



# Evaluation of the Bradford Dementia Friendly Communities Programme

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by Janet Dean, Kay Silversides, Janet Crampton and Julie Wrigley

This report identifies the distinctive features of the Bradford Dementia Friendly Communities programme, and examines how people with dementia can influence what a Dementia Friendly Bradford should be like.

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How can the development of and support for dementia friendly communities be enhanced to inform future work and share learning with other organisations?

This evaluation of the Bradford Dementia Friendly Communities Programme was carried out to help answer these questions.

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## **The report identifies:**

- the distinctive features of the Bradford Dementia Friendly Communities Programme, which reflect the diverse geography and culture of the district;
- how people with dementia can influence what a dementia friendly Bradford should be like;
- the main challenges which will need to be addressed to ensure that progress continues;
- the learning for others who are trying to build dementia friendly communities.

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# Executive summary

This is a report of an evaluation of the impact of, and learning from, the Dementia Friendly Communities (DFC) Programme in Bradford, jointly supported by Bradford Council and JRF for two years from April 2013 to March 2015.

The objective of the evaluation was to enhance learning about the process of developing and supporting DFCs, inform future work in this area and share learning with other organisations.

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The evaluation was conducted over a ten-month period from February to November 2014 using a range of approaches including individual interviews, group discussions and an online questionnaire. In addition a range of meetings was observed, and the evaluation team hosted a 'sounding board' workshop in November which tested initial findings.

In summary the evaluation found that, by the end of 2014:

- There has been a specific 'Bradford approach' to creating DFCs across the many geographical and culturally diverse parts of Bradford city and district. A strategic approach by the council, their health and voluntary and community partners, the Alzheimer's Society, the Joseph Rowntree Foundation and local people with dementia, and their carers, has helped to consolidate local ambitions to become more dementia friendly.
- Further development will help Bradford to evolve into a dementia friendly community which meets people's needs and aspirations.
- Uncertainty about the future commitment to long-term investment in DFC programmes, exacerbated by the acute instability of public sector funding, causes concern that the progress being made in Bradford may not be sustainable. While there is clearly something of a 'movement' gathering momentum, this needs to be constantly underpinned by active promotion and investment.
- Bradford supports some particularly strong culturally sensitive services involving faith communities and voluntary and community organisations. For mainstream health and social care services to work effectively for black and minority ethnic communities in Bradford district, however, there needs to be more understanding of distinct cultural and community needs.
- There is a recognition that the experience of people with dementia in their communities is affected by other factors, such as economic circumstances, ethnicity and gender, and that these need to be taken into account to ensure that there is a widespread common experience of dementia friendly communities.
- There are still variable levels of awareness and consequently scope for increased training and promoting dementia awareness. Practical difficulties such as accessing appropriate public transport and the patchiness of some services and resources need to be addressed so that people with dementia can carry on their normal lives as much as possible.
- Finally, the need to provide support for carers is essential when trying to help families support their relative with dementia. People living without close family carers may need support to identify the network of people who can help them to sustain a good quality of life.

Overall, the evaluation shows that there is a strategic approach to building dementia friendly communities across a geographically and culturally diverse district. This has engaged key partners at local and strategic levels. The experience of living with dementia is affected by existing inequalities in the population, such as those based on race and economic deprivation, and this means that barriers for some people are worse than others. More involvement of people with dementia and their carers will lead to a better understanding of what makes a DFC for different groups and how to achieve this.

# 1 Introduction and methodology

This evaluation report of the impact of, and learning from, the Dementia Friendly Communities (DFC) Programme in Bradford, was commissioned by the Joseph Rowntree Foundation and carried out by a consortium of Dean Knight Partnership Ltd, Qa Research and 2020 Commissioning. The objective of the evaluation was to:

- enhance learning about the process of developing and supporting dementia friendly communities;
- inform future work in this area;
- share learning with other organisations.

The evaluation has a direct link to national policy on dementia, and specifically to the Prime Minister's challenge of March 2012 to encourage towns and cities across the UK to become dementia friendly communities (DFCs). Bradford, supported jointly by funding from the Joseph Rowntree Foundation and Bradford Council, was in the first wave of places aspiring to become dementia friendly. This evaluation was commissioned to identify positive outcomes as well as persistent challenges, to spread the learning across the UK and beyond, and also across the many agencies in the public, private and voluntary sectors who are contributing to DFCs.

The initial questions which the evaluation sought to address were:

- How effective have the initiatives been overall, within the resources available?
- What has been the influence on/challenge to local perceptions and understanding of the experience of living with dementia?
- What examples are there of practical influence or outcomes (beyond attitudes and perceptions) e.g. on quality of life, inclusion, range of options, etc?
- What evidence is there of benefits to local partner organisations (e.g. commercial or cost-saving benefits; improvements in customer service; positive outcomes for organisational objectives)?
- How have people with dementia been involved in the projects?
- What can and should JRF and other key partners learn from the projects?
- What more could or should be done to create DFCs in Bradford?

As part of its proposal the evaluation team suggested some additional questions:

- What are the indicators of a dementia friendly community that are visible? Which are hidden?
- How well has the idea of a DFC been communicated, and how well has it been understood?
- Who are the custodians of DFC for the future, on an ongoing basis? Can DFC be a reality, more than an initiative, and how will that happen, be funded, and made mainstream?
- How does Bradford link to the regional and national networks?
- How do the projects enable people with dementia and their carers to co-create DFCs
- What are the success measures for the future – in 5, 10, 20 years' time what will be happening?

The evaluation was primarily, but not exclusively, directed at people in Bradford who had some connection with the Dementia Friendly Communities Programme. The evaluation framework (see Appendix 1) aimed to situate people with dementia at the heart of the investigation and to include carers, supporters and family members where appropriate. Key stakeholders were partners across public, private, voluntary and community sectors and people leading funded projects. Those working in services,

businesses and projects which were used by people with dementia and their carers and supporters were also surveyed as part of the evaluation.

The evaluation was carried out over a ten-month period from February to November 2014 using face-to-face and telephone interviews with individuals, and an online questionnaire. The evaluation team also attended a variety of meetings where they observed proceedings, asked questions or led group discussions. Groups observed included the Bradford Dementia Action Alliance and the Dementia Friendly Communities Project Advisory Group, as well as a range of local and district-wide groups of people with dementia and their carers associated with the DFC Programme. In November 2014 a half-day workshop helped test initial findings with a group of 20 stakeholders, including people with dementia. There were 31 responses to the online survey, 15 stakeholder interviews, and five in-depth interviews/structured conversations with people with dementia, some accompanied by carers. This means that 71 people fed into the evaluation directly, with the voices of around 100 in total being heard including wider observations. The evaluation report uses direct quotations from interviews and from the survey and draws on the content of published progress reports, statistical analyses, and media and press coverage.

Drawing on earlier work for JRF by Janet Crampton, Janet Dean and Ruth Eley in *Creating a Dementia Friendly York* (<http://www.jrf.org.uk/publications/creating-dementia-friendly-york>) the Four Cornerstones analytical tool was used to assess the impact Bradford's progress towards becoming dementia friendly had on all aspects of the lives of people with dementia, their carers and supporters. Full details of the methodology and the survey instruments and models used are in Appendix 1.

# 2 Background to Dementia Friendly Communities

## National developments

The Alzheimer's Society defines a dementia friendly community (DFC) as 'A city, town or village where people with dementia are understood, respected and supported, and confident they can contribute to community life. In a dementia friendly community 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' ([www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=1500](http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1500)).

The concept of dementia friendly communities has developed out of a longer established age-friendly movement, which is supported by the World Health Organization (<http://www.who.int/ageing/age-friendly-world/en>). Over the last decade awareness has grown of the impact of increasing longevity resulting from long-term improvements in general health and medical advances. The increased prevalence of dementia, though not a consequence of old age, means that the number of people with dementia is continuing to grow, with projections of around one million people by 2025 (<http://www.alzheimers.org.uk/statistics>).

In the UK a National Dementia Strategy (Living Well with Dementia) was put in place in 2009 ([www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy](http://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy)). Emphasis on earlier diagnosis focused attention on the growing number of people with dementia remaining at home in their communities for longer. In 2011 JRF and others started to focus on what needed to happen in communities to make life easier for people with dementia and their carers and supporters.

In the 2012 Prime Minister's Challenge on Dementia ([www.gov.uk/government/publications/prime-ministers-challenge-on-dementia](http://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia)) David Cameron called for increases in early diagnosis and research as well as more dementia friendly community support and the creation of at least 20 dementia friendly communities. The three strands of work are overseen by a Prime Minister's Champions Group. In September 2013 the Alzheimer's Society launched a report, Building Dementia friendly Communities: A Priority for Everyone' ([www.alzheimers.org.uk/site/scripts/download\\_info.php?downloadID=1236](http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=1236)) outlining the ten key areas which needed focus to create more dementia friendly communities. It has published guidance and criteria for recognising a dementia friendly community. The recognition scheme enables business, organisations and services to apply to meet criteria to enable them to display the distinctive forget-me-not logo ([www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=2136](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2136)).

By February 2015 more than 82 places across England had committed to become dementia friendly. This was complemented by significant progress in raising awareness through the creation of one million Dementia Friends, the engagement of large businesses and progress towards establishing dementia friendly standards and awards ([www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020/prime-ministers-challenge-on-dementia-2020](http://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020/prime-ministers-challenge-on-dementia-2020)).

Alongside these initiatives, the statutory framework now includes responsibilities placed on local health & wellbeing boards and clinical commissioning groups and the annual national operating frameworks for the NHS. The government's *Vision for Adult Social Care: Capable Communities and Active Citizens*, (Department of Health, 2010) emphasises the need for 'Empowered people and strong communities [who] will work together to maintain independence. Where the state is needed, it supports communities and helps people to retain and regain independence' ([http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH\\_121508](http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_121508)).

The implementation of the 2014 Care Act in 2015 created a duty to provide for the wellbeing of people in need of care, with an intention to prevent and delay the need for intensive residential and nursing



services or hospital care. It also introduces a right to assessment for carers to enable them to continue to support people longer at home. The Care Act prioritises community support and is therefore positive in terms of dementia friendly communities, although it leaves unresolved the task of shifting resources from health to social care commissioners.

At ground level, local Alzheimer's Societies and other groups supporting people with dementia have begun to think about how people with dementia and their carers could be more involved in improving the quality of their lives, especially in early and middle stages of dementia. There has also been a growing awareness – helped by increasingly easy web access to information – of international movements, and innovative work in the USA, Japan and Australia, as well as in Europe. These developments are referenced in *Creating a Dementia Friendly York* (Crampton, *et al.*, 2012).

An important accelerator in the development of dementia friendly communities is the collective voice of people with dementia. Facilitated by individual supporters and dementia activists people with dementia have used the growth in the internet to connect with one another internationally. In the UK, JRF's support for the Dementia Engagement and Empowerment Project (DEEP) (<http://dementiavoices.org.uk>) has been a significant driver in allowing the voices of people with dementia not only to be heard, but to enable people with dementia to shape and redefine what they mean by dementia friendly communities.

## The Bradford context

Bradford district covers an area of approximately 400 square kilometres comprising the City of Bradford and the major towns of Bingley, Ilkley, Keighley and Shipley. It is located in the north west of West Yorkshire, bordering the areas covered by Leeds City Council to the east, Kirklees Council to the south and Calderdale Council to the south west. To the north lie Harrogate and Craven councils and to the east lies Pendle Borough Council. It covers a mixture of urban and rural communities.

Information from Bradford's Public Health Observatory indicates that around half a million people currently live in the Bradford district ([www.observatory.bradford.nhs.uk/Documents/2\\_1\\_Population.pdf](http://www.observatory.bradford.nhs.uk/Documents/2_1_Population.pdf)). Over the past ten years the population has been growing steadily and by 2033 the population is forecast to be approximately 640,000, an increase of 28 per cent. It is predicted that there will be 25 per cent (29,300) more children than there are now and 50 per cent (41,300) more old people. The very elderly will see the largest percentage increase, with the number of over 90-year-olds expected to increase from 2,800 to 8,700, an increase of 200 per cent.

Bradford district contains a rich mixture of ethnic groups and cultures. Black and minority ethnic (BAME) communities form 28.8 per cent of the population. This is the second highest total and fifth highest proportion of any district outside of London. The Asian ethnic population accounts for 19.8 per cent of the total district population. Nearly 70 per cent of the Asian ethnic population have a Pakistani heritage ([www.bradford.nhs.uk/wp-content/uploads/2011/08/JSNA-executive-summary-2012.pdf](http://www.bradford.nhs.uk/wp-content/uploads/2011/08/JSNA-executive-summary-2012.pdf)).

The composition of the population in terms of age structure varies throughout the district, with the inner city wards having younger populations than outlying areas. Around 25 per cent of the population in the outlying wards of Baildon, Craven and Ilkley is of pensionable age.

The Bradford Health Needs Assessment for Dementia was published In July 2014 (<http://bit.ly/1CBwOpl>). It estimated that more than 5,000 people had dementia in Bradford; by 2025 the number is predicted to rise to around 6,000. Most people with dementia are living at home, but around a third of people with dementia live in care homes (60 per cent of all care home residents). The assessment recognises the importance of dementia friendly communities in enabling people with dementia to remain independent and stay out of care for longer. The assessment recommends that 'the local Dementia Friendly Communities project should continue to be supported at every level, including political, clinical, commissioning, provider and local community groups and area committees'.

# 3 The Bradford approach to Dementia Friendly Communities

The Dementia Friendly Communities Programme in Bradford is managed by the Alzheimer's Society, and jointly funded by Bradford Council and the Joseph Rowntree Foundation.

Anticipating the Prime Minister's Challenge in 2012, Bradford had been working to become dementia friendly since 2011, with support from Bradford Council. The local Alzheimer's Society had built links with eight organisations to work on dementia awareness and develop good practice. Small community organisations and bigger companies, including a branch of Lloyds TSB, the Diocese of Bradford, Bolton Road Gurudwara and a local pharmacy, took part in a dementia friendly communities pilot scheme. Once organisations committed to becoming dementia friendly, they were helped to draw up an action plan identifying what changes they could make and how they would implement them.

Bradford purposely started small so that it could learn about what worked before rolling out on a larger scale. The second stage of the Bradford pilot programme was to target a council ward with a high proportion of older people. Ward councillors and council officers worked with organisations in the ward – shops, businesses and community groups – facilitated by the Alzheimer's Society.

In 2012 JRF was considering practical expressions of its commitment to dementia friendly communities through its Dementia Without Walls Programme ([www.jrf.org.uk/topic/dementia-without-walls](http://www.jrf.org.uk/topic/dementia-without-walls)), and chose to support development of the Bradford programme. The joint funding enabled the appointment of a Dementia Friendly Communities development officer to build further DFC work in communities and with local businesses. A formal target of creating 20 dementia friendly communities, both geographical and communities of interest was established, alongside initiatives with businesses and service providers.

Governance of the DFC programme is the responsibility of the project advisory group which includes the commissioning body representatives from Bradford Council and JRF, as well as health, social care, voluntary and community sector representatives. This group helps to scope and implement the programme as well as overseeing the delivery of agreed outputs.

During the life of the programme, Bradford has also established a Dementia Action Alliance (DAA). There is some crossover of membership with the project advisory group, and involvement of the Alzheimer's Society in both groups, but the DAA has a broader focus on engagement across sectors to build awareness of DFCs and encourage organisations to change and adapt their approach to make them a reality.

The programme achieved its target of working with 20 communities by the end of March 2015, with work in 17 geographic communities and three cultural communities, i.e. the LGBT group Equity Partnership, the Sikh community and two learning disability groups. A report on DAA activity confirmed 37 member organisations, 7 supporters, and 15 organisations actively working towards membership.

The Bradford district DAA has hosted regular quarterly meetings since its launch in June 2013, each meeting having a different theme. Recent meetings have focused on faith and ward perspectives, the experience of living with dementia, and sport, leisure and entertainment. The officer supporting DAA work is actively engaged with a range of organisations across all sectors, including Bradford Council, Bradford football and rugby clubs, shopping centres, GP surgeries, schools and the National Media Museum.

The work has developed within the communities in Bradford in different ways. In many cases the DFC programme has responded to initial interest within a community prompted by a ward officer, local councillor or a resident with personal experience of dementia. The DFC co-ordinator has also attended area committee meetings to raise awareness about the programme and in many cases this has resulted in wards expressing an interest in getting involved. This has often been followed by a public

meeting/awareness raising event to generate further interest and to establish which issues are most pertinent within each community.

From this starting point, the programme has worked alongside ward officers and an active core of residents to identify priorities and actions. Ward officers have been crucial in facilitating and administering the development of local action groups, liaising with the DFC co-ordinator to arrange dementia awareness sessions, and cascading information about DFCs to other individuals who work closely with older people within the community e.g. sheltered housing wardens.

The Bradford DFC programme has a third strand, to engage with people with dementia. Work in this area supports the focus group of people with dementia and carers which meets every six weeks. The group has recently been involved in consultation on changes to council services, Alzheimer's Society work on national standards, and the development of a dementia friendly garden. They may also nominate one or two members to be on the project advisory group as it moves to the next phase.

The Bradford Face it Together (FIT) group is part of the DEEP programme, a national network of influencing groups of people with dementia.<sup>1</sup> The Bradford DFC programme has drawn on the resources and expertise generated within the DEEP programme to support the involvement of people with dementia and to connect people in Bradford to individuals and groups in other areas. The FIT group has recently spent time discussing places to go out to eat and socialise, and sport and leisure provision, as well as being involved in regional and national work on how to involve and engage people with dementia.

The programme has also drawn on the resources and expertise of the Bradford University Dementia Group. Bradford University hosted Bradford & District DAA inaugural meetings and continues to support awareness raising and the development of DFCs. It regularly hosts other events to encourage involvement of people with dementia, along with their carers, in the development of dementia friendly environments, and has established a panel of people with dementia and their carers, who are 'experts by experience'.

The panel advises on a whole range of aspects of raising awareness and breaking down negative stereotypes, including experiences in the community and how to develop more dementia friendly responses. Professor Downs from the Bradford University Dementia Group and the DFC co-ordinator co-wrote a chapter on dementia friendly communities for *Excellence in Dementia: Research Into Practice* (Downs and Bowers, 2014).

Towards the end of the evaluation, confirmation of an extension of funding by the council and JRF was given with a new focus for the programme. The key elements of the new work will be:

- the full involvement of people with dementia and their carers in directly influencing, leading and taking part in developing a Dementia Friendly Bradford district;
- the embedding of Bradford Council's work in becoming a dementia friendly council by supporting its identified champions;
- the establishment of the Bradford Dementia Action Alliance as an independent hub for promoting and driving forward dementia friendly initiatives and sharing best practice between organisations, businesses and all relevant stakeholders;
- developing an up-to-date and sustainable resource of information and best practice in order to inform the initiative's work and the work of stakeholders.

Remaining under the overall management of Bradford District Alzheimer's Society, the Dementia Friendly Community co-ordinator and Dementia Action Alliance co-ordinator roles will continue. The project advisory group will be relaunched and the focus group encouraged to send representatives to its meetings and the DAA steering group.

The approach focuses on long-term sustainability by supporting the development of resources and the capacity of stakeholders and people with dementia. It involves the Alzheimer's Society in advising and supporting others rather than doing as much direct work itself.

## 4 Strengths and achievements

Bradford is already known as a city working towards becoming dementia friendly and attracts interest from across the world, as well as regionally and nationally. Bradford featured prominently in the Alzheimer's Society Dementia Friendly Awards 2014 with an award for the Bolton Road Gurudwara project for work raising awareness of dementia in the Sikh community. The Bradford Dementia Friendly Communities project itself and Dixon's Allerton Academy were also finalists in the local initiatives and schools and colleges categories.

These are some of the key strengths identified during the evaluation.

### Local focus

As described above, the focus on local areas and communities is a particular feature of the Bradford DFC programme. The target of some activity in 20 communities has been reached, and there is a clear sense of progress in the 'early adopter' areas where most interest was expressed first. This might have been built, for example, on enthusiastic local political support as evidenced in Wyke ward, or a clear enthusiasm in the community generally that a need was there to be met, as evidenced in Queensbury. Respondents described this as a 'coalition of the willing'. In Idle, people still recall a vibrant meeting held in treacherously icy conditions as the starting point for the Idle Memory Club. The club supports both people with dementia and carers on a fortnightly basis as well as a wider network of social and leisure activity within the ward. The work that began in Idle has developed, and more memory cafes have grown out of this in Shipley & Keighley.

Specific work around dementia now features in several ward assessments and action plans including in Idle & Thackley, Queensbury, Shipley, Baildon and Ilkley. This represents a sustainable mainstream approach not contingent on the DFC programme.

There is evidence that the ward based assessment work is beginning to have an impact on awareness and understanding across the community. One example cited is that of a neighbourhood warden who, on finding a woman with dementia who was disoriented and had lost her way, was able to give a positive, appropriate and confident response. The warden was able to attribute his handling of this situation to the recent dementia awareness raising in Bradford South.

Larger towns within the Bradford metropolitan district, like Keighley, Bingley and Shipley, support a range of activities and enable people to network effectively. A clear benefit for people with dementia and their carers is information, and living in or being connected to an active lively community provides a ready means of support. Where there are more networks and resources, work on DFCs accelerates, as Keighley demonstrates.

"The steering group here has now constituted as an organisation in their own right so they can hold funds, and is planning a 'one year on event' to celebrate successes and promote future work. Support and information sessions are happening monthly in the shopping centre. Members of the group are also involved in the healthy high street's dementia friendly garden. It seems likely that work of DFC Keighley will be highlighted with a visit for new elected members as part of the new members induction programme."

Extract from report to Project Advisory Group, March 2015.

### Specific cross-district communities

The Bradford DFC programme has been proactive and successful in engaging with different communities of interest, for example, faith groups and the LGBT and learning disability community. Bradford's DFC co-ordinator has engaged with the groups and found common interests and links between the creation of DFCs and the existing work of individuals/organisations. Some of this work pre-dates the Bradford DFC programme, although some is more recent.

The Sikh Gurudwara has demonstrated an inspiring approach to culturally specific work with people with dementia. This has been recognised with a dementia friendly award and its achievements communicated widely both nationally and internationally.

Meri Yaadain, a service for older South Asian communities, is well established within Bradford Council, and has engaged positively with the Bradford DFC programme to extend knowledge and awareness of what a dementia friendly community means in a particular cultural setting. It is particularly successful at reaching parts of the South Asian community that other services fail to reach.

In the Church of England, Bradford diocese has an adviser on dementia issues, who works as part of its disability task group. She supports work in Shipley and other parts of Bradford using church premises to hold parallel groups for people with dementia and their carers, meeting their different needs at the same time. The adviser has worked closely with Bradford's DFC co-ordinator from the outset on awareness raising and the development of a memory club in Idle. This work has now expanded and memory clubs are now also held in two venues in Keighley, and one in Shipley. The memory clubs all follow a similar format whereby people with dementia and carers meet fortnightly; the group splits and carers/family members meet together as a support group while people with dementia socialise with each other and take part in a range of activities designed and facilitated by the adviser to provide cognitive stimulation.

Bradford diocese has recently expanded into West Yorkshire and the Dales, so the adviser has worked with the DAAs involved to ensure that good practice is extended out across the new area, in particular making sure that DAAs have a joined up approach to how 'working towards dementia friendly' stickers are awarded. The diocese has developed a model which has been adopted by the West Yorkshire Methodist group.

Initial discussions between the DFC programme and the Equity Partnership highlighted the specific experiences of older LGBT people and the fact that many difficulties faced by older people are magnified for those from the LGBT community. The two organisations developed a guide to dementia for people from Bradford's LGBT community, with representatives from Equity Partnership's older women's group and the Labyrus Trust (a group for older lesbians offering support and befriending across Bradford and Calderdale). The leaflet received positive feedback and has been distributed widely across West Yorkshire and beyond to audiences within the LGBT community and those concerned with dementia and ageing, e.g. Yorkshire & Humber Regional Forum on Ageing and the Social Care Institute for Excellence ([www.equitypartnership.org.uk/wp-content/uploads/Dementia-leaflet-3.pdf](http://www.equitypartnership.org.uk/wp-content/uploads/Dementia-leaflet-3.pdf)). Following on from this work the Equity Partnership has signed up to Bradford DAA and is producing an action plan which includes actions to make their premises more dementia friendly in terms of signage and to increase staff awareness. The work has helped to strengthen links and encourage referrals between the Equity Partnership and Bradford Alzheimer's Society.

The programme has also worked with the disability community as a community of interest. The DFC co-ordinator was aware that individuals with learning disabilities are at increased risk of developing dementia and made contact with a range of organisations in Bradford such as Bradford Talking Media (a social enterprise which work to provide those who cannot read with the opportunity to access information in audio formats), Bradford Aging Learning Disability and Dementia Group (BALDAD), and Bradford District Care Trust. The topic of issues affecting people with dementia and a learning disability was the main theme of the April 2014 Bradford DAA meeting with attendance from several learning disability organisations new to Bradford DAA. Following on from this, Bradford Talking Media, along with its regular learning disability group, has been working on an easy-read booklet about how to be a friend to someone with dementia.

The work with BALDAD identified that family carers of people with learning disabilities and dementia are not being offered routine support in the way that people without learning disabilities are. Alzheimer's Society Bradford is supporting the national dementia friends programme to adapt sessions by and for people with learning disabilities to raise awareness within their communities.

## Raising awareness of dementia and of dementia friendly communities

The national programme of work, led by the Alzheimer's Society, to raise awareness about dementia, and particularly the creation of a recognition scheme and the recruitment and training of Dementia Friends in communities and organisations across the country, has coincided with the local programme. Although evidence from the evaluation's survey suggests that people are more likely to be aware of the Alzheimer's Society and Dementia Friends than of Bradford DAA itself, respondents also commented that their awareness and understanding of dementia had increased over the past year and tended to attribute this to having attended training or an event in their local area.

The concept of dementia friendly communities was thought to be snowballing as a social movement, partly due to national and local media campaigns, and dementia is talked about in more positive language. There are more positive examples of people with dementia coming forward and being more visible, though more are needed. Respondents told us that the work in Bradford (along with the national push) had raised awareness about dementia and more people were talking openly about it.

*"When I was working in this area 10 years ago the door was shut in getting people to acknowledge dementia was something they should worry about – that door is now open."*

DAA member, Bradford

Respondents also emphasised that day-to-day conversations were an ideal opportunity to 'reframe' other people's perceptions:

*"People are talking about it, there seems to be an openness about it now. During one of our events, one of our senior managers came to me and said 'there's people with dementia here? Well who are they?' I said, 'They don't walk around with a sign on their heads!' It's conversations like that that can make a big impact."*

DAA member, Bradford

Dementia Friends are growing in number, individual training is valued and the opportunity to pass awareness on to others is seen as positive. It was felt that the raised profile of dementia was leading to better understanding and increased awareness in other services. Furthermore, it was noted that there were programmes of awareness running in the local education sector in universities, colleges and schools. Specifically mentioned was awareness training in the Church of England run by West Yorkshire & Dales Dementia Diocese Group, and Tong High School upper sixth planning to deliver Dementia Friends sessions in the school. People thought that this kind of work might lead to other groups being influenced, perhaps through inter-faith and professional networks.

## Changing organisations

In the Bradford DFC Programme there is a particular emphasis on raising awareness and influencing businesses and organisations to become more dementia friendly. The programme has used a range of approaches to engage with businesses. They have been invited to awareness sessions within their ward and the DFC co-ordinator has attended conferences and business networking events to raise the profile of the programme and make contacts. The programme has found it challenging to engage with businesses, and this is a pattern that is reflected nationally. A new project worker was therefore recruited part way through 2014 to increase engagement with local businesses, and during the evaluation, a number of strengths were noted in this area.

Work with commercial organisations has not only been successful locally, but has also influenced regional and national policy. By focusing on training, action planning and sharing good practice, local shops and branches of larger organisations have demonstrated that they can remove barriers for people with dementia.



Work to raise awareness of dementia and train staff undertaken by the Co-op stores in Bradford, for example, has been communicated throughout the broader Co-operative organisation. Alzheimer's Society Bradford made a video documenting this work ([www.youtube.com/watch?v=m19cXnWi59k](http://www.youtube.com/watch?v=m19cXnWi59k)). Local banks have been responsive to the dementia friendly message, and connected to national initiatives developed through the Dementia Action Alliance. TSB and Marks & Spencer were also cited as having a positive approach towards people with dementia. Recently, inroads have been made into engaging with pharmacies and a number are now signed up to the DAA.

Solicitors for the Elderly, a national association of lawyers providing legal advice to older people, their family and carers, offer guidance and action on lasting powers of attorney, Court of Protection/Office of the Public Guardian as well as giving practical advice, and firms such as Pudsey Legal engage in consultation events and workshops.

The involvement of people with dementia in influencing the Westfield Shopping Centre is seen as a key achievement and people said that just a few years ago this simply would not have happened. In Bingley a Dementia Day has focused on businesses across the town to raise awareness of how they can change to help people with dementia.

Bradford Council has engaged in Dementia Friends training specifically for ward officers to support local work, and to cascade awareness to colleagues. A proposal is in development to deliver awareness sessions as part of elected member induction. The Assistant Director for Integration and Transformation in Bradford Council's adult services department now has the responsibility for championing the need to make the council more dementia friendly at a senior level within the organisation. This is an important leadership commitment, and a further significant observation by respondents is that the programme has 'opened the doors to decision-makers'.

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.

**"We are looking at all the contracts that we have with people, making sure that they are on board with DFCs. As a mental health organisation, we don't want to be working with people who aren't signed up to that dementia friendly approach."**

Health commissioner, Bradford

Bradford also has a Dementia Strategy Group which includes representation from key partners including Bradford Council, Bradford District Care Trust, Bradford Districts CCG, Bradford City CCG and a range of voluntary sector organisations and private sector care providers. This group also has close links with Bradford Dementia Action Alliance (currently chaired by the Dementia lead from Bradford District Care Trust's Older People's Mental Health Services). Dementia Friendly Communities is a standing item on the agenda of the Dementia Strategy Group. The Dementia Strategy Group also has a direct link with Bradford Older People's Partnership, which in turn reports into the Bradford and Airedale Health & Wellbeing Board. The Bradford and District Health and Wellbeing Strategy includes dementia as a strategic priority – 'improve diagnosis, care and support for people with dementia and improve their, and their carers', quality of life' (Bradford and Airedale Health and Wellbeing Board, 2013).

There has also been some impressive work with Bradford Teaching Hospitals NHS Trust to make hospital environments dementia friendly. For example, work has taken place at St Luke's Hospital to redesign the hospital's public areas for people with dementia. This has included clearer signage, better use of colour and light and two dementia gardens. The hospital also uses the forget-me-not campaign to improve the experience for people with dementia. This involves placing the blue flower symbol in patients' case notes and above their beds, with the permission of the patients and relatives, to help ensure those with the condition are easily identified by staff and their care is planned accordingly. Bradford Teaching Hospitals NHS Trust has also worked with the Bradford DFC Programme's focus group to consult people with dementia about their new finger-food menu.

This work is being embedded within the organisation via the hospital's dementia champions and is included within Bradford Teaching Hospitals NHS Foundation Trust strategy. St Luke's was the first hospital in the UK to be awarded 'working to be dementia friendly' status.

Similar work has also taken place at Airedale Hospital. Environmental improvements have been made in the dementia ward including clearer signage, and a colour coded wayfinding scheme. Airedale Hospital is also developing a butterfly room in Accident and Emergency for people with dementia. This is linked to the Butterfly Scheme which the hospital has already adopted. The Butterfly Scheme uses its own butterfly symbol to represent the request by people with dementia for the Scheme's specific care approach. Hospital staff then refer to an information sheet about the person provided by family members, as well as applying the Scheme's targeted, skills-based care approach, known as the REACH Response.

A wide range of businesses and organisations – including ambulance services, coach tours, legal firms, shops – have connected through the DFC Programme and the Bradford Dementia Action Alliance. This has led to raised awareness, and organisations are promoting the fact that they are dementia friendly. People across the board, including businesses, are willing to be involved, and the positive aspects of dementia friendly organisations are starting to be recognised.

## Integration and inclusion

The aim of dementia friendly communities is to bring about inclusion of people with dementia, by concentrating on the removal of barriers to mainstream activity and services. There are also clear benefits to some separate services and resources being provided for people with dementia and/or their carers and supporters, including peer support services or peer activity. In Bradford there is evidence of the benefits of both.

For example, there is a positive age-friendly approach to new city centre developments which, while not explicitly dementia friendly, is seen as good for people with dementia.

The Idle Memory Club runs a carers group alongside the club, so that partners can go to the same venue together, while having different interests addressed. In Idle, The Walking Club, which is not just for people with dementia and has members who are understanding and helpful, enables people with dementia to feel part of the community, not separated from it. The Dementia Action Committee in Idle includes a person with dementia.

One of the most successful and vibrant groups is the focus group of people with dementia and carers, who both benefit from and contribute to the programme by sharing their experiences and offering mutual support and encouragement. The group demonstrates that involvement in groups and 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 FIT (Face it Together) group has been running since late 2013 and is part of the UK-wide Dementia Engagement & Empowerment Project (DEEP) funded by JRF and Comic Relief. The group is for people with a diagnosed dementia and meets monthly at the offices of Bradford Alzheimer's Society. The group has around eight members and three also attend the focus group. This group is wholly user-led and participants identified that as part of the group they wanted to be able to:

- discuss the impact of dementia on their lives;
- support each other and take part in awareness raising;
- think about campaigns that they want to pursue.

The group has been involved in a range of activities including a trip to St Ives (near Bingley) to consider the area and its visitor's centre, café and toilets from the perspective of someone with dementia. The group sent initial feedback (mainly around poor signage) to The Friends of St Ives and the council who expressed an interest in the feedback to see if any suggestions made by the group could be implemented. The group plans to carry out similar visits in the future to other venues, e.g. sports centres. Other activities have included involvement in the St. Luke's Hospital refurbishment and sitting on interview panels for a DFC post in Bradford Community Trust and the Dementia Action Alliance co-ordinator post.



# 5 Barriers and challenges

## Commitment to long-term investment in the programme

The Bradford DFC Programme is a development of an Alzheimer's Society project which aimed to focus on development at ward level, within specific communities and within the commercial and business sectors. A concern which people raised in a number of ways is related to the short-term nature of the initial two-year programme.

As noted above, the ward focus is very successful in many places, but has progressed at different speeds and with variable levels of interest. Our respondents questioned who will take this work forward. Ward officers in the neighbourhood teams raised concerns that they might not have the time or resources to continue the dementia friendly work alongside their other responsibilities which respond to whole community needs.

Alzheimer's Society colleagues raised concerns that there had been considerable reliance on the programme to do all the work needed to promote dementia friendly communities, and this might mean that there is no embedded commitment to continue in other agencies. There was also some concern about the potential disconnection between the Dementia Friendly Communities Programme and the Dementia Friends initiative which has a separate website and a more top-down approach to raising awareness about dementia and dementia friendly communities. The question here is whether investment in both sets of activities will be sustainable.

During the evaluation fieldwork respondents expressed concern about who the major stakeholders are and who would commit to taking the DFC Programme forward after the end of the formal funding period in March 2015. There is some initial concern from partners that there is a risk to the continuing progress of ward based work and work with specific communities which has been supported so far.

It is positive to note, however, that since the evaluation fieldwork was completed, Bradford Council and JRF have committed to two more years' funding at the same level, although with a changed focus that will still require partners to consider how investment in dementia friendly communities will be secured over the longer term.

## Constraints on public sector funding

There was an underlying concern about the impact of spending restraint on public services which people felt was having, or had the potential to have, a detrimental effect on the Bradford DFC Programme. This is not so much about the effectiveness of the programme itself, but about the impact which budget cuts and diversions might have on the programme. For example, people felt that health services specifically for people with dementia had been affected by 'massive cuts' to the extent there is an issue of sustainability. While the precise facts which underlie this perception were not clear, people felt that this was the reason why services were patchy.

Respondents said that carers' needs assessments were not offered consistently, although there was optimism that this might change for the better with the introduction of the Care Act.

Respondents raised concerns about a lack of 'social prescribing', for instance referrals to social groups, leisure and creative activities, that might be central to dementia friendly communities projects. Such resources could be seen as low priority in comparison with the need to respond to more acute or chronic needs.

Views were expressed about the inability to effectively link up services, leading to cuts in some services which had a detrimental effect on others. One example given was a new Bradford Council policy to reduce day care and respite services in favour of individual personalised care. There is a tension here and

a potential contradiction that increasing personalisation of care services might undermine investment in dementia friendly communities.

## Transport

Getting out and about was a particular concern of people with dementia in Bradford. Willingness to travel very far afield reduced with the loss of confidence associated with diagnosis and progression of dementia. Specific transport problems included timetables being difficult to read and LED displays at bus stops only being available in towns. There is a feeling that taxi firms could be more involved in the DFC programme, and this could be a future target for business engagement. There was felt to be insufficient community transport provision, although there was recognition that this had been a growth area.

Transport is one of a set of resources which support people with dementia, and lack of such resources (see more on this below) often restricts participation in everyday life and presents barriers to dementia friendly communities. People with dementia who can afford transport costs including taxis, or who have a driving spouse or carer, have more chance of participating than those who do not have these resources. In a dispersed district like Bradford most people with dementia will have some need for support with transport at some point.

## Mixed levels of awareness

Despite confirmation that awareness of dementia and of dementia friendly communities is growing, respondents still felt there is further to go. Specific suggestions for where more could be done in Bradford included schools, post offices and sport and leisure facilities. Some people felt there were not many DFC stickers to be seen, and it is true that there are only a small number. Awareness of this element of the DFC programme was quite low even among carers and people with dementia who were closely involved with the programme.

“Things are changing...very slowly...I have noticed some changes in Keighley. I helped [Bradford DFC Programme] with a film for the Co-op about the difficulties people with dementia face going shopping. I'm very open about it, generally supermarkets I have found are the worst...hustle and bustle... and they change things on the shelves and [it is difficult] if you need to take time at the checkout...but the Co-op is good and Morrisons.”

Person with dementia, Bradford

There were practical suggestions for improving awareness in areas where the dementia friendly message had not yet penetrated – for example suggestions for a slow lane in supermarkets, or a ‘slow day’, indicated that there was still more to do to encourage patient and supportive customer service in shops. Another suggestion for improving awareness was to involve people with dementia in work with schools. A directory of dementia friendly activities was felt to be a positive idea, but had not been taken up. Some people felt that, while there was increased awareness amongst service leaders, frontline staff were still not showing the same levels of knowledge about what would support people with dementia in their communities.

The opportunity for people with dementia to play an important role in encouraging others to be open about their dementia was seen as a significant step in widening awareness. While more people with dementia are helping to raise awareness, there is still a lot of fear and concern about prejudice and discrimination which prevents many people from revealing their dementia in the early stages, and forces them to retreat from society earlier than they might wish.

Several people reported being patronised when they say they have dementia, for example by people taking over their handling of money in shops. There is a challenge to consider supportive empowerment and to think about those people with dementia who lack confidence and feel less positive about being ‘out’. Support groups can be helpful, but they are not right for everybody.

## Patchiness in services and resources

Some respondents mentioned gaps in, or uneven distribution of, services, unmet needs and a restricted vision of what a dementia friendly community means.

Despite considerable progress with the Westfield Shopping Centre there were still no plans for specific facilities for family friendly/dementia friendly facilities such as a changing place, although discussions are continuing.

Even with early and significant success, it continues to be challenging to engage businesses, and Bradford DAA has scaled down the commitment to allow for 'supporters' who are not full members and therefore not required to submit full action plans. The appointment of a project worker within the Bradford DFC Programme during 2014 was designed to support further engagement with businesses and organisations, and this additional capacity showed results during the evaluation period.

**"One of the hardest groups to engage has been businesses and the shops...the average butcher in the street, this has been slower but this is a trend across the country."**

DFC Programme Staff, Bradford

A need for more consistent frontline training and support was identified, which would not rely on individual customer service skills, but higher standards all round. The challenges of engaging small businesses were also noted, and although some work in specific places (like Bingley) had helped to raise awareness, this was not replicated across Bradford district. There was also a certain disparity between large organisations signing up to national initiatives through the Dementia Action Alliance, but this not being replicated in the local organisation.

GP services and responses are seen as patchy, particularly on diagnosis. One person said: *'the last place my GP wanted to go was a diagnosis of dementia'*. This patient was diagnosed with depression and needed their carer to push for a dementia diagnosis.

Some people with dementia reported negative experiences in hospital. One specific example related to a negative experience in Accident & Emergency:

**"I broke my foot and went to A & E; there was no dementia awareness there at all. The receptionist said to me 'who's your next of kin?', and bombarded me with questions, I had to say to her 'look I'm sorry I've got Alzheimer's'. It was like everybody around me just stopped and looked and she just said to me 'go and sit in that corridor there' and it wasn't a positive experience really."**

Person with dementia, Bradford

There are continuing issues of patchy services within black and minority ethnic (BAME) communities, despite innovative cultural work. Asian GPs refer in very low numbers and there are continuing cultural sensitivities in families and communities, which could mean that people find their own community less dementia friendly than they need it to be. This is a national trend with individuals from BAME communities being more likely to be diagnosed late and less likely to be diagnosed or use dementia services (Cattan and Giuntoli, 2011). Previous research in Bradford (Meri Yaadain Dementia Team, 2010) has identified many reasons why people from south Asian communities find it difficult to engage with support services. For example, there is a tradition to care for older members of the community within 'family kinships'. Women who are often the primary carer may want support but traditional roles within the family mean that it can be difficult for female carers to seek support, although this is not confined to BAME communities, as recent work on women and dementia has highlighted ([www.alzheimersresearchuk.org/about-us/policies-reports/women-and-dementia](http://www.alzheimersresearchuk.org/about-us/policies-reports/women-and-dementia)). It has also been identified that some assessments (particularly memory assessments) are not culturally appropriate, i.e. they can refer to specific British historical events or culture, although Bradford Memory Clinic does have an adapted version for the south Asian community.

## Social and economic barriers

A strong sense of 'haves and have nots' was felt among a range of respondents, both people with dementia, professionals and volunteers. There are real differences in the experience of Bradford as a dementia friendly community for people who have resources (money and support, particularly, but also transport and good general health) compared with those who do not. The most significant issue for people with dementia is not being able to join and attend groups. This is acutely felt in rural communities where transport is infrequent or non-existent and population density is low. One person commented – *'I can't just visit a neighbour'* – when talking about how to connect with other people with dementia. Some people with dementia also talked about how they would value 'proactive' support and outreach, for someone to reach out to them regularly, particularly during a 'bad spell'.

*"We need more care in the community and support along the way, people would cope better and it would be cheaper. Since I was diagnosed I haven't seen anyone professionally apart from my GP, she has been good, I see her every six months but if I am having a bad day I might not think to ring anybody and nobody would know. That is what everybody in the group says, it would be good to have someone that kept in contact with you when you might not think to pick up the phone."*

Person with dementia, Bradford

A Bradford commissioner was prepared to describe dementia friendly communities as a 'postcode lottery', acknowledging that services and resources were unevenly distributed across the district. Professional colleagues and people with dementia also raised the question of whether statutory services (GPs, social services, health and the police in particular) were working together as well as they could in helping each other to identify where people with dementia are.

Some respondents said that they felt they were 'lucky' to have received the support they had during the period of diagnosis and beyond. Several spoke of other people they knew who had not been so 'lucky':

*"We had no problem finding information...we've been very lucky...we were picked up and put on the right track. I definitely feel that things could have been different...it was the circumstances that led to [his] diagnosis that has led to us getting all this stuff in the right place at the right time. I don't think if we were just going to the doctors we would have had this support."*

Carer, Bradford

From discussions with people with dementia, it became apparent that it is important to have frequent opportunities to choose what support is needed, and when. For many people support is only offered in later stages when people with dementia or carers can no longer 'cope'. But what people want from a dementia friendly community is the chance to live as good a life as possible for as long as possible. One respondent (diagnosed seven years ago) told us about her experiences:

*"I was diagnosed about seven years ago, in my early 50s while still working. It was quite a blow really; I was given the Aricept and told to give them a ring when I couldn't cope anymore. It took me two years to come to terms with my diagnosis, you can't see a life beyond the diagnosis – only the end result, but there is a life, a good life, with the right support. It was my GP who suggested the Alzheimer's Society and I contacted them three years later... I fumbled through, it was a very dark time."*

Person with dementia, Bradford

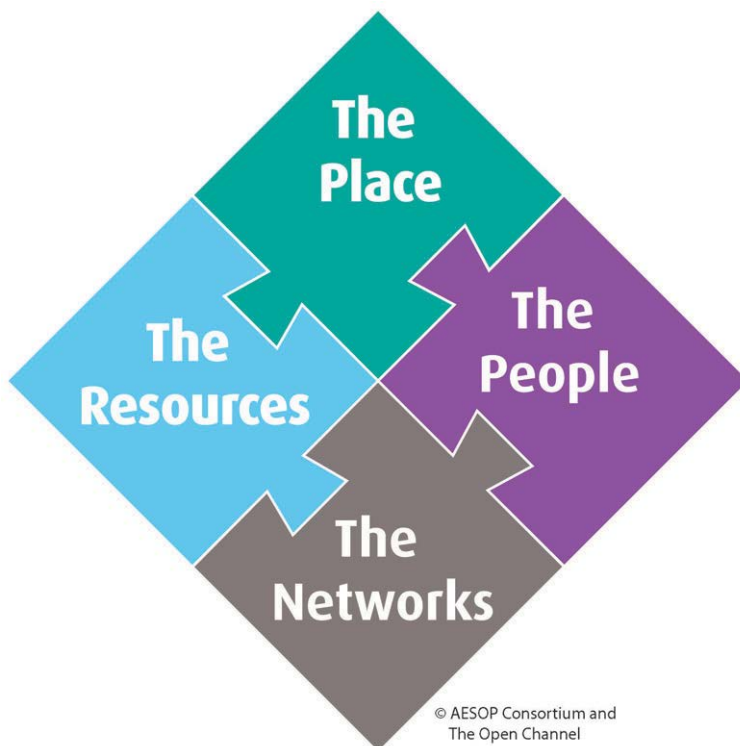
Another gap noted by people with dementia was opportunities for volunteering. More of these might maintain social connections, confidence and skills, as well as combating loneliness and isolation, and making a real contribution to dementia friendly communities.

# 6 What can we learn from Bradford?

In earlier research, Janet Crampton, Janet Dean and Ruth Eley (2012), developed the four cornerstones model as an analytical tool to help them to assess how dementia friendly a community might be. This was based on observations that dementia friendly communities are multi-faceted and deficits in one area could still have a significant impact on people's experience and quality of life even if other aspects were positive.

The four cornerstones model has been used to help to draw out wider lessons from the evaluation of the Bradford Dementia Friendly Communities Programme.

**Figure 1: The four cornerstones model**



## Lessons about place

In the 'place' cornerstone all aspects of a person's home environment, their neighbourhood, and access including transport are considered. In relation to the ten elements of a dementia friendly community identified by the Alzheimer's Society in their recognition scheme ([www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=2136](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2136)) they map on to a good physical environment, appropriate transport and maintaining independence by delivering community based solutions.

Key messages which have emerged from the Bradford evaluation, and which have wider resonance, are:

### Focus on local communities

The aim of the Bradford Dementia Friendly Communities Programme is to try to make the whole of Bradford as dementia friendly as possible. Bradford is a geographically diverse city district, however, with

a mix of urban concentrations and dispersed rural settlements. People will experience Bradford as their village, town or neighbourhood first, followed by the city centre and other parts of the district they know, but rarely as the whole district. 'One size fits all' therefore might not be a sensible strategy for Bradford and the strong geographical element of the programme has had many benefits in connecting with people and addressing issues which are relevant to the local geography.

A key risk in this approach, however, is to further compound the 'postcode lottery' which people felt already existed in relation to mainstream health and social care services.

*"There is very little actual support in Ilkley district. Some dementia friendly work in the community would be useful. Yes we can contact the Alzheimer's group in Bradford for some advice but that is it. We could use some outreach workers in the area."*

Service provider, Bradford

The Bradford programme's facilitation of cross-district networking of groups and individuals, and the establishment of activities, events and information sharing which can be applied across the district as a whole, helps to counteract the effects of a postcode lottery.

## **Inequality of access, including transport, is a barrier to DFCs**

It is important to recognise the physical assets which people with dementia may or may not have, and how these create barriers to experiencing a dementia friendly community. Many people interviewed or met face-to-face could only do that because the evaluation team went to their neighbourhood, or arranged or paid for transport, or because they were accompanied by a carer. People might have a range of issues, from the inability to drive or use public transport, to difficulties reading signs, negotiating complex street patterns or building designs, or sensitivity to traffic noise or crowded places. Many of these issues are challenges for us all, not just for people with dementia, but they represent some of the most common and immediate barriers which make places distinctly unfriendly for people with dementia. It was not clear how commissioners and partners were systematically trying to address these issues for people with dementia as a whole group, or in different areas.

*"I believe the council should make a clear statement that they aim to make public places dementia friendly."*

Service provider, Bradford

Transport appears to be a widespread and persistent problem. If people are to engage more in their communities, they need to be able to move around and network with others easily. Some further thought about how to increase access to transport for people with dementia is required, including better advice and shared experience about continuing to drive, access to volunteer transport 'buddies' and more community transport in rural areas.

## **The housing needs of people with dementia are not well understood**

Respondents said that there were continuing problems with housing, though they were less able to provide specific examples to illustrate this. There is good advice for carers about how to make the home more dementia friendly (<http://dementia.stir.ac.uk/housing-dsdc/design-housing>), there is specialist housing design guidance and there has been an increase in awareness of dementia among social housing providers. It was not possible to assess the impact of this in Bradford, however, or to find particular examples of innovative practice in supporting daily living at home which we could share. There is specialist sheltered housing and extra care schemes which were well regarded, but these accommodate only a small proportion of people with dementia. There is more to do to try to understand what the issues are for individuals and families, and to create opportunities to share experience and resources between people with dementia and professionals.

## Lessons about people

The 'people' cornerstone considers how carers, families, friends, neighbours, health and social care professionals (especially GPs) and the wider community respond to and support people with dementia. It is also concerned with how people with dementia themselves engage in, influence and help to create dementia friendly communities. In relation to the Alzheimer's Society recognition criteria, it covers challenging stigma and building awareness, empowerment and recognising the contribution of people with dementia, and shaping communities around the views of people with dementia.

Issues arising from the Bradford evaluation which have wider implications are:

### **Awareness is building but change takes longer**

People reported on the one hand that awareness of dementia and dementia friendly communities was snowballing and on the other hand that very few people were conscious of what dementia actually is and how DFCs can support people with dementia. While there is a feeling of an emerging dementia friendly movement, it is as yet very small, and awareness of it is more or less confined to those involved in it.

There are interesting developments in wider society which might help, not least in increased awareness through popular cultural references. While there have been other novels, plays and films about dementia, two new ones at the start of 2015 put dementia in the mainstream, and also opened up knowledge of dementia to younger people which creates wider interest and awareness. *Elizabeth is Missing* (2014) by Emma Healey is narrated by a 90-year-old woman with dementia, and the film *Still Alice* features a younger woman with early onset dementia (the female lead Julianne Moore won an Oscar). In the USA it has been reported that the book *Still Alice* (Genova, 2009) will be given to people on diagnosis (<http://readingagency.org.uk/adults/news/reading-well-books-on-prescription-for-dementia-booklist.html>).

People felt that Bradford is still some way from the reality of a dementia friendly community that operates automatically to remove barriers for people with dementia and their carers. The first phase of the DFC Programme in Bradford has been mainly about the Alzheimer's Society 'doing'. The proposals for funding a second two-year programme recognises that this now needs to move to co-ordinating other people and organisations doing things themselves.

### **There is an increasing focus on the rights of people with dementia**

This evaluation also raises the question of the extent to which the needs of people with dementia is becoming a rights issue. Dementia is still emerging as a condition that is openly discussed in society, and for some it is still a matter which bears a great deal of stigma and shame. But, given the progress that has been made through the disability rights movement, and the challenge to age discrimination, respondents indicated that it could be time to consider the particular needs of people with dementia as an equality issue.

There has been significant emphasis in the Bradford programme on groups which empower people in many ways to identify what will make their city dementia friendly. However there was no substantial evidence to suggest that an awareness of people's rights is building around this issue. Indeed there is evidence in some areas that decision-makers do not yet accept that people with dementia do have the same rights as other people to the removal of discriminatory barriers, and these persist. Examples include difficulties around planning controls, building design, access and transport which do not address the specific needs of people with dementia.

The potential is there, however, through continued networking and building of confidence, for people with dementia in Bradford to consider their rights to live in a dementia friendly community. This might develop through the involvement of the FIT group in the DEEP network. DEEP is evolving nationally with an emerging desire for a social movement of people with dementia expressing their rights directly. Where people with dementia themselves remain capable of expressing their needs and wishes, a rights movement can be driven by their voices, but the needs and wishes of people with dementia who do not have capacity, or the desire to speak out personally, may need championing by carers and supporters, families, professionals and ultimately by politicians and legislators. Other rights movements and



campaigns have much to offer people with dementia in terms of learning and shared experience and these include movements which have led to legislative change (as enshrined in the Equality Act, for instance) as well as changes in social awareness (such as Age UK's work on ageing, and the Time to Change campaign on Mental Health [www.time-to-change.org.uk](http://www.time-to-change.org.uk)).

## **It is important to understand diversity and address its impacts**

While there are wide variations in health outcomes across the district, in aggregate terms Bradford fares worse than the rest of England, and the rest of West Yorkshire on a number of health indicators, such as lower life expectancy and excess winter deaths ([www.england.nhs.uk/wp-content/uploads/2013/01/la-pack-e08000032.pdf](http://www.england.nhs.uk/wp-content/uploads/2013/01/la-pack-e08000032.pdf)).

These indicators are often associated with wider economic and social deprivation and are likely to compound the experiences of people with dementia in Bradford who experience low resources on a number of dimensions. Many people in BAME communities have poor education, illiteracy, and experience of poverty and poor housing – all factors which contribute to older people from these communities presenting late to services. There are concomitant consequences for diagnosis and support (Cattan and Giuntoli, 2010).

The JSNA Statement on Ethnicity and Dementia (<http://bit.ly/1Ka5aCW>) published in August 2014 has a useful section on ethnicity and dementia and points to particular risks around vascular dementia, low service take-up and higher levels of early onset dementia in the BAME population. It recommends that the dementia strategy should explicitly take into account the rising numbers of BAME people across Bradford district.

In addressing issues of diversity, there should be some recognition that a degree of 'intersectionality' applies – that is, people with dementia may be so disadvantaged by other social and economic factors that they cannot benefit from the gains of a Dementia Friendly Community. It is important therefore that specific needs are addressed and culturally relevant solutions found to overcome persistent barriers for people with dementia.

## **The role and contribution of carers is vital**

There is a sense of partnership with carers running through the Bradford DFC Programme, and recognition of the indispensable support they give to people with dementia. They are an integral part, for many, of what makes a dementia friendly community. The programme also facilitates the vital time that people with dementia and their carers need to spend apart, by supporting people with dementia on their own, and by encouraging parallel groups of carers.

Asserting the rights of people with dementia can present a challenge for carers, especially where close family relationships are involved, and there are differing perceptions of risk between the person with dementia and their carers. This calls for careful handling by professionals, volunteers, the wider family and community. A better balance is likely to be achieved if the needs and contributions of carers are recognised alongside the needs and wants of the person with dementia. In Bradford, support for carers was felt to be less consistently available than it ought to be, and there is more to be done to understand and respond to the needs of carers in order to secure their effective support for people with dementia over the longer term.

## **More support is needed from general practice**

In recent years Bradford has seen a marked improvement in terms of dementia diagnosis rates and referrals to memory clinics. According to Department of Health figures, around 65 per cent of cases in the city are being formally recognised – higher than the national average of 48 per cent – and almost 100 per cent of those identified are being properly referred to memory clinics for the help they need ([www.bradfordcityccg.nhs.uk/wp-content/uploads/2013/05/Bradford-City-annual-review-2013-14.pdf](http://www.bradfordcityccg.nhs.uk/wp-content/uploads/2013/05/Bradford-City-annual-review-2013-14.pdf)). A dementia self-care pack produced by Health Action Local Engagement (HALE) (in partnership with Bradford Council, and the three Bradford CCGs) is available to help GPs direct people with dementia to a range of support organisations, and this guide includes a reference to dementia friendly communities ([http://www.pictonmedicalcentre.nhs.uk/website/B83614/files/Dementia\\_Self\\_Care\\_Pack\\_FINAL.pdf](http://www.pictonmedicalcentre.nhs.uk/website/B83614/files/Dementia_Self_Care_Pack_FINAL.pdf)).



However, it is not clear how widely or consistently this is used and, as such, it remains an ongoing priority to ensure that people with dementia are referred appropriately for support with social and community needs.

Respondents said that GPs' responses to people with dementia varied across Bradford, as they are across the country. People said that some GPs avoided referral for diagnosis for as long as possible, and, after diagnosis, consultants and GPs tended to refer into health services, without a wider assessment of the personal, social and community needs of a person with dementia. It is suggested that more can be done to raise awareness among GPs of the concept of a dementia friendly community, 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.

We also heard in Bradford 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. While variation in diagnosis by ethnicity is a national trend ([www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=404](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=404)), local data on ethnicity and dementia is patchy, as acknowledged within the Bradford Joint Strategic Needs Assessment. It has also been identified, however, that the south Asian community is poorly represented in referrals to memory assessment and treatment services compared with the general population ([www.observatory.bradford.nhs.uk/Pages/Default.aspx](http://www.observatory.bradford.nhs.uk/Pages/Default.aspx)).

## Lessons about resources

The 'resources' cornerstone considers if there are sufficient services and facilities for people with dementia and if these are appropriate to their needs and supportive of their capabilities. How well can people use the ordinary resources of the community? In relation to the Alzheimer's Society recognition scheme criteria they are closely related to early diagnosis and personalised and integrated care as the norm, maintaining independence by delivering community based solutions and businesses and services that respond to people with dementia ([www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=2136](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2136)).

Lessons learned about the resources from the Bradford evaluation include:

### Investment in health and social care needs balancing

The opportunity of a dementia friendly community is to make all the resources of a community – everything from shops and banks, to theatres and sports facilities – available and accessible to people with dementia. The bigger prize for society over the longer term is to enable people with dementia to stay healthy and connected to their communities for longer, so delaying the need for intensive and expensive health and social care. This principle is now enshrined in legislation in the Care Act 2014.

With the continuing ageing of the population, increased prevalence of dementia, and stretched resources, there is concern that the future of our health and social care services will be bleak. This concern was well articulated in Bradford. There is more work to be done to identify how community support – which can harness voluntary capacity – can contribute to rebalancing the health and care system for people with dementia.

**“Funding via public health is due to be cut – especially for the voluntary sector including befriending services, this I believe will have a detrimental effect for dementia sufferers and their carers.”**

Service provider, Bradford

Because of the pressure on public funds, there is risk and fear that fewer services will be commissioned from the private and voluntary sector, threatening the concept of a dementia friendly community. Some small-scale investments could be vital in supporting people to continue to live a comfortable life in the community. Examples suggested by respondents included a second point of contact (other than next of kin) for people with dementia, for example a GP, or pharmacist. Another good idea was a 'small steps' campaigns by the local council under the banner of general neighbourliness. This might include asking

people to check if their neighbour has remembered to put their bins out, or asking local shops and businesses to become 'safe havens' for people with dementia.

There has been greater success in Bradford in linking into existing community activity ('not trying to reinvent the wheel') so that people with dementia can enjoy better access to local social and community facilities, particularly at neighbourhood level, and linked to existing groups like faith groups. The surge of political will to make every ward in Bradford district dementia friendly is admirable and a positive strategic move to include people with dementia in everyday life. However, without additional investment there is a challenge to the capacity of paid and voluntary workers to manage demand and there may be a risk of spreading resources too thinly with insufficient impact.

Generating interest in dementia friendly communities through public events has been effective in Bradford, but interest and goodwill only go so far, and there is a feeling that when groups are established they need a focus on making change happen to avoid frustration setting in.

**"There has been publicity around workshops and enthusiasm about being 'dementia friendly' but I haven't seen any actual evidence of changes."**

Service provider, Bradford

In Bradford there is recognition of the benefits of social prescribing – for instance to engage in leisure or social activity – for people with dementia. Although this is reasonably prevalent now as part of the approach to treating people with mental health problems, it is not yet widely available for people with dementia. There is a widespread acceptance of the positive benefits of early diagnosis, but in a medicalised model of care, social and preventative health interventions are not consistently recommended. What this means is that there is a continued emphasis on medicines and NHS treatment for individuals rather than a wider commissioning of dementia friendly communities 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 dementia friendly communities is not yet happening and there is little sign of significant transfer of resources from health into the community. The opportunity for change is there – Airedale, Wharfedale & Craven, Bradford City, and Bradford Districts 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](http://www.airedalewharfedalecravenccg.nhs.uk/wp-content/uploads/2014/08/Bradford-and-Craven-five-year-forward-view.pdf)).

## **There is scope for more dementia friendly resources to be identified**

In Bradford, the work to connect with and persuade a wide range of organisations and businesses to become dementia friendly has been energetically addressed and successful to a very positive extent. It has been acknowledged that this is a difficult area, and an additional co-ordinator has been appointed to specifically work in this area.

There are some high profile and important alliances with major retailers like the Co-op and high street banks, as well as with smaller businesses in local communities. The Dementia Action Alliance is well established but there is recognition that this is challenging work because all organisations and businesses do not yet see the benefits of being dementia friendly, and if not compelled to act, would rather not engage. This has led to what some see as a watering down of the requirement to commit to an action plan for DAA members. Other issues to consider include the process for monitoring and following up action plans.

In other areas there has been success in widening the net of engagement in businesses and organisations to include all sectors, and particularly in connecting to programmes of activity which support people with dementia alongside mainstream programmes – for instance in sport and leisure in York, and in arts and cultural services in Leeds. This is an area where work has started but there may be future opportunities for Bradford.

## Should dementia friendly activities be integrated or separate?

The evaluation asked participants about the pros and cons of 'dementia only' activities, services and resources. In Bradford there is perhaps slightly more emphasis on groups and activities for people with dementia, rather than people with dementia having access to the same facilities and resources as everybody else.

There is a strong feeling among people with dementia that the label of diagnosis is in itself a disadvantage and a burden, and what people would like is to just to carry on with their lives. Indeed, and linked to the rights issues we discussed above, it is a core aspiration of a dementia friendly community that people with dementia should be able to access mainstream services and resources alongside everybody else. At the same time, people with dementia should also of course have the right to choose to engage in specific dementia only activities as well.

It is important to ensure that activities for people with dementia adequately reflect the diversity of the dementia population. Some younger people with dementia would welcome the opportunity to access activities with others of a similar age. There is also a need to consider people with dementia still in employment;

"I'm the youngest in the group; my age group is forgotten really, it's seen as an older person's condition. There isn't anything in Bradford but there is in Leeds. So we need a younger people's group, and help for people to carry on work...I finished work when I was 56, I took early retirement. At that point I didn't want to say what was wrong with me ...awareness was low."

Person with dementia, Bradford

There is an overwhelming feeling that what people do not want is to be excluded because of their dementia. Some places like Idle, for instance, are able to show how this might work by supporting activity that is both open to everybody and specifically for people with dementia.

Faith groups are key players and well placed to engage with older people within the community. They often have community rooms and gardens which could be used as quiet places and spaces, and should be a source of comfort and solace. There is more work still to be done to raise awareness within churches and other faith establishments, however.

"Churches are a big mixture, some will be caring and friendly and some are afraid of dementia. I wouldn't be 100 per cent confident that someone wouldn't get an offhand comment from somebody."

DAA Member, Bradford

While Bradford is able to consider a wide range of needs across its diverse population, smaller groups and more recent migrants, for example Eastern Europeans, may be currently overlooked.

## Lessons about networks

The 'networks' cornerstone considers whether 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. In mapping across to the Alzheimer's Society recognition criteria, shaping communities around the views of people with dementia and their carers, and befrienders helping people to engage with everyday life are relevant here, although there is perhaps less emphasis put on networks at different levels of neighbourhood and across communities.

Key lessons about networks which were evident in the evaluation were:

### The idea of a dementia friendly 'movement' is growing in importance

Being part of a wider regional, national and international movement has been significant for the Bradford programme. The establishment of a national dementia action alliance of organisations committed to

creating and supporting dementia friendly communities, and the roll-out of regional and local DAAs on the same model 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.

The DFC project manager and other staff and partners involved in the Bradford programme have contributed to and learned from regional, national and international events, research and publications which have enhanced the dissemination of ideas and built knowledge around the programme. Connections have been made with a wide range of individuals and groups, and these have often involved people with dementia and their supporters as well as professional and voluntary staff. One example is the visit by members of the Stockport EDUCATE group to Bradford – facilitated by DEEP – which provided an early impetus to involving people with dementia in raising awareness about dementia friendly communities. Other examples include the contribution of the Bradford programme to *Excellence in Dementia: Research Into Practice* (Downs and Bowers, 2014) and to a 24-hour workshop in the Republic of Ireland run by the training company Genio. These illustrated the worldwide nature of DFC developments and how good practice is shared and disseminated.

Bradford has its own local advisory group which oversees the work of the DFC programme, and this has links to, and some shared membership with, the Bradford Dementia Action Alliance. Both groups also link with the Bradford Older People's Partnership Group with its position in the wider health and well-being board governance arrangements, and there is a clear dementia strategy and action plan owned by partners. The public health needs assessment has flagged dementia as a priority for Bradford and the council's senior public health lead has a role as dementia friendly communities champion for the council and is very supportive of the programme.

The strength of being part of this wider movement and linked to mainstream work is that it helps to make dementia friendly communities a real possibility for the future, not 'just a fad' which some respondents feared. The national publicity campaign by The Alzheimer's Society which launched the concept of 'dementia friends' within the same time frame as the Bradford DFC Programme was a boost to raising awareness in the general population about dementia and securing direct support for people with dementia. Dementia Friends' champions have received training to enable them to recruit the targeted one million Dementia Friends by 2015 and this has been led by the Alzheimer's Society. Despite the positive impact of this movement, there remains a feeling that this needs to be linked more closely to other initiatives and there is a 'so what?' element to improved awareness unless it leads to real change on the ground.

Indeed, despite the recognition that awareness of dementia is growing and attitudes are changing, people said they would be surprised if the vast majority of the general public knew much about it.

## **Professional networking is crucial for a dementia friendly community**

There are strengths in professional networking in Bradford, which people with dementia and their carers and supporters recognised as effective and helpful. Within the networks provided by the programme advisory group, the DAA and their links to other networks across the health and social care system and beyond, professional staff knew what was going on and could capture the benefits of that knowledge in their own work areas. There were, however, questions about whether the role and remit of the project advisory group, the local DAA and the regional DAA are sometimes overlapping or duplicating, creating work for people that might be focused elsewhere.

Professional networking was also extremely effective and practically applied both in neighbourhoods and in communities of identity, where people seemed to find it easier to find out what was going on, and what support was available. Places of worship, community centres and local service centres, all provide a physical presence for networking where people can find notices and leaflets as well as 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 programme, given its short-term funding. The Dementia Action Alliance itself is a

network or organisations committed to contributing to a dementia friendly community, and will hopefully have a life beyond the DFC programme. Models like the Doncaster Dementia Forum and the mainstream partnership work which surrounds that are also worth considering for the future. The forum, which is part of the DEEP network, enables people with dementia and their carers to network with, and influence, local services. It has a formal role in holding the local Older People's Mental Health Strategy Group to account, and is therefore connected to long-term decision-making which supports people with dementia and their carers.

There are some practical opportunities for considering how to pool information and make it more accessible to people with dementia and their carers, to join up information sources and make them more relevant for each stage of the dementia 'journey'. These might be care navigator roles carried out by workers or volunteers, or virtual models being developed within the public health arena. Speaking about an app being developed by Bradford Care Trust and Bradford Council's Public Health Department, a health commissioner envisaged:

*"...when you click on it, it [would] show you all the available services...A bit like the London Underground... If you are at this stage, this is where you can get off and what you can access...you will get on and off at different points of your dementia and access different services...a pathway, navigator thought those services."*

Liverpool John Moores University and MerseyCare NHS Trust are also developing a digital app to help people live well with dementia as part of their Year of Action on Dementia (see [www.bbc.co.uk/news/uk-england-merseyside-29642804](http://www.bbc.co.uk/news/uk-england-merseyside-29642804)).

## **The active involvement of people with dementia, carers and supporters is vital to the future of Dementia Friendly Communities**

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). There is clear evidence to suggest that both people with dementia and their carers and supporters gain great strength from meeting face-to-face with others in a friendly environment, with a social as well as therapeutic aspect to the engagement.

People with dementia and those that support them use the knowledge in these groups to find out about dementia, its characteristics and trajectory, and value this information based on experience 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, and in Bradford people reported that the socialising aspect is very important. Groups can also offer development opportunities if desired, and enable people with dementia to shape the services and resources they might use. It is important to continue to listen so that people with dementia are not only identifying what they want but how they want it, and to support leadership and lobbying activity which may challenge funders and service providers. The FIT group's growing confidence as part of the DEEP network is beginning to influence the progress of Bradford as a dementia friendly community, although there is scope for more challenge with decision-makers.

Even with these positive models, people with dementia recognised how difficult it can be for others to talk about dementia. Some people will avoid the subject and might even walk away and there are still people who think it is a disease which can be caught. While the engaged respondents with dementia who responded to the evaluation felt that it was generally better to reveal their diagnosis, there was acknowledgement of the risks of being immediately negatively labelled.

There is clearly a need to treat people as individuals and to protect people from exploitation, discomfort or distress, but there is also an opportunity to encourage people to try new experiences and specifically to articulate their own views about what makes a dementia friendly community and how that should be achieved. In Bradford there are opportunities for people to attend groups and events on their own, and with carers and supporters. There is an understanding that, again, circumstances vary according to individuals' relationships and preferences – some people will always want to be accompanied by a

supporter, while others will not. Some groups have found that meeting separately but at the same time is both practical and liberating.

Hearing how people with dementia describe their view of a dementia friendly community and then hearing their carer or supporter expressing what they feel is important can reveal more precisely how to overcome barriers. As noted above, access to resources, including the physical, financial or practical support of another person can be the reason a person with dementia is able to participate in the community at all. It is clear that dementia friendly communities 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.

# 7 Conclusions and recommendations

This evaluation has attempted to understand the strengths and weaknesses of the Bradford Dementia Friendly Communities Programme, to assess the impact it has made and to identify lessons for other places and for the future. The evaluation captures a moment in time in a short-term programme, and many respondents questioned what would happen next – will the Bradford Dementia Friendly Communities Programme continue, and if so, how will it be sustained?

Towards the end of our fieldwork it was confirmed that there had been agreement to continue funding for the Bradford DFC Programme for two more years. The role of the Alzheimer's Society will change from direct provision to facilitation and expert support, to enable other organisations to contribute more to making Bradford dementia friendly.

Respondents saw the current political and financial climate as not necessarily auspicious in terms of investment in dementia friendly communities. There were widespread concerns about service patchiness which people did not expect to improve. Despite the support of David Cameron through his Prime Minister's Dementia Challenge, dementia was not a high profile issue during the 2015 general election campaign, and although there is a continuing emphasis on the challenges of funding of health and social care, there is no specific government drive to identify how dementia friendly communities might contribute to this. The absence of a new dementia strategy means there is no compulsion to direct investment into new and innovative approaches, so it will be the responsibility of local partners to ensure that the momentum of the current DFC programme is sustained.

In summarising the conclusions of this evaluation of the Bradford DFC Programme the questions included in the evaluation brief and the additional questions suggested by the evaluation team have been used as a template.

Phase 1 of the Dementia Friendly Communities Programme in Bradford has been successful overall. There are visible strengths in 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 dementia friendly communities develop, challenging the consistency of support and provision across the district, and widening the impact on more mainstream resource areas including leisure and culture.

Within local communities 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. Some businesses and organisations have also been influenced and changed their approach to become more dementia friendly. Even so, awareness is still concentrated among those 'in the know' and a real understanding of what dementia friendly communities means is not widespread. There is now high level corporate support across public sector partners, although this has been slower to secure than had been originally hoped.

In terms of practical influence and outcomes, for some people with dementia and their carers involvement in the programme itself has been transformational. It has increased insight into their own dementia and given them the confidence to live the life they want. Support with transport, particularly for single people and those on lower incomes, has made a significant difference to quality of life and inclusion. Networking within the programme 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.

Organisations that have embraced the DFC programme 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.

People with dementia have been at the heart of work at ward level and in cross-district networking, and have been involved in and consulted about the programme as it has developed. Individuals have supported programme staff in promoting and reporting on the programme at a range of events and conferences. People with dementia have been involved in helping the Bradford District Alzheimer's Society recruiting staff and improving the organisation generally.

Although there is a formal visibility in the DFC initiative, which includes stickers and badges which participants can display, the test of a Dementia Friendly Community for most respondents was the absence of barriers, enabling people with dementia to participate fully in society. It is often, therefore, easier to see what is wrong than what is right, although people know which shops are friendliest, which cafes have good service, whether their GP has a positive approach or not, and so on. There were mixed views about the pros and cons of a formal labelling system, and while many people with dementia support the DFC initiative, they would prefer their community to be dementia friendly without the fuss.

The programme has communicated the idea of a Dementia Friendly Community well, with evidence of activity and engagement across the four cornerstones of place, people, resources and networks. However, many respondents felt that although the idea was better understood, it was not yet reaching far beyond those with a vested interest in it.

If a dementia friendly Bradford is to be a reality for the future, it needs to be in the ownership of more than just a short-term programme. It is positive that project funding has been extended, but making a dementia friendly community part of the everyday needs mainstream change. Key custodians are people with dementia themselves, their carers and supporters who might be in a position to assert their rights to inclusion and quality of life, but this is a movement which needs wider ownership among partners across the public, private and voluntary sectors, and indeed, among the public as a whole. At the moment, partners are able to commit on paper to a DFC within their dementia strategy, but there is a certain amount of scepticism among respondents about whether the investment will be there to provide the kind of community support that is needed. This is why people are starting to raise the issue of a rights campaign which might challenge decision-makers, legislators and funders to consider dementia friendly communities to be a mainstream issue.

While strong on localism, the Bradford programme is also outward looking, and staff and advisory group members have engaged well with the DAA regionally and nationally, enabling a transfer of ideas and knowledge to flow. The programme officers have spoken at many regional and national events (and included partners and people with dementia) spreading knowledge about Bradford and bringing ideas back.

It is clear that people with dementia and their carers in Bradford have had a strong voice and influenced how the programme has developed, but there is more to do to engage more people and to empower them to envisage and co-create their dementia friendly communities. We think that support from the DEEP network in the future will continue to be helpful in this respect.

In terms of success measures for the future, in 20 years' time in Bradford there might be a level of awareness and adjustment in communities which is similar to that achieved for people with physical disabilities. It has been difficult, however, for people with mental health needs to benefit so directly from Equality Act provisions because of continuing stigma. The task for the coming ten years perhaps is to tackle the fear that exists around dementia, and ally with other mental health campaigners to achieve this. Perhaps it is most important to encourage the growth of a mutually supportive movement which challenges how society responds to people with dementia and their carers, setting standards for what should happen post-diagnosis and planning appropriate community responses to ensure the best quality for people's lives with dementia.



## Recommendations

There are many things that could be done to continue the creation of a dementia -friendly Bradford, but it is suggested that concentrating on some strategically key areas will have the most comprehensive and best effect.

### Empower

- Continue and extend support for people with dementia to shape the vision of what a dementia friendly community means in Bradford.
- Enable people with dementia to connect across the city and more widely to add their voices to the DFC movement and to share experiences and support one another
- From (and before) diagnosis, empower people with dementia to determine what they want to enjoy the best quality of life and harness social prescribing and good healthcare to support their vision.

This requires the DFC programme to continue to work with the DEEP network to support the empowerment of people with dementia.

### Encourage

- Seek out and support people and groups who are action focused and can provide practical support for building a dementia friendly Bradford, developing awareness through behaviour not just words.
- Share, celebrate and talk about what works already for people with dementia and their carers in making their everyday lives easier and enjoyable.
- Make better use of the cultural, social and leisure resources of Bradford to improve the quality of life of people with dementia and their carers.
- Refresh activity supporting dementia friendly communities to take account of social trends and new technology.

This is a real opportunity for the DAA to focus its role within the next phase of the DFC programme.

### Equalise

- Identify those issues and areas, including economic, social and geographic, which impact on people with dementia and their carers and commission to address inequalities.
- Harness the capacity of GPs to improve consistency in diagnosis and referrals, across communities of interest and geography.
- Focus on key areas which could have greatest impact – such as transport – to the greatest number of people .
- Thoughtfully evaluate health and social care commissioning to make sure that changes in one area do not have negative impacts in another.

These are areas where the key responsibilities are for health and social care commissioners

## Last word

This report of the Bradford dementia friendly communities programme evaluates progress at the end of the first phase. An early adopter of the dementia friendly approach, Bradford has benefitted from programme funding from the council and JRF. This has enabled the Alzheimer's Society to provide a consistent resource which has supported and enabled partners to develop both skills and resources which support people with dementia and their partners. A particularly distinctive aspect of the Bradford approach is its focus on geographic communities and communities of interest and experience. As a second phase of work has been funded, there is scope to build on success and to learn from the first phase, with the potential to enable more people with dementia to engage in the programme and to build awareness more widely across the district.

# Notes

- 1 Within the Dementia Without Walls Programme in 2011, JRF funded the Dementia Engagement & Empowerment Project (DEEP), initially a one-year project that aimed to investigate, support, promote and celebrate groups of people with a dementia diagnosis across the UK that were trying to influence services and policies affecting the lives of people with dementia. The project found that engagement was at an early stage for most people with dementia, the number of groups involved in leadership and lobbying was low, but that there was potential to support people with dementia through further networking and support for groups. Following a report [www.jrf.org.uk/publications/stronger-collective-voice](http://www.jrf.org.uk/publications/stronger-collective-voice) on its initial year, JRF has funded DEEP to continue to develop a network of groups who are exploring involvement and empowerment of people with dementia across the UK.

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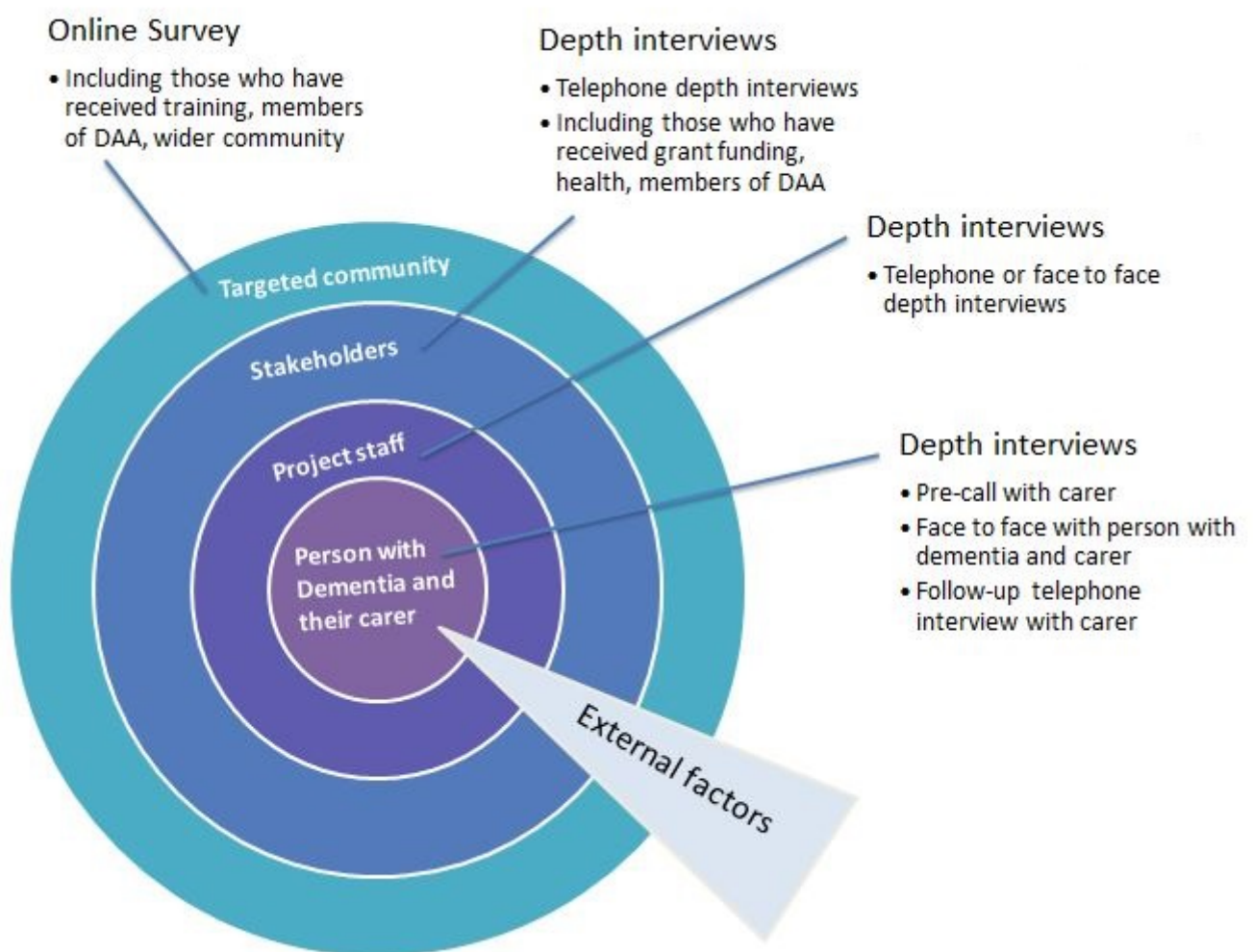
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# Appendix 1: Detailed methodology

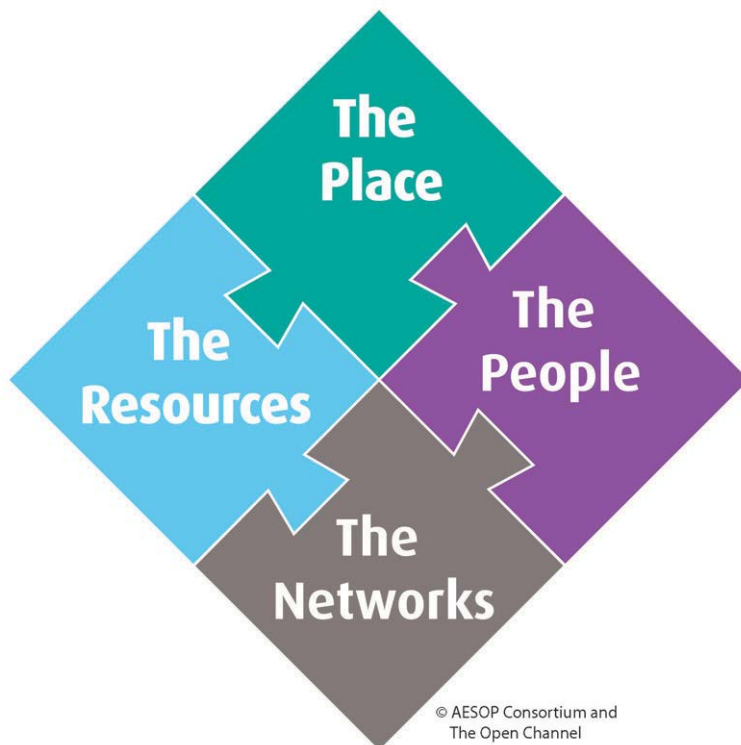
The design for both projects has been based on an evaluation framework which gathers evidence from the full range of stakeholders and participants using a range of appropriate techniques.

Our approach placed the person with dementia at the heart of the evaluation framework, on the basis that the primary beneficiaries of dementia friendly communities are people with dementia themselves. We then conceptually moved outwards from the person with dementia to identify stakeholders and potential respondents from within the family and caring relationships, health and social care services, the neighbourhood and community, the public service system as a whole, and the place with all its resources.

The following demonstrates this approach:



We have used the four cornerstones model developed by AESOP Consortium in their research for JRF which is a model which captures the key dimensions of any dementia friendly community with people with dementia at its heart.



This model has been used (with slight adaptation) by the LGA in the development of a toolkit for dementia friendly communities and is increasingly being adopted as a framework for building the capacity of partners to understand how to make communities more dementia friendly. AESOP Consortium in collaboration with The Open Channel (a leadership development brand co-owned by Janet Dean) has developed an accelerated learning programme based on appreciative enquiry and participatory involvement, learning and action for dementia friendly communities based on the four cornerstones model which has been piloted and is now being rolled out in other localities.

## Scoping phase

We took as our starting point a range of stakeholders and potential respondents who were easily identifiable from within the current projects, including:

- people with dementia;
- carers, normally close family relationships;
- family members, and personal networks and supporters of people with dementia;
- health and social care professionals and providers in public, private and voluntary sectors;
- public, private and voluntary service providers of housing, transport, community safety, leisure, cultural, sporting, educational, faith and other neighbourhood services;
- commercial service and product providers including shopping, eating out, banking, insurance, legal services, communications and personal services (such as hairdressing) which impact directly on people's lives;
- other community services and resources which can enhance people's lives or create barriers – ranging from membership associations to online services.

Once we had identified the range of stakeholders/potential respondents and had a clearer understanding of the 'reach' of the projects we then decided on the most appropriate method to adopt, e.g. face-to-face, telephone interview or online survey invitation.

## **In-depth interviews**

In the main, we have used individual face-to-face and small group methods of gathering qualitative data from people with dementia and their carers.

## **Attendance at meetings and observation**

We also attended a variety of meetings and where we observed proceedings, asked questions or led group discussions.

## **Targeted survey**

We have taken a different approach to gathering feedback from professionals and groups of commissioners, service providers or commercial and voluntary sector providers, and members of the Dementia Action Alliance. For these stakeholders, we used both small and larger groups or events for face-to-face contact, and (primarily) online surveys for research questions where we wanted to look at the scale of impact as well as the depth. The online survey link was distributed to wider networks by KIVCA and Bradford CVS.

## **Analysis**

The small group and individual in-depth interviews were audio recorded (with consent), transcribed and analysed to identify themes, and areas of consensus and disagreement were noted. If useful for illustrative purposes, direct quotes of the participants are included in the report. As a research team, we reflected on interview findings on an ongoing basis in order to ensure that our findings were consistent.

Responses from the targeted online survey were analysed using statistical software.

## **Ethical issues**

We have followed guidelines issued by the Social Research Association (SRA) and have abided by its research governance in terms of limiting our research only to the scope of the project and not straying beyond its boundaries, and acknowledging and making accountable our methodologies and our findings. For the research to be of benefit to society and the groups and individuals within it, we have ensured the highest standards of objective impartiality, neutrality, confidentiality and the privacy of the individuals who volunteered to be interviewed or otherwise take part in the research. We have sought consents where they are needed, or used proxies where appropriate without diluting or compromising the data, and have adopted a non-intrusive and sensitive style of conversational enquiry. All conversations and transcripts are confidential and depersonalised (with the exception of those instances where interviewees allow us to use their words as a direct quotation), and we will not divulge anything said to us in confidence.

Qa Research abides by the SRA guidelines and also those of the Market Research Society (particularly in relation to the administration and management of online survey research).

# Appendix 2: Case studies

## Case study: Focus group

The focus group of people with dementia and carers meets every six weeks and is the key 'influence' group for linking in with other organisations who are working to make their services or environments dementia friendly. The DFC co-ordinator works with the group to set the agenda. Since its formation in early 2013, the group has helped to review the menu to be used at Bradford Royal Infirmary, and has met with Bradford Council's development officer for inclusion and mobility to provide their perspective on improving navigation around the city centre. The group has also influenced developments at the new Westfield Shopping Centre, e.g. signage and accessibility.

It is evident that members of the group value the opportunity to share their experiences and support each other while at the same time taking the opportunity to influence and campaign on dementia issues. A few of the group members are strong advocates of being open and honest with others about their dementia and have spoken at events (on behalf of the Bradford DFC Programme) about their experiences in the hope that they can help others to understand how to communicate better with people with dementia and to help others to have the confidence to talk about their diagnosis. As one carer reflected:

"[He's] not afraid to stand up in front of an audience and tell people how it makes him feel and that its nothing to be ashamed of, sometimes he gets frustrated and wants to cry but the more people know about it and how the community can respond by speaking slower and don't bombard them with questions..."

Carer, focus group

"I think as a person with dementia, you've got to be prepared to say that you've got dementia and then people can take it from there because they don't know what to say to you but if you say then it makes it easier, they know that they can talk to you...Sometimes I have to ask twice if I haven't understood it the first time, if we've already explained there's a problem it's not a hassle for them."

Person with dementia, focus group)

"We go out with the dog and they got talking about [dementia] and I said 'I have it', and they said, 'how do you cope?' I said 'I get on with my life'"

Person with dementia, focus group

## Case study: Face it together

This local Bradford group which has been running since late 2013 is part of the UK-wide Dementia Engagement & Empowerment Project (DEEP) funded by JRF and Comic Relief. The group is for people with a diagnosed dementia and meets monthly at the offices of Bradford Alzheimer's Society. The group has around eight members and three also come to the focus group. This group is wholly user-led and participants identified that as part of the group they wanted to be able to:

- discuss the impact of dementia on their lives;
- support each other and take part in awareness raising;
- think about campaigns that they want to drive forward.

The group has been involved in a range of activities including, a trip to St Ives (near Bingley) to look around the area, visitors centre, café and toilets from the perspective of someone with dementia. The group sent initial feedback (mainly around poor signage) to The Friends of St Ives and the council who expressed an interest in receiving feedback to see if any suggestions made by the group could be implemented. The group plans to carry out similar visits to other venues, e.g. sports centres. Other activities have included involvement in the St. Luke's Hospital refurbishment and sitting on interview panels for a DFC post in Bradford Community Trust and the Dementia Action Alliance co-ordinator post. Members of the group attended a Leeds DFC conference, the Dementia Friendly Awards ceremony in London, and the JRF Dementia Without Walls mid-term event in London.

"The groups are very useful, it's good to be with others in the same situation. We can laugh about things between us that you couldn't with others; I'm a big believer that the more active you keep when you've had this diagnosis the benefits are great..."

Person with dementia, FIT group

"I can't remember how long I have had dementia now... a few years... and I do find that coming here helps to clarify some issues..."

Person with dementia, FIT group

"We felt as though we had walked into a brick wall and were stunned, we didn't know what to think, we thought the worst but it's not like that, this group helps and you can still carry on with your life."

Carer, FIT group

It is clear that participants value the group and gain a great deal from it in terms of mutual support. It is important, however, to acknowledge that participating in groups like this can be challenging, at and times, uncomfortable. As this comment illustrates, a rewarding experience can sometimes also be problematic.

"The event in London was an incredible experience. I met people suffering from similar problems, but most were in no way near suffering the way I was suffering... nowhere near that level. When it came to the second day I was taking part in discussions...well, sitting in on most of them, it went straight over my head – it was like I was floating just below the surface. Up to that point I have always been able to react very quickly to what people were saying but I was in no man's land...I would never have felt like that before at that point."

Person with dementia, FIT group



## Case study: Idle Memory Club

The community in Idle was one of the first to engage with the Bradford DFC Programme and to take the opportunity to build on activities that were already happening in the ward such as a day-care centre housed in Idle Baptist Church. The work centres on the development of Idle Memory Club (and peer support group), a walking group and a local action group. The local action group is now sufficiently well-established not to require much support from the Bradford DFC Programme, with representation from local residents, people with dementia and carers, the local ward officer and partner organisation Health on the Street.

The Memory Club provides an opportunity for people with dementia and carers to socialise together at the beginning of the group. The group then splits and people with dementia take part in activities facilitated by the group's co-ordinator while carers meet in a nearby room for a chat and to offer each other mutual support. The format of the club appears to work particularly well for both parties by providing activities that are cognitively stimulating for people with dementia while enabling them to socialise independently with others. Carers are able to spend some time with other carers sharing experiences and information.

"My husband hasn't been diagnosed yet, they are organising the brain scan, it's all waiting, waiting, waiting...but I do like coming here and he likes coming. At first when I mentioned it he wasn't keen...he's a proud man... but he loves to come. Our daughter found the info on the website... if it was my idea it might have been different."

Carer, Idle Memory Club

"I sat in on the other group to see if I noticed any difference in my mum, they have a great time, they were talking about things that used to be in our house in the 60s they all take part and prompt each other..."

Carer, Idle Memory Club

"[He] is normally very quiet and has never liked to meet new people, he always complains when we come in, but says how much he enjoys it afterwards. I have been told he is sometimes the first to speak..."

Carer, Idle Memory Club

### **Case study: Queensbury Dementia Action Group**

Queensbury began its journey towards becoming a DFC in April 2014 with a successful public meeting attended by about 30 members of the community. The ward officer was able to get support from a local Tesco store; the store's community champion was very supportive and provided refreshments.

This initial event was in response to a suggestion received by the ward officer from an active local resident with a personal interest in dementia. Following on from this, a local action group has formed with 8–10 regular attendees. The group meets monthly and progress has been made in raising awareness by visiting various community groups. The group has decided that support for carers is a priority in Queensbury as nothing exists. The group is planning to work in partnership with local carer's organisation Carer's Resource to liaise with GP surgeries about the possibility of setting up a support group, either to take place at or be publicised by a local surgery.

In a fairly short space of time, the group has had considerable success in engaging with local organisations and encouraging them to adopt an inclusive approach for people with dementia. The group approached a local golf club and were able to arrange for people with dementia and carers to access an 'unhurried' round of golf on a Monday when the club is quieter.

*"What we are trying to do is let people continue to live their lives as they were. It might take three times as long to get a round of golf in, but if there's nobody there stressing them then that's fine."*

Ward officer, Queensbury

The group has also been able to secure some office space for a 'base' from Queensbury Community Partnership which has helped in raising awareness about its work within the community.

### **Case study: Sikh Gurudwara**

Organisations working with the south Asian community in Bradford were keen to reduce the stigma surrounding dementia and to increase understanding of the condition within the community. Families within the south Asian community are very self-reliant, however this can sometimes mean that there is a reluctance to seek help for elderly relatives with dementia. To help address these issues Bolton Road Gurudwara provided dementia awareness sessions and adapted the physical environment of the temple with improved signage to make it more dementia friendly. Bolton Road Gurudwara was the first in Britain to make these changes and this work was recognised at the Alzheimer's Society Dementia Friendly Awards 2014 with an award. The success of this work has led to the dementia friendly programme now being rolled out in Sikh communities throughout the UK.

Following the award-winning work at Bolton Road Gurudwara, representatives from the Sikh community approached Bradford DFC Programme for support to help to widen their reach both locally and across the Sikh community in Bradford. This resulted in the production of a short video which illustrates the benefits to the community (see [www.youtube.com/watch?v=6KYZy0kSgFk](http://www.youtube.com/watch?v=6KYZy0kSgFk)).

The Bradford DFC Programme has run sessions at other Gurudwara, including sessions in Punjabi.

This work has had international impact, with a feature in the Hindu Times. A website has been developed to share information and knowledge about the work, see <http://dementiafriendlygurudwaras.com>

### **Case study: Bingley Awards**

In December 2014 a community champion's awards ceremony took place in Bingley. Members of the community voted for businesses and individuals who they felt should be recognised for 'going the extra mile' for their communities. Keighley & Ilkley Voluntary and Community Action (KIVCA) had been working in the community to raise awareness around dementia and decided to link in with Bingley awards to launch Dementia Friendly Bingley. This approach differed slightly from the activities in other Bradford communities in that it was decided to focus on and draw attention to businesses that were already making positive progress towards becoming age- and dementia friendly; in Bingley a hairdressers, post office and café were nominated by the community.

"Rather than going in and saying 'we need you all to be like this' – we asked people to nominate people who were already doing good work to encourage more to follow."

Service provider, Bradford

Following this launch event a small steering group formed to consider ways to continue raising awareness and drive forward Bingley's journey to becoming dementia friendly.

### **Case study: Co-operative stores**

Local Co-operative stores have been involved with the DFC work in Bradford from the early stages. As is often the case, this was championed by an individual who had her own personal experience of supporting a family member with dementia and could see the benefit in working to make the stores dementia friendly. The ethos of the Co-operative as a community retailer with a strong focus on social responsibility made it a perfect fit for the aims of the DFC programme in Bradford. Initial work included tours of the stores with people with dementia to understand how they experience a shopping trip. Staff have also received awareness training, and a short film was made to illustrate how shops can raise awareness and implement changes (see [www.youtube.com/watch?v=m19cXnWi59k](http://www.youtube.com/watch?v=m19cXnWi59k)).

The work of the Co-operative has continued to develop and more stores across the country are signing up to become members of their local dementia action alliances, e.g. in Norfolk, Suffolk and Essex, Walsall, and Lincolnshire.

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Face it Together  
Joseph Rowntree Foundation  
Kirkgate Centre  
KIVCA  
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