dementia in the delivery or design of specific initiatives - the focus of this paper.

One example is the Open Doors Project which employs two people with dementia and leads on the development of a range of initiatives across Salford, UK. These include a dementia café providing post-diagnostic education and support in conjunction with memory services, a friendship and support network for individuals newly diagnosed, participation in steering groups in relation to key service redesign, provision of education to professionals in relation to dementia,

and support for and dissemination of research in conjunction with Manchester University. For further information on this initiative contact cath.riley@gmw.nhs.uk.

Giving people an active role in project design and delivery often involves working at many of these levels simultaneously. To explain what we mean by that - we need to go into a little detail about co-design, co-production and co-creation.

2.2 Co-design, co-production, co-creation

The best way to understand this is to think about the process of solving a problem.

For this to happen we need to decide what the problem is - and then decide on a way to help - and then actually do it.

Asking people what they think and giving choice can help us to work together to determine the problem. This can be the first step in **co-design**. Working with people to decide on a way of helping with the problem is the second part of **co-design**.

Working with people to actually deliver the help is **co-production**.

Co-creation is when people get involved in both.

The DEEP guidelines referenced throughout this paper are a good example of co-creation whereby people with dementia worked with DEEP to define the problems, design the solutions (guidance papers) and then helped to write them.

CASE STUDY - BRIAN & TOM

Brian and Tom both had poor experiences of diagnosis. They felt unsupported during the process and explained this to others at a peer support group they attended. More people with dementia had reported similar problems during a consultation exercise carried out across Kent.

Brian and Tom worked with others in the Maidstone Peer Support group, the Alzheimer's Society, and the Kent and Medway NHS and Social Care Partnership Trust (KMPT) to talk about what would have helped them - and together they designed a mentoring project.

*These two parts - identifying the problem and designing a solution is **co-design**.*

Tom and Brian now provide direct support and mentoring to others with a recent diagnosis of dementia, with support from Alzheimer's Society and KPMT.

*This part of the process is **co-production**.*

*The whole process has been **co-created** with people with dementia.*

Read more about Maidstone Mentors here: dementiafriendlykent.org.uk/maidstone-mentors.

2.3 User-led and professional-led

These terms capture two extremes of the involvement continuum in which at one end users make all the decisions and at the other control is firmly in the hands of professionals.

Your challenge is to make sure that the involvement of people with dementia is as strong as it can possibly be, without forgetting that without support, only those most articulate and confident will be engaged.

Many DEEP groups could properly be described as user-led – though this is not without support from others with things like administration and facilitation. It is how this is done, and where and how decision making is located which is the key - and something which is currently being explored with DEEP groups.

3. How to involve people with dementia in project design

When thinking about involving people with dementia in project design, ideally you would be moving towards as much engagement as possible, but you may start off with consulting people with dementia about their wishes and needs and using this information to project plan. If you are planning to work in this way, we have attached a starting checklist for you to consider. See Appendix.

You can then take a look again at the tools and approaches below to help plan how you will keep people with dementia involved through the project cycle.

3.1 Communicating with people with dementia

However we engage with people with dementia, effective communication is important, and is the key to successful 1-1 discussions.

People with good communication skills, who care about people and have a good set of eyes and ears have pretty much all they need to do a great job in engaging with people with dementia.

The better our communication skills the more effectively we can get to know the people we are working with and the easier it will be to engage them.

Good basic communication skills will go a long way, but the more advanced a person's dementia becomes, the more it is likely that people will need more enhanced skills. The better the skills the further into dementia we will be able to go with people without having to resort to proxies.

There are a range of communication skills training courses in dementia such as: www.scie.org.uk/dementia/open-dementia-e-learning-programme/7-positive-communication.asp.

There are some great tools available to help with communication if people have begun to struggle with speech or understanding:

- Physical cues and prompts can aid communication and help people focus on the discussion. Pictures or cards with single emotions written on them have been successfully used to stimulate discussion or express opinion. (Allan 2001).
- For gauging strength of opinion, rather than 'on a scale of 1 to 10', emoticons or a 'swingometer' between two extremes can also be used.
- Voting cards, with 'yes' or 'no' can be used with people who struggle with speech.
- 'Talking Mats' is an interactive resource that uses three sets of picture communication symbols; topics, options and a visual scale and a space on which to display them. This can either be a physical, textured mat, or a digital space, for example a tablet, smart board or computer screen. Once the topic is chosen e.g., 'activities' or 'people', the participant is given the options one at a time and asked to think about what they feel about each one. The person

can then place the symbol under the appropriate visual scale symbol to indicate what they feel. Talking Mats help people to organise and express their views. Research has shown that Talking Mats help improve the ability of people at all stages of dementia to communicate (Murphy, Gray and Cox, 2007). There is evidence that Talking Mats help people to express their views because they:

- Focus on the essential words and omitting non-essential language.
- Give information in multiple channels – visual, auditory and tactile.
- Help people process concepts by breaking information down into small, manageable chunks.
- Reduces demands on memory and cognitive load.
- Reduces distractions.
- Allows the person time to process information and respond in their own time.
- Gives control to the person being interviewed.
- Provides a structured framework for open questions.
- Avoids direct confrontation.
- Gives people time.
- Helps people to say "no".

See www.talkingmats.com for more information and to see Talking Mats in action.

(It is important to note that these factors are also extremely relevant whatever approach you are using, especially with people with more advanced dementia.)

3.2 Involving people with dementia in wider groups (i.e. non-dementia specific groups)

Perhaps the most significant long term impact can be achieved by looking at the accessibility of everyday organisational processes.

Not only will this improve access to decision-making and engagement for people with dementia - **but will also make it easier for everyone else at the same time.**

Think about the ways in which people get their voices heard within your organisation - and that includes staff, volunteers and other stakeholders.

➔ Are the written materials that you use accessible?

For example, when asking for feedback about your service, or collecting wider views are the forms written in plain English? What about the agendas or minutes of meetings - can they be easily understood? Here's a link to DEEP guidance on producing dementia-friendly information: dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Writing-dementia-friendly-information.pdf.

The Plain English Campaign also have some great guides to writing clearly - free to download here: www.plainenglish.co.uk/free-guides.html.

➔ Are your meetings, groups and events accessible?

Make sure that the groups and events you run to help you understand what people think and need are accessible. This might include engagement events on specific issues or regular forums

either internally or externally. How accessible are they to people with dementia? For example, are meeting lengths kept short, with breaks? Are the buildings and spaces you use accessible to people with dementia?

You will find more guidance about making meetings more accessible, including "choosing a dementia friendly meeting space" here: dementivoices.org.uk/resources/deep-guides. You will also find Innovations in Dementia's guide to doing an access audit of buildings here: www.innovationsindementia.org.uk/HowToDoAnAudit.pdf

3.3 Support to be involved in meetings, groups and events

Making our organisational processes accessible to as many people as possible is probably the most important step you can take to increase the involvement of people with dementia in the long-term.

But you can also involve more people, and keep them involved for longer by supporting them to engage.

The kind of support that people might need will vary according to the situation - but examples might include:

- Offering transport to and from a meeting.
- Offering someone to help prepare for a meeting beforehand to allow time for a person to think things through.
- Offering someone to accompany a person to help them to articulate their views, or explain what is happening.

In terms of project design, there may be occasions when it is thought to be

appropriate to involve a small number of people with dementia as members of more organised and formal steering/advisory groups, alongside professionals and service practitioners.

On these occasions it is beneficial to all to make these groups as accessible as possible and for appropriate adjustments to be made to make the experience a positive one for people with dementia. Many of the suggestions below are equally relevant to good planning for a range of engagement processes:

- Ask the people with dementia beforehand about the best ways to support them to participate in the meeting. For some this has included raising their hand when they have something to say (rather than relying on them finding a gap within discussions) or by the chair asking direct questions of them at appropriate intervals. Standard meeting protocol e.g. “hold that thought” or “can that go under AOB” can be problematic for some people, who may struggle to recall their point later in the meeting.
- Meeting notes and summaries of issues to be discussed at the meeting should be sent out in advance.
- Send out good instructions and maps of the meeting venue. Ensure it is easy to access the building on arrival (e.g. signage). Make sure the meeting room or venue is as accessible as possible. A dementia friendly audit resource is available at: www.innovationsindementia.org.uk/HowToDoAnAudit.pdf.
- Make sure you have communicated how expenses will be paid. Where possible, organise and pay for expenses in advance (e.g. booking trains or taxis).
- Identify a consistent link person from the advisory group to be in touch beforehand (and afterwards) with the person with dementia. They should be able to respond to all practical questions relating to the meeting.
- Offer a phone (or face-to-face) pre-meeting to help people to prepare for the full meeting.
- Use visual materials where possible during the meeting to back up discussions (e.g. powerpoint presentations, handouts). Create these in a dementia friendly format.
- Plan breaks and refreshments into the meeting schedule at regular intervals.
- Ask other participants to slow down their discussions, to avoid using acronyms and to explain all acronyms if used.
- Consider the timing of these meetings, perhaps evening meetings are not the best time of day for the person with dementia. This will be specific to the individual.
- Consider the frequency of these meetings, long gaps between meetings can be difficult from the individual’s perspective in remaining connected to the topics discussed.
- Provide opportunities within the structure of the meetings for the members to consider their willingness to remain as members.

3.4 Creating separate involvement processes for people with dementia

Making changes to organisational involvement processes to make them more accessible will help hugely - as will offering additional support to people who need it to engage in those processes.

However, there will always be a need for separate involvement processes to include the voices of people with dementia, and the greater a person's needs around their dementia the more likely it is they will need specialised support.

There are a range of tools and technologies that can be drawn on to involve people with dementia in the design of services and supports and in research and projects which are informing service development. These include; focus groups, one to one conversations, walking the patch and using filming and audio recordings.

➔ Focus Groups

Joining a discussion with other people with dementia can help people to articulate their own viewpoint and can feel less pressurised than a one-to-one interview. Many people with dementia will be happy to work in a group especially if it is an established group where people know and feel comfortable with each other. Also many people tell us that hearing the views of others can also help them to articulate their own thoughts and gain confidence and maintain focus.

Consideration should be given to the way the focus group is organised including:

- Identifying a dementia friendly meeting venue. The meeting space can help people to understand the focus of the discussion. For example, a discussion about dementia friendly communities could take place in a local library, police station or company headquarters.
- Staff and supporters need to be available to help people participate in discussions and express their views.

- Travel arrangements to the focus group and expenses should be available.

More detailed recommendations and considerations for running a focus group with people with dementia can be found in the DEEP guide "Collecting the Views of People with Dementia": dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Collecting-views.pdf.

➔ One to one conversations

People with more advanced dementia will often have more particular needs in relation to communication. They may find group working more challenging and may be sidelined by more vocal group members.

One to one interviews can give people the space in which to think and construct a response. The interview process can allow people to build trust and establish good communication with the interviewer, with questions being adjusted for understanding and relevant/individual prompts being given. Interviews can also be repeated to give people more than one opportunity to articulate their viewpoints or to build an opinion.

Don't forget that people with dementia have good days and bad days. If you are working regularly with someone, and they are having a bad day you can always come back to the conversation another day.

➔ Walking the patch

This is a way of finding out from people, how they experience their environment, or service. For example, people might walk a particular route to a building or

a park. They may try to plan and book a journey from a train station, or go to a hospital or doctor's appointment.

All the time the person is carrying out their task, they are explaining what their thought processes are. Prompt questions can help here, e.g.:

- What are you looking at?
- How did you choose between this way and that?
- Can you see that notice? What do you think it means?
- Is it easy to find the entrance to the building?

We recommend that a 'walking the patch' exercise doesn't take any longer than 45 minutes. Some people have done a 'walk the patch' using video cameras to show the difficulties they have.

➔ **Using film and audio recordings**

Film making or audio recording can be a good way of capturing people's views. As a medium, it can encourage people to focus on the main issues they wish to convey, and can be organised in a way that enables a wider range of people with dementia to have a say, in comfort, in their own time, and in a form that allows their voices to be heard forever. Filming is a very interactive process. Whilst filming, the consent process is often very obvious, with people being clear when they don't wish to appear on film. People can also review film footage and sound recordings, acting as a reminder and allowing people to confirm their viewpoint, www.innovationsindementia.org.uk/Telling%20our%20stories.pdf.

Use your imagination and listen.....

Some of the methods described above might be familiar to your organisation, and perhaps you already use them to good effect.

Other methods might be less familiar, such as 'walking interviews', which can be done indoors and outdoors and which can have great results.

Often people with dementia can struggle to concentrate for long periods indoors so incorporating some outdoor 'fresh air' time can really help.

You may have found that, perhaps counter-intuitively, some people also find it easier to talk when they are doing something else like podding peas, folding sheets, eating or drinking. This is sometimes referred to as 'naturally occurring data'. It's basically 'things we find out'. Very often day to day conversation and non-verbal communication with people with dementia reveals a wealth of information about views and wishes. Combining this information with data collected from more formal ways of involving people can provide a really powerful and broad-based narrative.

In many organisations however, a lot of the really valuable information about what people think and how they feel, which could make a really strong contribution, is simply lost because it is not considered to be part of a consultation process.

By making sure that staff, volunteers and clients know what questions are under consideration you are more likely to be able to capture this data as people will simply be more attuned to the issues.

So, for example, in addition to a consultation exercise about the creation of a dementia friendly community in your

town, why not prime staff and volunteers to pick up on what people tell them about their experiences in town, the places where they go, what they like and so on.

These can be recorded through staff or volunteer meetings, supervisions, the use of post-it notes. Any way which makes it easy for staff to record what people say or how they behave around the issue at hand is helpful.

However, beyond systems the most powerful way to ensure that this information is routinely gathered and acted upon is to create a listening culture within your organisation.

3.5 Creating a listening culture

Organisations that are really focused on listening to their people, clients, staff and volunteers will find it easier to provide services that meet their needs.

A listening culture is not about having processes and events to listen to people, important as these things are, it's about having a culture which is clearly communicated to all staff, volunteers and strategic partners and which is based on the primacy of the voice of the people the organisation is set up to serve.

Staff and volunteers who understand that the needs and aspirations of people are at the heart of what you do are more likely to communicate those values to clients, encourage participation and ensure that people's voices are heard throughout the organisation.

So - It's not just a one-off.....

Learnings to date from projects involved in the HSE & Genio Dementia Programme show that hearing the voice of people with dementia in project design, is not

simply a one off engagement occurring in a particular way, but rather a use of combinations of the above examples happening regularly through the stages of project design, development of initiatives and implementation of services.

Listening to the perspectives of people with dementia, working with people through various forums in a supportive way, engaging with existing groups in a targeted way to seek input, all contribute to an inclusive and informed project design. These approaches are not confined to use by one person in the project, but rather are approaches used by many within the project who are working to support people to live well in their communities.

The following case example of a project within the HSE & Genio Dementia programme reflects how different methods of engagement with people at different stages of dementia can inform projects from design through to implementation phase.

At pre-planning stages engagement occurred by meeting with people with dementia in an informal setting for lunch, asking them about their experience with dementia, what was helpful, what was challenging, what they felt was important for service delivery. For example, there was feedback from one of these meetings that they didn't want to be part of a group solely for people with dementia - they found it to be stigmatising and they wanted to be part of something that was available to all people in the community that they could attend as a community member. The project adjusted its perceptions and sought to work collaboratively with existing groups to promote social inclusion rather than creating new activities solely for people with dementia.

Engagement with a peer support group of people with early stage dementia identified the benefits they felt by being part of a community of people experiencing similar challenges. The feedback from this group was that they wanted opportunity to meet but to do ordinary things together such as shared outings. The project supported this to happen with positive feedback from all participants who now independently organise their own outings with the help of their facilitator.

Learning also occurred through feedback from people working with and supporting people at later stage dementia in the community. Through environmental observation, prompting discussion, and engaging with the person with dementia, they observed the need for continued social engagement, but recognised that it needed to be facilitated on a one-to-one basis for the person. The project introduced a re-ablement focus, life story work and purposeful engagement for people in their homes and communities. Dementia skilled workers provided this support on a one-to-one basis.

Watch this film about an advisory group of people with dementia called ThinkTank. People with dementia who are members of ThinkTank advise Innovations in Dementia about their work. In this film you will see a range of involvement methods and approaches being used to help people with dementia to have their say. See how many you can spot. The film can be viewed at: www.youtube.com/watch?v=vCuMYxZpU2o.

For more information about involving and engaging people with dementia:

The following resources provide further information about involving and engaging people with dementia:

- Dementivoices.org.uk - this link provides more information about DEEP - the Dementia Engagement and Empowerment Project.
- Various guides to engaging with people with dementia can be found at: Kate Allan JRF 2003 www.jrf.org.uk/publications/exploring-ways-staff-consult-people-with-dementia-about-services.
- RIPFA – Practice Tool – Involving and Engaging People with Dementia www.ripfa.org.uk/resources/publications/practice-tools-and-guides/involving-and-engaging-people-with-dementia-practice-tool-2015.

4. Perceived barriers when involving people with dementia

There are perceived barriers to engagement of people with dementia felt by both people with dementia themselves and practitioners who might seek to support that engagement. It is helpful to consider what those perceived barriers might be and ways in which they can be addressed.

4.1 The perspective of people with dementia

People with dementia themselves have identified barriers to getting involved in services or projects (taken from Litherland, 2014). They are:

- Fear that I will not be taken seriously.
- Lack of time for people to listen and to make relationships.
- Lack of money.
- Poor access to transport.
- Lack of diagnosis.

- Negative attitudes about the abilities or rights of people with dementia.
- Being asked about issues that are not relevant.
- Lack of feedback about what has happened as a result of being involved.
- Lack of personal identification with issues of 'dementia' or 'Alzheimer's'.

Solutions to many of these perceived barriers have been discussed throughout this paper. Key to successful engagement and involvement is taking the appropriate amount of time to build a trusting relationship with the person with dementia, in which their contributions are valued and respected, and they are supported to contribute to the process in ways that are helpful to them.

4.2 Perceived barriers to involving people with dementia in projects

Participants in the Genio workshop also identified the following barriers to involving people with dementia in projects:

1. The **stigma attached to dementia** can make people with dementia reluctant to get involved; it can also affect the perceptions of practitioners and decision makers in relation to how positive they are about involving people with dementia.

Solution: *To counter this, organisations must be prepared to challenge negative stereotypes about people with dementia and what they are capable of. Basic awareness-raising can go some way to help here - as can leading by example - people with a positive experience of engagement are more likely to get involved again and inspire others to do so.*
2. Increasing the involvement of people with dementia **relies on organisational structures that can make involvement a reality**. As well as motivated staff members who want to involve people with dementia, you need an organisational culture that values hearing and acting upon the voices of people with dementia, and that provides the necessary support such as time, covers expenses for people with dementia, and is willing to act upon the feedback of people with dementia.

Solution (see 'creating a listening culture' pg. 13-14).
3. A concern about '**over using or consulting**' with a small number of people with dementia, and that this may lead to exploitation and/or "tokenism". In terms of project involvement it may be initially that only one or two people with dementia are interested in getting involved at a more strategic level, and that it then becomes easy just to involve these identified people in advisory groups, formal meetings etc.

Solution: *See point 4 below.*
4. Service providers can act as gatekeepers to people with dementia, helping to identify people who would like to get more involved, and also capturing viewpoints. They need also to be **aware of the 'power' that they exercise**, in terms of who they approach to get involved ('cherry picking' e.g. people who do not need much support, or people who will provide a positive perspective) or how they represent or interpret viewpoints that people with dementia present.

Solution: *The two points above illustrate why it is important to use a variety of approaches as well as thinking about making mainstream 'listening functions' more accessible to all. The more inaccessible a process is the more it will only engage a smaller number of people.*

5. People with dementia may be worried that if they comment honestly about a service or project that this may **jeopardise the support they receive.**

Solution: *This is mainly about culture - and the extent to which people with dementia feel they can trust those that support them - which is why building trust is such an important prerequisite for engagement.*

6. People with dementia **may not know their diagnosis or identify with having a type of dementia**, making it difficult to engage openly in discussions about dementia projects or services.

Solution: *Sometimes it might be helpful to talk in terms of 'memory problems' - notwithstanding the fact that dementia is not just about memory - but in fact this is not an argument against engagement - more an argument for effective diagnosis and proper communication.*

5. Conclusion

This paper has focused on ways to support the active involvement of people with dementia in the design of services and supports and in research and projects which are informing service development. It has sought to unpack the perceived challenges that have traditionally been attributed to including people with dementia in designing supports and services by providing simple and accessible solutions to promoting engagement and involvement.

As we have seen, there are many ways we can support people at varying stages of dementia to contribute to design of services in a meaningful way. Key to their successful inclusion is a response that supports their needs so that they can optimise their engagement. We know that there should not be a predetermined or rigid "approach" to supporting the inclusion of people with dementia, rather there are a range of methods available to support engagement, and choosing which one or combination of these is appropriate will take account of the needs of the individual that you wish to engage with. We hope this paper has given you some food for thought, that it has strengthened the case for involving people with dementia, and shown you some practical ways of ensuring that voices are heard and unique perspectives harnessed.

We have looked at how a listening culture and a supportive organisational environment will help successful engagement. We hope that it has reassured you that your organisation is likely to already have many of the skills and attributes that you need to make involvement a reality - common sense, good listening skills, and a commitment to giving everyone a fair say.

We hope we have also shown that many of the ways to support people with dementia to actively engage also have relevance in creating conditions that support the engagement of many, from staff to volunteers and other key people whose input is of value. We hope that the opportunity for you to reflect on how you currently hear the voices of people with dementia in your work, will inform how your organisation engages with everyone to support effective, accessible and enjoyable participation.

Appendix

Getting Started Checklist

- Ask yourself how the voices of your customers, staff, and volunteers are heard within your organisation. This includes things like questionnaires and meetings - but also the general culture - is it a listening culture - does what people say get fed through to the relevant people?
- Ask yourself how accessible to people with dementia these processes are? (you could involve people with dementia in helping you with this - for example by looking at how meetings are organised, what kind of written materials you might be using, what the buildings you use are like).
- Ask yourself what can be done to make them more accessible. (guidelines from DEEP and others listed above can help here).
- Ask yourself whether there are ways of supporting people to engage in these processes.
- Ask yourself whether there is scope for a parallel process specifically for people with dementia.

References

1. Allan, K. (2001) *Exploring ways for staff to consult people with dementia about services*. Available online www.jrf.org.uk/report/exploring-ways-staff-consult-people-dementia-about-services [Accessed 22 July 2016].
2. Alzheimer Society of Ireland. *Advocacy in ASI - Irish Working Group of People with Dementia*. Available online www.alzheimer.ie/Get-Involved/Campaigning/Advocacy.aspx [Accessed 22 July 2016].
3. Government of Ireland. (2015) *Assisted Decision Making Capacity Act*. Available online www.oireachtas.ie/documents/bills28/acts/2015/a6415.pdf [Accessed 22 July 2016].
4. Dementia Engagement & Empowerment Project DEEP. (2013) *Collecting the Views of People with Dementia*. Available online www.dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Collecting-views.pdf [Accessed 22 July 2016].
5. Dementia Engagement & Empowerment Project DEEP. (2013) *Writing dementia-friendly information*. Available online www.dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Writing-dementia-friendly-information.pdf [Accessed 22 July 2016].
6. Dementia Engagement & Empowerment Project DEEP. Available online www.dementiavoices.org.uk [Accessed 22 July 2016].
7. Dementia Engagement & Empowerment Project DEEP. *DEEP Guides*. Available online www.dementiavoices.org.uk/resources/deep-guides [Accessed 22 July 2016].
8. Dementia Services Information and Development Centre (2014). Available online www.dementia.ie [Accessed 22 July 2016].
9. Department of Health (2014). *The Irish National Dementia Strategy*. Available online www.health.gov.ie/wp-content/uploads/2014/12/30115-National-Dementia-Strategy-Eng.pdf [Accessed 22 July 2016].
10. Inclusion Ireland. *Capacity and the Assisted Decision Making Bill*. Available online www.inclusionireland.ie/capacity [Accessed 22 July 2016].
11. Innovations in Dementia CIC. (2015) *How to do an access audit*. Available online www.innovationsindementia.org.uk/HowToDoAnAudit.pdf [Accessed 22 July 2016].
12. Innovations in Dementia. (2011) *Telling our stories: using film to hear the voices of people with dementia*. Available online www.innovationsindementia.org.uk/Telling%20our%20stories.pdf [Accessed 22 July 2016].
13. Kent Dementia Action Alliance. (2016) *Maidstone Mentors*. Available online www.dementiafriendlykent.org.uk/maidstone-mentors [Accessed 22 July 2016].

14. Litherland, R. (2015) *Developing a National User Movement of People with Dementia*. Available online www.jrf.org.uk/report/developing-national-user-movement-people-dementia [Accessed 22 July 2016].
15. Litherland, R. (2015) *Involving and engaging people with dementia: Practice Tool*. Available online www.ripfa.org.uk/resources/publications/practice-tools-and-guides/involving-and-engaging-people-with-dementia-practice-tool-2015 [Accessed 22 July 2016].
16. Litherland, R. and Capstick, A. (2014) *Involving people with dementia in service development and evaluation*. In: Downs, M. and Bowers, B. (eds). 'Excellence in dementia care: research into practice.' 2nd ed. Maidenhead: Open University Press. pp. 401-416.
17. Murphy J., Gray C., Cox S. (2007) *Talking Mats: the effectiveness of a low technology communication framework to help people with dementia express their views*, *Journal of Assistive Technologies*, Vol. 1 Iss: 2, pp.30 – 34.
18. Plain English Campaign. (2016) *Plain English Free Guides*. Available online www.plainenglish.co.uk/free-guides.html [Accessed 22 July 2016].
19. Sage. Available online www.thirdageireland.ie/sage [Accessed 22 July 2016].
20. Social Care Institute for Excellence SCIE. (2009) *Positive Communication - Dementia E-learning Course*. Available online www.scie.org.uk/dementia/open-dementia-e-learning-programme/7-positive-communication.asp [Accessed 22 July 2016].
21. Talking Mats Limited. Available online www.talkingmats.com [Accessed 22 July 2016].
22. Innovations in Dementia. (2010) *Think Tank*. Available online www.youtube.com/watch?v=vCuMYxZpU2o. [Accessed 22 July 2016]

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