



**Wicklow Dementia
Support**

People with Dementia as Influencers

Enabling people with dementia to have a voice in
shaping policy and practices



October 2018

Preface

This review of research and programmes that enable the involvement of people with dementia in shaping policy and practices is one of a number of resources being developed as part of a Community Foundation of Ireland funded project called 'People with Dementia's Voice Matters'. The main objective of this project is to develop capability and potential of people with dementia to have their say in relation to services and developments in their local areas to ensure that they are supported to live well in their communities.

The project is being undertaken by Wicklow Dementia Support (WDS), a voluntary organisation that supports people with dementia through befriending services, social clubs and carer support groups. As a member of Wicklow Dementia Working Group and Wicklow Public Participation Network, WDS wants to ensure that the voice and experiences of people with dementia shape policy, attitudes and decisions that effect their lives – locally and nationally.

Introduction

Currently there are 55,000 people living with dementia in Ireland. The majority (30,000) live in the community. The number of people living with dementia is set to double by 2031. Approximately, half a million people live in families that have been affected by dementia¹.

Dementia is a term which describes a range of conditions which cause damage to the brain. This damage affects memory, thinking, language and the ability to perform everyday tasks. Dementia is a disability and is recognised as such under Irish Equality laws and under the United Nations Convention on the Rights of People with Disabilities.

A principle of the Convention on the Rights of People with Disabilities is the full and effective participation and inclusion of people with disability in society². This is also a key principle underpinning the Irish National Dementia Strategy. Principle 2 of the Strategy seeks to support and encourage the enablement of people with dementia to live well as valued citizens³.

As citizens, people with dementia are entitled to the same from life and their community as everyone else. They should be active agents in shaping their own lives and experiences. The will, preferences and priorities of people with dementia (and their families as appropriate) should inform the supports and services that are provided to them. However, negative perceptions and misunderstandings of dementia can act as a barrier to people with dementia in having a 'voice' and influencing policy and community decision-making processes.

These barriers include:

- A belief that people with dementia are unable to contribute their viewpoints
- Low expectation about what user involvement could mean for people with dementia
- Lack of training and confidence amongst stakeholders to facilitate people with dementia to input into public consultation processes.
- Narratives (accounts) used to give a particular position on dementia. For example linking aggressive behaviour with neurological problems precludes any discussion of other causative factors such as aggressive behaviour being provoked by frustration or misunderstandings⁴.

¹ <https://www.alzheimer.ie/About-Us/News-and-Media.aspx>

² <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

³ <http://health.gov.ie/wp-content/uploads/2014/12/30115-National-Dementia-Strategy-Eng.pdf>

⁴ <http://www.sciencedirect.com/science/article/pii/S0890406508000248>

People with dementia therefore, lack opportunities to use their expertise, their stories, to inform the development of health and social care services and wider community policy and practices in the areas they live in. This person with dementia sums up how this feels:

It hurts when I am second-guessed or when people ignore me and talk to my family before talking to me. I do not like being treated like a child or treated as though I am not there. I sometimes do not feel validated, or I feel that I am no longer considered 'an expert' capable of making valid decisions⁵.

If people with dementia are to be supported to live well in their communities, their direct involvement in the planning and delivery of services and in what happens in their community is essential. People with dementia are in a unique position to share what it is like to live with dementia; they are experts by experiences. Listening and learning from people with dementia benefits the individuals, services and policy development.

Definition

Involvement, participation and engagement are used interchangeably within documents referring to interaction between groups/communities with public bodies and organisations (who in the main have the power to make decisions). Community involvement therefore is 'any process by which ... service users and/or stakeholders can influence decision-making concerning the development, delivery, management, or evaluation of services'⁶. It is actively engaging people in designing services and developing policy. Involvement therefore is an ongoing process where people are supported to engage, connect, participate and influence at many points and in many ways.

⁵ <https://uwaterloo.ca/murray-alzheimer-research-and-education-program/education-and-knowledge-translation/products-education-tools/by-us-for-us-guides/enhancing-communication/communication-challenges-family-friends>

⁶ https://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/Evidence_Review_Engagement_with_Older_People.pdf?dtrk=true

Enabling public participation through Local Authority (LA) structures

Public Participatory Networks (PPNs) have been set up to enable the public to take an active formal role in the policy making and oversight activities of the LA's area of responsibility⁷. The values underpinning PPNs include participation and inclusive. The aim is to ensure that people's basic needs are met, 'that people have a sense of purpose, and that they feel able to achieve important goals, to participate in society and to live the lives they value and have reason to value'⁸

Models of empowerment of people with dementia to have a voice

There are a growing number of local, national and global groups of people with dementia⁹ working to influence policies, practices, and people to ensure that people living with dementia, are included in every decision that affects their lives.

1. In Ireland, the Irish Dementia Working Group is a national advocacy group which is involved in development and influencing work. The aims of the group include:

- Ensure that the voice of people with dementia influences policy.
- Support discussion and debate around important issues for people living with dementia.
- Promote the direct involvement of people living with dementia in decisions and developments pertaining to them.

Activities and influencing work of the Irish Dementia Working Group include-

- Actively influencing the development of the National Dementia Strategy in Ireland, ensuring that the voice of the person with dementia is central within policy developments.
- Using various media, such as videos, radio and press to influence opinions and policy and to raise awareness.
- Participation in research and consultations for a range of academic and government agencies.
- Drafting guidelines to inform the designs and adaptations required to overcome challenges people living with dementia may experience in their homes.

⁷ <https://www.socialjustice.ie/sites/default/files/attach/civil-society-article/4398/ppnuserguidev1may16.pdf>

⁸ <https://www.socialjustice.ie/sites/default/files/attach/civil-society-article/4398/ppnuserguidev1may16.pdf>

⁹ <https://www.dementiaallianceinternational.org/three-nations-dementia-working-group/>

2. In the UK, the Dementia, Engagement and Empowerment Project (DEEP) brings together groups of people with dementia. DEEP supports these groups to change attitudes, services and policies that affect the lives of people with dementia. Their influencing work includes lobbying politicians, auditing the lay out of public spaces, imputing into local dementia practices and strategies and challenging the existing narrative of what it is like to live with dementia¹⁰.

Members of DEEP overcome the challenges of having to fit within the 'one size fits all' structures for public engagement, by using innovative ways that enable people with dementia to have a voice and influence policy and practice.

Strengths based approach to get the voice of people with dementia heard

DEEP in collaboration with On Our Radar¹¹ (a not-for-profit communication agency for unheard communities) and Innovations in Dementia, set up Dementia Diaries, a series of audio diaries, which brings together people's diverse experiences of living with dementia as a way of getting the voice of people with dementia heard and changing attitudes. It serves as a public record and a personal archive that documents the views, reflections and day-to-day lives of people living with dementia¹².

DEEP have also, developed a range of guides informed by their experiences to help stakeholders engage appropriately with people with dementia¹³.

Having a voice matters

An evaluation of the impact of DEEP found that members were actively involved in local influencing work through creating dementia friendly communities, raising awareness, involvement in health and social policy and practice. Being part of the DEEP network, gave members the confidence to voice their viewpoint and use their skills and expertise. They felt they had a sense of purpose and valued for the work they were doing¹⁴.

¹⁰ <http://dementiavoices.org.uk/>

¹¹ <https://www.onourradar.org/>

¹² <https://dementiadiaries.org/>

¹³ <http://dementiavoices.org.uk/resources/deep-guides/>

¹⁴ <https://www.jrf.org.uk/report/developing-national-user-movement-people-dementia>

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 services that people need and want;
- using people's skills and experience, their unique expertise from the 'lived experience' challenge stereotypes;
- people have a role, are occupied and maintain a sense of value and purpose.¹⁵

A number of factors have been found to be critical in supporting people with dementia to have their voice heard. For people with dementia, local groups offer the support to find their voice through opportunities to participate in organised discussions on issues of interest to the group. To ensure everyone gets an opportunity to contribute, it is important to:

- Build confidence of person with dementia by giving the person the space to communicate their ideas, and provide individual support to those that need it, e.g. from a volunteer¹⁶;
- Make the person feel comfortable, for example use small discussion groups, have sticky notes available for people to write down ideas;
- Get the timing of meetings right;
- Set ground rules e.g. turn taking, using props such as a red card to indicate when a person wants to speak, carers should not speak on behalf of person with dementia but on their own behalf¹⁷;
- Build relationships with key local decision-makers who can assist to take forward the issues¹⁸.

Service Users Reference Group (SURF)

A UK dementia group invite local representatives from public bodies and organisations to their meetings. This gives people with dementia an opportunity to set their own agendas and speak about their priorities. This approach has led to the SURF group undertaking an audit of the accessibility of a local GP practice for people with dementia.

If organisations are to hear and act on the voice of people with dementia:

- There must be the belief that participation is central to responsive policy and practice, and an environment in which everyone expects, promotes and supports participation¹⁹;

¹⁵ <https://www.jrf.org.uk/report/developing-national-user-movement-people-dementia>

¹⁶ <https://www.jrf.org.uk/report/developing-national-user-movement-people-dementia>

¹⁷ <https://www.jrf.org.uk/report/stronger-collective-voice-people-dementia>

¹⁸ <https://www.jrf.org.uk/report/developing-national-user-movement-people-dementia>

- Organisations and public bodies must have the capacity to develop a variety of opportunities for users/stakeholders to get involved and the drive to keep a priority²⁰;
- Appropriate funding of local groups to maintain and strengthen the relationship between people with dementia and decision-makers;
- Offer practical supports such as covering expenses and arranging travel for participants;
- Ensure accessibility including written material, use of straightforward language (avoid use of acronyms), well structured events and meetings, restricted agendas and opportunity for feedback after people have been involved;
- Operate an appropriate consent procedure that is accessible for people with dementia to ensure that people with dementia are consenting to be involved and engaged²¹;
- Use a range of methods to help people with dementia to understand the issue or the engagement activity and to enable them contribute their viewpoint e.g. visual prompts such as photos and pictures, walking interviews, flipcharts to record ideas and summarise discussions .

Tools to support people with dementia to communicate their viewpoint point

People with dementia may experience difficulties with communication. These difficulties can be isolating. Effective communication encourages engagement and is central to building relationships and sharing knowledge. It includes both verbal and non-verbal. Both means of communication are important. Effective and meaningful communication is said to involve non-verbal communication, with body language accounting for 55 per cent, whilst words account for 7 per cent and tone of voice 38 percent²². For people with memory issues, non-verbal communication becomes even more important for example a meaningful glance can convey the need for assistance.

Various tools have been developed to enhance communication skills. For example, the Sonas Programme is a therapeutic activity for people with significant communication impairment, primarily as a result of dementia²³.

In general, success factors for enhancing communication skills centre on:

- Using clear language
- Finding an accessible starting point for discussion

¹⁹ Hernandez, L., Robson, P., Sampson, A (2010) Towards Integrated Participation: Involving Seldom Heard Users of Social Care Services. The British Journal of Social Work, Volume 40, Issue 3, 1 April 2010, Pages 714–736, <https://doi.org/10.1093/bjsw/bcn118>.

²⁰ ibid

²¹ <https://www.jrf.org.uk/report/developing-national-user-movement-people-dementia>

²² https://en.wikipedia.org/wiki/Albert_Mehrabian

²³ <https://sonasapc.ie/the-sonas-programme/>

- Using appropriate pacing and timing
- Exploit spontaneous communication opportunities

Approaches found to be beneficial for effective communication include working with pictures, communicating during other activities and focusing on non verbal communication. For example 'Talking Mats' help people to organise and express their views²⁴

People with dementia, like everyone else, have different personalities, different ways of dealing with life and their own personal style of communicating. Whilst the effect of dementia will be experienced by people differently depending on the area of the brain affected, factors unrelated to the disease can have a bigger impact on the person's life. Social isolation can be as a result of stigma, loss of confidence and feeling less valued. To support people with dementia to engage, connect, participate and influence policy and community decision-making processes therefore requires confidence building, a focus on abilities and to develop capability and potential.

Building confidence

Focusing on the person's strengths has the potential to increase confidence of people with dementia empowering them to speak up. Cognitive Stimulation Therapy is based on a philosophy of optimising cognitive functioning. The focus is on opinions rather than facts; new ideas, thoughts and associations, maximizing potential, inclusion, involvement, building and strengthening relationships²⁵. This approach creates a 'failure free' environment as there is no right and wrong opinion, everyone is entitled to give their own opinion, sharing similar opinions creates connections between people.

The sessions developed as part of cognitive stimulation therapy includes Current Affairs as a topic. An evaluation of the sessions found that people with dementia expressed a great interest in current affairs and stated that they loved reading newspapers²⁶.

Creative arts

The creative arts offer the opportunity for expression and communication, which can be particularly helpful to people who find it hard to express their thoughts and feelings verbally.

²⁴ <http://www.talkingmats.com/>

²⁵ Cognitive Stimulation <http://www.cstdementia.com/page/the-manuals>

²⁶ <https://www.ncbi.nlm.nih.gov/books/NBK424178/>

For example Participatory Art requires professional artists to collaborate with people to create original artistic works that relate to and/or express to others the participants' experiences, outlook and/or community context in some way²⁷.

According to an increasing body of research, the arts are a powerful medium for challenging taken-for granted assumptions, and for promoting personal and social change. Creative and artistic opportunities offer people with the dementia an opportunity to tell their stories from their experience, thus creating new understanding.

A Canadian Community-based, arts-based project

Persons with dementia and their family members worked with visual and performance artists to co-create an artistic reflection of what the person with dementia wanted the world to know about them. The visual and poetic expressions created, challenged taken-for-granted assumptions of decline and dysfunction, instead demonstrated how persons with dementia are supported by loving networks, embracing life, remaining active and engaged²⁸.

Film is another powerful medium that can be used to allow people with dementia to tell their own stories in their own words.

Using film to hear the voices of people with dementia

People with young on-set dementia from Age Concern, Woodley took part in a filming workshop. They outlined their experiences in a booklet 'Telling our stories: using film to hear the voices of people with dementia'²⁹.

Performing Arts

The performing arts can also provide a medium for people with dementia for self-expression.

²⁷ <http://baringfoundation.org.uk/wp-content/uploads/2011/04/EvidenceReview.pdf>

²⁸ Dupiuis, S et al (2016) Reclaiming citizenship through the arts. *Dementia*, Volume: 15 issue: 3, page(s): 358-380
<http://journals.sagepub.com/doi/abs/10.1177/1471301216637206>

²⁹ <http://www.innovationsindementia.org.uk/Telling%20our%20stories.pdf>

Play writing and performing

The Early Dementia Users Co-Operative Aiming to Educate (EDUCATE) in Stockport³⁰ worked with HayLo Theatre group to write a play about their experience of living with dementia. Haylo performed the play 'Over the Garden Fence'³¹³².

Conclusion

The involvement of people living with dementia in service development and community decision-making processes has lagged behind that of other groups because of the assumption that they are unable to communicate their needs and perspectives. This has led to social exclusion and a failure to address the barriers that prevent people with dementia living fulfilled lives in their communities.

Engaging with people with dementia in a targeted way to seek their input and supporting people with dementia through various forums will contribute to strengthening the voice of people with dementia ensuring their inclusion in communities. Public bodies and organisations that are really focused on listening to people with dementia will find it easier to create an environment that is responsive to their needs.

It is society which disables people. It is attitudes, actions, assumptions - social, cultural and physical structures which disable by erecting barriers and imposing restrictions and options. Disability is not inherent³³.

³⁰ <http://www.educatestockport.org.uk/>

³¹ <http://dementiawithoutwalls.org.uk/wp-content/uploads/2016/10/Making-An-Impact-Together.pdf>

³² <https://haylotheatre.com/productions/>

³³ Oliver, M (2004). If I had a hammer: the social model in action. In: J. Swain, S. French, C. Barnes and C. Thomas, (eds). *Disabling Barriers – Enabling Environments*. SAGE, London