

Living a normal life

Supporting the development of Dementia Friendly Communities

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Written by Melanie Henwood

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This work was researched and compiled by Melanie Henwood of Melanie Henwood Associates

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Executive summary

1. Skills for Care funded a programme of 12 pilot projects, across 11 organisations, for 12 months in 2013/14 in order to support the development of Dementia Friendly Communities (DFCs), by improving community understanding and awareness of dementia and supporting people living with dementia and their carers to participate in their communities.
2. The model of DFCs has been developed and promoted by the Alzheimer's Society and 10 steps have been identified (see Box 1 and Figure 1) as central to achieving a dementia-friendly community.
3. There has been growing interest in and awareness of dementia over the last couple of years, particularly following the high profile Challenge on Dementia launched by the Prime Minister in March 2012. There are three key areas in the challenge concerned with: driving improvements in health and care; creating dementia friendly communities, and undertaking better research. The overall concern is to find a cure through research, but until such time as this is possible, the focus is also on steps to improve the lives of people with dementia and of their families and carers.
4. Section 1 of the report provides an introduction both to the underlying objectives of the programme, and to the participating pilot sites. The 11 pilot projects were all supported by Skills for Care officers and were required to submit 6 and 12 month progress reports. In addition, this independent evaluation was commissioned in 2014 to draw together the emerging messages and learning from across the programme. The methodology for the evaluation included analysis of written reports; and one to one semi-structured interviews with project leads. All interviews were digitally recorded and fully transcribed.

5. The pilot sites featured a mixture of provider organisations including supported housing providers; care homes; and domiciliary and personal and community support organisations. Four pilot sites were local authorities with responsibilities for commissioning care and support.
6. Section 2 presents an overview of the cross-cutting themes and issues identified across the sites. Understanding what a DFC means in practice was demystified by many of the projects who described it in familiar terms of being ordinary and enabling people to live normal lives through greater acceptance and kindness.
7. The language of DFCs, and related terms such as Dementia Action Alliances, Dementia Friends and Dementia Ambassadors, was identified by some projects as creating confusion and lack of clarity, or misleading people into believing that signing up would be more demanding than was actually the case.
8. The report highlights the importance of motivation and personal engagement as driving forces. Typically, the lead officers responsible for each project had a commitment and passion to dementia issues, and often this related to personal experience. Recognising the importance of personal connection is also an important finding in understanding how to reach the wider community audience; dementia has to be part of people's world, or they need to see how it could be if they are to have an interest in engaging. It was apparent in the experience of many of the pilot sites that difficulties with engagement often reflected public fear and the stigma which continues to surround dementia.
9. Most projects encountered difficulties – to a greater or lesser extent – in trying to work with the wider community in developing awareness and understanding of dementia. While this caused considerable frustration, projects persevered and generally found solutions or realised they needed to take a different approach in targeting their audience. Typically projects needed to take time in building contacts and developing relationships – such as with businesses and retailers – as a basis for looking at dementia awareness.
10. Some projects had been extremely successful in engaging with large numbers of people wanting to have Dementia Friends training. In some situations this success built on an established history of related work or a local dementia strategy.
11. Considerable innovation was in evidence and projects were proud of achievements which indicated the community was in some ways becoming more dementia aware and friendly. Adjustments that might appear small could in practice make an enormous difference to people's experience and confidence to engage with their community once more.
12. A few of the projects were addressing intergenerational dimensions of dementia awareness and were working with schools, or were planning to develop such work. Again, building the links with schools and negotiating access took considerable time to develop and was not something that could be achieved overnight.

13. In working with a range of local partners many projects were deliberately engaging with the NHS in general and with GPs in particular. Some had found that a clash of perspectives and understanding could be an impediment and were working to counter an often prevalent view that dementia was a hopeless diagnosis, to developing an understanding of positive ways to support people with dementia, and their carers, in the community. The low rates of diagnosis of dementia were often a reflection of a medical view that there was no point in early detection if there was 'nothing to offer' in terms of a cure. Being able to point to increased diagnosis rates was seen as a positive outcome by a number of projects.
14. Training and education were not only about outreach and working with the wider community, but also within organisations that were already involved in care and support. Even where people were providing such care, they often have a relatively low level of knowledge or expertise in dementia matters, and increasing take up of Dementia Friends and Dementia Champions development were significant achievements. The principle of 'cascading' training and awareness was widely recognised as the way forward so that individuals who had been trained would take responsibility for passing on their knowledge and skills to other colleagues, who in turn would roll things forward. Not only did this provide a means of spreading knowledge and awareness, but it also helped embed and sustain cultural change in organisations. Evidence of change in the physical and social environments of residential services were cited as having resulted directly from dementia awareness training with service providers. As well as targeting frontline staff it was recognised that the commitment and understanding of managers is essential if organisations are to commit to and deliver change.
15. Assessing the total impact and outcomes of the programme is complex and in many ways challenging to quantify. The monitoring and reporting that projects undertook was typically concerned with recording activity and process; being able to judge the impact of such endeavour was recognised as important but few projects had been able to address this in substantive terms. Being able to measure the change in how a community 'feels' is not straightforward, but most projects were gathering qualitative feedback and similar 'soft' data pointing to shifts in experience. Some projects were able to highlight more direct changes, such as in working practices, or in a generally greater interest in dementia (such as in more providers responding to dementia-specific tender opportunities). Certainly some were interested in exploring the potential for demonstrating outcomes and impact such as in increased dementia diagnosis rates, or reduced dementia-related residential admissions, but this was work in progress.
16. The overview report of the 11 pilot projects is not an attempt to evaluate each project in detail. Rather, it draws together the key themes and experiences across the programme and highlights key lessons learned. The programme enabled considerable innovation and exploration of what makes and stimulates a dementia friendly community to develop and thrive. All the pilot sites had plans to continue to develop their work and recognised that changing hearts and minds and organisational cultures takes time to bring about but can have powerful and lasting

impact. Equipping people with the skills and understanding to respond to the needs of people with dementia has great potential to bring about transformational change and to enable genuine social inclusion.

1. Introduction

1. Introduction

1.1 The concept and terminology of ‘Dementia Friendly Communities’ is becoming increasingly widespread and familiar. The Alzheimer’s Society established the Dementia Friendly Communities programme in 2012 with the aim of improving inclusion and quality of life for people living with dementia, by creating Dementia Friendly Communities throughout the country.

1.2 What does this mean in practice? The Alzheimer’s Society describes itself as being “at the forefront of the creation of dementia friendly communities”, and particularly by working with governments, and other bodies such as members of the Dementia Action Alliance, “we are supporting communities who want to become dementia friendly.”¹

1.3 The Prime Minister’s Challenge on Dementia was also launched in 2012 with the central objective of delivering major improvements in dementia care and research by 2015. The Prime Minister, David Cameron remarked:

“One of the greatest challenges of our time is what I’d call the quiet crisis, one that steals lives and tears at the hearts of families.

We’ve got to treat this like the national crisis it is. We need an all-out fight back against this disease; one that cuts across society.”

1.4 The PM’s Challenge focused on three key areas:

- Driving improvements in health and care.
- Creating dementia friendly communities.
- Better research.²

1.5 While the overall vision is – in time – to find a cure through research, in the meantime the Challenge recognised that there needs also to be a focus “to improve the lives of people with dementia and their families and carers.”

¹ Alzheimer’s Society (2013), *Building dementia-friendly communities: A priority for everyone*, London: Alzheimer’s Society, P.1.

² Department of Health (2012), *Prime Minister’s Challenge on Dementia. Delivering major improvements in dementia care and research by 2015*. P. 5.

Defining 'dementia-friendly communities'

1.6 While the phrase 'dementia friendly communities' has gained currency, it is important to clarify its meaning and intention. The Alzheimer's Society offers the following:

"A dementia-friendly community is one in which people with dementia are empowered to have high aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them."

1.7 In order to achieve this, the Alzheimer's Society urges a focus on 10 key areas as set out in Box 1, and summarised in the graphic below.

Box 1

10 Steps to Dementia-friendly Communities

1. Involvement of people with dementia.
2. Challenges stigma and build understanding.
3. Accessible community activities.
4. Acknowledge potential.
5. Ensure an early diagnosis.
6. Practical support to enable engagement in community life.
7. Community-based solutions.
8. Consistent and reliable travel options.
9. Easy to navigate environments.
10. Respectful and responsive businesses and services.

Source: Alzheimer's Society (2013), *Building dementia-friendly communities: A priority for everyone*, London: Alzheimer's Society, pp viii-ix.

Figure 1: A Vision of Dementia-friendly Communities



Source: Alzheimer's Society (2013), *Building dementia-friendly communities: A priority for everyone*, London: Alzheimer's Society, p.x

- 1.8 The different stages are not sequential, and while ideally a Dementia Friendly Community (DFC) would address all elements, in practice many initiatives begin by focusing on one or two aspects.

Skills for Care and Dementia Friendly Communities

- 1.9 Skills for Care – in conjunction with the Department of Health and the Alzheimer’s Society – developed a small programme of work during 2013/14 supporting 12 pilot sites (in 11 organisations) to address two major objectives:
- To support the development of wider community understanding and awareness of dementia, and support the community to engage with people with dementia and their carers.
 - To support people with dementia and their carers to enjoy living in their communities and to access their community networks and services.
- 1.10 All the projects were supported by Skills for Care area officers, and were required to submit brief progress reports at 6 and 12 month intervals. In addition, this independent evaluation was commissioned to draw out the over-arching messages and learning from the programme. The consultant had access to the reports from the projects, and undertook in-depth telephone interviews with the 12 project leads. All interviews were digitally recorded and fully transcribed, providing a rich source of qualitative material and reflections on experience.

Introduction to the pilot sites

- 1.11 Before turning to explore the experience and outcomes of developing dementia-friendly communities, the report introduces the pilot sites. The sites were a mixture of providers of care and support services (including housing, residential care, domiciliary support, and advocacy), and councils with responsibility for commissioning adult social care and support. Table 1 summarises some organisational information.

Table 1: Organisations and sites developing Dementia-Friendly Communities

Organisation	Type	Objectives
Anchor	Anchor is England’s largest not for profit housing association, providing housing, care and support for people aged 55 and over.	Focus on developing a dementia-friendly community around two facilities (Northbourne and Tolson Grange)
Sanctuary Housing	Sanctuary is a leading	Focus on East

Organisation	Type	Objectives
	provider of care, housing and community services.	Cambridgeshire district, a rural and sparsely populated area. Concern to develop community resilience to support people with dementia at home.
Wren Hall nursing home	Wren Hall has been a nursing home since 1989, and a specialist dementia home for five years.	Developing excellence in caring for people living with dementia, and working with the local community to develop understanding of dementia.
Cherish Care	A rural home care company in West Sussex, supporting people to live independently.	Aim to identify local businesses and services and work with them to develop understanding of dementia.
City of London	Adult Social Care Service.	City of London dementia strategy developed; working with partners across the borough to make the City dementia friendly and accessible.
Cloverleaf Advocacy	Advocacy and involvement services across the North of England.	Developing dementia friends awareness groups and working with local partners in developing dementia friendly communities.
Coventry City Council	Adult Social Care Services	Recognising dementia as everybody's business, and working with social care providers in realising dementia friendly

Organisation	Type	Objectives
		communities.
Making Space	UK wide charity providing care, support and enablement to people in the community.	Working with local partners to promote dementia friendly community awareness, and to develop local Dementia Action Alliance.
Home Instead Senior Care	Companionship-based care provided for people in their own homes.	Focusing on two local communities and running dementia friends information session to increase awareness, as well as addressing awareness with own staff.
Surrey County Council	Older People's mental health services.	Developing a dementia friendly community strategy in east and mid-surrey.
Gloucestershire County Council	County Council and Forest of Dean District Council, working with Crossroads Care.	Working across the community with faith groups, schools, lunch clubs, businesses etc to develop dementia friendly community, and supporting the Council's workforce.

1.12 Section 2 turns to explore the experience and achievements of the projects and to draw out the wider lessons from the programme.

2. Key findings from the research

2. Experience and outcomes: Key themes

- 2.1 As Table 1 indicated, the organisations hosting the pilot projects included a range of bodies including local providers, large national providers, and local council commissioners of care and support. The organisations therefore brought different skills and experience to the initiative, but it was also striking that there were significant similarities between them. A thematic approach has been adopted in the analysis which draws out shared themes and issues, as well as those which were less widespread.
- 2.2 As noted in Section 1, the narrative around dementia has become more developed and familiar in recent years, not least following the PM's Challenge on Dementia. Phrases such as 'Dementia Friendly Communities'; 'Dementia Champions', and 'Dementia Action Alliances', have all gained currency. However, people often use terms to refer to different things, and it is worth exploring the ways in which the pilot projects interpreted and understood some of these key words.

What is a dementia-friendly community?

- 2.3 Some of the project leads who were interviewed had a very clear view of what a DFC is all about, and expressed it succinctly. A few examples make the point:

"It's really about being a good citizen (...) it's about being aware of your neighbour, having some understanding of the person standing next to you (...) that's our aim."

"It's just about person-centred practice and just being ordinary, you know. And the big problems people face, are just ordinary little day to day things. And it's about listening, being perceptive, being there to reassure people whatever situation they're in."

And

"To encourage people with dementia and their carers to just live a normal life in their community."

"It's just about being kinder to people within our communities. (...) if people take the time to learn a bit more about dementia they can be kinder to people who they interact with on a daily basis."

"Dementia Friendly Communities to me is getting to the heart of people, whether they own a business, whether it be your local hairdressers or your local café, and getting them to be aware of what dementia is, how they can help practically on a day to day basis."

- 2.4 These helpful and clear expressions of understanding did not, however, tell the entire story. Some interviewees highlighted areas of confusion or lack of clarity with terminology and 'ownership'. For example:

“I think a lot of organisations are reluctant to kind of get involved because they think it’s more work than it is. I think the whole Dementia Friendly Communities programme as a wider thing is quite confusing for people.”

“We have Dementia Action Alliances, we have Dementia Friendly Communities, Dementia Friends. It becomes quite confusing, the different ways that people can get involved. We have our local Dementia Action Alliance and people don’t really understand where Dementia Friends fit in. And when we go to approach businesses and organisations, they kind of look at us like ‘what on earth are you talking about?’ It doesn’t make any sense.”

- 2.5 The ‘common sense’ understandings of the meaning of DFC in many ways get to the heart of what such a community might look and feel like. The Alzheimer’s Society also describes such communities as those “that are more inclusive of older people and those with dementia, and support them to live independently and well.”³ Nonetheless, the Alzheimer’s Society goes beyond this interpretation to something more formalised and requiring a ‘recognition process’ or validation:

“that enables organisations and communities to be part of an officially recognised group working towards becoming dementia friendly. It is also essential that they are all working towards common evidence-based standards that will truly change the things that matter to people affected by dementia.”

- 2.6 The experience of the Skills for Care DFC pilot projects overall would seem to suggest that DFCs can – and do – develop both with and without such formalisation.

Motivation and Engagement

- 2.7 Time and again, discussions with project leaders revealed that the key to success and momentum could often be attributed to personal passion and commitment. People were generous in sharing their personal experiences and insights into what drove them to improve support for people with dementia, and often this was based on direct personal experience of dementia. The following comments are typical of many that were made; they are not attributed to any projects because of their personal nature.

“My father had dementia so we nursed him through, at home until he passed away.”

“X has been working in social care for many, many years (...) she was a carer herself (...) so she’s very personally impacted by it and very passionate about the area.”

“Well the reason I went into social care in the first place actually was my Nana had Alzheimer’s (...) I became a social worker; I’ve always worked with older people with dementia, so it’s just been an interest of mine since then really.”

³ Alzheimer’s Society (2013), *Response to the consultation on the recognition process for dementia friendly communities*. P.2

“Most of the people that come to our Dementia Action Alliance or come to a Dementia Friends session have some kind of personal interest or involvement with dementia.”

“I look back at what’s made us succeed, and I’ve had a lot of vision and passion and enthusiasm for it.”

- 2.8 As some interviewees acknowledged (and as we will explore more fully below), tapping into passion could also be central to successfully involving the wider community in dementia awareness, for example:

“I think one of the barriers has probably always been kind of helping people to really understand why it’s important for them to consider dementia. You’ve got to find people who are passionate about dementia in their local kind of area and their company and their field of work.”

- 2.9 As the brief pen portraits in Table 1 indicate, the broad objectives across the individual projects were often similar. The practical interpretation of these on the ground was, however, diverse and reflected a number of different variables. Engagement with the wider community, and attempting to nurture DFCs, was a common objective, but in practice there was a continuum of experience ranging from deep frustration to great satisfaction.

- 2.10 Despite the increased profile that dementia matters have gained in recent times, many projects acknowledged that the most common response of the general public is still one of fear and a reluctance to have anything to do with the issues unless and until they have been touched by personal experience. As these interviewees commented:

“They’re scared that they may have dementia or may be facing dementia in the future (...) I know it’s on the television a lot and you’ve got posters everywhere, but I think the general community are just not wanting to know until it actually happens.”

And:

“I think the biggest difficulty, and I can understand why, if the general public have not been personally touched by dementia, they don’t think it affects them. They don’t see the need to get involved.”

“Dementia is either something that people don’t generally know about, but also if they know a little bit about it sometimes they don’t want to know much more. And just to give you an example, we were in a shopping centre doing some awareness raising work and people would just walk past. They would see the word ‘dementia’ or something and they’d very quickly grasp that this was something going on probably related to dementia, and then they wouldn’t want to know any more.”

- 2.11 For some people a general fear to acknowledge dementia is accompanied by some irrational and misinformed beliefs and assumptions about the condition, as this project leader had experienced:

“That really gave reassurance to residents on the schemes who were perfectly well but who might have neighbours who had dementia or were developing dementia; it was

really good in disarming all those kind of irrational sort of fears that people would (...) start to shun them out of embarrassment or just plain ignorance. You know, people thought dementia was somehow contagious.”

Working with the wider community

2.12 Involving and engaging the wider community ranged from general awareness raising and information giving, to more focused attempts to involve specific retail, business and service sectors. Again, the experience was a mixed one, but the projects adapted and refined their approaches as they developed.

2.13 One of the Anchor Trust projects described initial frustration in trying to engage the community in Dementia Friends training:

“We invited lots of local businesses, people in the community, but nobody turned up for any of the sessions (...) the only people that actually came were our own residents.”
[Anchor, Northbourne]

2.14 Other strategies were attempted, but with limited success and primarily attracted people such as district nurses and social work students who already had an awareness and knowledge of dementia. Trying to take Anchor customers into the community to increase inclusion also brought frustrations, for example:

“We are very discouraged by it, but we’ve not given up (...) but people were really intolerant (...) like tutting when we were travelling around places or trying to get on buses or people were agitated and wanted to walk around. It was quite uncomfortable.”

2.15 The project was persevering and determined to try different approaches, but had drawn some clear lessons from the experience:

“The main one would be don’t assume everyone has an interest. And to prepare for that because we just assumed people would be interested and would want to come along and get advice.”

2.16 Making Space similarly described the challenges of trying to raise awareness when attempting to get 20 local businesses to become dementia-friendly:

“Walking into a shop and speaking first of all with the correct person, that was difficult. I turned into a salesperson! And although I’m passionate about this, it did wear me down. You’re trying to convince somebody – a manager or whatever in a shop – who has got no idea about health and social care most of the time, unless they have been touched by dementia itself.” [Making Space]

2.17 Other projects had more positive experiences. Wren Hall nursing home had a long history of involving and welcoming the local community, and built on this approach in trying to raise awareness:

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“For people to be able to access the community without being stared at you know, and all the stigma that goes around people [with dementia]. Because the general public don’t understand dementia, they’re fearful of it, and because they’re fearful they act in ways that they may not act if they had some understanding.” [Wren Hall]

- 2.18 Nonetheless, even with an established history of working with the community it was apparent that working with them to become more dementia-friendly was still challenging and took time to achieve. A ‘simplistic vision’ at the outset which anticipated local community organisations and businesses enthusiastically engaging with Dementia Friends sessions, came up against a different reality. However, progress had been made and the strategy was continuing. As the project manager commented, it was also evident that some retailers and services were aware of customers with dementia, but were unsure how they should respond, and the Dementia Friends training was able to explore such issues:

“There are people that shop assistants are very aware of, and they are supporting them. I mean one of the examples was ‘what do I do when somebody is constantly coming in and buying exactly the same every day, and we know they can’t possibly have eaten it all, and how do we get round that?’ Once we did the Dementia Friends session there were lots of examples that people had recognised, but what they didn’t know is how to help them. For instance, an example was given about a man who regularly gets on the bus to go to the neighbouring village, but he’s wearing his pyjamas. So the conversation was around well, what can we do?” [Wren Hall]

- 2.19 Other businesses were apparently unaware of the potential significance of dementia or its prevalence among their clients, as this comment highlights:

“I went into a hairdresser in East Surrey when I was basically trying to raise awareness of the training programme that we were offering, and the guy just said to me, you know, I don’t see how this is relevant to us because we don’t tend to get, you know, the kind of clients with dementia. He might not know, he might not have recognised, but he just felt that he didn’t have that much contact with that clientele, so there was no real need for him to release his staff, his resource to go and do this training.” [Surrey County Council]

- 2.20 The gradual progress, and the need to take time to develop awareness, was also something other projects experienced. Cherish Care recognised that involving retailers and services is not something that can be done overnight, and:

“It takes an awful lot of work (...) It’s about building relationships. It’s to open a door in order for people to have that conversation.”

However, once those conversations took place, there were examples of changed understanding and behaviour towards people with dementia. For example:

“I’ve got a gentleman who goes with his carer to a local garden centre and they always go for a coffee and a cake when they’re out and about, but he would stand in the queue and get really agitated. But the staff now are trained, they know him, they know what he likes. The carer will sit down with him and one of the staff will bring over his coffee and

cake and ask him to pay for it still. So he still feels as though he's involved, but they're watching for him so he doesn't have to stand in line and wait for it." [Cherish Care]

- 2.21 Cherish Care had developed a leaflet to give out to local businesses with '12 tips on how to help somebody who comes into your business', which had been very successful in getting staff to be more familiar and comfortable with scenarios:

"Even the local garage wanted to know how to cope if somebody came in who'd got a bit of memory loss."

- 2.22 Some of the projects had been strikingly successful in engaging with parts of the wider community. Home Instead, for example, had delivered Dementia Friends sessions to nearly 1,000 local people and "the whole thing has taken off." In this situation things had also been slow to get started, but had then built steadily. Particular barriers were encountered – as in several of the projects – where people had no prior knowledge or experience of dementia and did not think it was relevant to them, and engaging this wider community continued to be a matter of frustration. The project had focused on two small local communities in Hertfordshire and working through a member of staff who had become a Dementia Champion. Six months into the project it had been decided to target specific groups within both communities rather than to offer open public information sessions, and this proved highly effective. Following one such Dementia Friends session, the Dementia Champion was invited by the Fire Service to run sessions for local crews, and similar invitations followed from the District Nursing service and from the Police Force in Hertfordshire Constabulary.

"The Fire Service has been fantastic – there was a particular incident that one of their crew members spotted because of this session that we'd run out. The person they went to see had dementia and obviously needed a little bit more help than just the fire being put out." [Home Instead]

- 2.23 Gloucestershire County Council/the Forest of Dean project reported "overwhelmingly positive" results and experiences from their project. This built on a foundation of work that pre-dated the National Dementia Strategy, and included the establishment of an integrated workforce development strategy for dementia across health and social care. The work on promoting DFCs started – like many others – with an open session inviting people to come along if they were interested, but this group the generated a smaller number of people that actively wanted to engage and be part of the initiative:

"People that would be willing to not only learn more about dementia, but then take that back into their professional role or their community role and actually come up with an action plan of how they would support their community or their setting."

"And some of the things that then came back – we had a supermarket manager who introduced a slow lane, if you like, in the checkouts. It was a 'no hurry lane' it was

called, so you know for people that just may have difficulty with remembering their PIN number, or just maybe want a little bit more time.” [Gloucestershire]

- 2.24 The people who signed up to take things forward included retailers, people working in banking, the local Chamber of Commerce, the Police, and a variety of others. The initial ‘trickle’ of interest quickly “gathered momentum.”

Intergenerational aspects

- 2.25 A number of the pilot projects had incorporated intergenerational dimensions (primarily through working with schools) or were planning to do so. As the project lead for the Anchor Northbourne project observed:

“We thought if we could get into schools, and younger people who will talk about it with their parents and grandparents, it may well be a start.”

The other Anchor project (Tolson Grange) had already begun working with a local primary school:

“We think the younger they are, the better understanding they’ll get.”

“We explained we’d like to invite the children to our home to join in with some activities, and vice versa – we’d go to the schools and do talks to them. And that’s probably been the best partnership that we have developed because for the whole year it’s been quite consistent.”

- 2.26 For some projects, timing issues had frustrated plans to engage with schools, and others had encountered difficulties in negotiating access. Such discussion can be time consuming, and with limited resources projects were not always able to achieve all they would wish. As this interviewee remarked:

“We’ve tried to make some provision for schools, and again you know it’s the ongoing thing of having the capacity to keep chasing, to keep building those relationships with headmasters, or governors etc to make sure they take it up.” [Surrey County Council]

- 2.27 Engaging with schools was not dropped as an aspiration, and Surrey was able to borrow the ideas that had been developed by Kent County Council in supporting the publication of the [Dementia Diaries](#)

“So one of the legacy bits of work that we wanted to do was to make sure that at least primary schools and secondary schools had at least a copy of this within their library. So we purchased – we joint purchased quite a few of these books with Kent County Council, and then we distributed them to schools. We distributed some through our sort of community health team so they could then pass them onto families with young children. So while, you know, the frontal assault with schools wasn’t really that productive, that fruitful, again thinking about more long term we’ve positioned these resources in some of the schools.” [Surrey County Council]

- 2.28 Finally, Gloucestershire had also developed work with schools as part of a wider programme of support under the banner of the Prime Minister's Dementia Challenge (and not directly as part of the Skills for Care funding):

“So there’s been a lot of work in Gloucestershire – through the Prime Minister’s Dementia Challenge, we were a pilot site to introduce dementia awareness in schools. So we’ve worked with teachers (...) we started at secondary level, year eight (..) and the year eights were empowered and enthusiastic and trained up to go and work with primary schools. So then they have done sessions for primary school children. And then the other spin-off from that has been we’re trying to put care homes in touch with primary schools.” [Gloucestershire/Forest of Dean]

Engaging with GPs and the NHS

- 2.29 For several of the projects, working with local partners included engaging with GPs and the health service. Some of the project leads commented on the difficulties of getting GPs to take a more positive approach to dementia, as the following comments highlight:

“The GP that visits our care home really struggles to understand what dementia is and how to support people in the best way.”

I do think there is a big problem with GPs because most people who have a diagnosis of dementia tell me that they had an issue getting through the GP in the first place to get a diagnosis. Because GPs kind of write people off with dementia almost, so you know the message that people get when they are diagnosed isn’t a positive message.”

“I’ll give you an example – a gentleman just diagnosed, and we were running a presentation (...) and he said ‘I’ve just been diagnosed’, just out of the blue. The local GP in the medical centre had written to him to say you’ve got frontotemporal dementia; you can’t work anymore and you can’t drive! And he ran his own business. That’s how he was informed!”

“So the lead GP is now working with us so that she can work with the other GPs and we’ve designed a leaflet called ‘Just Diagnosed’.”

- 2.30 The issue of early diagnosis was similarly one in which a better understanding of support could make a difference:

“That’s been one of the positives – a more multidisciplinary way of working. I think the biggest debate we’ve had (...) has been with our GP practice because I think historically there was an issue of you know, what good is there telling people they have dementia? This whole kind of message of early diagnosis caused quite a sticking point. To begin with there was a sense of, well, you know, what are you going to give these people?”
[City of London]

“We’ve done a [KETS](#) event around what people with dementia and their carers want in a community, and they see that their GP is either not visible or not approachable or doesn’t actually know what community services are out there for people to access.”
[Making Space]

And

“A lot of GPs will say to me there’s no point in diagnosing someone with dementia because there’s not really any treatment; there’s no services.” [Coventry City Council]

- 2.31 In the Coventry project there had been an increase in new referrals of people with a primary diagnosis of dementia which was believed to be largely due to the work that had been done with the GP practice, and recognising that a diagnosis was not just about giving bad news but could lead to people being supported and given appropriate interventions. Making Space had been trying – with mixed success - to engage GPs through signing up to use the [Cantab Mobile App](#).

“It is a memory screening tool; so a practice is trained in how to use it and you can test people. It’s a 15 minute test and the results from that test are linked to their own GP. The results come up like a traffic light system on their GP’s screen: so, ‘Red’ – you need to see this person, make an appointment; ‘Amber’ – they might be a little stressed, you know, make an appointment for six weeks time, or ‘Green’ – they’re fine.”

- 2.32 Engaging with schools was not dropped as an aspiration, and Surrey was able to borrow the ideas that had been developed by Kent County Council in supporting the publication of the [Dementia Diaries](#)

“So one of the legacy bits of work that we wanted to do was to make sure that at least primary schools and secondary schools had at least a copy of this within their library. So we purchased – we joint purchased quite a few of these books with Kent County Council, and then we distributed them to schools. We distributed some through our sort of community health team so they could then pass them onto families with young children. So while, you know, the frontal assault with schools wasn’t really that productive, that fruitful, again thinking about more long term we’ve positioned these resources in some of the schools.” [Surrey County Council]

- 2.33 Finally, Gloucestershire had also developed work with schools as part of a wider programme of support under the banner of the Prime Minister’s Dementia Challenge (and not directly as part of the Skills for Care funding):

“So there’s been a lot of work in Gloucestershire – through the Prime Minister’s Dementia Challenge, we were a pilot site to introduce dementia awareness in schools. So we’ve worked with teachers (...) we started at secondary level, year eight (..) and the year eights were empowered and enthusiastic and trained up to go and work with primary schools. So then they have done sessions for primary school children. And then the other spin-off from that has been we’re trying to put care homes in touch with primary schools.” [Gloucestershire/Forest of Dean]

Engaging with GPs and the NHS

- 2.34 For several of the projects, working with local partners included engaging with GPs and the health service. Some of the project leads commented on the difficulties of getting GPs to take a more positive approach to dementia, as the following comments highlight:

“The GP that visits our care home really struggles to understand what dementia is and how to support people in the best way.”

I do think there is a big problem with GPs because most people who have a diagnosis of dementia tell me that they had an issue getting through the GP in the first place to get a diagnosis. Because GPs kind of write people off with dementia almost, so you know the message that people get when they are diagnosed isn't a positive message.”

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The results come up like a traffic light system on their GP's screen: so, 'Red' – you need to see this person, make an appointment; 'Amber' – they might be a little stressed, you know, make an appointment for six weeks time, or 'Green' – they're fine."

- 2.37 The concept of 'cascading' training and awareness raising was recognised by many as a vital part of bringing about lasting cultural change within organisations and services. Cloverleaf Advocacy, for example, described their approach:

"What we tend to do is just demonstrate good practice wherever we can and cascade it. Kind of our aim is to include staff, so if we're doing something perhaps with a domiciliary care company or a residential unit we try to include the staff if we can, so that they can cascade it when we're not there."

- 2.38 It is striking that some provider organisations that deliver care and support to elderly and other people in the community may have limited knowledge and understanding of dementia. Coventry City Council described providing dementia awareness training for providers:

"They had a Dementia Friends session and then they learned about what their contribution could be to Dementia Friendly Communities (...) But basically feedback from the day – people were saying that they didn't really know much about dementia beforehand."

- 2.39 Subsequently dementia friendly matters had been incorporated within the agenda of the local learning network that met with providers – making the issue "more mainstream." There had also been an attempt to ask providers to commit to continuing to focus on dementia, for example:

"In Dementia Awareness Week in May we also asked providers to commit to doing something around the DFC agenda, so quite a lot of them held coffee mornings where members of the public could kind of drop in to find out more about dementia. And one of them held like a fifties/sixties theme social for people with dementia. A few of them had stalls up in their offices and care homes. So we asked them to kind of follow up after the training with doing an event or some kind of awareness raising." [Coventry City Council]

- 2.40 Sometimes the impact of dementia awareness training was tangible:

"There's six or seven care homes where they've made substantial changes to the environment to make them more dementia friendly, which is really good. And a couple of those care homes only did that because they came on the training and they learned about dementia friendly environments, and they didn't know about it before."

- 2.41 With some other projects dementia awareness training was building on an existing foundation, as Home Instead described, for example:

"We have a dementia training programme for all our staff that we are rolling out, and the Dementia Friends initiative with Skills for Care that we got involved with, that was fantastic because virtually all our staff now are Dementia Friends. They would have that Living a normal life - Supporting the development of Dementia Friendly Communities 24

initial awareness anyway because we incorporate it into their induction, and now it's incorporated into our induction work with all new staff."

- 2.42 Gloucestershire County Council similarly described an approach to dementia awareness training that extends across all staff as a minimum, with some more intensive training for certain groups or for those who wish to advance. This integrated workforce development strategy pre-dates the Skills for Care work but provided an invaluable platform from which it could develop further:

"So we have dementia e-learning and then a dementia awareness half day and then a two day dementia programme that's available for everyone. Most people will go as far as the half day dementia awareness; not everyone can be released for two days (...) as an organisation and Council we insist all our social workers for example do the two days, you know, so there are certain staff groups that we would say it is mandatory for them to do the two days. And through our commissioning 'clout' we can put in contractual requirements of our care homes and our domiciliary care providers for example."

- 2.43 The focus with training had initially been to prioritise frontline staff, but it was soon apparent that in order for this to succeed, there needed to be understanding and commitment from managers. Box 3 describes the approach.

Box 3

Getting the Support for Frontline Staff from Managers in Gloucestershire

"With the dementia link workers – we had manager approval obviously for staff to go on and be a link worker – but what we did find was that they were coming back after doing this lengthy programme, being really enthused and fired up, and having developed their action plan for how they were going to change things within their setting, be that around the environment, meal times, activities etc. and sometimes the managers were not allowing it, and that happened quite often. And that was because the managers themselves didn't understand – there wasn't the leadership understanding; and they just saw it as a cost, you know, we can't do that it's too expensive.

So what we do now is to insist that in any area we have a dementia leadership programme and the relevant senior manager or owner of the care home or registered manager, has to sign up to do the dementia leadership programme first and then nominate some link workers to go forward. Because then you get the ownership and the understanding. Because it is horrible for those link workers to be empowered, to really get it, and go back to work and then not be allowed to put these changes into practice.

So although we didn't want a top-down approach, we wanted to raise basic awareness at frontline level, but you do have to have that buy in from senior levels."

Impact and Outcomes

2.44 As noted previously, all of the pilot projects provided brief outcomes reports to Skills for Care at 6 month and 12 month intervals. The reports were completed using a template from Skills for Care and for the most part these accounts described activity and process (i.e. essentially what the projects were doing or intending to do). The question of what difference the activity made is more difficult to address, particularly within a short time frame and without significant resources dedicated to monitoring or evaluation. Nonetheless, most of the projects recognised the importance of being able to demonstrate impact and some had made significant progress in doing so.

2.45 The broad objectives of the programme (supporting greater awareness and understanding of dementia in the community) are in many ways quite intangible. Most projects described the improvements in awareness raising, or the numbers of people who had become dementia friends, and many talked about things ‘feeling different’ in the community. As Surrey County Council described:

“What I found personally is that while you can set up infrastructure, that does not necessarily mean that a Dementia Friendly Community is evident. Because it’s kind of an intangible thing; it’s not – you know – it’s not just signs in windows of shops. It’s a sort of ‘community feel’ which supports people who are vulnerable, including people with dementia, so that kind of attitude can take, will take, longer to see.”

2.46 In some projects it was possible to identify changes in practice. For example, the City of London pointed to the empowerment that had resulted for social workers and how this was changing their approach:

“We’ve increased social workers’ confidence and knowledge; we’ve developed our [client] review to look at medication and to be more challenging of the review process – you know, what have been the changes? (...) I think kind of empowering the team to be more enquiring, particularly about people we have placed who are very elderly and have received a dementia diagnosis.”

2.47 Both in their reports and during interviews many projects indicated that they found the question of ‘what difference has this made’ difficult to address. Partly because this was still work in progress and too early to know what impact it would have, but also in terms of how it might be measured. Coventry City Council had plans to undertake a ‘mystery shopper’ exercise using people with dementia to sample experience with providers, but this had not taken place at the time of the fieldwork. Nonetheless, there was some evidence of providers changing their approach, for example:

“I think things have changed with some providers. So we put out a couple of tenders recently around dementia specific services and we used to not really get that many

submissions, but we've had a lot more providers now who are interested in working with people with dementia, and with people with behaviour that challenges.” [Coventry City Council]

- 2.48 Other projects pointed to qualitative and anecdotal evidence that they accumulated – such as feedback from people who had participated in training, or people with dementia and their families who had experienced improvements in being able to use their community etc, and such ‘soft’ evidence is important and provides rich information about the impact on people’s lives. Some projects were also exploring how to bring a harder edge to evaluation. Sanctuary Housing, for example thought that there might be opportunities through Public Health:

“You would have thought that they ought to be able to plot dementia-related admissions or dementia-related pick-ups by the ambulance service or something like that. Ideally what you'd want to plot is some sort of longitudinal tracking.”

- 2.49 This tracking might monitor dimensions such as prevalence and diagnosis, and examine whether greater dementia awareness among health and care professionals was leading to greater early diagnosis of cases. In the City of London concern about under-diagnosis led to targeting dementia awareness work with the sole GP practice in the area:

“There have been seven new referrals of people formally diagnosed since we began this work and started our work with the practice and the CCG (...) to have seven new referrals is, I think, quite significant within one year within this team given that it's such a small area.”

- 2.50 Surrey County Council reflected on the importance of being able to demonstrate impact, and particularly to co-design activity with people who use services and “ask them if the project has made a change to their life – that’s the whole reason we are doing this.” Public Health colleagues had also been involved in Surrey in surveying public attitudes and knowledge around dementia:

“(...) and we've seen some improvement. It's not massive improvement but it's a significant improvement. Probably that's not just down to our activity, but our activity has helped with that.”

- 2.51 Finally, Gloucestershire pointed to being able to evidence tangible change in services:

“...through people doing these education programmes, we've seen whole services change. I've seen a group of care homes change their service delivery model completely from being you know, you get up at this time, you have breakfast, you sit around etc, you know the mechanistic (...) to: this is your home, and what's important is your wellbeing and therefore we gear everything to the individual's wellbeing and activities are introduced that are more meaningful.”

2.52 Some “fantastic examples of where things have really changed” were celebrated and it was acknowledged that it was important to commit time and resources to capturing case studies and evidence of this nature, although this wasn’t always easy when resources were stretched.

3. Conclusions

3.1 This report has provided an overview of the eleven pilot projects supported by Skills for Care in developing Dementia Friendly Communities. As the report has highlighted, the projects were diverse and distinctive, but as well as having specific experiences many shared similar issues and identified similar barriers and opportunities to achievement. It was evident that the projects thrived on the enthusiasm and commitment of those most closely involved in the work. In many instances there was a significant history of endeavour around dementia, but for other projects this was new or relatively new territory.

3.2 There was considerable innovation in evidence in working with the wider community as well as across health and care partners. People were passionate about what they wanted to achieve, and this comment by the project leader in Cherish Care was typical of many:

“I think it’s about inclusivity. It really is about saying people with dementia should be walking along the street; people should understand about it and be able to say ‘that person’s looking a bit lost, can I help?’ and not be frightened by it. Just being able to be part of the community with no stigma.”

3.3 Achieving such a vision takes time, and most projects reported the frustrations of trying to make headway with the wider community and to engage people who may not have seen dementia as anything to do with them. Home Instead offered this reflection to people embarking on similar work:

“Be aware that people aren’t interested in dementia unless it’s personal, and sort of work out different ways of getting people engaged (...) I think that’s been the hardest thing.”

3.4 Persistence paid off in most cases and projects found creative ways of engaging with different audiences, whether through targeted training, or through information through pop-up shops or dementia cafés. Cascading training and awareness raising through the stages of creating Dementia Friends, and Dementia Champions was generally seen as a positive way of spreading awareness through communities and building sustainability rather than creating something that would last only for the duration of a project. As Gloucestershire County Council observed:

“We want a percentage of people to come forward to be Dementia Link Workers, then the Dementia Champions, because that’s how it sustains. They support people then, you know so they support their colleagues.”

- 3.5 It was apparent that although there is a major challenge in working with communities to develop a wide understanding and awareness of dementia, and to enable people living with dementia to more easily access services, there is a similar challenge in working with care and support services that may have relatively little understanding of dementia despite the nature of their professional work. Several projects described their experience in working with providers to improve awareness through education and training, and the value of doing so was clear. One project (Gloucestershire) had located responsibility for the work within their HR department and had approached dementia as a key aspect of workforce development and was considering how best to support people in the workforce who have had a diagnosis of dementia.
- 3.6 The support from Skills for Care to this programme of work was modest in financial terms, but enabled projects room to innovate (for example using funding to arrange room hire and refreshments when working with the public). Several project leaders expressed their wish to have known more about other projects that were active and to have had opportunities for sharing of ideas and experience.
- 3.7 Dementia has achieved a higher profile in recent times, not least in the wake of the Prime Minister's Challenge on Dementia. However, it is clear that this is – and will remain – work in progress rather than something that can be judged to have been achieved in a short time. Changing hearts and minds and organisational cultures takes time, but can have a major and lasting impact. In many ways recruiting others to become Dementia Friends and Dementia Ambassadors is a powerful method for passing the baton throughout communities and ensuring that the message continues to spread and multiply, rather than it being seen as the responsibility and remit of a given department or officer. Equipping people with the necessary skills and understanding has the greatest potential to bring about transformational change and to enable genuine social inclusion for people living with dementia.

Skills for Care
West Gate
6 Grace Street
Leeds
LS1 2RP

Telephone: 0113 245 1716
Email: info@skillsforcare.org.uk
Web: www.skillsforcare.org.uk