

Executive Summary

This report presents a review of the evidence that demonstrates where there is robust evidence for community engagement activities, what is important to think about and consider when planning new or revised activities and additionally outcomes that can inform current work and future service development.

We wanted to understand, the dominant approaches to promoting community engagement with and awareness of dementia in the UK, the underlying assumptions/theories about how they work and how impact is assessed. There is not one definition of community engagement. Alzheimer's Society currently describes Dementia Friends (DF), Dementia Action Alliance (DAA), Dementia Friendly Communities (DFC) and Public Awareness as community engagement activities. Definitions depend on the perspective; the community in question and how that is defined, the intended outcomes (e.g. engagement with healthy lifestyles or with local decision making) and the types of activities. It is not necessary to have a fixed definition, but rather to be clear what operational definitions are being used by different individuals, groups or organisations.

The first phase provided an overview of what is known about community engagement activities specifically focussed on dementia. We found these clustered around the following activities: awareness raising to normalise living with dementia, co-ordination and integration of services to be dementia aware and responsive, promoting inclusion in culture and leisure activities to reduce social isolation, environmental adaptation and, digital technology to support orientation and involvement.

We found three key motivations for community engagement that all need to be underpinned by awareness and understanding of dementia.

- **Compassion:** 'we must do something' driven by concern for the wellbeing of people affected by dementia
- **Utilitarian:** 'we must do something' driven by practical cost-benefit or utilitarian analysis
- **Rights-based:** 'we should not be excluded' driven by a social justice/disability rights/citizenship based perspective

In phase two, we focused on the proposition that Community Engagement that is grounded in a rights based approach is likely to be more effective in achieving the short and long term goals of the inclusion of people with dementia in their local community and wider society. To do this, phase two considered a wider literature beyond dementia specific work. It included evidence from research on health inequalities and disability rights initiatives (including those with learning disabilities) to look for activities and approaches that help to explain what needs to be in place to support a rights based agenda that supports the inclusion and participation of people with dementia. We took a realist approach which focuses on understanding and unpacking the key factors and interactions by which interventions work (or fail to work), so providing an explanation, as opposed to a judgment about how they work. Realist approaches pay careful attention to how different resources and contexts trigger different responses in those involved and thus acknowledges that a particular approach or intervention may work well in one context but not another.



There is good evidence that empowerment approaches work and are the most sustainable. Participation is key, yet we must remember that presence does not necessarily equate to participation and measuring impact needs to account for this, (for example counting who attends an event or service does not tell you about a person's involvement or if it is an activity they benefit from and want to do).

Strategies for achieving CE through a rights-based approach depend on:

- Secure, appropriate and predictable resources for Community Engagement work over time
- The sharing rather than the delegating of responsibility between organisations for making Community Engagement work
- Moving beyond the immediate world of those living with dementia and their peers to engage with those unaffected and largely disengaged.
- Addressing how 'normal' and 'participation' are defined in a society that values a person's potential to be economically active and fit with ideas of what are desirable and acceptable behaviours/skills/attributes.

Through four key factors,

1. a **language of inclusion**
2. a clear identity for people living with dementia **that is separate from** those who provide support and care
3. an expectation that the person with dementia **should and could participate** and that their **contribution is valued**
4. space, time and support for people **to articulate their views and choices**

Activities and programmes based on this approach should then enable people to continue to feel comfortable in place, keep and make new social connections that have a level of reciprocity and, contribute to their community as much as they want and are able to.

This means that the 'dementia awareness' people need to have should be that, **people living with dementia have a right to keep living and be part of their community**. The concept of citizenship is a useful framing to consider how people can participate and be included, not necessarily as 'activists' but in the ordinary and domestic spheres.

Some important possible unintended consequences are a side-lining of the role of care partners, and even those who may not want to exercise choice, voice and control in ways advocated by leaders in the rights debate. Evidence of efficacy of a rights-based approach is currently weak: particularly around understanding the benefits or disbenefits of the dementia 'label' and how a rights-based approach applies beyond the early stages of dementia. As this is a new research area there is value in taking a realist approach to develop a body of evidence and appropriate impact frameworks. The current relevant research landscape is coming from two broad areas; one from a health and care perspective looking at community support and active and independent living, the other looking at activism, inclusiveness and citizenship, both these feed into ideas, interventions and activities of inclusive and supportive communities. The report details these research groups and projects.

Potential tools for digital engagement are likely to be technologies that can capture in the moment experience and enhance social interaction, rather than substituting social interaction which could promote further isolation.

Keeping an acute awareness of the changing roles and shifting balances of power between different players from policy makers to local activists and enabling that negotiation may be a key role for Alzheimer's Society as it pursues a rights based agenda.