



**UNIVERSITY OF LEEDS**

## **Age UK's Dementia Friendly Programme**

### **Evaluation Report**

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## Key messages

### Successes

- The Dementia Friendly programme has exceeded the goals set out in the bid to the Big Lottery Fund and met most of the expectations of participating local Age UK partners.
- It has provided 46 local Age UK partners with three days of consultancy support and a grant of £5,000 to help shape existing, and develop new, dementia friendly services. Cohort meetings, workshops and a webinar were also organised where participating local Age UKs shared ideas and resources, and focused on a particular aspect of dementia friendly work.
- The programme helped local Age UK partners to create a framework for becoming more dementia-friendly through the development of locally specific action plans. The plans focussed on: training staff and volunteers; making changes to buildings, signage and printed materials; and developing new dementia-friendly physical activities or well-being services. The programme has contributed to a more positive, inclusive attitude towards service users living with dementia.
- Many local Age UK partners felt that their original expectations had been met and that the programme was well organised, relevant, flexible, manageable and practical. Nearly all local Age UKs have used the grant to pay for training and thus raise dementia awareness among staff and volunteers.
- Many local Age UK partners utilised local networks to disseminate the learning from the programme and had successfully secured funding to deliver local services and developing good working relationships with local funders.
- The programme's Advisory Group was instrumental in the successful delivery of the Dementia Friendly programme primarily through bringing together local Age UKs which participated in the pioneer cohort, the consultants and the Project Manager at Age UK National. The Group also played a crucial part in encouraging Age UK National to take steps towards becoming more dementia-friendly.
- Plans for ensuring the longer term impact of the Dementia Friendly Programme are outlined in the exit strategy. The main elements are: the Dementia Friendly Toolkit; the resources guide; the *Dementia Peer Support Network*; and providing ongoing support to the Dementia Friendly Programme within Age UK National.

## Challenges and Key Learning points

- The main challenge to the delivery of the programme was logistical. An additional third cohort (which was not originally planned) boosted the outcomes of the programme but put time pressures on the project team. Nevertheless, the project team successfully dealt with the ongoing logistical pressures, and local partners felt satisfied with the programme overall.
- Commencing the Advisory Group earlier would have allowed more time for 'fine tuning' the structure of the offer to local Age UK partners.
- When implementing their action plans local Age UKs struggled with a lack of resources, both in terms of staff time and financial resources. Partners who relied on one co-ordinator, often a very busy senior staff member, to implement the action plan faced more challenges in implementing their plans.
- Sustaining the high level of training and ensuring that local Age UK partners have the capacity to work towards becoming more dementia-friendly beyond the lifetime of the programme was a challenge for some.
- While the newly established *Dementia Peer Support Network* meets the expectations of local Age UK partners overall, the lack of funding may pose challenges to local Age UKs who want to participate in the network.

## Recommendations

- Local Age UK staff who are 'passionate' about making services more dementia-friendly would benefit from more individual support to ensure that their knowledge and experience is fully utilised.
- It is important that the learning from the Dementia Friendly programme is successfully disseminated to local Age UK partners and embedded in the work of Age UK National.
- To ensure the longer term impact of the programme the *Dementia Peer Support Network* needs to be well co-ordinated, and learning from the Dementia Friendly Programme should be implemented in the future work of Age UK National.

## 1. Introduction

CIRCLE (Centre for International Research on Care, Labour and Equalities), University of Leeds was commissioned by Age UK to evaluate its **fit as a fiddle** portfolio 2013-15 (which includes three projects: *fit for the future*; Dementia Friendly; and Cascade Training) funded by the Big Lottery Well-being Programme.

The purpose of this report is to provide a detailed evaluation of Age UK's Dementia Friendly Programme. The Dementia Friendly Programme is a 'development project' of the **fit as a fiddle** 2013-2015 portfolio. The programme builds on Age UK's experience of the '*Including People with Dementia – Shaping Generic Services project*' (pioneers cohort), as well as other projects developed by Age UK London (as part of the original **fit as a fiddle** programme 2007 - 2013).

### ***Aims & Objectives***

Three cohorts of local Age UK partners participated in the Dementia Friendly programme which, according to Age UK's original proposal to the Big Lottery Well-being programme, had four key interrelated aims:

- To support local Age UKs to examine and review ways in which they can shape their services to be more inclusive of people living with dementia.
- To enable more local Age UKs to become dementia friendly organisations.
- To develop the concept of dementia friendliness into well-being services.
- To enhance the quality of life for people with dementia and their carers.

An additional aim also emerged during the course of the programme:

- To raise the profile of local Age UK partners as service providers for people living with dementia.

### ***Structure of the report***

The remainder of the report is divided into eight main sections. Section 2 provides a summary of the methods used; Section 3 provides a brief description of the programme, and Section 4 looks at the programme's outputs and the changes, or impact, at the local level to determine whether the programme has met its stated aims. The report then looks at the experiences of local Age UK representatives, consultants and the Project Manager in Section 5, exploring what worked well and what worked less well in the delivery of the programme. Section 6 outlines some of the key challenges to the Dementia Friendly

programme at the local level. Section 7 focuses on the role of the Advisory Group and briefly discusses how the programme has influenced Age UK at the national level. Section 8 discusses the sustainability of programme, and the final section discusses the overall impact, challenges, and lessons learnt.

The Appendices contain detailed information: a list of all local Age UKs participating in the programme is included in Appendix 1; a list of actions and activities included in the action plans developed by local Age UKs is provided in Appendix 2; and Appendix 3 contains a detailed list of the expectations local Age UKs had before signing up for the programme.

## 2. Methods

The following research methods were deployed by the research team for the evaluation of the Dementia Friendly project:

- Interviews with representatives of eight local Age UKs from cohort one of the programme in Autumn 2014 and Spring 2015.
- Interviews with 14 local partners from cohorts two and three in Spring 2015.
- Telephone interviews in Autumn 2014 and again in Spring 2015 with: the three members of the Dementia Friendly Advisory Group who represent local Age UKs from the 'pioneer' cohort; the consultants from Dementia Adventure (DA) and Innovations in Dementia (IiD); and the Project Manager at Age UK National.
- Analysis of the expression of interest forms and the completed action plans .
- Analysis of workshop feedback forms.
- Analysis of a survey conducted by Age UK of all cohort members, through Survey Monkey (19 responses in total).
- Two site visits to observe how local Age UKs in Cohort three worked with the consultants.

### 3. The Dementia Friendly programme

The Dementia Friendly programme has utilised expert consultants from two organisations, both of which are Community Interest Companies (CIC). The first, Dementia Adventure, provides consultancy, training, and research to connect people living with dementia with nature and a sense of adventure. The second, Innovations in Dementia CIC, works nationally with people with dementia, partner organisations, and professionals with the aim of developing and testing projects that can enhance the lives of people with dementia. The two organisations worked with local Age UK partners in England, as part of this programme, to help them assess how dementia friendly their services are and to support them to shape their services to become more dementia friendly in the future. This included support to develop new services, including well-being services.

The support provided in the Dementia Friendly programme was organised in three cohorts, as previously mentioned. Cohort one incorporated 15 local Age UK partners, with the support days taking place November 2013 to June 2014. Cohorts two and three included 31 local partners receiving support July 2014 – March 2015 (a full list of participating partners is provided in Appendix 1).

The programme included three cohort meetings (in London), three days of consultancy support and a grant of £5,000 given to each local Age UK partner participating in the programme. In addition, all three cohorts were invited to attend four workshops: the first one, *'How to engage people with dementia'*, took place in June 2014, and was followed by *'A review of dementia training programmes'* (December 2014) and *'How to audit home and office environments for people with dementia'* (March 2015). The final workshop *'Risky Business'* took place in May 2015. In an effort to start using online resources, a webinar entitled *'Being dementia friendly'* was organised in March 2015 and finally, an event launching the Dementia Peer Support Network (to be discussed in more detail in Section 7) was held in June 2015.

Cohort one was provided with consultancy support based on the methodology developed in the pilot project *'Including People with Dementia – Shaping Generic Services'*. Innovations in Dementia (IiD), worked with seven local Age UK partners, and Dementia Adventure (DA), with eight<sup>1</sup>. Three support days were offered to the local Age UK partners by the consultants which included: an organisational audit of local Age UKs; an environmental audit of their premises; and work on an action plan.

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<sup>1</sup>Including People with Dementia – Shaping Generic Services, Project Report, available at [http://www.ageuk.org.uk/Documents/EN-GB/Including%20people%20with%20dementia\\_May%202014.pdf?dtrk=true](http://www.ageuk.org.uk/Documents/EN-GB/Including%20people%20with%20dementia_May%202014.pdf?dtrk=true)

Cohorts two and three followed a different model, with each participating organisation spending one day with a consultant from DA and another day with a consultant from liD. The local Age UKs involved in Cohorts two and three could then choose which consultant organisation to spend the third support day with (if participants preferred they could seek support from both consultants but would need to fund the extra support day themselves). Working with cohort one, both consultants offered the same support, although they brought their different expertise to the work, while for cohorts two and three each consultancy offered different types of support. For Cohorts two and three, liD continued to work with local Age UKs on 'auditing' the organisation and its services, using the five-domain approach (discussed in more detail in Section 3), while DA concentrated on developing and/or creating services which include physical activities, especially outdoors.

### **Summary**

- The Programme provided participating local Age UK partners with three days of consultancy support and funding of £5,000, to help shape existing and develop new dementia friendly services, based on an action plan.
- Cohort meetings and workshops were also organised where participating local Age UKs shared ideas and resources, and focused on a particular aspect of dementia friendly work.
- There were three cohorts altogether, the first cohort received support from either liD or DA, the second and third cohorts (which ran concurrently) received initial support days from both consultants, and then chose one consultant to deliver the third support day.
- With cohorts two and three, liD supported local Age UKs through 'auditing' the organisation and its services, while the support day with DA concentrated on developing and/or creating services which include outdoors activities for people living with dementia.

## 4. Programme Outcomes and Impact

As explained in Section 1, the Dementia Friendly programme had four initial key aims, with a fifth that developed during the programme's implementation: to support local Age UKs to examine and review ways in which they can shape their services to be more inclusive of people living with dementia; to enable more local Age UKs to become dementia friendly organisations; to develop the concept of dementia friendliness into well-being services; and to enhance the quality of life for people with dementia and their carers; to raise the profile of local Age UK partners as service providers for people living with dementia.

The following section explores each of these aims in turn, considering the extent to which each has been met. The findings presented here are based on the following data sources: interviews with local Age UK representatives from all three cohorts; analysis of their action plans; and interviews with members of the project team.

### ***a. To support local Age UKs to examine and review ways in which they can shape their services to be more inclusive of people living with dementia***

Participating Age UK partners worked closely with the consultants to review how inclusive their generic services were, focussing on the five 'domains' that previous work by IiD identified as being the most relevant for inclusive organisations. The five domains are: the voice of people with dementia; the place; the people; networks; and resources.

Local Age UKs felt they had benefitted from this kind of external support in reviewing their activities:

*'If you are involved in the services it is hard to have a dispassionate look, so it's always a good thing to have someone from outside to see if there is anything we have missed.'*

The local Age UK interviewees highlighted the 'instant' benefits of looking at the 'place', that is the buildings which prospective clients are likely to first enter and the printed materials that are distributed to them. At a more general level, all interviewees reported learning something new from the organisational audit, with many finding it a useful reflective tool. Many also reported developing an increased understanding of the needs of service users with early stage dementia, which is essential for shaping mainstream services to become more inclusive. Finally, many interviewees reported an increased confidence in the value of their work and an enhanced appreciation of the 'unique position' of their organisation to deliver inclusive services for people with dementia, without a requirement to develop specialist provision.

Follow-up interviews with participants in cohort one suggested that the support days helped local partners in creating a framework for longer term independent work. Having an expert personally visiting local Age UKs was highly appreciated, even several months after the actual visit, and interviewees felt this was a very efficient way of providing support:

*'That was the highlight for me, to get a site visit from someone who knows what they are talking about.'*

Local Age UKs from cohort one appeared to carry out environmental audits independently later, successfully using the tools and the guidance they had received from the consultants. The issue of environmental audits brings us to the difference in consultancy support between cohorts one and later cohorts. In cohort one, all our interviewees reported carrying out an environmental audit with the consultant, while in cohorts two and three only those local partners who worked with liD on the third support day had time for this. While all local Age UKs in cohorts two and three were given a tool and attended a one-day workshop which was dedicated to environmental audits, interviews with cohort one suggested that the tools alone were not as powerful as conducting an audit with an expert.

Three local Age UK partners from the first cohort emphasised that they had learnt a great deal by observing the consultants in the environmental audits:

*'It was very good to be able to see [the consultant] ... and for us to learn from that.'*

Cohort meetings and workshops also supported local Age UKs in reviewing and developing their services. Around half of those interviewed from all three cohorts reported that the cohort meetings helped them gain new information, including that on best practices. In one example, a local Age UK was planning to develop a home audit service for people with dementia, having got the idea from another participant at a cohort meeting. Some follow-up interviews with Age UKs in cohort one also highlighted that cohort meetings had been important for participants, and former peers continued to be seen as a potential source for shared learning:

*'We have their contact details and can call on them if we have a question or encounter a problem.'*

In addition to working with local Age UK partners directly, the consultants have created and gathered a variety of resources to further support participants in reviewing and shaping their services, including training materials. These resources have been shared with

participants during support days and at cohort meetings and workshops, and are now also available in the public area of the Age UK website. An interviewee from cohort one has found the resources very useful both in the short and the long term:

*'All of the resources ... are excellent. I use them to this day, I refer other people to them, they have been my lifeline.'*

The Age UK project team have reported that local Age UK partners from the pioneer cohort are increasingly producing such resources themselves.

#### ***b. To enable local Age UKs to become more dementia-friendly organisations***

In this section we consider the extent to which local Age UK partners have become more dementia-friendly, and explore how this has been achieved. We look at the planned and reported changes in services, using the action plans<sup>2</sup> and interviews with local partners as sources of data.

Local Age UK partners were required to develop action plans with the support of the consultants. Although the individual plans varied a great deal, depending on local circumstances, many referred directly to the five 'domains' that liD had previously identified as being the most relevant to inclusive organisations<sup>3</sup>. Most local Age UK interviewees indicated that they felt they 'owned' their action plan and it enabled them to continue to work independently:

*'The action plan is quite useful and gives me something to work with. It allows us to make changes; it gives you the ability to implement changes.'*

Action plans were created in close co-operation with the consultants and all the plans made reference to the work of the consultants, which indicates that they continued to be an important source of support and information beyond the three support days. In cohorts two and three, the local Age UK partners were more likely to ask for consultancy support for the action plans for their third support day. One local Age UK representative reported that some actions points had been included in their action plan as a result of information sharing

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<sup>2</sup>At the time of fieldwork only one Age UK partner in cohorts two and three had completed their action plans, thus the interviews with later cohorts did not cover the action plans in great detail. The research team received the action plans later and the information from the plans has been used in this report.

<sup>3</sup> Including People with Dementia – Shaping Generic Services, Project report by Steve Milton, Innovations in Dementia (CIC), available at [http://www.ageuk.org.uk/Documents/EN-GB/Including%20people%20with%20dementia\\_May%202014.pdf?dtrk=true](http://www.ageuk.org.uk/Documents/EN-GB/Including%20people%20with%20dementia_May%202014.pdf?dtrk=true)

with peers at the cohort meetings, and another reported that knowledge gained in the local Dementia Action Alliance had helped shape their action plan.

One local Age UK partner, in cohort three, reported that the organisation had not had the time to put an action plan in writing, but were nevertheless making changes:

*'We don't have a formal written plan; we have been auditing our spaces and have developed case studies with support from [the consultant]. I appreciate this more than a written action plan, as ... we are all very busy...so it's useful that we could make the plan loose. I didn't want to be left with a big written action plan that ends up in a drawer.'*

In contrast, follow-up interviews with local Age UK partners in cohort one suggest that the action plans were useful in the long-term, as most of them reported using their plans successfully and indeed, in a flexible way. Only one interviewee from cohort one reported that their original action plan was *'too ambitious'* and they had modified it to be *'more realistic'* and to better reflect their resources (the implementation of cohort one action plans will be discussed later in more detail). The action plans seemed to evolve over time. Participants reported that parts of their action plan *'haven't been progressed'*, while new items had been added or the scope of certain planned actions had been broadened. One local Age UK partner, for example, had opened up more specialist dementia training to volunteers but as the interviewee explained *'this was not part of the action plan, but it has come up.'*

Two local partners stated that they had found the action plans particularly useful, not only as a road map for implementing changes within their own organisation but also as a tool to be used in local dementia networks:

*'We use the plan in executive meetings and in conversations before a Dementia Action Alliance meeting. ... We are also using it in discussions with the council [about becoming a dementia-friendly city]. The plan has been used as a basis for bigger things, really.'*

Another important area to explore around the action plans is that of the organisational arrangements for overseeing their implementation and review. Based on interviews with Age UK partners in cohort one, we have found that these processes varied a great deal, according to the circumstances of local partners. In some smaller organisations overseeing the implementation and reviewing the action plan was the responsibility of only one staff member, such as the Chief Executive Officer or the *'dementia lead'*, in consultation with a board member / trustee. In the larger Age UK partner organisations it was a common

arrangement for one more senior staff member to share the task of co-ordinating the implementation of the plan, as the following quote illustrates:

*'Three people are involved in carrying out the action plan: the services manager, the dementia advisor and the befriending coordinator. I tend to follow up on action points with colleagues.'*

Methods for monitoring the implementation of the action plans again vary from organisation to organisation, ranging from informal chats and *'keeping things in mind'* to more formal arrangements. A common method is that the lead contact from the local Age UK reports the developments to their line manager, as part of their regular supervision.

### **c. Changes to generic services**

Here we review changes related to generic services, structuring the discussion around some of the key issues in the five domain approach. A list of actions, based on our analysis of action plans, can be found in Appendix 2. The interviews conducted with local Age UK partners at the time or soon after their participation in the programme ended indicated that some local Age UK partners had started to implement their action plans immediately after the support days. Although a few interviewees in cohorts two and three reported that it was *'early days'* when asked to discuss how their organisations were transforming, all were working toward changing at least in some of the five *'domains'*.

#### ***'The place'***

Local Age UK representatives interviewed for this evaluation mentioned that looking at the environment where services are offered and the printed materials distributed to clients was a highly relevant and useful part of the support. In cohorts two and three actions which involved auditing / changing the physical environment were prompted by the liD support day(s). The aim was to make the local Age UK premises more accessible to people with dementia, particularly through re-designing signage, re-arranging furniture and making cosmetic changes, with one organisation stating they had employed staff and/or volunteers to ensure the guidelines were followed. A few interviewees mentioned that they were looking to train staff to carry out future building and home audits. Most interviewees had changed or were in the process of revamping information materials according to the dementia-friendly guidelines. Many participants in cohort one had implemented changes to the content and design of information materials. The following quote, from one local Age UK partner refers to quite radical change to information materials:

*'Instead of putting the information about all our new services on one leaflet, we have designed four postcards – one for each new service. Just a*

*few bullets, this is what we do, this how you can access it and if you want more information, call this number.'*

Some of the newly designed materials will only be printed and distributed when all copies of the old versions have been used.

### ***'The people'***

Both consultants emphasised, when they were interviewed, that the most important aspect of making local Age UK partners more dementia-friendly is 'the people': staff and volunteers who meet clients, some of whom have dementia. The Dementia Friendly programme was designed to shape the attitudes and behaviour of 'the people' through the consultants sharing information about dementia and the needs of people with dementia (during support days, cohort meetings and workshops) and by them recommending suitable training tools and/or providing training about dementia. Some local Age UK representatives mentioned that they, personally and their colleagues, had become familiar with up to date information about dementia during the programme, and for some of them this meant 'unlearning' previous knowledge.

Most interviewees from all three cohorts saw dementia awareness among staff and volunteers as an important condition of long-term change, stating that volunteers and staff at all levels had to be '*on board*' (for cohorts two and three liD support days had been particularly useful). At the time of the first interviews most local Age UK partners had arranged or were arranging dementia-friendly awareness training for all staff and volunteers, with some staff becoming 'dementia champions', who could then deliver future training themselves in-house. Some organisations changed the training courses that they offered to concentrate on general awareness raising, rather than on specialist information about dementia more suitable for healthcare settings, as one participant explained:

*'We changed the content and title of the dementia training course that we deliver. It was called 'dealing with dementia', it is now called 'dementia awareness', which all staff are now encouraged to attend.'*

Many interviewees reported an increased level of confidence amongst staff and volunteers as a result of attending consultancy days or workshops and subsequent training. One interviewee, indeed, stated that volunteers in frontline services were *now 'more comfortable helping people with dementia and not trying to place them in day care.'* Another felt that staff and volunteers had moved away from the mind-set that people with dementia were not suited to mainstream services, making them more aware of what they could offer. A local Age UK representative from cohorts two and three commented that the DA support had made her realise how important spending time outdoors was to the well-

being of a person with dementia. Some interviewees also mentioned that they were taking steps to shape the attitudes of clients, as the following quote from cohort one illustrates:

*'If you have an existing group ... and you want to make the group more inclusive, you have to start with the existing participants. They have to welcome the newcomers who may have dementia.'*

Further, long term change in delivering services can also be expected as many local Age UK partners felt they had successfully adopted a new approach to working with people with dementia and thus to designing and delivering more inclusive services:

*'Now that we've got into the right mindset, [being dementia friendly] is more of a forethought and not an afterthought.'*

Examples for more inclusive services included the provision of lunch clubs, and music and singing sessions. The interviews revealed some of the tangible changes to their current generic services, such as offering reminders (activity time and dates) to service users living with dementia and including activities which provide a change of pace in group sessions, if the facilitator notices, for example, that participants with dementia are becoming 'restless'.

Encouraging local Age UK partners to think about potential service users with dementia has led to unexpected outcomes. For example when the inclusion of people with dementia into a new service was considered, one local Age UK in cohort one decided not to offer the service to those with more advanced dementia:

*'We have started a befriending service and we decided we will not offer it to people with more advanced dementia, because our volunteers are not trained. It wasn't a positive outcome, but it shows our awareness of dementia. We refer these people to specialist service providers.'*

Whilst the programme does not formally suggest adopting any particular approach with regard to how those with dementia should benefit, many delivery partners reported that services were geared toward older people in 'earlier stages' of dementia. Issues relating to how a person with dementia is conceptualised is returned to in Section 9.

#### ***d. To develop the concept of dementia friendliness into well-being services***

When applying for funding from the Big Lottery Fund's Well-being Programme, Age UK stated that the Dementia Friendly project aimed to embed the knowledge about the link between increased physical activity and the well-being of people with dementia. However, after the first cohort had completed the support days, an interview with Age UK National's

project team revealed a concern about how successful the programme was at encouraging local Age UK partners to focus on the link between physical activity and dementia when shaping their services. Although many interviewees in cohort one were looking at making their well-being services more inclusive and / or developing new activities, the national project team hoped that if all participant organisations in later cohorts had a support day with Dementia Awareness, the 'physical activity' and 'outdoors' aspect would come through stronger.

Of those interviewed in cohorts two and three, around half had created such activities, with dementia walks and sensory gardens being the most popular. Some reported that the support days with DA had enabled them to focus on what people with dementia *can* do and take a more '*adventurous approach*' rather than how to provide sufficient care, with a few referring to DA's '*positive risk taking*' or '*risk versus benefits* approach as contributing to a culture change in the way their organisation approached well-being services. As this element of the programme is of key importance and the offer of support days has been changed to achieve better outcomes, we provide some more extensive quotes from interviews with local Age UKs:

*'We used to have a risk averse attitude to delivering services, but we are now looking at making sure we are not closing down opportunities for people with dementia...the team have made commitments to take forward gardening activities, organising a summer day out, walks, and looking to develop 'men in sheds', working with a local dementia association.'*

Another partner reported that after initially believing that the DA support would not be particularly useful for them, it turned out to be very much so, and they are now developing dementia walks:

*'We weren't looking to expand activities, but [the DA support] changed the mind of the organisation. We used to keep people in secure rooms, delivering services in buildings, apart from the garden, we hadn't recognised to opportunity to get people safely into [outdoor] spaces.'*

Local Age UKs reported that they were now inviting people with dementia to balance and stability classes and COPD exercise groups. New activities included developing '*men in sheds*' for older men with dementia, walking football, walking cricket, a sports day and organising days out, such as trips to the seaside:

*'Having that bit of extra knowledge and training..., we took some residents to the seaside to have fish and chips. One lady started crying, as*

*she hadn't done anything like this for so long and had been stuck within four walls. So the training, it inspired us to do something a bit different.'*

However, some local Age UKs in cohorts two and three, while finding the support day with DA *'inspiring'*, felt that the offer did not fit with the strategic aims of their organisation, and another felt that the activities suggested by DA were somewhat *'idealistic'* and were not a priority for their organisation.

***e. To enhance the quality of life for people with dementia and their carers***

While the research team could not directly assess the programme's effect on the lives of people with dementia or their carers, the evaluation has shown that the activities of the programme are guided by a clear focus on enhancing the quality of life for people with dementia. The methods and resources used by the consultants are all based on the principle that the *voices of people with dementia* should be at the centre of making services more inclusive. The action plans and the interviews with local Age UK partners have confirmed that this principle had been adopted, and as the following quote from a local Age UK partner shows, all clients are likely to benefit from it:

*'We are now doing much more consultation with service users, which we didn't do before, asking them what they think. It's a really good thing to do.'*

A local Age UK partner from cohort one reported using dementia-friendly methods in these consultations with service users. An interviewee (from cohorts two and three) who worked with people with advanced stages of dementia felt the support had changed how they approached working with this client group:

*'I now focus more on improving the person's quality of life rather than focusing on the incontinence. People with dementia have high rates of depression..., so I'm trying to help improve mood by doing things they want to do. I did not previously look at it from this perspective.'*

Another interviewee suggested that their attitude toward people with dementia who approached services with a carer had now changed:

*'When advising someone with dementia, if a family member or carer is with them, we are clear on who our client is, who is asking for advice. If it is the person with dementia that person is our client and the other person is in a supportive role.'*

Most local Age UK partners felt that the programme had increased the confidence of staff and volunteers, resulting in better quality service delivery:

*'Staff are braver about delivering sessions to people with dementia, they now feel more confident and try to make sessions more fun and engaging, they wouldn't have been as confident without the training.'*

The programme's focus on carers appears to be less clear. Carers were mentioned only in some of the action plans and interviews despite being included in the aims of original proposal. The reasons for this are likely to be complex: firstly, the programme's main focus was on people with early stage dementia, as a group who can benefit most from inclusive services. These people are less likely to need care and be accompanied by a carer. Secondly, the focus on the voices and the needs of the people with dementia has meant a shift away from the earlier and perhaps more established thinking about dementia which focussed on the voice of carers and the difficulties they face.

### ***Working with local strategic partners and the wider community***

The action plans and interviews showed that local Age UK partners have concentrated on utilising their local networks to disseminate the learning from the programme. This included a variety of actions, from very simple ones, such as sharing the results of the environmental audit with the management of a rented venue, so everyone using the rooms can benefit from the changes, to more substantial co-operation with other local stakeholders. Many local partners have joined Dementia Action Alliances following the support days, and have got involved with their local Alzheimer's Society and with other Third Sector partners to use the knowledge gained through the programme and exert influence in the wider community.

Some local Age UKs in cohort one have reported that they are now commissioned by local authorities to provide adult social care services (home care, home from hospital, social prescribing) and are involved in local projects designed to promote the integration of health and social care services. An example of this is the *Care Navigator* pilot projects where local Age UKs are planning their work using the learning from the Dementia Friendly programme when training new staff and focus on keeping the needs of those with dementia in mind. One cohort one Age UK partner organisation is part of a local consortium developing a major new project to reduce loneliness and social isolation among older people and has taken on the role of providing dementia awareness training to other organisations in the partnership.

Some interviewees told the research team that after the support days and subsequent training, staff and volunteers felt better able to communicate with their own family and

friends, including, for example, encouraging them to seek an early diagnosis if they are having cognitive difficulties.

Most Age UK partners were holding dementia-friendly events to raise public awareness of dementia within their local communities; one interviewee has asked the consultants to speak at one such event. Another interviewee reported that without becoming involved in the programme she would not have had the confidence to hold a dementia friendly week in her local Age UK. As a result of this concentration on strengthening local networks through their action plans we can expect that local Age UK partners will have a higher profile as service providers to people with dementia and as experts in the field, as the following quote shows:

*'[Our city] is aiming to become a dementia friendly city, and we have a good relationship with the council – they often consult us and ask for our opinion, so we are hoping to influence them.'*

Thus, in the longer term, the programme is likely to contribute to raising the profile of local Age UK partners as service providers for people living with dementia and as experts in the field. A representative of a local Age UK in cohort one has expressed this very clearly:

*'Our goal, outlined in our strategic plan is that when people hear the word dementia, they automatically think of us.'*

Some local Age UKs reported benefitting from advice from both the consultants on how to frame inclusive generic services in the wider policy context around dementia and thus engage more confidently and hopefully, more efficiently with local and regional commissioning and funding bodies:

*'Before [the programme] we were almost embarrassed because we said we weren't specialist providers, yet [we] had service users with dementia coming to see the organisation. But [now] ... we realise that we are working successfully at this end, at providing mainstream services, so it has increased [our] confidence.'*

Some interviewees in cohorts two and three reported finding the case studies developed with liD particularly useful in mapping their services against the expectations of commissioners, as the following quote illustrates:

*'It has planted a seed of opportunities; we initially thought it was just about obvious things such as training and auditing, but through conversations*

*with Steve (liD) we realised there were gaps in the market and opportunities out there for funding.'*

Indeed, some local Age UKs in cohort one reported that they were planning to start income generating services, such as delivering dementia awareness training to local businesses.

Discussing the long-term outcomes of the project, one Age UK representative mentioned that they cannot report 'continuous improvement', the long term effects are better described as incremental change in organisational culture: *'It's more of a culture change. We have the basic tools we need [for future improvement].'* Others emphasised that such cultural change is taking place with the increased dementia awareness among staff and volunteers as they gain more experience of providing inclusive services:

*'I think the staff thought that this lovely old lady would come along and occasionally she would put on a cardigan inside out and we would look after them. And now they understand that we need to develop a different attitude – we are not doing something for people, we are doing it with them.'*

Some local Age UKs from cohort one emphasised that having staff as Dementia Champions was an important step towards making the investment in raising dementia awareness more sustainable. These members of staff were practically 'in-house' dementia awareness trainers, able to provide accessible and cost-efficient training to new staff. Having their own trainers also allowed some organisations to 'roll out' training to all their volunteers more easily. Some local partners reported that dementia awareness training is now part of the induction process, in other words, compulsory for all staff and volunteers. One local Age UK from cohort one has made more in-depth training available to those volunteers who were interested in becoming involved in providing specialist services.

The organisational change is expressed in efforts to make existing generic and well-being services more inclusive and to think about people with dementia when developing new services. This is done by listening to the voices of people with dementia – a local Age UK developing a new *Information and Advice* service was organising focus groups which included people with dementia at the time of writing this report. In a similar vein, another local Age UK representative from cohort one summed up the learning from the programme in this way:

*'The most important thing I've learnt: if you want extra advice, go to someone with dementia.'*

Finally, for some local Age UKs in cohort one, providing inclusive services to people with dementia has become part of their three-year strategic plan after their participation in the programme. Another Age UK representative also reported that participation in the Dementia Friendly Programme contributed to making dementia-related work a more important priority within their organisation:

*'Whatever we do [related to dementia] is included in the plans, and the board discusses it all the time, it didn't use to happen, but now it does. It's partly because of the political context, but the [Dementia Friendly] programme has pushed it further to the forefront.'*

Interviews with the project team support the (not particularly surprising) finding that it may take longer before all the outcomes of the Dementia Friendly Programme to emerge. Some local Age UK partners from the pioneer cohort (2012) have recently, almost three years after their participation ended, produced excellent resource materials relating to working with people with dementia.

A final note on funding the activities carried out and the changes implemented by local Age UK partners is in order here. All participating local partners were eligible for a grant of £5,000 to assist in the costs of implementing the programme, and all partners interviewed felt that the financial support helped them to gain maximum benefit from the Dementia Friendly programme. Most partners used the grant to pay staff who were involved in the programme and / or who had participated in dementia awareness training resulting from the action plans. The grant was also used to pay external trainers delivering dementia awareness training and events, to make changes to the buildings (signage, equipment), and to fund the production of information material.

## **Summary**

- The consultancy support days helped local Age UK partners to create a framework for becoming more dementia-friendly.
- All local Age UKs benefitted from the organisational audit, with many finding it to be a useful reflective tool. Many local organisations have made changes to buildings, signage and printed materials.
- Following the DA support day, many local partners developed new dementia-friendly physical activities or well-being services.
- Providing the tools to carry out environmental audits without consultancy support was not as effective as direct learning from an expert consultant.
- While some respondents found the DA support day 'inspiring' others did not feel it fitted in with the strategic direction of their organisation.

- Nearly all local Age UKs interviewed were using the support received to raise dementia awareness among staff and volunteers, which contributed to a more positive, inclusive attitude toward service users living with dementia.
- Many local Age UK partners utilised local networks to disseminate the learning from the programme and had successfully secured funding to deliver local services and develop good working relationships with local funders.

## 5. Experiences

This section draws on the experiences of local Age UK partners, consultants and the project manager and is organised in three sub-sections: firstly the expectations of local Age UKs are summarised; followed by a look at the elements of the programme which have been successful; and then a summary of some of the key challenges which have emerged.

### ***a. Expectations of local Age UKs***

All local Age UKs representatives who were interviewed were asked the reasons why their organisation wanted to become involved in the Dementia Friendly Programme and to recall their expectations at the outset. While a few reported having no real expectations, many provided a range of responses including: the need to respond to increased demand from clients; a wish to improve mechanisms of collecting feedback from clients; a desire to better involve and communicate with people who have dementia; plans to network with other local Age UKs; a desire to strengthen partnerships; and to benefit from an *'independent observer'*. Many hoped the programme would assist them in adopting a *'whole organisation approach'*, whereby staff and volunteers in all roles, from *'cleaners to managers'* would gain a greater awareness of dementia and *'challenge current values and assumptions.'* While a few local Age UKs hoped to apply learning to specialist services, for the majority the main focus was on generic provision. In terms of the expected effects of the programme some local Age UK partners wanted to see changes across all their services, whereas others had less ambitious aims, hoping the programme would give their organisation *'a nudge in the right direction.'*

Overall, local Age UK partners felt that their original expectations had either been met, or that they were heading in the right direction (for those in cohorts two and three who had not yet completed the programme). A few felt that embedding change throughout the organisation and having the resources to develop new services was more challenging than expected (discussed in more detail when challenges are considered below).

### ***b. Successful elements of the programme***

On the whole, local Age UK partners reported that the programme was well organised, flexible and relevant to their needs, with all reporting that it had been a positive experience for their organisation. For example one partner said:

*'the mix of setting the scene through the cohort meetings, followed by practical support through consultancy was an excellent model'*.

Another participant suggested that the programme's design was so effective that it should be used as a model for other third sector services, including those who do not work exclusively with older people.

A few partners outlined that the programme was manageable, practical and easy to engage with:

*'I was pleasantly surprised at how easy it was. I expected it to be more arduous really, [but] it is a very user-friendly project.'*

Others also liked the fact that changes could be made to the action plan as they engaged in the implementation process. Learning directly from the example of the consultants was also highly appreciated, as one Age UK partner said:

*'I read [about the dementia-friendly principles] lots of times before but it was different when it was actually done.... When you see something, it is completely different from reading about it.'*

Finally, some local Age UKs mentioned that they benefitted from having time to focus on one area of their work only (i.e. shaping the organisation to become more inclusive):

*'We are such a busy organisation - when you come up with an idea it tends to get lost in the medley of things. So with this programme we could concentrate our minds on what we want to achieve and push it all the way through.'*

### **Consultancy support**

On the whole local Age UK partners were satisfied with the work of the consultants, with all learning, or applying something new, as a result of the support. Many local Age UK partners felt that they had learnt a great deal by observing how the consultants engaged with people with dementia (during the environmental audit):

*'It was very good to be able to see [the consultant] interact with this lady and for us to learn from that.'*

Further, those interviewed in cohort one felt that the consultants were flexible in their approach, adapted to local circumstances and responded to the needs of participants, which was not always easy:

*'The consultant brought the best out of the participants on the first day, and it required his skills. No, it wasn't an easy task (laughing).'*

Local Age UKs from all cohorts linked the positive outcomes of the consultancy support to the personalities of both key consultants from DA and liD, who were described as approachable, enthusiastic and by some, even as *'inspirational'*, with the ability to motivate staff and volunteers and thus influence change within their local Age UKs. It was also mentioned by local Age UKs in cohort one that both the key consultants tended to do more to help local partners than they were supposed to. Another consultant from DA was also described by some as *'positive, upbeat... well planned and energetic'*, another participant from cohorts two and three felt he could talk to the key consultant from liD *'for hours, as he is full of useful information.'* Finally, all except one of those interviewed from cohorts two and three welcomed the opportunity to engage with both consultancy organisations, with many feeling they *'got something different from both'*. Some interviewees from the first cohort who chose to work with both consultants also mentioned that the two consultants *'complemented each other'*.

The two consultants interviewed for this report welcomed the opportunity to work with local Age UK partners, Age UK National and with each other. Both of them appreciated that local Age UKs on the whole embraced the programme and felt that the commitment at local level has contributed greatly to the success of the support days. They were aware that it was often difficult for staff at local Age UKs to fit the support days and the additional work into their busy schedules.

The liD consultant felt that organisational audits were becoming shorter towards the end of the programme, as the increased public awareness around dementia-friendly societies meant that local partners in cohorts two and three were on board from the start and there was less need to explain the rationale of making generic services more inclusive. This freed up time to think about how the organisations fitted into the local care economy and how they could better promote their services. The DA consultant was happy with the change to the structure of the offer to local partners, as he felt that the *'physical activity'* support day was more in line with the organisation's strengths than the work they carried out with cohort one and because local organisations in later cohorts had more time to concentrate on embedding physical activity in their work.

The consultants also felt that it was relatively easy to work with Age UK National on delivering the support to local partners and negotiating changes to the offer. Both of them felt that their relationship with Age UK National was based on mutual trust which facilitated solving problems that sometimes arose during the programme.

### ***Cohort meetings and workshops***

Nearly all interviewees reported that meeting other local Age UKs at cohort meetings to share ideas and learn from each other had been a valuable element of the programme. For

example, one partner was developing home audits, and another was organising day trips to the seaside as a direct result of talking with other participants at the meetings. Of those who attended the workshops all reported that they had contributed to learning, and provided practical help and advice that could be applied in their own local settings. One interviewee stated that they preferred the workshops to the meetings, feeling they were a better use of time due to the focus on learning.

### **c. Challenging elements of the programme**

Overall the programme was very successful although there were three challenging elements that arose during implementation, which are discussed in turn below.

#### **Getting started: signing up for the programme**

A small number of local Age UK partners in cohort one mentioned that contracting with Age UK National took longer than expected. They felt that a discussion about the content of the contract at the first cohort meeting might have speeded up the process:

*'We had one email about the contract – perhaps a discussion about exactly what we were signing up to would have been useful.'*

#### **The cohort meetings**

Participants provided a variety of views around the cohort meetings. Some found these very useful both in terms of content and the networking opportunity they offered, appreciating the need to have such meetings. It was also reported that these were some of the few occasions when they could meet other local Age UK partners and exchange good practice. However, a few felt the meetings would have benefited from a tighter structure, with a suggestion that they needed to be more *'dynamic'*, and that too much time was allowed for reporting back to the facilitator, while other participants sat quietly, waiting for their turn:

*'They asked people to prepare a five-minute talk and some people were just much longer than that, and there were a lot of people, so by the time you got through that it was an hour and half. I didn't think it was a particularly good use of time.'*

Some from all cohorts felt that the meetings could have been designed to better facilitate learning, however, as learning styles vary a great deal, suggestions included *'hearing more from the experts'* and *'engaging in more actual group work'* and sharing action plans from all cohorts. Specifically in the first cohort, one participant would have preferred more detailed information around the programme itself:

*'I would have liked [the first cohort meeting] to be more factual and structured: this is what we expect of you and run through the nuts and bolts of the project, like the contract and the timeline, rather than finding out what others were doing. We could have found out about each other's projects later.'*

A number of interviewees felt that the meetings could have been shorter, suggesting that the meetings took up the time that would have been better spent on implementing the new ideas. Some in all cohorts felt it was travelling to London that took up too much of the day, perhaps making participants more critical, as they had to be away from their busy jobs for a whole day. A few also felt that there were too many meetings, with three participants in cohorts two and three referring to the meetings as an obligation:

*'I felt obligated to go, I didn't find the days useful or constructive or stimulating.'*

A local partner from cohort one mentioned that cohort meetings were *'not very productive towards the end'* of the programme, perhaps because that by that time members held very similar opinions:

*'I was coming to the meeting expecting to learn something new or listen to people who see things differently but by that time I think we were all of a similar mind and it was almost 'just in case you haven't listened the first time.'*

### **Consultancy support days**

Although in preparation for the programme, local Age UK partners were provided with supporting information<sup>4</sup> a few partners felt they would have benefitted from being provided with even more information prior to the consultancy support days, so they would have been *'better prepared'*. It was suggested by a participant in cohort one that the programme would have benefitted from a mapping exercise of the expectations of local partners before the programme was designed:

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<sup>4</sup> Local Age UK partners were provided with supporting information about the programme, including links to the professional pages on the website of Age UK National, with all the documents produced in the pioneer programme. Local partners were asked to complete an Expression of Interest (EOI) which allowed them to comment on areas they wanted to focus on. Before the consultancy support days took place, lead contacts at local partners were sent detailed information on what the consultancy support could do; and local partners in cohorts two and three were also able to ask for 'bespoke' support on their third support day.

*'I think that somebody should have asked the participants what their expectations were before we attended – it seemed [the consultants] had set ideas [about] what they were going to deliver but we weren't quite sure what we were going to get. Yes, we had huge benefits – but possibly this wasn't what people were expecting.'*

Similarly, one partner from cohorts two and three suggested that local Age UKs could have been provided with a questionnaire beforehand, so they could express unique challenges or support needed at the local level (this is returned to when challenges to the programme are discussed).

While cohort one reported consistently that the support offered by the consultants was excellent, the findings from cohorts two and three were more mixed. For example an interviewee from cohort one described a visit from the liD consultant as *'a very packed day'*, focusing on the *'voice of people with dementia'*, an audit of the reception area and an assessment of some communication materials. Yet in cohorts two and three, some reported not getting as much out of the first day of support with liD as expected, with a few stating that it did not feel tailored to the needs of their organisation. In some cases interviewees expressed very positive feedback for one consultant, but were less enthusiastic for the other. Some of these comments appeared to be linked to the direction an organisation saw itself as taking, with a few iterating that negative feedback was not the fault of the consultant. Other comments were related to the structure of the day itself: two partners from cohorts two and three suggested that whilst they found the day useful, they were *'expecting more'* from the initial meeting with the liD consultant. Another one said that

*'We were expecting an audit, but it was more general guidance, which left us to do a lot of the implementation...we expected more tangible outputs from the first session so maybe this was a mismatch of expectations.'*

Some suggested that the support day with liD would have benefitted from the consultant having a greater awareness of what each local Age UK partner did. Two partners felt the information provided on the first day was too *'general'* with one referring to it as *'feeling like a board room meeting'*.

While one interviewee described the support received from DA as generic, referring to it as *'laissez faire'*, other less positive feedback tended to be around its perceived relevance to local Age UK partners, with two reporting that it did not fit in with their organisation's strategic aims. A few others suggested that support from DA was *'very useful but idealistic'*

and another stated that they would have preferred the support if it had looked at more examples on how barriers to using outside spaces could be overcome.

Some local partners in all cohorts reported that they had to wait longer for liD to respond to requests than they had expected, however these local Age UK partners were aware that liD consultants had to divide their time among several participants. Equally some partners mentioned that delays were due to pressures on both sides: for example, one local Age UK wanted service managers to be involved in the support day, so finding a suitable time that was convenient to all was problematic.

The two consultants interviewed for this report did not mention any serious problems relating to the support days, although the project staff at Age UK National felt that several local Age UK partners cancelled the support days at the last minute. The project team felt that delivering consultancy support to cohorts two and three in parallel, with 31 organisations having a choice about booking their third support day involved a lot of administration and was at times challenging. The consultants mentioned that local organisations sometimes took longer than expected to contact them about preferred dates, and although they were aware of why these delays occurred, it sometimes made the arrangements difficult, in the words of one consultant: *'the longer they left it, the fewer days were available.'* The DA consultant was also aware that some local partners in cohorts two and three struggled with developing outdoor and physical activities with their particular client group, however there was evidence that other organisations benefitted greatly from having more time devoted to this element of the programme.

Commenting on their relationship with Age UK National, the consultants felt that discussions about their contract took an unexpectedly long time at the start of the programme and felt that these should have taken place earlier. They also felt that they would have benefitted from more administrative support from Age UK National at the beginning of the programme, but they were happy with the level of support they received later.

## **Summary**

- Local Age UK partners felt that their original expectations had either been met, or they were heading in the right direction. The programme was perceived to be well organised, relevant, flexible, manageable and practical.
- Most Age UK representatives interviewed for this report emphasised that they had benefitted from working with the consultants.
- Some local Age UK partners in cohorts two and three felt the support was not sufficiently tailored to their organisation (these comments related to both liD and DA).

- Most respondents appreciated the opportunity to network and learn from their peers at the cohort meetings.
- At the same time, many participants felt the meetings could have been structured differently to better facilitate learning, and long travelling time was a challenge for busy organisations.

## 6. Challenges to the programme at the local level

In this section we explore the challenges local partners from cohort one faced when implementing their action plans in the longer term. The interviews we draw on here were carried out nine to ten months after the formal participation of this cohort ended. The discussion is structured according to the five-domain approach referred to in previous sections. The research team felt interviewees from cohort one were honest and reflexive about the challenges they had faced and perhaps a little over critical about themselves and their organisation.

### **a. *The voice of people with dementia***

All local Age UKs in cohort one felt that engaging people with dementia was of key importance. Having seen the consultants and some of the pioneer cohort using video recorded case studies of local people living with dementia for awareness raising purposes, some in cohort one planned to produce similar videos. However, the implementation of this was more difficult than expected, and one respondent felt rather disappointed at the lack of success: *'Organising the film clip was very difficult – no one wanted to give their face to it. Even having a photo taken for the local newspaper seems difficult'*.

Another local Age UK reported a somewhat related challenge. They felt that despite their best efforts they had not succeeded in encouraging their clients with a dementia diagnosis to go out more and become more physically active. The interviewee felt that their older clients, many of whom were housebound, were *'just not interested'* in going out. Thus she felt that their action plan created during the programme and the needs of their clients were somewhat mismatched:

*'The programme was aimed at people who are more interested in going out and being active. Our clients are perhaps older and quite happy to stay in and just have a chat with a volunteer.'*

### **b. *'The place'***

Some local Age UKs anticipated that by sharing the results of the environmental audits and their newly gained knowledge about making buildings accessible to people with dementia with other local organisations, they could achieve changes to the buildings where their services were provided. One particular local Age UK felt the timing of the programme was ideal, as the new local authority owned premises where they would eventually have many of their groups were being designed and constructed. However, their expectations were not completely fulfilled, as the following quote shows:

*'We didn't succeed in convincing the Council that they need to follow the dementia – friendly guidelines, even though I showed them [the] Age UK... report. ... They don't care who may be disadvantaged by that.'*

The situation was further exacerbated as the interior designer declined an invitation to meet the consultant who had offered help with designing the signage. The local Age UK hoped that there would not be any serious problems for people with dementia accessing the new venue, but were prepared to refer the owners of the building to the appropriate sources if they had the opportunity.

In a somewhat similar case, another local Age UK had carried out an environmental audit of the church hall where their lunch club takes place, hoping that everyone who uses the venue would benefit from the proposed changes. The information and the suggestions for modifications were, however, not taken up by the owners and the Age UK were forced to retain the results of the audit and wait until the opportunity to implement changes arose again in the future:

*'We cannot force the church hall, all we can do is make them aware what they need to do improve the experience of people with dementia. Hopefully when they have refurbishment in a few years' time, they will think of it.'*

Some partners wished to make more substantial alterations to the physical environment, such as redecorating the building, using a different colour scheme or replacing several bathroom fixtures. As they did not have the necessary funds, only smaller changes have been implemented, and only one at a time, as they receive donations. Similarly, many local partners redesigned their printed information materials soon after the support days but had to wait several months, until they had run out of the old copies, before they could order the new prints.

### **c. 'The people'**

The challenges discussed under this heading are related to the people working within local Age UKs – the colleagues and volunteers who were not always as enthusiastic as the local co-ordinators of the programme. Some of these challenges were flagged up a few months after cohort one completed their participation. A member of the Advisory Group, delegated by a local Age UK from the pioneer cohort commented that:

*'This work is challenging because you have to take so many people with you – people who don't necessarily see how this programme is impacting their work'.*

Indeed, six months later some interviewees from cohort one appeared extremely busy yet still enthusiastic, but others sounded rather tired. One of them stated that *'managing the change takes a group of people, not only one or two'*. This person felt that in a large organisation like his, it would take a panel of people from the very beginning to co-ordinate the implementation of the action plan. In a similar vein, another interviewee felt that different staff should have attended different workshops and cohort meetings, rather than the same one or two members of staff, as this could have resulted in a greater sharing of the responsibility and the workload later.

Two interviewees mentioned that other clients may resist the inclusion of people with dementia in their groups, though one of them emphasised that this has only been an issue in groups where frail older people met newcomers with more advanced dementia:

*'Last week we had a lady, with quite advanced dementia, who wanted to kiss everybody, and they objected to it, which I thought was quite sad. And they did complain and one or two people stopped coming.'*

#### **d. Lack of resources**

The most common challenge faced by local Age UKs was the lack of resources, in particular time and financial resources. As mentioned previously, many have reported that the lack of funds hindered making some changes to the physical environment and the printed materials. The lack of time and /or the shortage of staff also meant that some relatively inexpensive changes had not been implemented. One local Age UK, for example, had only achieved what they referred to as 'quick wins' in their action plans, such as changing the signage and the processes around staff training. More complex elements of the plan have been delayed, because other, more pressing tasks, such as writing a funding application or arranging urgent help for a client have been given priority: *'We've got a bit stuck on developing the walks – that's basically due to the lack of time and having to deal with [other] things on an ad-hoc basis. We have to prioritise resources'* said one interviewee, who is a middle manager.

#### **e. Networks**

Almost all interviewees from cohort one reported that they had joined their local Dementia Action Alliances (DAA), with one of them belonging to two different Alliances. Local Age UK partners saw these groups as important for making local communities more dementia-

friendly, but also as opportunities to position themselves as service providers. One local Age UK reported that they simply had to be involved in the DAA but they were *'far ahead'* compared to most other members, who had just started to think about people with dementia and as a result, the local Age UK was often critical of plans emerging in the DAA.

A few local Age UKs from cohort one mentioned that receiving referrals from statutory bodies in health and social care had proved challenging, despite having formal agreements in place to provide adult social care services needed in the area. The lack of referrals meant that the local organisation did not receive the funding which they had counted on when developing the services. Other local Age UKs from this cohort also mentioned that they were trying their best to attract referrals from health and social care bodies by attempting to 'promote' their inclusive services and newly trained staff.

These challenges, especially those in relation to 'the people' and 'resources' should be kept in mind when designing arrangements for further support to local Age UK partners and more generally, when thinking about the sustainability of the programme. In addition, although it is important that senior officers of local Age UKs are involved in the dementia friendly programme, where a senior staff member co-ordinates the implementation of the action plan there is more risk of time conflict. Finally, local Age UK staff who are 'passionate' about shaping services and pushing for organisational change may need more individual recognition and support to ensure that the local and national organisation can continue to benefit from their knowledge and experience.

## **Summary**

- The most common challenge faced by local Age UKs when implementing their action plans was the lack of resources, both in terms of staff time and financial resources.
- Local Age UKs benefitted from having a team co-ordinating the implementation of the action plan rather than only one co-ordinator, who was often a very busy senior staff member.
- Staff who are 'passionate' about making services more dementia-friendly would benefit from more individual support to ensure that their knowledge and experience is fully utilised.
- Participation in local Dementia Action Alliances and working with statutory organisations were seen as challenging but essential to achieve longer term impact.

## 7. The Advisory Group

The Advisory Group, set up to guide the work of the Dementia Friendly programme, has been a very important element of the initiative. The 'core' Advisory Group included Age UK project staff, three local Age UK representatives from the pioneer cohort and the two consultants. The initial plan was to also include people with dementia, however, the group decided to seek other ways of including their voices. In addition to the core group, other relevant stakeholders were invited to attend the meetings. 'Invitees' included representatives from a number of Age UK departments, such as Information and Advice, People and Performance, and the Policy Team. At the last three meetings (September 2014, January and April 2015) several 'invitees' from Age UK National were present, as one of the core members of the group described it: "*we could hardly fit into the meeting room*".

The goals of the Advisory Group set out in the *Terms of Reference* continued to be modified after the group had started to meet, and all members of the group who were interviewed for this evaluation agreed that the goals were 'evolving'. The final *Terms of Reference* included the following: to provide an opportunity to bring together local organisations and Age UK personnel to discuss how they can work together in developing services for people with dementia; to discuss and disseminate examples of good practice around the development of dementia friendly services; to provide feedback and recommendations to Age UK on the development of dementia-friendly services and relevant resources; and to assist in the development of an exit strategy for the Dementia Friendly Programme.

Advisory Group members representing local Age UK partners emphasised that, from their perspective, the key role of the group was '*to raise the profile of working with people with dementia within Age UK [National]*' and '*to establish a direct link from the local to the national level.*' They felt that these goals were intertwined. It was through sharing information about the local level work that the Advisory Group hoped to encourage the national organisation to become more involved in dementia-related work, including increased efforts around research, lobbying and supporting the dementia-related work of local partners. As the work of the Advisory Group progressed, an additional goal of supporting Age UK National itself to become more dementia-friendly also emerged.

### ***a. Supporting the delivery of the Dementia Friendly programme***

All core members of the Advisory Group agreed that at the beginning of the programme the consultants and the project team had learnt a great deal from local Age UK members who provided valuable feedback on their experiences of participating in the pioneer cohort and of implementing the plans that had come out of their participation. Local Age UK members

felt their input was both highly valued and useful, as it complemented the knowledge and the perspective of the consultants:

*'[we brought] a local perspective. Maybe it helped the consultants as they went out there. We are getting feedback from clients and we are all at different stages.'*

Both consultants agreed that the delivery of the Dementia Friendly programme was improved by these early discussions.

In the later stages of the programme, however, it was suggested that the Advisory Group *'did not do much advising'* on the programme. An Advisory Group member thought that the group had moved away from advising and had become more of a forum for information exchange between the local and national levels of Age UK and a *'platform to learn and reflect.'* Another interviewee felt the local Age UK representatives were using the group to *'catch-up'* with the delivery of the programme. This was thought to have come about because although the consultants reported to the local Age UK partners in the Advisory Group meetings on the work in the cohorts, most decisions were made in separate planning meetings with only the two consultants and the project team present. Local Age UK members saw this division of labour as natural and emphasised that the atmosphere in the Advisory Group was open and supportive throughout, with all members having equal power. Indeed, the planning meetings appeared to reflect the flexibility and commitment of the project team and the consultants, thus allowing the *'full meeting'* of the Advisory Group to focus on the newly emerging goals.

Two interviewees felt the Advisory Group did not focus enough on the delivery of the programme itself, with one of them feeling *'quite removed from the project and the cohort.'* Another interviewee was more positive:

*'The cohorts were not neglected .... A large part of every agenda [was about the cohorts]. We needed a balance: if there is no change in the national body, then the local learning will not be put to good use.'*

Towards the end of the programme the Group focussed more intensively on the *'original'* aims of the Advisory Group again, contributing to the development of the exit strategy. Interviewees felt that the strategy and plans for the legacy of the Dementia Friendly programme were discussed in-depth and their input was valued and reflected in the strategy. The plans for programme's legacy and the future role of the Advisory Group are discussed in Section 8.

### ***b. Shaping Age UK National to become more dementia-friendly***

Not long after the Advisory Group was formed it was agreed that a discussion with Age UK National about the local experience of providing services for people with dementia was important and Age UK National personnel were subsequently invited to the Advisory Group meetings. While local Age UK representatives felt it had taken longer for their invitation to be accepted than they had expected, they all agreed that the first meeting of the 'extended' group (including Age UK National representatives) in September 2014 was a great success, with one of them stating:

*'I could see that there was an opportunity for something special to come out of local Age UK people working together with ... people from the national office.'*

The following two meetings were also judged to be successful, with more senior Age UK National personnel engaging in what was felt a productive dialogue with Advisory Group. Interviewees agreed that the Advisory Group was instrumental in engaging the local and the national levels of Age UK in a dialogue about dementia-related services.

The first tangible result of the Advisory Group influencing the national organisation was that, following their feedback, a planned new publication aimed at people living with dementia and their carers was modified to be more dementia friendly. Advisory Group members saw this as evidence of Age UK National taking their input seriously. Interviewees also felt that the Advisory Group generated a lot of interest and *'quite a bit of impact'* in the national organisation and they were optimistic about the longer term effects that the discussions in the group had on Age UK National personnel:

*'Everybody who came from other departments was really enthused and there were actual actions that they were going to do in their teams.'*

However, although some progress had been made, when interviewed at the end of the programme, Advisory Group members felt that there was still work to be done to raise the profile of dementia-related work at the national level. They felt very strongly that the learning from the discussions of the 'extended' group should be widely shared:

*'[it should] not [be] just a task and finish group but we have to disseminate this across the whole network.'*

They also emphasised that while making Age UK National more dementia-friendly is an important goal in its own right, it is also a way in which the learning from the Dementia

Friendly programme can be embedded in the national organisation. The Advisory Group discussed ways in which their work may be taken forward, which are discussed in Section 8.

**c. Discussion of the work and impact of the Advisory Group**

All interviewees felt that the Advisory Group had a strong impact, elements of which are discussed above. Evaluating the overall effect the Group's work, a local Age UK member focussed especially on the impact on the national organisation, as the following quote illustrates:

*'The group had more impact and value than I had thought at the beginning... The fact that so many departments have come along to the group perhaps gave it more use and value than we originally anticipated.'*

Another local Age UK representative commented that the dialogue between the local and the national level staff was perhaps part of a broader change:

*'There has been a recognition that the local level delivery is very important for the national teams. Maybe this awareness was there before, but it didn't come across, whereas now it comes across. It feels a stronger two way relationship.'*

Another said:

*'Our presence opened eyes to what is happening locally, and we listened to the national developments and took it home to our organisations.'*

Indeed, local Age UK Advisory Group members highlighted that their local organisation had also benefitted from their work in the Advisory Group, as the following quote illustrates:

*'Working towards influencing Age UK policy helped us reviewing our own policy and practice locally.'*

One of them mentioned taking away the learning about the benefits of physical activity for people living with dementia.

While acknowledging the overall positive effect of the Advisory Group, members also expressed some criticism about the perceived lack of planning and structuring of the Group. A few members felt that the Group would have benefitted from the creation of a better defined work plan before the start of the programme.

*'We need a clearer definition of what the role of the Group is and what we are trying to achieve... defined right at the beginning, so the impact can be better. There have been many changes as the programme went along, it has been difficult to keep to the original terms of reference. It worked out for the best in the end, but there has been a little bit of confusion at times.'*

One member thought that the Advisory Group should have started to work earlier, not only a few weeks before cohort one started, as this would have allowed the local Age UK members to have a stronger role in shaping the offer to the local partners. Similarly, both consultants felt that had they had more time at the start of the project to 'fine tune' the plans, the 'split' structure of support days could have been introduced much earlier for the first cohort, ensuring a stronger focus on physical activity in cohort one. A few interviewees felt it would have been better to separate the two 'roles' of the Advisory Group, although they agreed that the change of aims over the course of the programme was a natural development, especially as the Dementia Friendly programme was the developmental element of the portfolio of programmes funded by the Big Lottery.

Finally, some interviewees felt that having clearer aims for the Advisory Group would have helped the internal review of their work at the end of the programme. Indeed, one of them commented that there was no review of their work:

*'We haven't discussed whether the Group have met its goals set out at the beginning'.*

Another interviewee, however, was of the opinion that that the work was reviewed, albeit briefly, and this discussion benefitted from the input of invitees from the national organisation.

#### ***d. Experience of participating in the Advisory Group***

Describing their experience of working in the Advisory Group, all members interviewed for this research mentioned that the atmosphere in the Group was open and respectful. Two members said that they were 'sorry' when the group disbanded. Local Age UK members of the Advisory Group felt that working in the Dementia Friendly programme allowed them to 'take time out' of their everyday work to focus on just one aspect of their activities. They felt that being involved in the work of the Advisory Group personally benefitted them, as getting together with others who shared their passion for working with people with dementia was very motivating.

The consultants and the project staff also described the experience of working in the Advisory Group as very positive. However, they said that as the national level organisational change gathered momentum towards the end of the programme, additional planning meetings and the tasks and responsibilities emerged which increased their workload significantly beyond that originally planned.

### **Summary**

- The Advisory Group was instrumental in the successful delivery of the Dementia Friendly programme primarily through bringing together local Age UKs who participated in the pioneer cohort, the consultants and the Project Manager at Age UK National.
- The Group were seen to have played a crucial part in encouraging the national organisation to take steps towards becoming more dementia-friendly.
- Members agreed that the Advisory Group should have started to work earlier, allowing more time for 'fine tuning' the structure of the offer to local Age UK partners.

## **8. Sustainability**

In this section we present information on plans for the Dementia Friendly programme's impact beyond its current funded lifetime, and the first steps taken to implement these plans, drawing on evidence from the interviews.

### ***a. Planning the legacy of the Dementia Friendly Programme***

To ensure that the longer term impact of project is maximised, a number of ongoing activities are planned. The strategy was developed as the programme progressed. It was discussed in cohort meetings and in the Advisory Group, where the consultants and former members of the pioneer cohort could contribute. Former cohort members gave information on what resources they needed / would have needed after their participation ended, and discussed their experiences of implementing their action plans. The strategic aim is to ensure that the learning from the Dementia Friendly programme is shared and incorporated in future work at both the local and national level.

#### *Resources*

In addition to the Dementia Friendly Toolkit, and a resources guide which are to be produced by Age UK National as part of the exit strategy, consultants felt that the resources produced by individual local Age UK partners in the Dementia Friendly cohorts should also be widely shared and promoted.

#### *Dementia Peer Support Network*

The '*Dementia Peer Support Network*' was launched in March 2015 and is a peer network designed for all local Age UKs (not just those who participated in the programme), to access ongoing support from their peers and from Age UK National. The network is being co-ordinated by an officer at Age UK National and further support is to be offered by liD. Plans for the following 18 months of the network were presented and discussed at the launch meeting, and the Project Manager felt that the proposed agenda covers a wide range of topics, such as dementia friendly services, specific services for people with dementia, the political framework and funding. Interviews with cohort members revealed that expectations vary a great deal, with some wanting to meet with peers and share experiences, and others wanting to develop more strategic co-operations. Participation in the network is voluntary and there is no specific funding available for local Age UK partners to participate. At the time of writing this report it was, therefore, unclear how many local Age UK partners and from which regions of England will take part in the activities of the network.

### *The Advisory Group*

The Advisory Group completed its work in April 2015, however the three local Age UK members are happy to be involved in future work, on a voluntary basis. They perceive that their future involvement is dependent on how the Dementia Support Network takes shape, what activities the participating local Age UKs (will) engage in, and what support they (will) need. As one of the local Age UK representatives commented:

*'there is a role for the Advisory Group, as issues come up, but only if something really prevalent comes out of the network.'*

Members of the Advisory Group are ready to be involved in a number of different ways, for example to consult or give a talk to members of the peer network. They do not envisage further 'physical' meetings, only 'virtual' meetings, for example video or teleconferences.

Advisory Group members stated that they were happy to follow the emerging work of the peer support network and wait for the co-ordinators of the network to contact them when their input was required. However they were also prepared to take initiative, if required:

*'As long as the dementia network is being led and supported, we would be on the periphery, ready to step in if we are needed. But if it falls by the wayside, then I will raise whether we need to work as a group again.'*

They felt that their continuing support was relevant, as they had specialist expertise:

*'We have operational knowledge and we are getting feedback from [clients] and we are all at different stages. The experience of the consultants is valuable, but sometimes we have a very different perspective of how things work practically.'*

The two consultants, who were also members of the Advisory Group, have been added to the 'pool of experts' who regularly work with Age UK.

Finally, supporting Age UK National's longer term organisational change to become more dementia-friendly is also an important part of ensuring the longer term impact of the Dementia Friendly programme, and this aspect directly incorporates the learning from the programme.

### ***b. Discussion of plans to ensure the programme's long term impact***

In this section we discuss current plans for ensuring the programme's long term impact (the exit strategy, the dissemination of resources and the Dementia Peer Support Network, including ongoing support from members of the former Advisory Group) and examine the extent to which these plans meet the long term support needs of local Age UK partners. Desired types of long term support which have been suggested by local Age UKs in the interviews, but are not included in the current plans, are also discussed here.

Members of the Advisory Group felt that the exit strategy incorporated input from all stakeholders and was suitable for its purpose, however, members of the project team felt that if they had more time, they could have produced a more detailed plan. As for disseminating resources, some interviewees felt that access to existing dementia-friendly resources on the Age UK website is not very easy to navigate and could be improved. Cohort members reported that finding information on the LOOP<sup>5</sup>, or even logging onto the LOOP was often too time consuming and consequently some of them did not use this platform regularly. At the same time, some cohort members felt that webinars may be an effective medium to share information and were looking forward to future webinars. Improving access to resources on the Age UK website and on the LOOP is indeed part of exit strategy (which will be implemented in the near future).

A few local Age UK partners reported that they would like Age UK National to take the lead in disseminating a broader range of relevant information (such as progress in related policy areas or news from the national media) directly to local partners. One local partner suggested that a quarterly newsletter dedicated to dementia-related topics would be an ideal format.

As for the *Dementia Peer Support Network*, the discussion here focusses on the extent to which the plans known to the research team meet the expectations of local Age UKs from all three cohorts. Most interviewees felt it would be beneficial to have further support once their participation in the programme came to an end. Local Age UKs from all cohorts felt it would be useful to evaluate the implementation of their action plans six months and a year after the final cohort meeting, to reflect on what had been achieved and how to move forward. Some local partners prefer to have these reviews in a one-to-one format with the consultants, while others felt that keeping in touch with cohort partners would be the best way to discuss '*successes and pitfalls*'. It was suggested that networks would be more beneficial if virtual communication, such as video conferencing could be developed, to ensure that local Age UKs did not have to spend too much time travelling. It was further

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<sup>5</sup> This is an online communication platform only available for local Age UKs who are registered users.

suggested that an informal network would be a more useful format for receiving and giving support, so that the local Age UKs could ‘*dip in*’, dependent on their capacity.

Local Age UKs also listed a few areas in which they needed longer term support, including: exploring ways of overcoming the barriers in applying what they had learnt on the programme, for example when working with statutory bodies in the health and social care system or with care home staff; and how to secure funding for inclusive services and new, dementia-friendly well-being services.

Potential challenges to the success of the *Dementia Peer Support Network* were also mentioned by some interviewees:

*‘The network is going to be difficult to access, because of the cost of participating in the group – travelling and freeing up the staff... The idea is very good, but even if we have a session in [the region] ... that’s quite an expense.... Those sessions really have to offer something very positive for the organisations to say yes, ... because there is no external funding for it.’*

While many interviewees mentioned that ‘virtual’ meetings through the use of Skype and video conferencing could help, there is potential risk involved in some local partners lacking the necessary technical background to join the meetings, and those experiencing technical problems may be discouraged from attending ‘virtual’ meetings.

The final issue relating to the long term effects of the programme is how it will fit in with other dementia-related projects that are now run by Age UK National. Members of the Advisory Group expressed their concern that the Dementia Friendly programme may become just one of these parallel projects, which include the *Integrated Care Project* and the *Dementia Pilot Projects*. They emphasised that it is key that the Dementia Friendly programme and its legacy receives sustained attention so that it can achieve the greatest possible effect. It was also felt important that the dialogue between the local and the national level within Age UK continues and remains a prioritised element of Age UK’s dementia strategy.

## **Summary**

- Plans for ensuring the longer term impact of the Dementia Friendly Programme are outlined in the exit strategy. The main elements are: the Dementia Friendly Toolkit; the resources guide; the *Dementia Peer Support Network* and providing ongoing support to the *Dementia Friendly Programme* within Age UK National.

- The newly established *Dementia Peer Support Network* meets the expectations of cohort members overall, however, the lack of funding may pose challenges to local Age UKs who want to participate in the network.
- It is key that the learning from the Dementia Friendly programme is successfully disseminated to local Age UK partners and embedded in the work of Age UK National.

## 9. Conclusions and Key Learning

In this section we summarise and discuss the main findings presented in this report. An important caveat to the reader is that as the Dementia Friendly programme's main focus has been on shaping organisational culture of local Age UK partners rather than supporting the development of new local projects, many of the programme's outcomes will emerge after the official end of the programme and thus they cannot be entirely captured in this report.

### ***a. Key Achievements***

The report has revealed that the Dementia Friendly programme has achieved the goals set out in the bid to the Big Lottery Fund and met most of the expectations of participating local Age UK partners. Arguably the programme has 'over-achieved', as the key achievements listed below indicate:

- The programme was successfully delivered in 46 local Age UK partners in three cohorts (the original bid was for 30 local partners), all of which benefitted from: attending cohort meetings and workshops; receiving consultancy support; and a grant of £5,000.
- The local Age UK participants have been supported to examine and review ways in which they can shape their services to be more inclusive of people living with dementia focussing on five domains: the voice of people with dementia; the place; the people; networks; and resources.
- Many local Age UK partners gained new information and identified new learning, including that on best practices. They found the organisational audits a particularly useful and reflective tool.
- A variety of resources to further support participants in reviewing and shaping their services (including training materials) have been developed, collated, shared and disseminated more widely through the public area of the Age UK website.
- Participating local Age UK partners have developed an increased understanding of the needs of service users with early stage dementia, which is essential for shaping services to become more inclusive.
- Many Age UK partners have subsequently become involved in local Dementia Action Alliances and raised their profiles as providers of inclusive services.
- After their participation in the programme had ceased, local Age UKs from cohort one appeared to continue the work independently, successfully using the tools and the guidance they had received from their participation, thus highlighting the longer term sustainability of the programme.
- Additional funding from Big Lottery Fund has allowed the provision of up to two extra support days (although no accompanying grant), which has been taken up by 14 local partners after January 2015.

- A webinar entitled '*Being dementia friendly*' was delivered in March 2015.
- The programme has had a direct influence on the Dementia Friendly activities of Age UK National, partly as a result of the work of the Advisory Group. Age UK National is undergoing its own '*Dementia Friendly Programme*'. At the time of writing this report, over 300 people at Age UK National have undertaken the Dementia Friends Awareness training; recommendations with regards to branding guidelines and layout of the reception areas were being considered; and a report for the Senior Management Team was being prepared.
- Future plans for disseminating the projects outcomes included Age UK providing presentations about the Dementia Friendly programme at the following conferences: *Alzheimer's Show 2015* (June 2015); Age UK's annual conference entitled *For Later Life: brain ageing and dementia* (November 2015); and the *Dementia Congress* (November 2015).

#### ***b. Design and delivery of the programme***

Based on the evidence presented in this report, it appears that the structure of the programme (consultancy days, cohort meeting and workshops) has suited the goal of supporting local Age UKs to review their services and take steps to become more inclusive to people living with dementia. Two main themes have emerged from analysing the information about the delivery of the programme: the restructuring of the consultancy offer to local partners; and the human resources of the project team.

The introduction of a new, 'split' structure of support to cohorts two and three was carefully planned. When evaluating the work with cohort one, the project team and the consultants found that the outdoors element of the support had perhaps not received enough attention. This evaluative study has found that the project team's decision to change the structure of the offer to cohorts two and three and dedicate a full support day to organisational audits and another one to focussing on outdoor activities was justified and there was improvement as a result of these activities. At the same time, the new structure made additional demands on the time and human resources of the project team.

The start of the Dementia Friendly programme in autumn 2013 coincided with organisational change within Age UK National and some staff members who were involved in designing the programme left the organisation around this time. This consequently meant that the project team and the consultants felt rushed at the start of the project and there was perhaps not adequate time spent fine tuning the implementation plan of the programme. The Advisory Group, which included the consultants and the project team would have also benefitted from having more time for discussions before the first cohort of local Age UKs started the programme. While the work with cohort one was underway, Age

UK National successfully secured further funding from BIG, and a third cohort was organised to meet the demand from local partners. This cohort was run parallel with cohort two, which further 'stretched' the project team and the consultants. The restructuring of the offer to local partners, including the 'open ended' third day of support and the additional planning meetings have led to continuing time pressures on the consultants, the project manager and the administrative support staff.

How then have these changes affected the delivery of the programme? All local partners felt satisfied with the overall organisation of the programme, which suggests that the project team (including the consultants) successfully absorbed the ongoing logistical pressures. A few participants in cohort one felt that they had not been given enough information about the content of the cohort meetings prior to these events. As for the consultancy support, concern with the quality and consistency of the support offered were raised by a few local partners in cohorts two and three, particularly as more consultants became involved in the delivery of the programme.

***c. Developing the concept of dementia friendliness in well-being services***

The finding presented in this report that some participants did not fully appreciate the importance of embedding outdoor activity in services to people living with dementia is not particularly surprising. Firstly, the relationship between increased levels of physical activity and the improved well-being of people living with dementia was perhaps new information to some participants. Secondly, some Age UK partners were arguably not yet ready for thinking about how they could incorporate more outdoor activities into their services. Comments from two participants from the pioneer cohort (who were members of the Advisory Group) support this explanation: they felt that when they started to review and shape their generic services to become more dementia-friendly, they would not have been ready for looking at outdoor activities. One of them suggested that some local Age UKs needed time to '*do the basics first*' and as they gained more experience and confidence in working with people with dementia, they would become more open to new ideas. The research team believes that ongoing support from the nascent Dementia Peer Support Network and Age UK National, including help with securing further funding would be necessary to maintain and improve the outcomes in this area of the programme.

***d. Achieving long-term cultural change in local organisations***

Improved dementia-awareness of staff and volunteers of participating local partners through training is a key outcome of the programme which is expected to contribute to long-term culture change. While collecting data for this report the research team encountered local Age UK staff who were highly committed to making their organisations more inclusive, however a few of them suggested that their commitment was not always

shared by all their colleagues, including senior staff. Sustaining the high level of training and ensuring that key local staff continue to have the capacity to work towards becoming more dementia-friendly beyond the lifetime of the programme may be a challenge for some local partners.

The issue of funding further dementia-related work has been raised by every interviewee. Many alluded to the 'paradox' of securing funding for inclusive mainstream services, arguing that local health and social care service commissioners were more likely to fund 'specialist' services for people living with a dementia diagnosis, as the following quote explains:

*'The challenge is going to be finding the balance between not putting the label on [clients], but getting funding for it.'*

The research team believes that this paradox is the greatest challenge to the Dementia Friendly programme in the long term and agrees with one of the consultants who suggested that Age UK National will have a key role in bringing this issue to national level decision makers in the health and social care systems, thereby influencing change. A related question was raised by some local Age UK partners who felt an ethical tension between including people with dementia in their generic services without labelling them on the one hand and ensuring that those with potential additional support needs were identified on the other hand.

Other challenges to achieving dementia-friendly culture change in local organisations has been the resistance of current service users, some local partners, such as staff of care homes and hospitals, but also that of the wider community, including friends and family of people living with dementia. Participants of the programme who have joined local Dementia Action Alliances and are working in various partnerships will have a key role in breaking down these 'external' barriers and would benefit from ongoing support from the Dementia Support Network and experts at Age UK National. This leads us to the theme of the programme's sustainability.

#### ***e. Sustainability***

The Advisory Group has very successfully facilitated a dialogue between local and national levels of Age UK around dementia, and this dialogue has increased the national organisation's understanding of the Dementia Friendly programme and more broadly, the understanding of the dementia-related services provided by local partners. The dialogue and the increased awareness of local level work may contribute to the Dementia Friendly programme having a stronger and more general influence beyond its lifetime, provided that this facilitating / co-ordinating role continues to be performed within the national

organisation. As there are now various strands of dementia-related work in progress within Age UK National, it is key that all the different strands are co-ordinated and the learning from the Dementia Friendly Programme is implemented.

Another aspect of the programme's sustainability to be discussed is the *Dementia Peer Support Network* (peer network). The evidence presented in Section 8 suggests that the plans for the network, overall, match the needs expressed by cohort members. The challenge of funding local partners' participation in the network has been highlighted, especially by those interviewees who participated in the pioneer cohort and thus have the most experience of 'follow-up' work. The research team has found their concerns and arguments convincing, and thus the main point is reiterated here: *'We have to make sure [that participation in the peer network] it is not seen as a luxury, it is given importance.'*

Finally, the peer network is ideally placed and potentially has a key role in collecting evidence of longer term outputs and outcomes of the programme from local partners, in sharing resources and good practice. Members of the peer network may also be the most suitable partners to continue the dialogues around dementia between the local and the national levels of Age UK, which were started by the Advisory Group.

Successful dissemination of existing results and resources is the key to supporting local Age UK partners in their long term dementia-friendly transformations. This can be achieved by promoting learning from peers and perhaps preventing unnecessary experimentation and parallel 'pilot' projects being carried out. The resources produced by local age UKs and consultants during the lifetime of the programme need to be effectively shared both among local partners and the teams of Age UK National and made available to external partners and professionals. Local Age UKs have reported that they would benefit from the online communication platform (the LOOP) becoming more user-friendly, and although dementia-related resources have become more accessible on the Age UK website since the start of the programme, there is still room for further improvement. Most of these concerns and suggestions are addressed in the Exit Strategy – the implementation of which is key to the sustainability of the Dementia Friendly programme.

To conclude the Dementia Friendly programme has been successfully run at a very fortunate time, when the attention of national politics turned towards dementia, leading to growing interest in the programme from local Age UK partners and providing new opportunities for Age UK National to successfully raise the profile and increase the scope of the programme, maximising the positive outcomes. Although the programme comes to an end in June 2015, local partners and Age UK National have more work to do to ensure that the results of the programme are taken forward. To quote a participant from the pioneer cohort:

*'This is not about dementia, it is about being inclusive. In an ideal world there would be no need for this, but we don't live in an ideal world, so we have to work towards it.'*

## Appendices

### Appendix 1: Participating Local Age UKs

<b>Cohort 1</b>		
Ashford	East Sussex	Northamptonshire
Bromley and Greenwich	Harrow	Redbridge
Camden	Herefordshire and Worcestershire	Sunderland
Dacorum	Lincoln	Wakefield
Ealing	North Staffordshire	Winchester
<b>Cohort 2</b>		
Berkshire	Horsham District	Somerset
Brighton	Maidstone	South Staffordshire
Cambridgeshire	Merton	Surrey
Darlington	North Lincolnshire	Tameside
Hereford	Runnymede and Spelthorne	Wolverhampton
<b>Cohort 3</b>		
Bedfordshire	Hillingdon	Nottingham and Nottinghamshire
Brent	Leicestershire and Rutland	Oldham
Cheshire	North Craven and North Yorkshire	South Lakeland
Cheshire East	Leeds	South Tyneside
Exeter	Newcastle	Warwickshire
Gateshead		

## Appendix 2: Actions and activities listed in Action Plans developed by local Age UKs

Note: some of the categories overlap

Voice of people with dementia	<ul style="list-style-type: none"> <li>• Organising regular client forums – done in a dementia-friendly way</li> <li>• Organising focus groups that include people with dementia before new service is developed</li> <li>• Involving people with dementia in environmental audits</li> </ul>
People: training / awareness raising	<ul style="list-style-type: none"> <li>• Sharing the learning from the programme with staff members</li> <li>• Dementia awareness training for staff / volunteers and home care workers (online and offline training)</li> <li>• Making dementia awareness training part of the standard induction to staff / volunteers</li> <li>• Staff workshops</li> <li>• Training staff members to become ‘Dementia Champions’</li> <li>• Specialist training: complementary therapist completing ‘massaging people who have dementia’ course</li> </ul>
Place: physical environment	<ul style="list-style-type: none"> <li>• Carrying out physical environment audits – with consultants and/or independently using the resources</li> <li>• Carrying out home audits in the homes of people with dementia</li> <li>• Where necessary, making changes to signage and reviewing changes</li> <li>• Making cosmetic (repainting rooms) and more substantial changes to the environment (new bathroom fixtures)</li> <li>• Negotiating with architects and owners of venues about making facilities dementia-friendly</li> </ul>
Place: information material	<ul style="list-style-type: none"> <li>• New, dementia-friendly information material designed, printed and distributed</li> <li>• Consulting staff within Age UK (e. g. Information &amp; Advice) about communicating changes to their availability in a dementia-friendly way</li> </ul>
Generic services	<ul style="list-style-type: none"> <li>• Dementia awareness is embedded in the new strategic plan of the organisation</li> <li>• Developing new services in a dementia-friendly way (e. g. training staff of new I&amp;A service)</li> <li>• Taking into account the needs of people with dementia when organising daytrips</li> <li>• Providing reminders (activity time and dates) to service</li> </ul>

	users living with dementia
Well-being services	<ul style="list-style-type: none"> <li>• Ensuring existing well-being services are more inclusive, e. g. by introducing music and colour to exercise sessions</li> <li>• Taking the needs of people with dementia into account when starting new physical activity groups, such as tai-chi, chair-based exercise groups, walking football, walking cricket, dance classes, walks and sports days daytrips</li> <li>• Using new tools such as ‘reminiscence boxes’ and ‘memory balls’</li> <li>• Creating new activities, such as music and singing sessions</li> </ul>
New specialist services	<ul style="list-style-type: none"> <li>• Working with people with dementia to produce a ‘life story book’ / ‘memory book’ and a video-record memories</li> <li>• Using memory balls [day care centre]</li> <li>• Creating ‘sensory gardens’ and dementia cafes</li> </ul>
Networks and raising public awareness about dementia	<ul style="list-style-type: none"> <li>• Joining the local Dementia Action Alliance</li> <li>• Co-facilitating the local DEEP group</li> <li>• Age UK staff who are dementia friends to volunteer in GP surgeries and hospitals</li> <li>• Working more closely with local carers’ organisations</li> <li>• Working with other Third Sector organisations and statutory agencies (health and social care) to ensure that dementia awareness is an overarching principle in these partnerships</li> <li>• Working with Alzheimer’s Society</li> <li>• Provide dementia-related training / capacity building to local Third Sector partners</li> <li>• Organising dementia awareness week</li> <li>• Disseminate information in monthly newsletter</li> <li>• Development of case study mapping tool to apply for funding more successfully</li> </ul>
‘Enterprise’ – generating income	<ul style="list-style-type: none"> <li>• Delivering dementia awareness training to local businesses</li> </ul>
Other	<ul style="list-style-type: none"> <li>• Staff can now better recognise symptoms of dementia and encourage clients to seek earlier diagnosis</li> </ul>

### Appendix 3: Reasons for getting involved in Dementia Friendly Programme

- Programme seen as timely as dementia awareness is currently high on political agenda.
- To update current practice, ideas, policy and research in this area.
- Responding to customer need, which many viewed as necessary due to increased demand. More specifically maximise accessibility and inclusivity.
- Ensure they can support *volunteers* who may develop cognitive impairments.
- To gain an outside/expert view of current service provision; what is working and potential improvements.
- To gain a better understanding of position in the local market place for providing services.
- Receive support in developing and bidding for new services (local commissioning).
- Receive support in developing staff and volunteer awareness.
- To increase networking/learning with other local Age UKs.
- Improve partnership working with other local organisations and with local community.
- Personal goals (for some this was a “passion”, another interviewee was inspired by attending a conference in which Dementia Adventure introduced their services).