

HOW CAN WE MAKE OUR CITIES DEMENTIA FRIENDLY? SHARING THE LEARNING FROM BRADFORD AND YORK

What's the issue?

Dementia friendly communities (DFCs) aim to be accessible, inclusive, welcoming and supportive to those affected by dementia, enabling them to contribute to, and participate in, mainstream society. More than 80 places across the UK are now working towards becoming more dementia friendly, with similar movements gaining ground overseas.

York and Bradford – two very different Yorkshire cities – are among those leading the field. This paper contributes to the emerging evidence base by drawing out the key messages from independent evaluations of their DFC programmes.

Ways forward

- The active, meaningful engagement of people with dementia and their families is fundamental.
- DFCs must engage with, and achieve equity for, all people with dementia, whatever their circumstances.
- Practical barriers to inclusion must be addressed if normal lives are to be continued.
- The human rights of people with dementia and carers must be recognised and promoted.
- DFCs must be underpinned by ongoing awareness raising, training and positive media coverage.
- Connections and networks, within and beyond the community, are at the heart of DFCs.
- Local grassroots community activity is the bedrock of DFCs.
- This activity must be supported by strong strategic planning, commissioning and leadership.
- Both primary and secondary health providers have a vital role to play in supporting social inclusion
- There is no template - each community must develop its own approach.

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BACKGROUND

DFCs have been defined as places *'where people with dementia are understood, respected and supported, and confident they can contribute to community life. In a DFC people will be aware of and understand dementia, and people with dementia will feel included and involved, and have choice and control over their day-to-day lives'* (Alzheimer's Society and Dementia Action Alliance, 2013). The concept developed from the more mature 'age-friendly' movement, which is supported by the World Health Organization.

Over the last decade awareness has grown in the UK of the impact of increasing longevity and the increased prevalence of dementia – by 2025 one million of us may be living with dementia (Alzheimer's Society Dementia, 2014). The National Dementia Strategy (Department of Health, 2009) focused on the growing numbers who will be remaining at home in their communities.

When David Cameron announced that DFCs were one of the three priorities in his Dementia Challenge 2012 (Department of Health, 2012), both York and Bradford DFCs were already up and running. The following year, the Alzheimer's Society outlined the key elements of DFCs, producing guidance and criteria for recognition. Businesses, organisations and services meeting the criteria can display the distinctive forget-me-not logo. By February 2015 more than 80 places across the UK had committed to become DFCs. This movement has been complemented by the creation of a million 'dementia friends' and the engagement of large businesses.

Though DFCs have blossomed quickly into a widespread social movement, the evidence base is underdeveloped. This paper draws on the separate evaluations of the DFC programmes in Bradford and York (Dean, *et al.*, 2015a; Dean, *et al.*, 2015b).

The approaches in York and Bradford

Bradford district encompasses both urban and rural communities with a rich mixture of ethnic groups and cultures. Economic and social deprivation are likely to compound the experiences of people with dementia who face disadvantage on a number of dimensions ('intersectionality'). It is estimated that more than 5,000 people have dementia (up to 6,000 by 2025).

Bradford had been working to become dementia friendly since 2011, with support from Bradford Council. The local Alzheimer's Society built links with eight local organisations, including Lloyds TSB, the Diocese of Bradford, Bolton Road Gurudwara and a pharmacy, to work on dementia awareness and develop good practice, and also targeted a council ward with a high proportion of older people. Since April 2013 the DFC programme has been jointly supported by Bradford Council and JRF. The jointly funded DFC development officer has a formal target of creating 20 dementia friendly communities (both geographical and communities of interest), alongside initiatives with businesses and service providers.

The work in Bradford developed in different ways, but typically in response to interest from a ward officer, local councillor or a resident with personal experience of dementia. The programme has worked alongside ward officers or other community leaders, and an active core of residents, to identify the priorities. During the life of the programme, Bradford has also established a Dementia Action Alliance (DAA), with a broader focus on engagement across sectors to build awareness of DFCs and encourage organisations to change and adapt their approach to make DFCs a reality.

York has a strongly performing modern and mixed economy, and is an internationally recognised centre of excellence for education. Although income levels are relatively high, and there is a good general level of health, there are still inequalities between different parts of the city. In 2014 an estimated 2,700 people were living with dementia in the city and its surrounding villages: this number is expected to rise to 3,200 by 2020.

The York approach to DFC differs from that in Bradford, with no single overall co-ordinating body and JRF's role more that of facilitator and funder. There have been three distinct but connected strands of work:

- Supporting partners to deliver a dementia friendly York: awareness training funded by City of York Council (CYC), and provided by local organisation Dementia Forward, has been key in securing specific buy-in from organisations across all sectors – as has the establishment of a local DAA to connect all those who are involved or interested.
- The dementia small grants programme: JRF has awarded over 30 small grants worth in total around £130,000 to seed-fund DFC projects ranging from music, art, gardening, cycling and croquet, to a café, a film archive and a youth programme.
- Creating a DFC within JRF/JRHT: as part of demonstrating its commitment to DFCs, JRF and JRHT have embarked on a programme of work to become more dementia friendly as an organisation.

Non-statutory services are mainly provided by two charities. Dementia Forward provides dementia awareness training and, since 2014, has been commissioned by the clinical commissioning group (CCG) and North Yorkshire Partners to provide care navigators, dementia advisors and a dementia café. Selby and York Alzheimer's Society is funded to provide adapted sports activities, Singing for the Brain, Reading Aloud, peer support groups and dementia cafes.

Key findings from the evaluations

Engagement and voice

Key message: The active, meaningful engagement of people with dementia and their families is fundamental. It must be encouraged, resourced and nurtured.



“We would encourage people to become dementia friendly.
The more we know, the more we can understand.

The **dementia education** our staff received was invaluable. It's helped us deliver excellent customer service, not just for people living with dementia, but for all our customers.”

Peter Bayliss and Jim Love, Fleetways Taxis

Promotional postcard

In Bradford, a focus group of people with dementia and carers has contributed to the programme from the start, sharing their experiences and offering mutual support and encouragement. The group demonstrates how personal connections help to tackle the impact of a dementia diagnosis, prevent isolation, maintain confidence and skills and contribute to supporting a better quality of life for longer. The more recently established Face it Together group (FIT) is wholly led by people with dementia. FIT has already been involved in a range of activities, including feeding back on signage and accessibility; advising on St. Luke's Hospital refurbishment; planning the Westfield Shopping Centre; and interviewing for Bradford Community Trust and DAA posts.

In York people with dementia have been involved in planning, initiating, implementing and evaluating attempts to create a DFC. Inevitably, several of those involved in the early phases have since died but a new 'core group' of individuals is now involved in the York programme; evaluating bids for funding; auditing physical spaces; making or reviewing films; giving media interviews; writing blogs; speaking at conferences and events. Some

have achieved national influence. Blogger Wendy Mitchell (<https://whichmeamitoday.wordpress.com>) has recently appeared on the BBC 2's Victoria Derbyshire programme. The short JRF film of Peter and Avril Jones in Haxby has been nationally and internationally applauded (<https://vimeo.com/9804222436>) as has the film and blog about young Annie and her nana Liz (www.youtube.com/watch?v=Ab9eKFb_tD8).

There are challenges in involving a range of people so that key players are not too heavily relied on or seen as the 'usual suspects'. It has not been easy to make wider connections with people with dementia, especially those who live alone or are from different ethnic or sexuality groups. However there are signs that this is beginning to happen through Minds & Voices (previously York Dementia Forum) which is demonstrating the ability to engage with people who might otherwise not have a voice.

JRF's support for the national network, Dementia Engagement and Empowerment Project (DEEP) (<http://dementiavoices.org.uk/>) has been vital in enabling people with dementia not only to speak out, but to shape and redefine what they mean by DFCs. Those who have done so have played an important role in encouraging others to be open about their dementia – a significant step in widening awareness. Both York Minds & Voices and Bradford FIT are part of the DEEP network, whose members are starting to find a common discourse based on rights.



Chris Gilliver, a member of the new Bradford FIT group

Despite this progress, it remains a challenge to engage people in actual projects and activities. Small new projects find it hard to go 'cold' into the community, needing time to establish relationships and connect into existing networks and individuals. More consistent use of 'social prescribing' by health staff could do much to encourage involvement in these projects (see The role of health providers below).

Although people with dementia and their carers have influenced both DFC programmes, the next step is to enable and empower them actually to co-create DFCs.

Equity and diversity

Key message: DFCs must seek to engage with, and achieve equity for, all people with dementia, whatever their economic or social circumstances, ethnicity, gender, age, sexuality or additional impairments.

There are many examples in both York and Bradford DFCs of imaginative approaches to addressing inequity and multiple marginalisation, engaging with different communities of interest, for example black and minority ethnic (BAME) communities; the lesbian, gay, bisexual and trans (LGBT) community; people with learning disabilities, and women.

BAME communities: Nationally individuals from BAME communities are more likely to be at greater risk of early onset dementia and vascular dementia: diagnosed late or never; less likely to use dementia services; and poorly represented in referrals to memory assessment and treatment services, compared with the general population. Previous research in Bradford (Rauf, 2011) has identified many reasons why people from South Asian communities find it difficult to engage with support services, including traditional concepts of 'family kinship' and lack of support for (mainly female) carers. Some assessments (particularly memory assessments) are culturally inappropriate, although Bradford Memory Clinic does have an adapted version for the South Asian Community.

Bradford's DFC co-ordinator has engaged with BAME groups, finding common interests and links. The inspiring culturally-specific approach of a local Sikh Gurudwara has been recognised with a national award and Meri Yaadain, a well-established service for older South Asian communities, has engaged positively with the programme. Bradford & District Older People's Alliance (BOPA) and the University of Bradford have also run a series of roadshows for BAME groups, including eastern Europeans. But there is more work to be done, with continuing issues of patchy services, low referrals from Asian GPs and cultural sensitivities in families and communities. Smaller groups and more recent migrants may be overlooked. All these could mean that BAME people find their own community less than dementia friendly.

Women: A national conference at York University in November 2014 explored the issue of women and dementia (<https://pure.york.ac.uk/portal/en/publications/women-and-dementia%2810854dd4-ad83-477c-a900-1498800d377d%29.html>). Women's longer life expectancy increases the prevalence of dementia, and women also care more regularly than men, whether for partners, parents or other relatives, or as paid carers or nurses. Male carers are often supported earlier and with more resources than female carers. Women with dementia may be more isolated because of the reluctance or inability of their (male) carer to network in the way that female carers might. The work done by York-based academics, local dementia activists and creative artists in focusing on women and dementia has created a network of people who can raise awareness of this particular equity issue, and continue to highlight what women might want from a dementia friendly York.

LGBT community: The Bradford programme has developed a guide to dementia for people from the LGBT community, with representatives from Equity Partnership's older women's group and the Labyrus Trust, a local group for older lesbians. Equity Partnership has signed up to Bradford DAA with plans for more dementia friendly signage and increased staff awareness. The work has strengthened links, encouraged referrals and led to reciprocal training between Equity Partnership and the Alzheimer's Society. In York there has been less involvement with the LGBT community, in spite of it being a relatively gay-friendly city.

Learning disability (LD): The Bradford programme has worked closely with the LD community, forging contacts with several organisations and Bradford District Care Trust. Issues affecting people with dementia and LD were the main topic at one DAA meeting, with attendance from several LD organisations new to the DAA. Bradford Talking Media, a social enterprise providing information in audio formats, has been working on an easy-read booklet about how to be a friend to someone with dementia. Work with Bradford Ageing LD and Dementia group (BALDAD) identified that family carers of people with LD and dementia are not being offered routine support. Alzheimer's Society Bradford is now supporting the national Dementia Friends programme to adapt sessions by and for people with LD to raise awareness within their communities. In York a relationship with people with LD is emerging through the work of United Response and Krumbs Café, where people with dementia are encouraged to attend and volunteer in an established resource for people with LD.

There is of course much more work to be done in reaching out to those who are multiply marginalised. In York, carers felt that those with co-morbidities such as physical disabilities or sensory loss are ill-served, as dementia services did not address the impact of other conditions, and services specialising in other conditions were not dementia friendly. Carers also spoke about the specific experiences of younger people with dementia or those with more unusual forms of dementia (e.g. Pick's disease). It is often difficult to find age-appropriate support or support that can cater for some of the markedly different manifestations of behaviour which can occur with different types of dementia.

Addressing the practicalities

Key message: Practical barriers to inclusion must be addressed if normal lives are to be continued.

Practical issues such as transport, way-finding, safety, keeping fit and carers' needs can restrict participation in everyday life and severely reduce the benefits of DFCs. They must be proactively addressed to achieve maximum engagement and confidence.

Getting about is a persistent problem for people with dementia. The loss of confidence associated with diagnosis and progression of dementia affects a willingness to travel far. Challenges may also include ability to drive or use public transport, affordability, understanding signs and timetables, negotiating complex street patterns or buildings, or sensitivity to traffic noise or crowded places. People with dementia who can afford transport costs, or who have a driving spouse or carer, have more chance of participating. Others may be effectively excluded from joining and attending groups. Those providing activities and services report real challenges in getting people to venues. This is acutely felt in rural communities where transport is infrequent or non-existent.

However there are already some significant achievements. In York, local taxi company Fleetways has arranged dementia awareness training for all its drivers. Ground-breaking work has been pioneered by British Transport Police to raise awareness at stations and providers on the East Coast Main Line. This is rebuilding travel confidence in some people.

However further thought about how to increase access to transport for people with dementia is required, including better advice, shared experience about continuing to drive, access to volunteer transport 'buddies' and more community transport in rural areas. Greater involvement of taxi firms in the DFCs could be a future target for business engagement. Commissioners and partners should systematically address these issues.

Carers often fear that a person with dementia might get lost, and they want practical signage more than dementia friendly stickers. There are indications that commissioners and service providers are starting to address this. For example, CYC took advice from a dementia design expert when refurbishing King's Square, and Minds & Voices has been involved in the redesign of York's signage and way-finding system. The brief for a new community hub includes dementia friendly principles. In Bradford, FIT has advised on the new Westfield Shopping Centre.

Keeping safe is a key issue for people with dementia and a major concern of carers. They consider the roles of police, fire and rescue and banks as very important in DFCs, so there can be a good response to crises such as a missing person, a house fire or financial abuse. A frequent request was for places in shops and cafes where a person with dementia can sit safely while the carer pays for something or tries on clothes. Doorstep sellers and cold callers are also a major cause for concern. North Yorkshire County Council trading standards service is promoting the idea of 'protective neighbouring', which highlights financial abuse as well as criminal scams. It has raised awareness among staff of dementia and doorstep crime and disseminates learning across other local authorities.

Keeping physically fit is crucial for those affected by dementia. CYC sports and leisure services has identified activities which are particularly suitable for older people, and has led a programme of awareness raising, with materials to help coaches work in an inclusive way with people with dementia. Carer support is an integral part of what makes a DFC, and although many couples enjoy being together, carers often do want and need time to themselves. The Bradford programme facilitates this by supporting people with dementia on their own, and encouraging parallel groups of carers. DFCs demand appropriate support for carers, including those in employment and with their own personal needs, so they can provide the most relevant support for their person with dementia. However support for carers was still felt to be less consistently available than it ought to be, and there is more to be done to understand and respond to their needs – and in particular for support in a crisis.

Rights and wellbeing

Key message: The human rights of people with dementia and of carers must be recognised and promoted if real inclusion is to be achieved.

The themes discussed in the previous sections – engagement and voice, equity and diversity, and practical barriers – are all underpinned by the common issue of rights. Yet the discourse about the rights of people with dementia – and specifically in relation to the DFC movement – is only just beginning. There is evidence that some decision-makers do not accept that people with dementia have the same rights as others to the removal of discriminatory barriers. Planning controls, building design, access and transport often effectively exclude people with dementia from participating in mainstream

society. Assessments of need should take account of psychological, social and economic circumstances as well as health and care needs, and organisations need to consider how to use relevant legislation – and in particular the Equality Act and the Care Act – to protect the rights of people with dementia to engage in community life.

With the emergence of the new FIT and Minds & Voices groups, there is the potential for people with dementia in Bradford and York to highlight their rights to live in a DFC. Other rights movements and campaigns have much to offer people with dementia, including experiences of legislative change (as enshrined in the Equality Act for example) as well as changes in social awareness (such as Age UK's work on ageing, and the Time to Change campaign on mental health). The real goal for the future must be a level of awareness and adjustment in communities which is similar to that achieved for people with physical disabilities.

Awareness raising and training

Key message: Ongoing awareness raising, training and positive media coverage are fundamental to DFCs.

There has been a strong emphasis on raising awareness and influencing businesses and organisations to become more dementia friendly. This has been energetically addressed and largely successful. In Bradford an additional co-ordinator has been appointed to specifically work in this area. In York, Dementia Forward, funded by CYC, delivered over 70 education sessions to more than 3,000 attendees. These inputs have created a core awareness among a diverse range of organisations, including ambulance services, coach companies, legal firms and shops. Though many have been very willing to be involved, it continues to be challenging to engage businesses.

Work with commercial organisations has also had regional and national influence. The Co-op stores in Bradford, for example, have influenced the Co-op funeral services and the broader Co-operative organisation, through a video (of its work www.youtube.com/watch?v=m19cXnWi59k). Local banks have connected to national initiatives developed through the DAA. In both cities, Solicitors for the Elderly offer free guidance and action on Lasting Powers of Attorney.



The launch of Inspired Youth's project 'A Story like Ours' in York

In some places there is now definitely better awareness and understanding of DFCs, with more actual willingness to help and a 'can do' attitude in shops and businesses. The impact of the Dementia Friends Programme has been high, with people recognising the 'working to become dementia friendly' stickers. City of York councillors have demonstrated commitment by becoming dementia friends and including the logo on their emails.

York's love of the arts has opened up many opportunities to raise awareness. Examples include a very successful annual concert; the listing of *Dear Dementia* by a local author (Donaghy, 2014) in the national Reading Well Books on Prescription scheme, and a play by the Real People Theatre Company. The Yorkshire Film Archive's Memory Bank has been applied very successfully in a wide variety of community and residential care settings.

York has also been particularly ambitious and creative in its intergenerational work. Pupils based videos and plays on face-to-face meetings with people with dementia, and at the Harmony Café in a local church, York University students offer musical entertainment and social activities every month for people with dementia, their friends and families. In partnership with Harmony Café, Inspired Youth has engaged young people with people with dementia in film-making, posters and artwork, creating some fresh images and narratives of what living with dementia is like (www.youtube.com/user/koovine). Musical Connections' work in care homes and schools provides another way of breaking down barriers between younger and older people. JRF hosted a guest blog by Annie, a young carer for her Nana, Liz (www.jrf.org.uk/blog/2014/05/dementia-happens-your-whole-family). In Bradford there are also awareness programmes running in the local education sector, including Bradford University and Tong Sixth Form.

In spite of all this good work, and the sense of emerging dementia friendly 'movements' in both cities, there is much still to be done to. Awareness of the DFC stickers is still quite low and there are only a small number. Some people felt that frontline staff were not showing the same levels of knowledge about what would support people with dementia in their communities as service leaders. The York evaluation found some negative views from carers and other respondents about awareness raising for carers. It was felt that opportunities are still being missed to help them understand what might happen in the short and longer terms. This is a time when the importance of general wellbeing and staying connected to the community could be stressed and connections made to dementia friendly activities and resources.

Connections and networks

Key message: Connections and networks, within and beyond the community, are at the heart of DFCs.

York and Bradford have shown us how personal, professional and organisational networking all help to build the DFC 'movement', sustain morale and ensure that learning is shared. The work in both cities, as well as in the DEEP network, has highlighted that those affected by dementia really value opportunities to meet with each other. There is clear evidence that both people with dementia and their carers/supporters gain great strength from meeting face-to-face. Networking is fun, practically useful, challenging and empowering. The information gained about dementia, its characteristics and trajectory, is valued as much as, if not more than, medical or service based information from professionals and written material. People seem to respond well to the opportunity to share their positive and negative experiences between peers on an equal footing. Groups also offer the opportunity to continue familiar activities or take up new interests.

Bradford has achieved a great deal through the establishment of, and support for, existing groups in both geographic and communities of identity, including village groups, faith based groups and identity groups (such as the LGBT group). In Bradford there are opportunities for people to attend groups and events on their own, and with carers and supporters.

Groups can also offer development opportunities, and enable people with dementia to shape the services and resources they might use. More systematic local networking, as a way of people getting together to share their experiences of dementia, has begun to emerge through Minds & Voices in York and the FIT group in Bradford. Their growing confidence as part of the DEEP network is

beginning to influence the progress of Bradford and York DFCs, although there is scope for more challenge with decision-makers.

We know that in other places people with dementia network extensively using social media. This can be a very inclusive and liberating method of communicating for many people with dementia. There has been positive experience of the use of iPads in the JRF-funded small project work.

York has good networks, especially in the cultural, arts, sports and community sectors, and where the DFC programme has become known people with dementia can be connected to a wide range of resources. However sharing information is seen as a broad challenge, with data protection and data sharing still being a barrier to creating DFCs. Organisations need to collaborate to find a way of asking people if they can share their details across organisations in a safe but effective way. There is a sense of information being 'scattergun' and a danger of duplication because agencies and organisations are not communicating effectively. In York this sort of frustration is now being addressed by the Connect to Support website which is attempting to remove confusion and provide an information hub for public, staff and providers. Bradford is also developing a website dementiacarers.net.

Being part of a wider regional, national and international movement has been significant for both programmes. JRF brings its own network of national and international contacts into the programmes to share ideas, and people with dementia and carers have connected with many others at events and conferences, learning from and challenging one another. The establishment of a national DAA, and the roll-out of regional and local DAAs, has created a network of organisations, practitioners, activists and policy-makers able to share and explore new ideas about what makes a dementia friendly community and how to work towards making it a reality.

A visit by members of the Stockport EDUCATE group to Bradford gave an early impetus to involving people with dementia in raising awareness about DFCs. FIT has since hosted an event for counterparts in York and Sheffield to explore their notions of involvement in DFCs.

York too appears to link well to the regional and national networks, with strong connections to other cities around the UK and beyond. A particular link has been made between York and Bruges, which share many characteristics.

Professional networking is also important in creation strong DFCs. This needs to be strong at all levels, but it can be bedevilled by restructuring and changes in personnel. Neighbourhoods, communities of identity, places of worship, community centres and local service centres, all provide a physical presence for networking where people can find written information and people to talk to.

Some respondents did comment that there was a need for information to be more widely shared, particularly in terms of identifying where the people with dementia are, which is crucial when developing services. There is scope for more conscious and systematic networking around dementia, which is not primarily linked to the DFC programmes (the DAAs are networks or organisations committed to contributing to a DFC). There are some practical opportunities for considering how to pool information and make it more accessible and to join up information sources and make them make relevant for each stage of the dementia 'journey'. These might be care navigator roles carried out by workers or volunteers, or virtual models and apps being developed within the public health arena.

Community activity unearths innovation and creativity

Key message: Local organic grassroots community activity is the bedrock of DFCs: it unearths innovation, untapped assets, unsuspected champions and creative partnerships

Both York and Bradford DFCs have demonstrated the power of grassroots community activity, albeit using different approaches. The focus on local areas is a particular feature of the Bradford DFC programme, with a clear sense of progress in the 'early adopters'. Specific work around dementia now features in over half of all council ward assessments and action plans, representing a sustainable mainstream approach not contingent on the DFC programme. Larger towns within the Bradford district, like Keighley, Bingley and Shipley, support a range of activities and enable people to network effectively. Though the evaluators found that the ward focus has been very successful in many places, it has progressed at different speeds and with variable levels of interest. Some ward officers have



Visitors from dementia friendly Bruges visit Bradford

raised concerns that they might not have the time or resources to continue the dementia friendly work alongside their other responsibilities to the whole community, but community development workers have had DFCs added to their remit.

In York, the approach of encouraging ‘many flowers to bloom’ has led to a range of small initiatives influenced by people with dementia and carers and the JRF small grants stream has helped many of these to get off the ground. This is particularly driven by some individual and organisational ‘dementia entrepreneurs’ who have been supported by JRF. New services such as Getting Along which supports couples living with dementia, and My Dementia, a course for people with a new diagnosis, are demonstrating demand for early support to enable people to define how they want to live with dementia.

Faith groups have also been actively involved in both Bradford and York. As well as the work of a local Sikh Gurudwara mentioned above, the Bradford Diocese has an adviser on dementia issues

within its Disability Task Group has developed four local memory clubs. West Yorkshire Methodist group has also created a dementia friendly church. In York examples of positive community leadership include the Methodist Church's support for the Aroma Café and the wider DFC work in Haxby, the Catholic Church's support for the Harmony Café, and York Minster's broad engagement in the DFC programme. However, York, with its international spiritual significance, could perhaps do even more to harness the resources of faith groups across the city.

Places and projects where people have built up relationships over time include the Harmony Café, Singing for the Brain groups, the Secret Garden (where people with dementia can enjoy the therapeutic benefits of gardening) and Food and Fun, a social event for the over 50s which includes people with dementia and their carers. Across Bradford there is a big network of wellbeing cafes, all dementia friendly and used by a lot of people with dementia as well as other older people. In these situations close friendships develop and there is a real sense of peer support and making the most of each other's strengths.

Strategic planning and commissioning

Key message: Community activity must be supported by strong strategic planning, commissioning and leadership for DFCs to flourish and be sustainable.

Both Bradford and York DFCs have highlighted the importance of health, social care and other partners working together, and with the community, to maximise the potential impact of DFCs. In spite of the current climate of austerity, there are many opportunities for public bodies to demonstrate their strategic commitment and leadership. Integrated care pilots, care navigators, joint strategic needs assessments (JSNAs), public health needs assessments, dementia strategies and health & wellbeing strategies all offer a real opportunity to demonstrate effective joint working on dementia across the health and social care system. The government's Vision for Adult Social Care emphasises the need for 'empowered people and strong communities [who] will work together to maintain independence' (Department of Health, 2010). The 2014 Care Act created a duty to provide for the wellbeing of people in need of care, and introduces a right to assessment for carers. The Act prioritises community support and is therefore positive in terms of DFCs, although it leaves unresolved the task of shifting resources from health to social care commissioners.

In York, the council has embarked on Rewiring Public Services (www.rewiringyork.com), a major transformation of adult social care which emphasises preventative work, general health and wellbeing, stronger more resilient communities, and care at home and in local neighbourhoods.

York has also recently been announced as one of 11 integrated care pilots in which health and social care commissioners agree what to do, and providers across all sectors, including private and voluntary, deliver what is commissioned. If joint forward planning to avoid crises improves, this will help York to be more dementia friendly. Dementia Forward has been commissioned to provide a 'care navigator' role to support the joining up of information at each stage of the dementia journey. The council's workforce development unit has been running awareness training continuously since 2014 and is encouraging all council employees to become dementia friends.

However, as yet connections between the DFC work in York and mainstream work on ageing, mental health and dementia are less evident: it is harder to see how the York DAA, for example, connects to and influences the partnership structures which sit under the health and wellbeing board. Despite dementia being identified as a priority issue for York in the JSNA, it is not clear how the DFC programme was considered. The perception is that the clinical commissioning group (CCG) is proving slow to invest in community schemes which might address loneliness, isolation or wider wellbeing issues. If the concept of DFCs is not integrated into the mainstream of health and social care in York, there is a risk of it being seen as peripheral and not sustained. However, at the time of writing Vale of York CCG has just published its Integrated Operational Plan (2014–19) and is appointing a new mental health (including dementia) and LD services provider. The plan includes a commitment 'to work in partnership to develop DFCs to reduce stigma and improve early diagnosis and provide support to people to live independently for as long as possible'. (www.valeofyorkccg.nhs.uk/publications/5-year-plan/).

Bradford has its own advisory group which oversees the work of the DFC programme, with links to Bradford DAA. Both groups also link with the Older People's Partnership Group with its position in the wider health and wellbeing board governance arrangements, and there is a clear dementia strategy and action plan. The Assistant Director for Integration and Transformation in Bradford Council's Adult Services Department is championing the council's commitment to the DFC at a senior level within the organisation, an important leadership commitment. Bradford Council has engaged ward officers in dementia friends training and newly elected members had awareness training as part of their induction after the 2015 elections. DFCs are a standing item on the agenda of the Dementia Strategy Group (DSG), which includes representation from key statutory, voluntary and private sector partners. The DSG also has close links with the DAA and with Bradford Older People's Partnership. The Bradford and District Health and Wellbeing Strategy includes dementia as a strategic priority.

Bradford CCGs emphasise, in their five year forward view, the development of models of care 'closer to home' that support people (including those with dementia/mental health needs) to live safely and with social interaction in their own homes for as long as possible (www.airedalewharfedalecravenccg.nhs.uk/wp-content/uploads/2014/08/Bradford-and-Craven-five-year-forward-view.pdf). There is some evidence that the concept of DFCs is beginning to influence the commissioning strategies within elements of the health sector, particularly mental health.

In spite of these strategic arrangements, the evaluation suggests that the evidence of delivery is less robust than the strategic commitment to DFCs and there is an underlying concern in both cities about the impact of spending restraint on public services on the DFC programmes. The continuing focus of commissioners is on health and social care solutions, not on the personal, emotional, and social needs of people with early stage dementia. Commissioners do not yet seem to have real confidence that creating DFCs could lead to savings or improvements in the care and support of people with dementia, despite the Alzheimer's Society highlighting the difference in cost of caring for someone at home as compared to residential care (www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2761).

In Bradford, respondents said that carers' needs assessments were not offered consistently, although there was optimism that this might change under the Care Act. Views were expressed about the inability to effectively link up services, leading to cuts in some services which had a detrimental effect on others.

Many stakeholders, volunteers and people with dementia and their carers expressed concerns about the future of the DFCs. There is an opportunity to consider, through growing awareness and the recommissioning of health and social care services, how some of the smaller innovative projects which have demonstrated their benefit could be commissioned as part of services for people with dementia. These projects not only offer more diversity, but the opportunity for people with dementia themselves to decide what kind of communities they would like Bradford and York to be.

People who are diagnosed with dementia early are often keen to continue working or to take up volunteering, but the evaluations found little evidence of proactive working practices outside JRF, a few local firms and the Aroma café. However, the recent launch of the Alzheimer's Society Toolkit for Employers (Alzheimer's Society, 2015) is a key step forward nationally and York DAA is offering free training and support for employers to develop an action plan. There are specific opportunities during commissioning and procurement to consider which community services could be run by people with dementia, or use people with dementia as volunteers.

The role of health providers

Key message: Both primary and secondary health providers have a vital role to play in supporting social inclusion

The work in both Bradford and York has highlighted the central role of health providers in supporting the social movement of DFCs and the inclusion of people with dementia. But to achieve this, there must be greater understanding of the social model of disability as it applies to dementia (Thomas and Milligan, 2013) and of connections from the 'health' system into the 'social and community' system.

Table 1: The four cornerstones and the Alzheimer’s Society recognition criteria

Cornerstone	Key issues	Alzheimer’s Society recognition scheme criteria
Place	All aspects of a person’s home environment Their neighbourhood Access including transport	A good physical environment Appropriate transport Maintaining independence by delivering community based solutions.
People	How carers, families, friends, neighbours, health and social care professionals (especially GPs) and the wider community respond to and support people with dementia. How people with dementia themselves engage in, influence and help to create DFCs	Challenging stigma and building awareness Empowerment and recognising the contribution of people with dementia Shaping communities around the views of people with dementia
Resources	Are there sufficient services and facilities for people with dementia? Are they appropriate to their needs and supportive of their capabilities? How well can people use the ordinary resources of the community?	Early diagnosis Personalised and integrated care as the norm Maintaining independence by delivering community based solutions Businesses and services that respond to people with dementia.
Networks	Do those who support people with dementia communicate, collaborate and plan together sufficiently well to provide the best support and to use people’s own ‘assets’ well?	Shaping communities around the views of people with dementia and their carers Befrienders helping people to engage with everyday life

First, there are strong expectations that GPs diagnose earlier and more consistently – and a sense that this is starting to happen. Bradford has seen a marked improvement in dementia diagnosis rates and referrals to memory clinics, and almost all those identified are being properly referred to ‘memory clinics’ for the help they need (NHS Bradford City Clinical Commissioning Group, 2014). However there is a perception that some GPs still avoid referring for diagnosis for as long as possible – and the evaluation highlighted concerns about continuing differences in the rate of diagnosis of South Asian people with dementia compared with the White British population, restricting access to culturally appropriate support . Similar inconsistencies were reported in York.

Second, there is a clear opportunity for GPs, consultants and memory clinics to link in to DFCs, and to connect those who are newly diagnosed with what is on offer, potentially through social prescribing (connecting people to non-medical sources of support). The role of primary care as a focal point of information and referral also needs to be more consistent. In both cities there was a sense of inconsistency, and of a tendency to refer into health services, without a wider assessment of the personal, social and community needs of a person with dementia. What this means is that there is a continued emphasis on medicines and NHS treatment for individuals rather than a wider commissioning of DFCs which might result in better quality of life even if the progress of dementia cannot be slowed. This reluctance to connect the health system to the social and community system means that the longer term investment in DFCs is not yet happening and there is little sign of significant transfer of resources from health into the community. It is suggested that more can be done to raise awareness among GPs of the concept of a DFC, to see a person with dementia as a whole person and to prioritise continuing general health and wellbeing and social connectedness as well as specific treatment and support for dementia symptoms. The overall low number of formal social prescriptions is a missed opportunity to support general health and wellbeing, confidence and quality of life.

But there are opportunities for change. Vale of York CCG is working with Dementia Forward to develop awareness among GPs and practice staff of the range of dementia services on offer. In Bradford there is a strong team of dementia advisors and dementia support workers who offer support on diagnosis and also in the longer term. HALE (Health Action Local Engagement), Bradford Council and the three Bradford CCGs, have developed a dementia self-care pack to help GPs direct people with dementia to a range of support organisations (www.haleproject.org.uk/documents/DementiaSelfCarePack.pdf). However, it is not clear how widely or consistently this is used.

Secondary health care also has a vital role to play in DFCs. Poor dementia awareness, for example in reception staff, can result in very negative and stressful experiences for people with dementia who suddenly find themselves in hospital. However there has also been some impressive work in local hospitals. York Hospital has developed dementia friendly environments not only in several acute wards, but also in patient services such as shops and the chaplaincy. The hospital acknowledges that the DFC agenda has given the activity a real push and has illustrated that dementia affects the whole hospital. The preventative benefits of DFCs are also acknowledged in terms of helping to prevent or delay the need for acute care. Both Bradford hospitals (Bradford Royal Infirmary (BRI) and St. Luke's) have taken a lead. BRI refurbished two dementia wards and was the first to receive dementia friendly recognition. The redesign of St. Luke's Hospital's public areas has included clearer signage, better use of colour and light, and two dementia gardens. Both sites use the forget-me-not symbol in patients' case notes and above their beds (with the permission of the patients and relatives) to enable staff to plan their care accordingly. The Teaching Hospitals NHS Trust has also consulted the Bradford DFC Programme's focus group on its new finger food menu. All this work is being embedded in the organisation via the hospital's dementia champions and is included within the trust's strategy. Similar work has taken place at Airedale Hospital, with environmental improvements including clearer signage, and a colour coded wayfinding scheme. Airedale Hospital has adopted the Butterfly Scheme and is developing a Butterfly Room in A&E for people with dementia.

Conclusions

The practical work of creating DFCs in York and Bradford has enabled many ideas and approaches to be tested in the complexities of the real world. Many have been very successful, some have struggled.

We know that the active, meaningful engagement of people with dementia and their families is fundamental, and must be encouraged, resourced and nurtured. DFCs must seek to engage with, and achieve equity for, all people with dementia, whatever their circumstances, and the practical barriers to inclusion must be addressed if normal lives are to be continued. All these are, fundamentally, human rights issues – and these rights must be recognised and promoted if real inclusion is to be achieved.

Both cities have also demonstrated the importance of awareness raising, training and positive media coverage. Changing attitudes and improving understanding are fundamental – but it is a long journey. Connections and networks, within and beyond the community, facilitate the sharing of information, enthusiasm and ideas – but they also need resourcing so they are sustainable.

Local grassroots community activity is the bedrock of DFCs: it unearths innovation, untapped assets, unsuspected champions and creative partnerships. Without this approach, the movement would lack energy and personal commitment. But this activity must be supported by strong strategic planning, commissioning and leadership if DFCs are to flourish and be sustainable. Both primary and secondary health providers have a vital role to play in supporting social inclusion.

There is no strict template for a DFC. Each community must develop its own approach, based on its unique cultural, geographical, spiritual and human assets. York and Bradford have shown us how this can be done.

However the four cornerstones (Crampton, *et al.*, 2012) of people, places, networks and resources, offer a simple and helpful framework, as do the Alzheimer's Society recognition criteria (Alzheimer's Society in Partnership and Dementia Action Alliance, 2013). Table 1 maps these against each other.

Both cities have demonstrated real achievement in all these areas. The evaluators identified Bradford's key strengths as its local focus, addressing diversity and inclusion, supporting and networking between groups, business engagement with key players and in certain locations, and impacting on the strategic partnership agenda. Areas of opportunity for further development are the empowerment of people with dementia to really influence how DFCs develop, challenging the consistency of support and provision across the district, and widening the impact on more mainstream resource areas including leisure and culture.

York DFC's specific strengths have been in widening awareness and providing basic training, focusing on intergenerational work, developing dementia friendly businesses and organisations, drawing on cultural and community assets, and putting people with dementia at the heart of the programme. Awareness and training are becoming more embedded into the flow of life in York, with many more training opportunities and positive media coverage. It is positive to see more schools and young people engaged. Keeping people with dementia at the heart of future work is critical, and the net needs to continue to widen to include more people in more parts of the city. The biggest opportunity for York is in its chance to join up health and social care and to commission for the wellbeing of people with dementia in partnership with a wider range of organisations. The focus also needs to be on support for carers, and information and communication.

In both cities the influence on local perceptions and understanding of the experience of living with dementia has been strong. A sense of inclusion for people with dementia is developing, and local political support is very strong in some areas. There is now high level corporate support across public sector partners, although this has been slower to secure than had been hoped. Organisations that have embraced the DFC programmes have seen the benefit, primarily in good customer relationships and fulfilling corporate social responsibility obligations. Some small companies, like local legal firms, can see the marketing benefits in engaging with people with dementia and their carers, and larger companies have promoted their experience nationally as good practice in dementia awareness and improved customer service. Even so, awareness is still concentrated among those 'in the know' and a real understanding of what DFCs means is not widespread.

For some people with dementia and their carers, involvement in the programmes has been transformational. It has increased insight into their own dementia and enabled the confidence to live the life they want. Networking has improved information and access to services for people with dementia, and sharing experience has encouraged individuals to seek out support or to ask for something different.

If DFCs like Bradford and York are to be a reality for the future, they now need to be developed into long-term programmes. Making a DFC part of everyday life requires mainstream change, from the bottom up and from the top down. While the key custodians are people with dementia, their carers and supporters, this is a movement which needs wide ownership among partners across the public, private and voluntary sectors, and indeed, among the public as a whole. It will be a long journey, but there are already indications of the huge gains to be made.

About this paper

The evaluations, commissioned by JRF, were undertaken by a consortium led by Dean Knight Partnership Ltd. Their aim was to enhance learning about the process of developing and supporting DFCs, inform future work in this area and share learning with other organisations. The fieldwork for the two separate evaluations was carried out in 2014 using a range of approaches including face-to-face and telephone in-depth interviews with individuals, an online questionnaire, and observation of a variety of meetings. Philly Hare is Programme Manager of the JRF Programme Dementia without Walls and Janet Dean led the two evaluations.

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FOR FURTHER INFORMATION

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