

Mapping dementia-friendly communities across Europe

SUMMARY OF A STUDY COMMISSIONED BY THE EUROPEAN FOUNDATIONS' INITIATIVE ON DEMENTIA (EFID)



Executive Summary

The report “Mapping dementia-friendly communities across Europe” was commissioned by the European Foundations’ Initiative on Dementia (EFID) and carried out by the Mental Health Foundation (a UK non-governmental organisation) in 2014 and 2015. The research originated from a shared interest of the foundations engaged in EFID¹ in conducting an analysis of concepts and practices of what is commonly referred to as ‘dementia-friendly communities’ (DFCs) and similar initiatives across Europe. The aim of the report is to provide practical information, guidance and examples to support good practice around sustainable, inclusive and supportive environments for people living with dementia and their carers. The report is accompanied by an online collection of case studies that illustrate the diversity of ‘dementia-friendly community’ activity in Europe. The online ‘mapping paper’ “Dementia-friendly community case studies across Europe” is available on the EFID website (www.efid.info).

Europe is facing unprecedented demographic changes with an increasing ageing population. There are an estimated 8.7 million people living with dementia in Europe and this number is expected to rise. Although dementia is not a natural consequence of ageing, the impact of the condition on the elderly is set to grow. In the absence of a cure or universally effective treatments for dementia, in the foreseeable future, there is both the opportunity and necessity for creative, positive community-based initiatives to support people living with dementia, not only to live well but also be active participants in their communities. It is crucial that ‘dementia-friendly community’ initiatives situate people with dementia at the centre, maintaining a view of them as people, citizens, and equal members of society, not just service users or patients.

Communities come in all shapes and sizes, therefore community-based solutions to enable people with dementia to live well are also highly diverse. This report includes a number of examples of ‘dementia-friendly community’ work from across Europe that clearly demonstrates this. A participant of the research described his work as creating “*a social movement that mobilises all sections of the community*”. The survey showed that the ‘dementia-friendly community’ ‘movement’ is occurring in many different ways.

In the report, a number of good practices of DFCs are presented. However, the study is a ‘snapshot’ of ‘dementia-friendly community’ work in Europe and cannot claim to present a comprehensive picture of everything that has been occurring in this field.

Findings

The findings presented in this report are the product of a literature review, an online survey and telephone interviews. While the report summarises an analysis of these three elements, a detailed description of each is presented in the appendices of the report.

¹ Seven foundations are involved in the 2nd and 3rd phase of EFID (2013-2016). These are The Atlantic Philanthropies, the Fondation Médéric Alzheimer, the King Baudouin Foundation, the Robert Bosch Stiftung, The Life Changes Trust, The Joseph Rowntree Foundation and the Genio Trust. EFID is an initiative by the Network of European Foundations. For more information visit the website www.efid.info

At the start of the study, some definitions were adopted. These were as follows:

- a) The term 'community' was defined mainly as a geographical locality with few references to communities of identity (i.e. LGBT, ethnic minorities) or interest. The term 'dementia-friendly communities' describes a wide range of activities, projects and initiatives aimed at improving the quality of life for people with dementia and at creating inclusive and supportive local environments to enable people with dementia to be active participants.
- b) The mapping focused on people with dementia as citizens of the wider community, not on people defined by their dementia as 'patients' or 'service users'.
- c) Making an organisation or service 'dementia-friendly' is an important building block of developing a 'dementia-friendly community'; however, the former on its own does not create a 'dementia-friendly community'.

The report identified four essential factors to develop a DFC. These are:

1. Providing training, education and awareness-raising about dementia.

Raising awareness is a key element of developing a DFC. Levels of knowledge and understanding about dementia were generally found to be low, partly due to fear, shame and stigma. Awareness-raising activities are probably the most tangible in relation to developing 'dementia-friendly communities', because they potentially engage a wide range of community members. Yet the type of information that people receive and how they act upon it is much harder to measure. Furthermore, unclear information can be misleading and could inadvertently risk adding to stigma.

2. Active inclusion and involvement of people living with dementia in the communities where they live.

Although inclusion and involvement can be defined in many different ways, the key message expressed in the study is that people living with dementia should not be treated, in a 'dementia-friendly community', as passive objects or recipients of things 'done to them'. In this respect, the involvement of people living with severe dementia or people with dementia living in remote area was seen as particularly challenging.

3. Encouraging and supporting partnerships, networks and collaborations focused on developing 'dementia-friendly communities'.

Due to the nature of community, it is clear that no one organisation can initiate the development process of a 'dementia-friendly community' on its own. The study identified collaboration, both through formal and informal processes, as an essential element of developing a DFC. Successful partnerships tended to be diverse, involving: public services and officials (e.g. mayors); NGOs; businesses; public authorities; community groups; faith organisations; and people living with dementia and their carers. These partnerships had many functions including: sharing information; learning and resources; monitoring progress and impact; supporting members; promoting 'dementia-friendly communities'; and enabling community development and cohesion.

4. Securing and sharing resources for developing a 'dementia-friendly community'.

Although resources were mentioned less frequently in the survey, the study emphasised the importance (and the challenge) of having the right resources in place at the right time.

The study also collected information on policies and strategies relating to 'dementia-friendly communities'. In particular, findings from the research indicated that most 'dementia-friendly

community' activity was taking place at regional, municipal or local level. Six countries have government-led national dementia strategies that supported the development of 'dementia-friendly communities'. In several countries, the national programmes on DFCs are led by NGOs (usually Alzheimer's associations). Furthermore, some 'dementia-friendly community' initiatives, led by national organisations, regional or municipal governments, were quite centralised and 'top down' in their approach. Other initiatives were local, community, grassroots and very much 'bottom up'. Some 'dementia-friendly community' actions combined these two approaches well, while others perceived or experienced tensions. However, activity of either type (top down and bottom up) appeared to be beneficial by generating more dementia-friendly awareness and activities in the communities where it took place. Finally, there are some European-wide initiatives that include support for 'dementia-friendly communities', however no single agreed model for a 'dementia-friendly community' exists, nor is there a comprehensive European programme (other than EFID) supporting the development of 'dementia-friendly communities'.

Some strengths and challenges were identified relating to the development of 'dementia-friendly communities'. Strengths were observed when a number of European countries applied the four essential factors (outlined above) in practice. This, in turn, was perceived to improve the quality of life and well-being of people living with dementia. Furthermore, the diversity of people, organisations, and countries involved in the development of 'dementia-friendly communities' creates space for innovation, creativity, new partnerships and resources. More broadly, it generates new conceptualisations of dementia itself, and the way society responds to it.

Among the challenges, a lack of resources was a real concern for many DFCs, especially those located in countries where the "safety net" of public services is limited or under-developed. Addressing issues of resources and sustainability was considered to be vital; it is unrealistic to expect most 'dementia-friendly communities' to be initiated or sustained by communities themselves without some government commitment or support.

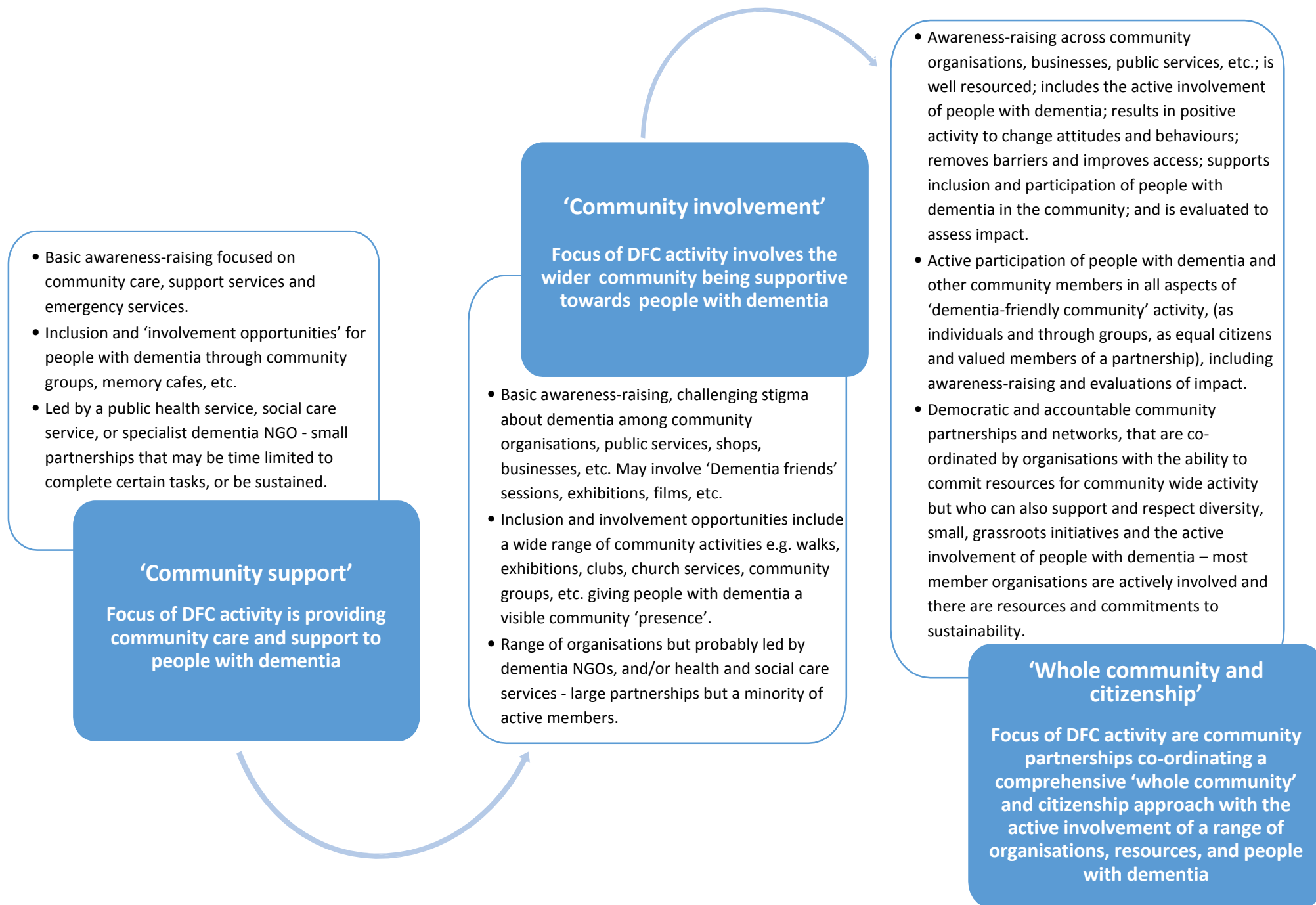
Finding ways of evaluating and demonstrating the impact of 'dementia-friendly communities' is crucial; however the study identified few examples of evaluation tools and measurements of impact.

[A taxonomy for 'dementia-friendly community' activity \(DEM-FACT\)](#)

Drawing upon the findings, the report identified three general "descriptors" or groupings that can be helpful for organisations wishing to be involved in developing 'dementia-friendly communities'. Diagram 1, 'A taxonomy for 'dementia-friendly community' activity' describes these steps. It is important to note that this is not necessarily a linear process. As such, some of the activities in one descriptor may also be occurring in another descriptor, while not all the activities outlined in a descriptor may necessarily occur at the same time.

Finally, the report concludes by outlining a number of possible areas of action or 'ways forward' to support further development of 'dementia-friendly communities' across Europe.

Diagram 1 - A taxonomy for 'dementia-friendly community' activity (DEM-FACT)



Some quotes from the online survey

“Challenging citizens to talk about dementia, get rid of taboos and embrace people with dementia as ‘normal’ citizens with some particular needs for support.”

“Create awareness and provide basic training to local community services... Awareness/training incentives should be rolled out in schools for students from 14 years up.”

“Working with groups in a positive way to look at how we can make things more dementia-friendly, what is working, having the person with dementia central to the conversation.”

“Public awareness at a national level...People in public services and sales should be trained to deal with disoriented people (bank, bus, supermarket, police, etc.).”

“We don’t consider dementia as a ‘burden’ to society but rather as an opportunity to get rid of stereotypes and change society’s practices. Our society has managed to give “time to life” but now it needs to give “life to time”.”