

Dementia-friendly communities: challenges and strategies for achieving stakeholder involvement

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Abstract: Dementia-Friendly Communities (DFCs) are a UK policy initiative that aims to enable people with dementia to feel supported and included within their local community. Current approaches to DFC creation rely on stakeholder involvement, often requiring volunteer assistance. There is though a lack of evidence that examines the reality of achieving this. This paper critically assesses the challenges and strategies for achieving stakeholder involvement in DFCs. The evidence base is drawn from an inter-agency project funded by the National Health Service in the South of England where seven DFCs were developed by steering group partners and four part-time project workers (PWs). Data from the independent evaluation undertaken in the first year (2013-2014) of the project was analysed: 14 semi-structured interviews and a focus group examined PWs experiences; whilst progress and key milestones are determined from monthly progress forms, good news stories, locality steering group minutes and press releases. Analysis was undertaken using a directed content analysis method, whereby data content for each locality was matched to the analytical framework that was drawn from Alzheimer's Society guidance. Challenges to achieving stakeholder involvement were identified as: establishing networks and including people representative of the local community; involving people affected by dementia; and gaining commitment from organisations. Strategies for achieving stakeholder involvement were recognised as: a sustainable approach; spreading the word; and sharing of ideas. By highlighting these challenges and the approaches that have been used within communities to overcome them, these findings form the foundation for the creation of DFC initiatives that will become embedded within communities. Stakeholder involvement is unpredictable and changeable; therefore reliance on this approach questions the long term sustainability of DFCs, and must be considered in future policies designed to enhance quality of life for people affected by dementia.

Keywords: dementia; community participation; evaluation; mixed methodologies; neighbourhood-based initiatives; practice and policy issues.

Word count: 5023 plus Abstract 290

Background

The number of people with dementia is increasing across the globe; in the United Kingdom (UK) alone it is estimated that there are currently 820,000 people with dementia, and this is predicted to rise to over one million in the next two decades (Alzheimer's Society, 2014a). Two thirds of people with dementia currently live within the community, rather than in residential or nursing care accommodation (Alzheimer's Society, 2014a). However, community dwelling people with dementia are often at high risk of social exclusion (Innes 2009), which can lead to a decline in physical, social, and mental stimulation (Adams et al., 2011). Nearly one in four people with dementia (24%) hide or conceal their diagnosis citing stigma as the main reason, whilst 40% of people with dementia report not being included in everyday life (Alzheimer's Disease International, 2012). Exclusion can lead to isolation from the local community (58%), feelings of loneliness (40%) and feeling unable to leave the house once a month or less (10%) (Alzheimer's Society, 2014(b)). Withdrawal from wider society and specifically from physical, mental and social activities can result in poor self-esteem and a reduced quality of life (Everald et al., 2000). This can then create a further dependence on carers, deterioration in health and social isolation. People with dementia and their carers need to be actively engaged and supported within a societal context to maintain and enhance physical, mental and social wellbeing (Phinney et al., 2007).

Finding ways to maintain and improve the quality of life and social well-being of people living with dementia and their families such as keeping physically, mentally and socially active is essential, particularly as there is currently no cure for the condition (Hall et al, 2009; Hill et al, 2010; Swan, 2012). Furthermore, a shift in thinking from a medical model of dementia to a social model has increased awareness that a significant difference can be made to quality of life by the way people with dementia are supported, and through their built and social environment (Monkhouse, 2003). The social environment in which individuals live, as well as their lifestyles and behaviours, can influence rates of illness in a community (Institute of Medicine, 1988). Long-term health improvements, which encompass quality of life, can be achieved when individuals become an active part of their community and work in partnership to create change (Hanson, 1989). Public policy has thus been used by health promotion groups to increase their ability to create positive

environments and strong community action (World Health Organisation, 1986). This emphasises how significant it is to engage the community in decision-making and community participation (Fawcett et al., 1993). A key component of community engagement relates to empowerment at a grass-roots level which enables people to influence and make decisions on important issues. A Dementia-Friendly Community (DFC) can engage the community by providing the important tools and resources so community members can influence their environment.

Policy context

Policies have recently focused on improving quality of life for older people living in the community (for example: CLG, 2008; ONS, 1999; 2005; Scharf et al., 2005; World Health Organization, 2002), and people with dementia (for example: Department of Health, 2009; 2012; 2013; 2015; HM Government, 2012). Terms such as Age-Friendly Communities (AFCs) and DFCs have become commonplace in policy rhetoric. Stemming from the World Health Organization's 'Healthy Cities' initiatives, a public health approach linking personal experience of health and social support with community participation (Henwood and Downs, 2014). AFCs encourage the public and professionals to create an inclusive society where everyone is treated equally and can participate in community activities (World Health Organization, 2007). It has been noted that by improving public spaces will enable older people to participate more fully in society (Crampton et al., 2012). For example, in the UK, the Neighbourhoods and Dementia Project has involved older people in planning the development of the city which has improved the physical and environmental access for older people and increased their confidence to become involved in decision-making. DFCs aim to improve the lives of people with dementia and their families, by empowering people with dementia to have 'high aspirations and feel confident', where they 'can contribute and participate in activities that are meaningful to them' (Alzheimer's Society, 2013: Viii). In the UK, DFCs were introduced in 2012, as one of three areas of action outlined in the Prime Ministers Dementia Challenge (Department of Health, 2012), alongside driving improvements in health and care and improving dementia research. The economic benefits of DFCs have been

recognised in terms of supporting people to live independently and safely in their own home, which leads to a reduction in the time needed in residential or hospital care (Department of Health, 2012). Diverse approaches to becoming dementia-friendly have been used by different communities. For example: in Scotland, DFCs have been taken forwards by a Community Interest Company (Dementia Friendly Community, 2015); in Suffolk, teams of volunteers provide support and information (Jackson, 2012); and in York accessible and affordable training has been provided to staff from local service providers (Crampton et al., 2012). In the main, these approaches rely on stakeholder involvement, often requiring voluntary assistance from people within the local community. Evaluations of DFC initiatives across the UK are starting to reveal key insights and ways forward (for example: Hare and Dean, 2015). However, little attention has been given to the practicalities of creating DFCs in terms of involving key people from the local community. This paper reports on the challenges and strategies for achieving stakeholder involvement in DFCs.

Methods

Project overview

This inter-agency project was funded by NHS South of England Dementia Challenge, and was delivered by representatives from ten organisations, including the local unitary councils, a university and charities that work with people affected by dementia. This project took place in one county in the South of England, where DFCs were developed in seven of the counties localities. Representatives met regularly as a steering group, whilst four PWs were employed on a part-time basis to develop these DFC initiatives within the seven localities (three PWs covering two localities each, and one PW covering one locality). Localities were selected based on population size and percentages of people aged 65 and over (see Table 1 for further details). Two seaside towns, three market towns, one town/borough and one borough/seaside town were selected. Rationale for developing this project in this county, is that it has one of the highest proportions of population above retirement age in the country (24% compared to 17% in the UK) (Office for National Statistics, 2013), and yet one of the lowest rates of dementia diagnosis.

<<Insert Table 1 about here>>

Research design

The evaluation was conducted over a 12 month period (April 2013 until March 2014). Qualitative empirical data was collected to examine the experiences of the PWs who were developing these DFC initiatives across the seven localities. Fourteen semi-structured interviews (IT) and a group interview (GI) with the PWs explored their experiences of developing these DFC initiatives. Progress and key milestones were determined through secondary data provided by the PWs: 34 x progress forms and good news stories; 20 x locality steering group minutes; 16 x press releases and news reports; 66 x local DAA Action Plans; and 14 x Memory Awareness Scheme forms.

Data Collection

Two semi-structured interviews were conducted with the PWs per locality, towards the start and end of the evaluation. The interviews lasted between 30 and 60 minutes each, and took place in an office at the university or at the PWs place of work. One of the PW was unable to take part in the first face to face interview and so the interview questions were emailed and their written response was received instead. To supplement the interview data and enable the research team to explore the similarities and differences experienced in each locality, a focus group with all PWs was undertaken. It lasted approximately 90 minutes and took place in an office at the university. Secondary data was emailed to the research team on a monthly basis by the PWs and filed by locality, ready for analysis.

Ethics and consent

Ethical approval was granted by the university ethics committee. PWs were provided with an information sheet outlining the purpose, design and timescales of the research; how the findings would be used; and the measures to ensure confidentiality and anonymity. All PWs participated in the study. The interviews and focus group were transcribed verbatim and anonymised prior to analysis.

Data Analysis

Data was analysed using a directed content analysis method (Hsieh and Shannon, 2005), that involved matching content from the data to an analytical framework. The analytical framework drew on the ten key areas that underpin a dementia friendly community outlined by the Alzheimer's Society (2013) guidance; see Table 2 for further details. Analysis was conducted per locality, with examples to support the analytical framework drawn out and grouped thematically.

<<Insert Table 2 about here>>

Rigour

Throughout the interviews and focus group the research team asked follow up questions to clarify and examine the answers provided and ensure a richness and depth from the data. One member of the research team independently analysed the data, this analysis was then scrutinized by the other three members of the research team until a consensus was reached (Lincoln and Guba, 1985).

Findings

Analysis revealed a similar level of progress in each of the seven localities against the analytical framework, with more progress consistently in the following areas: challenging stigma, accessible community activities, and respectful and responsive businesses and services. PWs also discussed similar experiences across the seven localities. This facilitated our identification of challenges and strategies for achieving stakeholder involvement within DFCs.

Challenges to achieving stakeholder involvement in DFCs

Particular challenges to achieving stakeholder involvement in DFCs were identified as establishing networks and including people representative of the local community, involving people affected by dementia and gaining commitment from organisations. These are discussed in turn.

Establishing networks and including people representative of the local community

Two approaches were used across the seven localities to becoming dementia-friendly. In six localities the guidelines for creating a local Dementia Action Alliance (DAA) (Dementia Action Alliance, 2015) were used and in one locality the guidelines for developing a Memory Aware High Street Scheme (MAHSS) (Innovations in Dementia, 2012) were drawn on. In the six DAA localities, DAA Steering Groups were established and was formed of between six and nineteen members of the local community (74 people in total). These Steering Groups enabled members of the local community to join together to take the DFC initiative forward. Initiating the involvement of people from the local community was challenging for the PWs, particularly at the beginning of the project when networks were less well established. As the project progressed, PWs found more people that wanted to be involved, however ensuring people were representative of the local community was problematic:

The steering groups came together fairly quickly, but not entirely representative of the whole community. (PW2: GI).

PWs identified some key challenges in forming the steering groups: finding people with a 'can do' attitude; getting people to come along in the first place (although once attending people were engaged and committed to the group); and formally engaging with people. PWs reported that it was more productive to meet informally and discuss topics. Steering Group members were actively involved in running awareness raising sessions, and seeking organisations to sign up local DAA Action Plans, thus helping to create something sustainable within each locality.

Involving people affected by dementia

The level of involvement of people affected by dementia varied from one locality to another, however it was apparent that carers (n=5) were more likely to be involved in Steering Groups than people with dementia (n=0) across all localities. Throughout the project the views of people with dementia and their carers were obtained in formal consultation exercises in four of the localities, whilst PWs in the three other localities took a less formal approach and talked to people with dementia and their carers informally. Different consultation approaches were undertaken in each locality, one effective method was to use post-it notes to collect positive and negative experiences:

..... all the yellow ones [post-it-notes] were the negatives, and they wrote down all the things that they could think of. It was great because people with dementia were there, and actually giving their feelings about it, ... I felt that we were empowering people who were feeling that they didn't have power. (PW3: IT)

PWs reflected that it was often difficult to talk to people with dementia themselves, as carers would often take over the conversation, minimising their interaction with people with dementia. Whilst one PW struggled to locate people with dementia to talk to in the first place:

I visited a number of different clubs and I'm struggling to find [people with dementia to talk to]... I went to a lunch club run by the Methodist church, and they had about 80 people there at the time, and they could only think of one or two people they thought might have memory issues. (PW1: IT)

PW (4) chose to talk to family carers or local care providers when it was not possible to speak to people with dementia directly:

...carers were involved in the consultation process ... they came to [community events]... they weren't able to bring the person that they were caring for... domiciliary care providers have given us an insight into what's important. (PW4: IT)

Gaining commitment from organisations

Staff from 72 local organisations (predominantly high street retailers and supermarkets) received awareness training, 66 businesses signed local DAA Action Plans and 14 signed up to be part of the Memory Aware Scheme. However, PWs stated that it was difficult to obtain commitment from organisations in the business community, particularly if dementia was not their work remit. Many businesses expressed concerns about their availability to attend events to hear about the schemes, and the amount of time required to complete DAA action plans. The level of involvement from organisations therefore varied from one locality to another:

Some people are happy to say yes... I'm going to do this, I'm going to commit. Other people will be, well I could tick that box, but I'd like to know a little bit more before I do it. (PW1: GI).

There were some examples of organisations that were really committed:

...they didn't want to put the sticker in the window until every member of staff had had an awareness raising session..... they said, we don't want somebody coming in and saying to a volunteer or member of staff, what does that sticker mean? And the person they ask doesn't know. (PW2: GI).

Although this was not the norm as PWs described the challenges of engaging organisations:

... there are a lot of very small businesses and again the feedback has been, my priority is to sort of.....make money (PW1: GI).

The time commitment required from people as Steering Groups members was also problematic. In one locality they were able to attend meetings and work together to fund and design a leaflet:

I have got quite a high representative of businesses.... and they attend the steering group.... they make things happen..... They're saying, actually let's do this, not talk about it.... In one locality.... they've put a leaflet together and funded that. (PW3: GI)

This was not the case in the other localities. One locality had adapted their approach in response to this and had business representatives that corresponded by email rather than in person:

I have got business representatives, from the financial, tourism and hospitality sector. ... they are difficult to get along for meetings, but do respond to emails.... it's really worth having them...when you do get somebody that's representing that sector they can do a lot of the hard work because the business communities are hardest to engage. (PW1: GI)

Other localities also continued to struggle to get this representation:

I don't have a business representative yet... they're the most difficult people to engage in terms of... actually committing time to it. (PW2: GI)

We've struggled to get people, I think we'd identified people that were from the statutory or the voluntary sector again, but getting that mix from the business community has been difficult. (PW4: GI)

Organisations were generally positive about the DFC initiatives scheme, especially those with staff members that had personal experience of dementia. Explaining the scheme personally to a representative of the organisation enabled PWs to develop a relationship with them, which was more effective than handing them a leaflet. PWs told retailers that by joining the scheme they were promoting the use of the high street and keeping the local community using the shops, rather than using online alternatives. Organisations with a social focus (i.e. charities) and larger organisations with corporate responsibility were easier to get on-board. Smaller organisations struggled to see the value and had limited time or finances to be able to commit. There were examples of businesses that were already confident about helping people with memory loss. For example, some banks had arrangements with customers who were known to have different needs); and some Post Office's helped customers type in their PIN numbers. It was problematic for PWs when they were provided with a ten minute slot to present to retail staff because managers were unable to pay staff to attend an hour's awareness training session. It was also time consuming approaching different organisations directly in person.

Strategies for achieving stakeholder involvement

A sustainable approach, spreading the word and sharing of ideas were recognised as strategies for achieving stakeholder involvement in DFCs. These are discussed in turn.

A sustainable approach

PWs and Steering Groups chose which approach to becoming dementia-friendly they would follow in each locality; all bar one used the DAA approach (the other developing MAHSS). At the start of the project, PWs felt overwhelmed by the number and range of contacts they made in a short space of time:

..... and it snowballs. You start with one contact and they put you in touch with somebody else. (PW1: GI)

...it's just a question of finding your starting point,... it can be overwhelming, how much there is to do. And prioritising that... has been a real challenge. (PW2: GI).

In six localities the DAA model was used to develop their approach to becoming dementia-friendly. The key elements of the DAA approach are the creation of a steering group of community members who will take the work forwards, and the signing of local dementia action plans:

... people have actually put something down on paper.. it gives them a constant reminder they have made a commitment to be dementia friendly. (PW2: GI)

However each locality chose to utilise the DAA guidelines in different ways, so there were similarities and differences in the approaches used in each locality:

... there have been some variations depending on the personality of the people sat on the steering groups.... So maybe the framework was consistent, but the way it actually was delivered, or used, has been slightly different. (PW1: GI).

In one locality the Steering Group established specific areas which they would target such as awareness raising for businesses and carers; safe haven environments; research into best practice and funding opportunities; dementia friendly tourism; and dementia GP surgeries. Each steering group member was identified to lead on each work stream. Whilst in another locality the Steering Group was formed of representatives from different sectors who would cascade information to their sector when required. This flexibility was beneficial as every community is different and will have a different approach to becoming dementia-friendly. Having a Steering Group in place enabled these six localities to work towards being self-sustaining. The MAHSS approach was followed as an alternative to the DAA approach, and focused primarily on approaching high street organisations:

No, I didn't have any guidelines at all..... I did look on the net and I looked at the information, but... because we'd already decided we were going... to work very directly with the high streets. (PW4: GI).

Establishing DAAs provided a framework and appeared to be significant in ensuring the sustainability of work beyond the funding of the project.

Spreading the word

There were examples of different approaches used within the seven localities to raise awareness of their work to create DFCs. 599 people attended awareness raising sessions, 448 people became Dementia Friends and 19 people became Dementia Champions. In localities where the DAA approach was followed, steering group members helped to spread the word. In some cases steering group members were delivering, or about to be trained to be able to deliver awareness raising sessions:

.... they're having a sub group of people that go out and give out action plans, and each of them are having packs that they're putting together... they are all completely committed to doing six monthly follow ups and to going out and getting new people to sign up to the alliance. So the steering groups are both absolutely poised and ready to do that now.... so that's exciting. (PW2: GI).

Some localities decided to publicise the DFC initiative in their area by holding a launch event. There were differences between the successes of the launches in each locality. For example, in one locality a business launch was held early in the project and had four attendees, whilst in another locality a public launch was held later in the project and had 75+ people in attendance. Factors that influenced the success of these events related to: having a steering group in place; waiting until the initiative was more established with something to showcase; time of the event (during the day) / day of the week; inviting 'strategic' figures (such as a mayor or council official); public event or open to businesses only.

PWs reported a total of 21 local media mentions for dementia and this stimulated local interest from people with concerns about their own or others memory issues:

....every time something goes in the paper I get calls... from people who are worried about their memory problems, and I've put them onto the dementia support workers. (PW2: G1).

The [name of locality] launch gave me a lot of coverage. And especially the press releases afterwards, people phoning up wanting support... weeks after saying that they've got a husband that's got dementia and they basically needed help. (PW3: G1).

Social media was utilised in one locality where the steering group created a Twitter account and were using this as a way to inform members of the public about their work and raise awareness of dementia in general. Providing one person within the local community with information about dementia was a valuable way to raise awareness of dementia more widely within the community. In one locality, someone attended a Dementia Friends session, then decided to become a Dementia Champion, and now runs regular Dementia Friends sessions and helps with a dementia friendly church service.

Sharing ideas

Simple actions can enhance the well-being of a person with dementia, and there were some examples in the project. PW (4) shared a story about a lady with dementia that has an appointment at the hairdressers every Saturday. Her family drop her off and go for a walk and a coffee whilst she is in the hairdressers. The hairdresser does not let the lady leave until her family come back to pick her up. This ensures the lady retains her independence and is safe, and the hairdresser has a regular booking. Learning from what has been undertaken in other localities before this project was beneficial. Talking over ideas enabled PWs and others involved in the DFC initiatives to share ideas, problems and successes with each other and ultimately learn from one another. In one locality a successful launch event sparked the interest of residents from another locality outside of the seven from this project, prompting them to develop their own local DAA. The development of Safe Havens

was another example of how an idea in one locality was replicated in three other localities.

Discussion

Creating sustainable Dementia-Friendly Communities

There were distinct differences in the progress made in the localities where the DAA approach was used, versus the MAHSS approach. The key difference in taking the MAHSS approach was, at the time of the evaluation, there were no mechanisms to ensure that the work would become self-sustaining (e.g. there was no steering group of local people set up, or method of reviewing the commitment of organisations that became part of the scheme). Those that set up a DAA steering group reported that this approach provided a framework (organisations sign up to the local or national DAA), which was flexible (organisations can commit to what suits/or is achievable), and could be reviewed (commitments reviewed every six to twelve months).

Following the DAA approach, these localities were able to create sustainable DFCs, led by local people on a voluntary basis (Department of Health, 2012). Conversely, organisations that become part of the memory aware scheme were not asked to commit to any actions, although they were provided with a sticker to display in their window to show they were part of the scheme. However, once they had been given the sticker no further action was taken, they were not expected to commit to any actions other than give their members of staff a booklet – which might not be read. The importance of asking organisations to ‘sign up’ to show their commitment to DFCs is demonstrated by the example of a local bank who was interested in joining the Memory Aware Scheme. As part of this scheme they had invited the PW to deliver awareness raising sessions to all staff, and were pursuing the possibility of offering Money Management courses to people with dementia and their carers (something they offer for other vulnerable groups nationally but not people with dementia). The member of staff leading this work relocated to another branch before signing up to the initiative. The new post holder had different priorities and the PW was then unable to pursue this within the organisation. This demonstrates the need for organisations and others working towards becoming dementia-friendly to outline

their commitments, as this provides a pathway for those 'building DFCs' (Alzheimer's Society, 2013) to be able to support, monitor and develop this work over time.

Creating dementia aware communities

The MAHSS provided less of a structure for the PWs to plan and monitor how their work was contributing towards becoming a DFC. The importance of acknowledging what you want, or are able, to achieve in any given timeframe became evident. The guidelines produced by Alzheimer's Society (2013) denote ten key areas that underpin a dementia friendly community; the analysis showed that across all seven localities there had only been significant progress in three areas. There is further opportunity to develop all ten of these areas as the DFC initiatives continue to progress over time. However this makes the distinction between an individual and an organisation being dementia aware and dementia friendly noteworthy. If an organisation allows its staff to complete an awareness raising session, then can it really claim to dementia-friendly? Becoming dementia-friendly involves a wider consideration of other factors in addition to awareness of dementia (such as signage, décor and lighting used within their offices or shops), we argue that this needs careful consideration. Guidance for being dementia-friendly and the design of marketing and publicity literature and items (like window stickers) should reflect this distinction between being dementia-friendly and dementia aware.

Implications for future research or practice

Stakeholder involvement can be unpredictable and changeable (Kuenkel and Aitken, 2014) and there are implications for DFCs if the approaches that are used to develop them are reliant upon such involvement. Longer-term reliance on stakeholders, particularly assistance from volunteers, has a number of challenges including high turnover and level of commitment of those involved. Reliance on stakeholder involvement questions the long term sustainability of DFCs, and must be considered in future policies that aim to enhance quality of life for people affected by dementia. These findings form the foundation for the creation of DFC initiatives that become embedded within communities.

Strengths and limitations

The originality of this paper in exploring the perspectives of the PWs creating DFCs is the strength of this study. The small and predominately qualitative nature of this research limits the generalisability of the findings reported in this paper. Whilst the data were rich and saturated in this study, it should be noted that levels of stakeholder interest and engagement may vary from one locality to another, meaning that the experiences in the geographical locality of this study may not be representative of those in other communities. Efforts were made by the research team to engage with other stakeholders involved in the seven DFCs (i.e. people with dementia, family carers, and businesses). However, the response rates were extremely low and for that reason has not been included within this paper.

Conclusions

DFCs have been developing across the UK since 2012, using different approaches to gain traction. Such approaches rely on volunteer assistance and this paper has examined the reality of achieving this, in practice. Combining empirical and secondary data was found to be an effective research strategy for evaluating this emerging policy initiative. The findings from the project reported here recognises challenges (establishing networks and including people representative of the local community; involving people affected by dementia; and gaining commitment from organisations) and strategies (a sustainable approach; spreading the word; and sharing of ideas) for achieving stakeholder involvement in DFC initiatives. This insight into the experiences of those that are developing DFC initiatives is key to informing researchers, policymakers and others working to develop similar initiatives of the implications of the reliance on stakeholder involvement on the long-term sustainability of such initiatives. By highlighting these challenges and the approaches that have been used within communities to overcome them, these findings will help to develop DFC initiatives that become embedded within communities. Stakeholder involvement is unpredictable and changeable; therefore reliance on this approach questions the long term sustainability of DFCs, and must be considered in future policies designed to enhance quality of life for people affected by dementia.

Acknowledgements

We would like to thank the Project Workers for their time and valuable contributions. Thanks also to the National Health Service South of England Dementia Challenge for funding the project. This project was developed by an inter-agency partnership involving the following organisations: Age UK (Dorset); Alzheimer's Society (Dorset); Bournemouth Borough Council; Borough of Poole Council; Bournemouth University Dementia Institute (BUDI); Dorset County Council; Dorset Clinical Commissioning Group; Dorset Health Care University Foundation Trust; Dorset Partnership for Older People Programme; and Prama Care. This paper reflects the findings of the independent evaluation conducted by Bournemouth University Dementia Institute. The views expressed are those of the research team and not necessarily those of the other organisations that were involved.

References

Adams, K. B., Liebbrandt, S., & Moon, H. (2011). A critical review of the literature on social and leisure activity and wellbeing in later life. *Ageing and Society*, 31, 683–712.

Alzheimer's Disease International (2012) World Alzheimer's Report.

<http://www.alz.co.uk/research/world-report-2012>, accessed 21st January 2015.

Alzheimer's Society. 2014(a). 'Statistics'. <http://www.alzheimers.org.uk/statistics>, accessed 21st January 2015.

Alzheimer's Society (2014(b)). 'Dementia 2014: Opportunity for change'.

http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2317, accessed 6th February 2015.

Alzheimer's Society (2013). 'Building dementia-friendly communities'.

http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2283, accessed 22nd January 2015

Crampton, J., Dean, J., Eley, R. (2012). 'Creating a dementia friendly York'.

<http://www.jrf.org.uk/sites/files/jrf/dementia-communities-york-full.pdf>, accessed 6th February 2015.

CLG. (2008) *Lifetime Homes, Lifetime Neighbourhoods: A national strategy for housing in an ageing society*. London: Department for Communities and Local Government.

Department of Health. (2015) *Prime Minister's challenge on dementia 2020*. London: DH Publications.

Department of Health. (2013) *Dementia: A state of the nation report on dementia care and support in England*. London: DH Publications.

Department of Health (2012) *Prime Minister's challenge on dementia: Delivering major improvements in dementia care and research by 2015*. London: DH Publications.

Department of Health. (2009) *Living well with dementia: A National Dementia Strategy*. London: DH Publications.

Everard, K., Lach, H., Fisher, E. And Baum, M. 2000. Relationship of Activity and Social Support to the Functional Health of Older Adults. *The Journals of Gerontology: Series B*. 55 (4)

Fawcett SB, Paine-Andrews A, Francisco VT, Vliet M. (1993). Promoting health through community development. In: Glenwick, DS; Jason, LA (editors). *Promoting health and mental health in children, youth and families*. New York: Springer Publishing Company

Hall, CB., Lipton, RB, Sliwinski, M., Katz, MJ., Derby, CA. And Verghese, J. 2009. Cognitive activities delay onset of memory decline in persons who develop dementia. *Neurology*. 73(5): 356-61

Hanson P. (1989) Citizen involvement in community health promotion: a role application of CDC's PATCH model. *International Quarterly of Community Health Education* 9(3):177-186.

Hare, P., and Dean, J. (2015) 'How can we make our cities dementia friendly? Sharing the learning from Bradford and York', <https://www.jrf.org.uk/report/how-can-we-make-our-cities-dementia-friendly>. Accessed 29th September 2015.

- Henwood, C., and Downs, M., (2014) 'Dementia-friendly communities', in M, Downs and B, Bowers (Eds.) *Excellence In Dementia Care: Research Into Practice*. Berkshire: Open University Press.
- Hill, N., Kolanowski, A. And kurum, E. 2010. Agreeableness and activity engagement in nursing home residents with dementia. *Journal of Gerontological Nursing*. 36 (9): 45 – 52.
- HM Government. (2012) *Caring for our future: reforming care and support*. London: The Stationery Office Limited.
- Innes, A. 2009. *Dementia Studies. A social science perspective*. SAGE publications
- Innovations in Dementia. (2012) 'Thinking about a "memory aware" high street scheme', <http://www.innovationsindementia.org.uk/DementiaFriendlyCommunities/Memory%20aware%20high%20street.pdf>. Accessed 27th February 2015.
- Institute of Medicine (1988) *The future of public health*. Washington (DC): National Academy Press.
- Jackson, L. (2012) 'This is: The Debenham Project', <http://www.the-debenham-project.org.uk/downloads/booklet/121209booklet.pdf>. Accessed 20th April 2015.
- Kuenkel, P., and Aitken, A. (2014) 'Key Factors for the Successful Implementation of Stakeholder Partnerships: The Case of the African Cashew initiative', in V. Bitzer, R. Hamann, M. Hall, and E. Wosu Griffin (Eds.) *The Business of Social and Environmental Innovation*. Switzerland: Springer International Publishing.
- Lincoln, Y., and Guba, E. (1985) *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications.
- Office for National Statistics (ONS) 2013 Mid Year Estimates.
- ONS. (1999) *Social Focus on Older People*. London: The Stationery Office.
- ONS. (2005) *Focus on older people – report for Office for National Statistics*. London: Palgrave Macmillan.

Monkhouse, C. (2003). Beyond the medical model – The Eden alternative in practice: A Swiss experience. *Journal of Social Work in Long-Term Care*. 2003, Vol. 2 Issue 3/4, p339-353.

Phinney, A, Chaudhury, H And O’connor, D. (2007). Doing as much as I can do: The meaning of activity for people with dementia. *Aging and Mental Health*. 11 (4)

Scharf, T., Phillipson, C., and Smith, A. (2005) ‘Multiple Exclusion and Quality of Life amongst Excluded Older People in Disadvantaged Neighbourhoods’, *Social Exclusion Unit report*. London: Office of the Deputy Prime Minister.

Swan, J. (2012). From pottery to plays: arts activities in the home. *Nursing & Residential Care* 14(4): 195-198

World Health Organisation. (2007). ‘Global age-friendly cities: A Guide’. Available at http://whqlibdoc.who.int/publications/2007/9789241547307_eng.pdf, accessed 21st January 2015

World Health Organisation. (2002) (World Health Organization, 2002) http://www.who.int/ageing/projects/age_friendly_cities/en/

World Health Organization (1986), Health and Welfare Canada, Canadian Public Health Association. Ottawa charter for health promotion; an international conference on health promotion. Ottawa, Ontario, Canada: November 17-21

Table 1: Locality demographic breakdown

Locality	1	2	3	4	5	6	7
Area Type	Market Town	Borough and Town	Market Town	Borough and Seaside town	Seaside Town	Market Town	Seaside Town
Population	10,325	47,752	19,060	147,645	9,474	7,014	32,583
Very good and good health (% of population)	81.10%	78.10%	80.50%	81.40%	80.60%	79.60%	70.88%
Poverty Indicator (% of population)	16.00%	16.20%	15.70%	0	11.60%	18.70%	21.80%
Number and % of population aged 65+	2,011 / 19.1%	14,685 / 30.6%	4,415 / 23.1%	30,158 / 20%	1,668/17.6%	1,905 / 27.6%	7148 / 20.25%
Health deprivation and disability domain (a rank of 1 = most deprived. 23,482 ranks available)	6,002	28,777	3,002	25,701	11,671	27,881	1143

(Source: Census, 2011; Housing and Council Tax Benefit March 2013; Council Tax Benefit September 2012 ONS 2012 Mid-Year Estimates; English Indices of Deprivation, 2010 Housing and Council Tax Benefit February 2014

Table 2: Analytical Framework

Ten key areas that underpin a Dementia-Friendly Community
<p>Involvement of people with dementia</p> <p>Shape communities around the needs and aspirations of people living with dementia alongside the views of their carers. Each community will have its own diverse populations and focus must include understanding demographic variation, the needs of people with dementia from seldom heard communities, and the impact of the geography, e.g. rural versus urban locations.</p>
<p>Challenge stigma and build understanding</p> <p>Work to break down the stigma of dementia, including in seldom heard communities, and increase awareness and understanding of dementia.</p>
<p>Accessible community activities</p> <p>Offer organised activities that are specific and appropriate to the needs of people with dementia. Also ensure that existing leisure services and entertainment activities are more inclusive of people with dementia.</p>
<p>Acknowledge potential</p> <p>Ensure that people with dementia themselves acknowledge the positive contribution they can make to their communities. Build on the goodwill in the general public to make communities' dementia friendly.</p>
<p>Ensure an early diagnosis</p> <p>Ensure access to early diagnosis and post-diagnostic support. Have health and social care services that are integrated and delivering person-centred care for people with dementia in all settings.</p>
<p>Practical support to enable engagement in community life</p> <p>Deliver a befriending service that includes practical support to ensure people with dementia can engage in community life as well as offering emotional support.</p>
<p>Community-based solutions</p> <p>Support people with dementia in whatever care setting they live, from maintaining independence in their own home to inclusive, high-quality care homes. Community based solutions to housing can prevent people from unnecessarily accessing healthcare and support people to live longer in their own homes.</p>
<p>Consistent and reliable travel options</p> <p>Ensure that people with dementia can be confident that transport will be consistent, reliable and responsive and respectful to their needs.</p>
<p>Easy-to-navigate environments</p> <p>Ensure that the physical environment is accessible and easy to navigate for people with dementia.</p>
<p>Respectful and responsive businesses and services</p> <p>Promote awareness of dementia in all shops, businesses and services so all staff demonstrate understanding and know how to recognise symptoms. Encourage organisations to establish strategies that help people with dementia utilise their business</p>

(Source: Alzheimer's Society, 2013)

