Knowing the foundations of dementia friendly communities for the North East

For the North East dementia Alliance

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The North East Dementia Alliance are happy for this report to be used to further the development of dementia friendly communities but ask that the North East Dementia Alliance and the author, Peter Prior, be acknowledged.

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Contents:

Foreword 6

Executive summary 8

1. Introduction 16

1.1 Aims of the project 16

1.2 Sources of information during the project 17

1.3 Structure of the report 17

1.4 Acknowledgements 18

2. The policy context of the project 19

2.1 Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015 19

2.2 The national policy context 20

2.2.1 Living well with dementia: A National Dementia Strategy 20

2.2.2 The Dementia Action Alliance 21

2.2.3 Quality Outcomes for People with Dementia: Building on the work of the National Dementia Strategy 21

2.2.4 Commissioning Pack for Dementia 21

2.2.5 The Operating Framework for the NHS in England 2012-13 22

2.2.6 Unlocking Diagnosis: All Party Parliamentary Group Report 2012 22

3. The difficulty of defining what dementia friendly communities are and the approach taken in this report 23

3.1 The difficulty of defining what dementia friendly communities are 23

3.2 How the project approached the issue of defining what dementia friendly communities are 24

3.3 The importance of the local context 25

3.4 What is a community?.....25

4. What do dementia friendly communities aim to achieve?.....27

4.1 Aims of dementia friendly communities as suggested in the literature review.....28

4.2 Aims of dementia friendly communities as suggested during the semi-structured conversations.....29

4.3 Summary on the aims of dementia friendly communities.....30

5. What factors need to be addressed in order to achieve the aims of dementia friendly communities?.....31

6. Supporting individuals living with dementia to engage with their community.....34

6.1 The importance of supporting individuals living with dementia to engage with their community.....34

6.2 How to support individuals living with dementia to engage with their community.....35

6.2.1 Supporting individuals living with dementia to understand that it is possible to live well with dementia.....35

6.2.2 Supporting individuals living with dementia to practically engage with their community.....36

7. Increasing understanding and awareness about dementia and the needs of those with dementia.....39

7.1 The importance of increasing understanding and awareness about dementia and the needs of those with dementia.....39

7.2 Raising awareness amongst local organisations.....40

7.2.1 Deciding which organisations to target.....41

7.2.2 How to get local organisation to 'sign up' to become more dementia friendly.....42

7.2.3 What is the most appropriate way to raise awareness amongst those working in local organisations?.....45

7.3 General awareness raising initiatives 47

8. Creating physical environments appropriate for people living with dementia.....48

8.1 The importance of dementia friendly physical environments.....48

8.2 Literature relating to the development of dementia friendly physical environments.....49

8.2.1 Dementia friendly indoor environments.....51

8.2.2 Dementia friendly outdoor and public environments.....52

9. Cross cutting themes that are relevant to the process of creating dementia friendly communities.....53

9.1 The need for those with dementia to be at the centre of the process of developing dementia friendly communities.....54

9.2 How to monitor the 'dementia friendliness' of organisations and the community as a whole.....55

9.2.1 Information regarding the use of an accreditation scheme as a means of monitoring 'dementia friendliness'.....55

9.2.2 Problems arising from the use of an accreditation scheme as a means of monitoring 'dementia friendliness'.....56

9.2.3 Alternative means of monitoring 'dementia friendliness'.....57

9.3 The role that local, regional and national networks play in the process of developing dementia friendly communities.....58

9.4 How to address the costs associated with developing and maintaining dementia friendly communities.....60

9.4.1 Costs associated with the development of dementia friendly communities.....60

9.4.2 Sources of income for the development and maintenance of dementia friendly communities.....61

9.4.3 Maintaining the momentum and funding over time.....62

10. Work to develop dementia friendly communities in the North East of England.....63

10.1 Regional initiatives.....63

10.2 Northumberland.....64

10.3 Redcar.....64

10.4 Stockton-on-Tees.....64

10.5 Sunderland.....65

11. Conclusion.....66

12. References.....67

13. Appendices.....70

Appendix 1: Case studies.....70

Appendix 2: Acknowledgements.....82

Foreword

Over the last 200 years life expectancy has increased by five hours a day. In 2003 one in three people were aged fifty or over, in 2033 this is predicted to rise to two in five. This change in demographics is shaping our society. Yet, despite knowing for decades that we are living longer, governments have only very recently acknowledged the challenge, let alone acting creatively and decisively to address it.

The North East Charter for Changing Age, adopted and endorsed by all the Local Authorities in the North East is a call to action to respond positively to the challenges and opportunities presented by an ageing population and address the prevailing negative attitudes to older people. It is grounded in 8 core principles:

1. **Increased Life spans represent one of humanity's greatest achievements**: For the great majority of the population, health and well-being have improved.

2. **Increased life expectancy is an economic good**: Increased longevity has made and continues to make an enormous positive contribution to our economy. Older people are contributors and consumers of products and services and add substantially to economic growth.

3. **Ageing Matters to us all:** Those who are young today will in time be old. Those who are old were once young.

4. **Each individual has an equal place in our society regardless of age**: Ageism in its present form can no longer be accepted. This wide inequality and divergence in life expectancy levels across the UK and within local communities must be eradicated.

5. **Much better information about older people is needed**: We need to know about the contributions, capabilities, needs and aspirations of older people in their enormous diversity. Older people should not be marginalized or treated as a separate category within society.

6. **Older People are an under-acknowledged asset**: The mental capital, experience and skills of older people should no longer go to waste. Arbitrary ages of exclusion from full participation in any social activity, including education should be in future abolished.

7. **We need to use and expand our scientific knowledge about ageing and health**: There is a wealth of internationally respected research on ageing and health. Transformational reorganisation and reprioritisation of health research and service provision is needed to take account of new advances in understanding the connections between ageing and health.

8. **We urgently need to adapt our infrastructure for an ageing population:** commitments are needed to begin as soon as possible to adapt national and local infrastructure for transport, housing and communications to accommodate the changing age structure. This will create major opportunities for industrial growth through innovation.

The core principles of the North East Charter on Changing Age are clearly relevant to our response to the challenge of dementia. As the UK population is aging and age remains the biggest risk factor for dementia, more people will experience dementia either themselves or as a carer. Future communities must be age friendly and dementia friendly.

But what exactly is a dementia friendly community and how do we know when we have achieved one?

Certainly one of the major challenges is to raise public and professional awareness and understanding about the experience of living with dementia – a role that excellent recent campaigns from the Alzheimer's Society and the Department of Health have done much to achieve.

Creating dementia friendly communities will be a long journey. It will demand innovative thinking, creative responses; fresh approaches, reshaping of our public services and design of our environments. Citizens with dementia deserve our communities to be respectful and understanding, high quality care provision with a motivated and skilled workforce.

The North East Dementia Alliance commissioned this report to inform our programme of work. We are grateful to Peter Prior who undertook the work of bringing together a diverse range of policy documents and activity from across the UK in such an accessible way. This report is intended as a resource to highlight best practice and to further our thinking so as to help Alliance members, and the wider community, consider what they might do, as individuals and organisations, to contribute to our communities in the North East being truly dementia friendly. Together we can help ensure that people with dementia and their families have the support they need to live well.

Dr Lynne Corner

Chair, North East Dementia Alliance
August 2012

Executive summary:

1. Introduction

Section 1 of the report outlines the aims of the project as well as the sources of information during the project.

The 'Knowing the Foundations of Dementia Friendly Communities for the North East' project was commissioned by the North East Dementia Alliance to inform their programme of work on dementia friendly communities for 2012-2013.

The particular areas of knowledge that the project sought to identify were:

- How to define what dementia friendly communities are, including:
  - What aims do dementia friendly communities seek to achieve?
  - What factors need to be addressed in order to achieve these aims?
- What is known about how to bring dementia friendly communities in to being?

The project's research included a literature review, semi-structured conversations and an analysis of information submitted by individuals who were, or had been involved in the development of dementia friendly communities.

2. The policy context of the project

Section 2 of the report outlines the relevant English policy context of the project.

Of particular relevance for those developing dementia friendly communities is that the creation of dementia friendly communities is one of the three challenges set out in the *Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015.*[1] The challenge to create dementia friendly communities is supported by four key commitments, these are:

- Dementia-friendly communities across the country
- Support from leading businesses for the Prime Minister's Challenge on Dementia
- Awareness-raising campaign
- A major event over the summer 2012, bringing together UK leaders from industry, academia and the public sector[2]

Also relevant to the policy context are:

- Living well with dementia: A National Dementia Strategy[3]
- The Dementia Action Alliance[4]

[1] Department of Health (2012) Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015. Department of Health: London

[2] Department of Health (2012) Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015. Department of Health: London p.6

[3] Department of Health (2009) Living well with dementia: a National Dementia Strategy. Department of Health: London

[4] www.dementiaaction.org.uk

- Quality Outcomes for People with Dementia: Building on the work of the National Dementia Strategy[5]
- The Commissioning Pack for Dementia[6]
- The NHS Operating Framework[7]
- Unlocking Diagnosis: All Party Parliamentary Group Report 2012[8]

3. The difficulty of defining what dementia friendly communities are and the approach taken in this report

Section 3 of the report outlines the difficulty of defining what dementia friendly communities are and the way in which the project approached the question of definition.

There is currently no authoritative definition of what dementia friendly communities are.

The project did not seek to produce a comprehensive definition of what dementia friendly communities are but instead focused on two questions, the answers to which will form an important part of any definition of dementia friendly communities. These questions were:

- What do dementia friendly communities aim to achieve?
- What factors need to be addressed in order to achieve these aims?

Decisions about *what* factors need to be addressed and *how* they are to be addressed may differ between localities and therefore any work to create dementia friendly communities should be context specific and informed by individuals living with dementia in that community.

During the project the phrase community was used to describe groupings of various "shapes and sizes", though most examples were targeted at the level of the city or town.

4. What do dementia friendly communities aim to achieve?

Section 4 of the report outlines the project's research relating to the question, what do dementia friendly communities aim to achieve?

The findings of both the literature review and semi-structured conversation can be grouped together under four headings which encompass all of the aims suggested during the project's research. It is therefore suggested that the key aims of developing dementia friendly communities are:

- To challenge stigma

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[5] Department of Health (2010) Quality outcomes for people with dementia: building on the work of the National Dementia Strategy. Department of Health: London

[6] Department of Health (2011) Commissioning Pack for Dementia [Online] Available at: http://dementia.dh.gov.uk/dementia-commissioning-pack/ (Accessed 1 August 2012)

[7] Department of Health (2011) NHS Operating Framework 2012–13. Department of Health: London

[8] All-Party Parliamentary Group on Dementia (2012) Unlocking Diagnosis: All Party Parliamentary Group Report 2012 [Online] http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1583 (Accessed 1 August 2012)

- Increase understanding and awareness about dementia and how to support individuals with dementia
- To support individuals living with dementia to remain active and included members of their communities
- To support individuals living with dementia to maintain their independence for as long as possible

5. What factors need to be addressed in order to make communities dementia friendly?

Section 5 outlines the factors that need to be addressed in order to create a dementia friendly community. The expression 'factors to be addressed' is used in the report to mean the tangible goals required to achieve the aims that were set out in section 4.

The report suggests that the factors which need to be addressed in order to achieve these aims and thereby make a community dementia friendly are:

- Supporting individuals living with dementia to engage in their community
- Increasing understanding and awareness about dementia and the needs of those with dementia
- Creating physical environments appropriate for people living with dementia

The project's research also yielded information relating to a number of cross-cutting themes that, while not the end goals of dementia friendly communities, are relevant to the *process* of creating dementia friendly communities. These themes are:

- The need for those with dementia to be at the centre of the process of developing dementia friendly communities
- How to monitor the 'dementia friendliness' of organisations and the community as a whole
- The role that local, regional and national networks play in the process of developing dementia friendly communities
- How to address the costs associated with developing and maintaining dementia friendly communities

6. Supporting individuals living with dementia to engage with their community

Section 6 outlines existing knowledge and examples of practice relating to the provision of support for people living with dementia so that they can engage with their community. As noted in section 5 this is one of the factors that must be addressed in order to achieve the aims set out in section 4 and thereby create dementia friendly communities.

Information gained in the project's research suggested that there are two issues that need to be addressed to support individuals living with dementia to engage with their community, these are:

- Supporting individuals living with dementia to understand that it is possible to live well with dementia
- The need for support to assist individuals with dementia to practically engage with their community

7. Increasing understanding and awareness about dementia and the needs of those with dementia

Section 7 of the report outlines existing knowledge about and examples of work undertaken to increase understanding and awareness about dementia and the needs of individuals living with dementia. This includes increasing awareness and understanding amongst targeted organisations within the community as well as wider awareness raising campaigns.

7.1 Raising awareness amongst local organisations

A number of common themes emerged relating to how to increase awareness and understanding amongst local organisations.

Deciding which organisations to target

The project revealed that communities had adopted a variety of approaches when deciding which organisations to target. Three alternative approaches were suggested these were:

- To target all organisations within the community
- To take a practical approach using and building up contacts and local networks
- To map the organisations that people with dementia come into contact with

How to get local organisations to 'sign up' to become more dementia friendly

The research highlighted a number of factors that might persuade organisations to commit to increasing the level of awareness and understanding amongst their employees. These included the potential increase in customer numbers, the fact that it could help satisfy an organisation's obligations under the Equality Act 2010 and result in improved customer care.

Despite the benefits of becoming more dementia friendly the research suggested that local businesses were still being put off from signing up to become more dementia because of a number of factors.

What is the most appropriate way to raise awareness amongst those working in local organisations?

The project's research revealed that there is a need to avoid 'overwhelming' organisations as in-depth training may deter local organisations and is not appropriate for all customer-facing staff.

Despite a common commitment to 'awareness raising' rather than in-depth training the exact way in which information was delivered varied between localities. In some areas dementia champions were providing hardcopy information while in other localities it was felt that short presentations were more appropriate.

7.2 General awareness raising initiatives

As well as targeting customer-facing staff in local organisations the research highlighted the need to increase awareness and understanding amongst the community more generally

8. Creating physical environments appropriate for people living with dementia

Section 8 of the report outlines existing knowledge about the role that physical environments, both indoors and outdoors, can play in developing dementia friendly communities and what physical environments are most appropriate for individuals living with dementia.

The section highlights two key sources that have, in light of the Prime Minister's Challenge on Dementia, summarised existing knowledge relating to the creation of physical environments appropriate for people living with dementia.

The *Checklists for dementia-friendly environments*[9] report suggest that the most important factors to be considered when designing internal environments appropriate for individual's living with dementia are the signage, lighting, flooring, seating and navigability.

The *At a Glance: a Checklist for Developing Dementia Friendly Communities*[10] report suggests that the key principles to be considered when designing appropriate outdoor spaces for individuals living with dementia are that such spaces should be familiar, legible, distinctive, accessible, safe and comfortable.

9. Cross cutting themes that are relevant to the process of developing dementia friendly communities

Section 9 outlines information relating to the four cross cutting themes that were highlighted in section 5. While these themes are not the end goals of dementia friendly communities they are relevant to the *process* of creating dementia friendly communities.

The need for those with dementia to be at the centre of the process of developing dementia friendly communities

Involving individuals living with dementia in the process of developing dementia friendly communities was found to be important as:

> *"Dementia-friendly communities need to be responsive to what people want, but perhaps more importantly, people with dementia should have the right to have a sense of ownership, investment, responsibility and of connectedness to their own communities"*[11]

[9] Innovations in Dementia (2012) Checklists for dementia-friendly environments [Online] Available at http://www.innovationsindementia.org.uk/DementiaFriendlyCommunities/Dementia-friendly%20Environmental%20checklists.pdf (Accessed 1 August 2012)

[10] Porteus, Jeremy (2012) At a Glance: a Checklist for Developing Dementia Friendly Communities. Viewpoint No. 25, Housing LIN [Online] http://www.housinglin.org.uk/Topics/browse/HousingandDementia/Design/?parent=5091&child=8525 (Accessed 1 August 2012

[11] Innovations in Dementia (2012) Finding out what a dementia friendly community means to people with dementia and carers [Online] http://www.innovationsindementia.org.uk/DementiaFriendlyCommunities/DementiaFriendlyCommunities_engagement.pdf (Accessed 1 August 2012) p.4

How to monitor the 'dementia friendliness' of organisations and the community as a whole

In a number of areas local organisations, that satisfy certain criteria, are being awarded a badge to display in their window which shows that they are dementia friendly.

However, this scheme raised a number of potential issues including the difficulty of ascertaining a 'cut off' point at which it was possible to say that an organisation has become sufficiently dementia friendly to be accredited. The research also suggested that developing dementia friendly communities is about "*more than a sign it's a movement*".

The most commonly suggested means of monitoring 'dementia friendliness' was through the use of a peer review scheme, in which stakeholders and in particular individuals living with dementia, are encouraged to monitor local organisations.

The role that local, regional and national networks play in the process of developing dementia friendly communities

It was suggested that the formation of local alliances or other networks were useful for the creation of dementia friendly communities as these groupings can:

- bring together those who live with dementia and those who are able and willing to shape how dementia friendly the community is, allows the voices of those with dementia to influence their community
- provide a platform for sharing ideas between local organisations and monitoring of progress through a process of peer review and feedback
- set local priorities specific to the needs of that particular community

In some areas regional alliances were proactively involved in the creation of local alliances. By contrast in other areas it was claimed that local alliances had arisen 'organically'.

How to address the costs associated with developing and maintaining dementia friendly communities

The potential costs associated with developing dementia friendly communities include:

- Employing a coordinator/facilitator to encourage the creation of local groups and alliances and help local organisations become more dementia friendly
- The provision of awareness raising sessions and materials
- Providing support services and associated facility costs

The potential sources of income for those developing dementia friendly communities, including:

- Contributions from local alliances and organisations
- Charging for awareness raising sessions
- Funding through city and parish councils and local authorities
- Registering as a social entity in order to secure funding

10. Work to develop dementia friendly communities in the North East of England

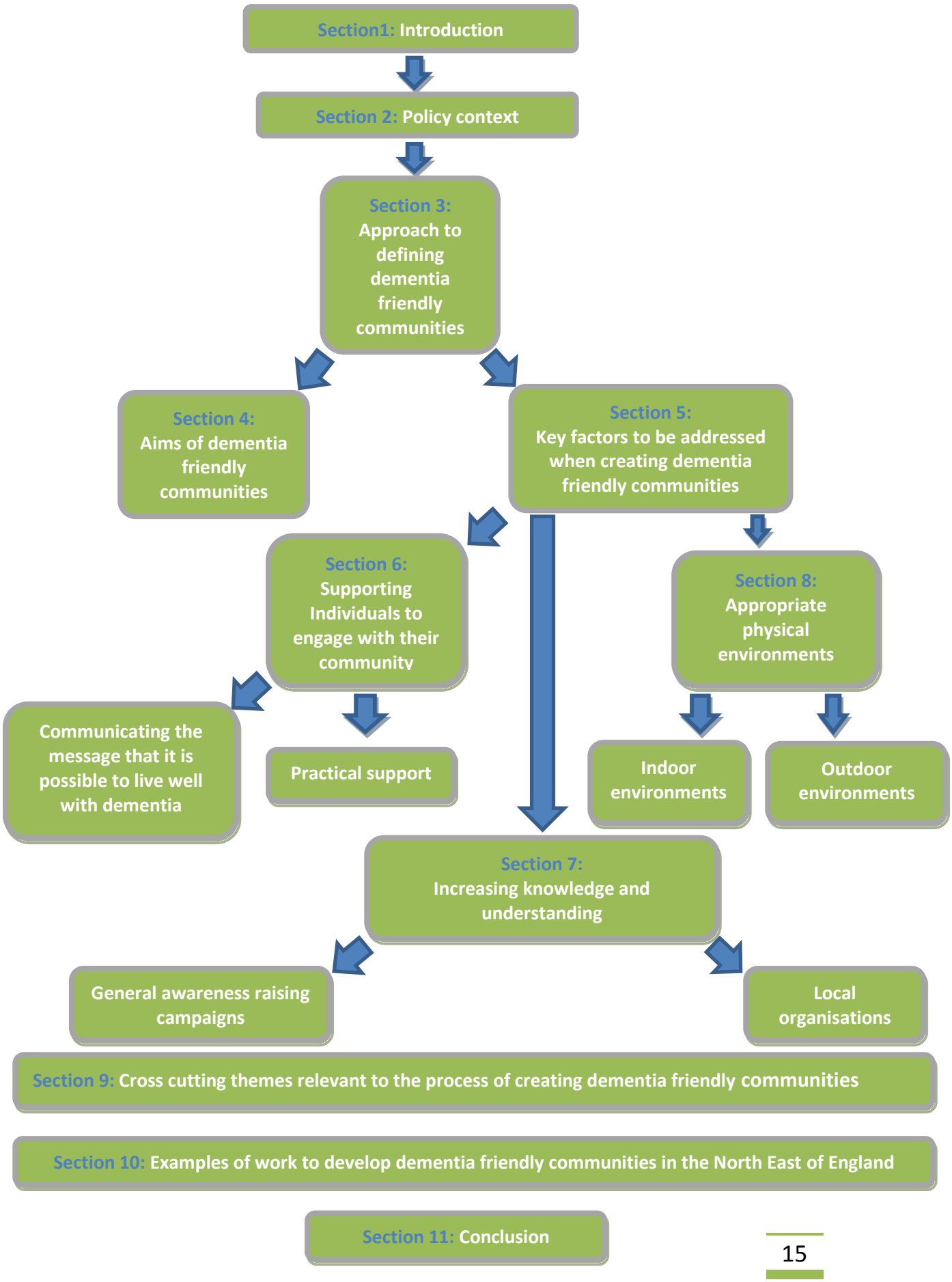
Section 10 of the report highlights the work currently being undertaken to develop dementia friendly communities in the North East of England. The information in section 10 is based solely on the written responses to a request for information about work that is being undertaken to develop dementia friendly communities in the North East of England.

Based on the dementia action plans of the localities in the North East of England it is likely that the localities not represented in this section are also undertaking work to develop dementia friendly communities however as this has not been verified it has not been possible to include the information here.

The localities detailed in this section are:

- Northumberland
- Redcar
- Stockton-on-Tees
- Sunderland

Report overview



1. Introduction

Section overview

- The 'Knowing the Foundations of Dementia Friendly Communities for the North East' project was commissioned by the North East Dementia Alliance as part of their programme of work on dementia friendly communities for 2012-2013
- The aim of the project was to provide information for the North East Dementia Alliance in order to inform their programme of work on dementia friendly communities for 2012-2013
- Although targeted at the North East of England the report is intended to be of use to interested parties outside of the region
- The particular areas of knowledge that the project sought to identify were:
    - How to define what dementia friendly communities are, including;
        - What aims do dementia friendly communities seek to achieve?
        - What factors need to be addressed in order to achieve these aims?
    - What is known about how to bring dementia friendly communities in to being?
- The project's research included a literature review, semi-structured conversations and an analysis of information submitted by individuals who were, or had been involved in the development of dementia friendly communities

This report will detail the findings of the project 'Knowing the Foundations of Dementia Friendly Communities for the North East'. This project was commissioned by the North East Dementia Alliance as part of their programme of work on dementia friendly communities for 2012-2013.

1.1 Aims of the project

The aim of the 'Knowing the Foundations of Dementia Friendly Communities for the North East' project was to provide information for the North East Dementia Alliance to inform their programme of work on dementia friendly communities for 2012-2013. Although targeted at the North East of England the report is also intended to be of use to interested parties outside of the region.

The project aimed to identify existing knowledge and practice relating to dementia friendly communities from both local and national sources. The particular areas of knowledge that the project sought to identify were:

- How to define what dementia friendly communities are, including;
    - What aims do dementia friendly communities seek to achieve?
    - What factors need to be addressed in order to achieve these aims?
- What is known about how to bring dementia friendly communities in to being?

1.2 Sources of information during the project

The project consisted of a literature review, semi-structured conversations and an analysis of information submitted by individuals who were, or had been involved in the development of dementia friendly communities.

The literature review included an analysis of existing research and reports on the issue of dementia friendly communities and other relevant documents. For the sake of clarity the literature review was restricted to documents that explicitly dealt with the issue of dementia friendly communities. The literature review yielded information on all of the project's intended knowledge areas and highlighted potential respondents for the semi-structured conversations.

The semi-structured conversations were with individuals who were, or had been, involved in the creation of dementia friendly communities as well as persons who may otherwise posses knowledge on the issue of dementia friendly communities. The initial respondents were chosen on the basis of their involvement in projects that had been highlighted during the literature review and these respondents were used to identify further respondents.

During the project there was also a request for information about work that is being undertaken to develop dementia friendly communities in the North East of England. This request was made through the North East Dementia Alliance members and the dementia leads in each of the localities within the region.

As a result of this sampling method the research cannot claim to be representative of all national knowledge and practice relating to dementia friendly communities however it is hoped that the research will have collated a significant body of existing knowledge.

1.3 Structure of the report

This report is organised into 11 sections including this section. Section 2 of this report outlines the relevant English policy context of the project. Section 3 details the problems that arise when trying to define what a dementia friendly community is and how the project approached the question of definition. Section 4 outlines what, based on the project's research, are the aims of a dementia friendly community. Section 5 suggests the three key factors that need to be addressed in order to develop dementia friendly communities as well as the cross-cutting themes that are relevant to the process of creating dementia friendly communities.

Sections 6, 7 and 8 detail the existing knowledge on *how* to address each of the key factors outlined in section 5. Section 9 sets out existing knowledge relating to the cross-cutting themes. Section 10 provides a summary of the work currently being undertaken to develop dementia friendly communities in the North East of England before concluding in section 11.

1.4 Acknowledgements

This report would not have been possible without the project's respondents who expended time and effort in order to share their knowledge and insights.

Thanks are also due to the North East Dementia Alliance for their oversight and advice throughout the project.

See Appendix 2 for a more complete list of acknowledgments.

2. The policy context of the project

Section overview

- This section of the report outlines the English policy context of the project
- The creation of dementia friendly communities is one of the three challenges set out in the *Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015*
- The challenge to create dementia friendly communities is supported by four key commitments, these are:
    - For up to 20 cities, towns and villages are to have signed up to become more dementia-friendly by 2015
    - For leading businesses to sign up to support the Prime Minister's Challenge on Dementia
    - For investment in a nationwide awareness raising campaign
    - For a major event over the summer 2012, bringing together UK leaders from industry, academia and the public sector
- The existing policy context against which the creation of dementia friendly communities takes place includes:
    - Living well with dementia: A National Dementia Strategy
    - The Dementia Action Alliance
    - Quality Outcomes for People with Dementia: Building on the work of the National Dementia Strategy
    - The Commissioning Pack for Dementia
    - The Operating Framework for the NHS in England 2012-13
    - Unlocking Diagnosis: All Party Parliamentary Group Report 2012

This section of the report outlines the English policy context of the 'Knowing the Foundations of Dementia Friendly Communities for the North East' project.

The policy outlined in this section is restricted to that which is relevant in England and may therefore not be appropriate for those in other areas of the United Kingdom.

2.1 Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015[12]

In March 2012 the Prime Minister, David Cameron, launched the *Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015.* The Prime Minister's challenge on dementia set out three key areas of focus these are:

[12] Department of Health (2012) Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015. Department of Health: London

- Driving improvements in health and care
- Creating dementia friendly communities that know how to help
- Better research

As part of the Prime Minister's second challenge, creating dementia friendly communities, the document set out four key commitments, these are:

- **Dementia-friendly communities across the country** By 2015, up to 20 cities, towns and villages are to have signed up to become more dementia-friendly.
- **Support from leading businesses for the Prime Minister's Challenge on Dementia** Leading national organisations have already pledged to look at how they and others can play a part in creating a more dementia friendly society and raise awareness of dementia.
- **Awareness-raising campaign** From autumn 2012, there is to be investment in a nationwide campaign to raise awareness of dementia, to be sustained to 2015. This will build on lessons learned from previous campaigns and will inform future investment.
- **A major event over the summer 2012, bringing together UK leaders from industry, academia and the public sector**, to take forward the Prime Minister's Challenge on Dementia.[13]

A Dementia Friendly Communities Champion Group has been created in order to lead the work on dementia friendly communities. The group will be co-chaired by *"Jeremy Hughes, Chief Executive of the Alzheimer's Society and journalist and broadcaster, Angela Rippon OBE and consisting of industry leaders, representatives from towns and cities and with people with dementia and their carers*".[14]

As part of this programme the Alzheimer's Society will work with the (national) Dementia Action Alliance to create formal criteria to be used in order to determine whether communities are dementia friendly. The Dementia Friendly Communities Champion Group will report to the Prime Minister in autumn 2012.[15]

2.2 The national policy context

2.2.1 Living well with dementia: A National Dementia Strategy[16]

The National Dementia Strategy was launched in 2009 and sets out improvements for dementia services in three key areas namely, raising awareness and understanding, early diagnosis and ensuring high standards for dementia services so that people are able to live well with dementia.

[13] Department of Health (2012) Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015. Department of Health: London p.6
[14] Information from the Alzheimer's society website. Available at: http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1843 (Accessed 1 August 2012)
[15] Ibid
[16] Department of Health (2009) Living well with dementia: a National Dementia Strategy. Department of Health: London

The National Dementia Strategy set out 17 objectives that have shaped subsequent priorities in the provision of dementia services. While there is no specific reference to 'dementia friendly communities' in the National Dementia Strategy, there is a significant overlap between the objectives of the National Dementia Strategy and the aims of dementia friendly communities. The implementation of many of the National Dementia Strategy's objectives will therefore form many of the building blocks of dementia friendly communities.

2.2.2 The Dementia Action Alliance

The (national) Dementia Action Alliance comprises of over 100 organisations who have signed up to the National Dementia Declaration and aims to improve the lives of people with dementia and their carers by the end of the National Dementia Strategy in 2014.[17] As stated in the report *Developing dementia-friendly communities Learning and guidance for local authorities,* the "*alliance was launched in October 2010 to provide an impetus beyond government to support the implementation of the National Dementia Strategy*".[18]

Since the launch of the Prime Minister's Challenge on Dementia the Dementia Action Alliance is working to establish Local Dementia Action Alliances across the UK.

2.2.3 Quality Outcomes for People with Dementia: Building on the work of the National Dementia Strategy[19]

The Quality Outcomes for People with Dementia document set out the Department of Health's revised, outcomes focused implementation plan for the National Dementia Strategy. This document prioritises:

- Good-quality early diagnosis and intervention for all
- Improved quality of care in general hospitals
- Living well with dementia in care homes
- Reduced use of antipsychotic medication

The document also links the future direction of dementia services to the Prime Minister's Big Society initiative. Quoting the Prime Minister's launch of the Big Society initiative the document outlines the need for "*a huge cultural change… where people, in their homes, in their neighbourhoods, in their workplace… don't always turn to officials, local authorities or central government for answers to the problems they face".*[20]

2.2.4 Commissioning Pack for Dementia[21]

The Department of Health has produced a Commissioning Pack to support clinical commissioners when commissioning dementia services. The pack "*includes inserts to generic*

[17] www.dementiaaction.org.uk

[18] Local Government Association (2012) Developing dementia-friendly communities: Learning and guidance for local authorities [Online] Available at: http://www.local.gov.uk/web/guest/ageing-well/what-makes/-/journal_content/56/10171/3489459/ARTICLE-TEMPLATE (Accessed 1 August 2012) p.18

[19] Department of Health (2010) Quality outcomes for people with dementia: building on the work of the National Dementia Strategy. Department of Health: London

[20] Ibid p.8

[21] Department of Health (2011) Commissioning Pack for Dementia [Online] Available at: http://dementia.dh.gov.uk/dementia-commissioning-pack/ (Accessed 1 August 2012)

contracts, together with information on documents and practical tools which may be of assistance to commissioners in developing a dementia-friendly community".[22]

2.2.5 The Operating Framework for the NHS in England 2012-13[23]

The NHS Operating Framework 2012/2013 describes the national priorities and financial requirements of NHS organisations. The Operating Framework states the need for Primary Care Trusts to work with their Local Authorities and publish dementia plans that set out progress in implementing the National Dementia Strategy (see section 2.2.1 for details on the relationship between the National Dementia Strategy and dementia friendly communities).

2.2.6 Unlocking Diagnosis: All Party Parliamentary Group Report 2012[24]

The All Party Parliamentary Group on Dementia released its Unlocking Diagnosis report in 2012 which detailed its inquiry into how it is possible to improve the rates of diagnosis of dementia across the UK. In the report the All Party Parliamentary Group suggested that:

"The champion group of the dementia friendly communities strand of the Prime Minister's challenge on dementia should consider the role a high diagnosis rate plays in a dementia friendly community".[25]

[22] Local Government Association (2012) Developing dementia-friendly communities: Learning and guidance for local authorities [Online] Available at: http://www.local.gov.uk/web/guest/ageing-well/what-makes/-/journal_content/56/10171/3489459/ARTICLE-TEMPLATE (Accessed 1 August 2012) p.18

[23] Department of Health (2011) NHS Operating Framework 2012–13. Department of Health: London

[24] All-Party Parliamentary Group on Dementia (2012) Unlocking Diagnosis: All Party Parliamentary Group Report 2012 [Online] http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1583 (Accessed 1 August 2012)

[25] Ibid. p.11

3. The difficulty of defining what dementia friendly communities and the approach taken in this report

Section overview

- There is currently no authoritative definition of what dementia friendly communities are
- The task of defining the concept remains problematic due to its emerging nature, the lack of literature on the subject and the outwardly diverse ways in which the idea has been used
- The project did not seek to produce a comprehensive definition of what dementia friendly communities are. Instead the project addressed two questions that will form important elements of any definition of what dementia friendly communities are. The two questions are:
    - What do dementia friendly communities aim to achieve?
    - What factors need to be addressed in order to achieve these aims?
- Decisions about *what* factors need to be addressed and *how* they are to be addressed will differ between communities and therefore any work to create dementia friendly communities should be informed by individuals living with dementia in that community
- During the project the phrase community was used to describe groupings of various "shapes and sizes", though most examples in the research were targeted at the level of the city or town

This section of the report highlights the problems that arise when attempting to define what dementia friendly communities are and outlines the project's approach to defining what dementia friendly communities are.

3.1 The difficulty of defining what dementia friendly communities are

Between the publication of the Prime Minister's Challenge on Dementia and autumn 2012 the Dementia Friendly Communities Champion Group is undertaking a public consultation with the aim of identifying what should be included in a formal checklist which can be used to determine whether communities are dementia friendly.[26] Prior to the publication of the findings of the public consultation there is no authoritative definition of what dementia friendly communities are. [27]

[26] Information from the Alzheimer's society website. Available at: http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1843 (Accessed 1 August 2012)

[27] See Milton, Steve (2012) What makes a dementia-friendly community? *Journal of Dementia Care*, 20 (2), p.12

The task of defining dementia friendly communities is problematic for a number of reasons including:

- The comparative newness of the concept
- The lack of research and literature on the subject
- The outwardly diverse ways in which the idea has been used

It was recognised by a number of respondents during the project's semi-structured conversations that creating dementia friendly communities could potentially involve tackling a wide range of issues. For example during the project respondents suggested that concepts as diverse as early diagnosis of dementia and the training of staff in local organisations both amounted to important elements of a dementia friendly community, while other sources have suggested that dementia friendly communities must address the design of a community's physical environment.

While the holistic nature of the concept was felt by some respondents to be a benefit as it involved *"joining up the dots"* of existing initiatives, other respondents suggested that the idea risked becoming indistinct and therefore little more than a tokenistic shorthand for any work that has been done to improve the lives of people living with dementia.

In the absence of a clear authoritative definition there is doubt about:

- Whether the concept of dementia friendly communities is an overarching and unifying concept that includes all other work done to improve the lives of people living with dementia
- Whether the phrase 'dementia friendly communities' possesses a meaning which is distinct from but complements other initiatives designed to improve the lives of people living with dementia, or
- Whether the concept represents a new focus which overlaps with existing initiatives to improve the lives of people living with dementia but also includes a focus on additional new factors

3.2 How the project approached the issue of defining what dementia friendly communities are

The project did not seek to produce a comprehensive definition of what dementia friendly communities are. Instead the project addressed two questions that will form important elements of any definition of what dementia friendly communities are. The two questions were:

- What do dementia friendly communities aim to achieve?
- What factors need to be addressed in order to achieve these aims?

Section 4 of this report details the information gathered during the literature review and semi-structured conversations relating to the first of these questions, while section 5 of the report outlines the factors that need to be addressed in order to achieve those aims.

3.3 The importance of the local context

It is important to note that during the semi-structured conversations a number of respondents highlighted the difficulty of defining what makes a dementia friendly community in the abstract. As stated by one respondent, "*what makes a community dementia friendly can only be decided by people in the community who are living with dementia".*

Although decisions about *what* factors need to be addressed and *how* they are to be addressed will differ between communities it is not certain from the research that this principle also applies when ascertaining the aims of dementia friendly communities. Instead it is possible that dementia friendly communities are characterised by common aims but different communities will possess different priorities depending on the local context.

A similar point was noted in the Local Government Association report *Developing dementia-friendly communities: Learning and guidance for local authorities* where it was noted that the two sites in which they worked adopted different approaches due to variances in their populations, geographies, histories and political environments.[28]

This report is not designed to be used by any specific community and is therefore only able to highlight general trends across the UK regarding what are the most common approaches to creating dementia friendly communities. Consequently it is recommended that any community seeking to become more dementia friendly should engage with the people in that community who are living with dementia in order to determine the factors and priorities most appropriate in that community.

For details about how to engage with people with dementia on the issue of dementia friendly communities see section 9.1 of this report.

3.4 What is a community?

Throughout the project's research, communities were usually characterised by relative geographical proximity however this view was refuted by one respondent who claimed "*we see a community to be something with a common bond not just a geographical area. This therefore means a dementia friendly community could… include for example a large employer in a specific county".*

Amongst other respondents the phrase 'community' was used to describe groupings at various geographical scales. The most common scale at which work was being done to create dementia friendly communities was at the level of towns or cities. However, one respondent did state that within their region the size of communities arose organically, explaining *"there is no set criteria… there can be 'communities' of all shapes and sizes… they can be neighbourhoods or cities what ever happens".*

Another respondent explained that they would be targeting their work to develop dementia friendly communities at *"individual areas at the sub-council ward level"*. It was however

[28] Local Government Association (2012) Developing dementia-friendly communities: Learning and guidance for local authorities [Online] Available at: http://www.local.gov.uk/web/guest/ageing-well/what-makes/-/journal_content/56/10171/3489459/ARTICLE-TEMPLATE (Accessed 1 August 2012) p.5

explained that this approach was being adopted as it was felt that this would be a manageable first step towards creating larger dementia friendly communities.

4. What do dementia friendly communities aim to achieve?

Section overview

- This section of the report outlines the information gathered during the literature review and the semi-structured conversations relating to the question, what do dementia friendly communities aim to achieve?
- The most frequently cited aims of dementia friendly communities during the literature review were:
    - To assist individuals living with dementia to maintain their independence by supporting them to access local facilities they know and feel safe with
    - To support individuals living with dementia to be included in their community and maintain their social networks
    - To increase understanding so that people with dementia are met with understanding and given support where necessary
- The most three commonly stated aims of a dementia friendly community amongst respondents during the semi-structured conversations were:
    - To increase awareness about dementia and how to support those living with dementia
    - To reduce the stigma associated with dementia
    - Allow people with dementia to be active and included as part of their community
- The findings of both the literature review and semi-structured conversation can be grouped together under four headings which encompass all of the aims suggested during the project's research. It is therefore suggested that the key aims of developing dementia friendly communities are:
    - To challenge stigma
    - Increase understanding and awareness about dementia and how to support individuals with dementia
    - To support individuals living with dementia to remain active and included members of their communities
    - To support individuals living with dementia to maintain their independence for as long as possible

This section of the report outlines the information gathered during the literature review and the semi-structured conversations relating to the question, what do dementia friendly communities aim to achieve?

As highlighted in section 3 of this report, this question is critical as the answer will inform any definition of dementia friendly communities.

4.1 Aims of dementia friendly communities as suggested in the literature review

This section of the report outlines the information gathered during the literature review relating to the question, what do dementia friendly communities aim to achieve?

The Prime Minister's Challenge on Dementia[29] does not explicitly outline the aims of creating dementia friendly communities. The document does however outline existing issues before setting out the Prime Minister's key commitments regarding dementia friendly communities. If it is assumed that these issues are the factors that the initiative aims to address then it could be stated that the aims of dementia friendly communities according to this document are;

- To assist people with dementia to remain independent for as long possible and retain choice and control over their life
- To support individuals living with dementia to achieve the "*everyday things we all take for granted – getting to the shops, spending time with friends and family, getting money from the bank, and going on holiday*"[30]
- To increase understanding about dementia and how to help people living with dementia

As the Prime Minister's Challenge on Dementia is unspecific about what dementia friendly communities aim to achieve it is helpful to look at other sources that are informative as to the aims of dementia friendly communities.

The report *Developing dementia-friendly communities: Learning and guidance for local authorities*, quotes the findings of a focus group held with individuals living with dementia. The report explains that the respondents of the focus group described a dementia friendly community as being a community that enables them to:

- Find their way around and be safe
- Access local facilities that they are used to and where they are known
- Maintain their social networks so they feel they continue to belong[31]

The Innovations in Dementia report *Dementia Capable Communities: The views of people with dementia and their supporters* quoted an individual living with dementia who explained that a dementia friendly community is;

> *"an integrated society where people with dementia live in 'normal' home like situations throughout their lives with support to engage in everyday community activities*" [32]

[29] Department of Health (2012) Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015. Department of Health: London

[30] Department of Health (2012) Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015. Department of Health: London p.21

[31] Local Government Association (2012) Developing dementia-friendly communities: Learning and guidance for local authorities [Online] Available at: http://www.local.gov.uk/web/guest/ageing-well/what-makes/-/journal_content/56/10171/3489459/ARTICLE-TEMPLATE (Accessed 1 August 2012) p.7

[32] Innovations in Dementia (2011) Dementia Capable Communities: The views of people with dementia and their supporters [Online} Available at:

The article *Breaking New Ground: The Quest for Dementia Friendly Communities* claims that:

> *"the development of dementia friendly communities, stresses the need to tackle the stigmatism, exclusion, loneliness and lack of control people with dementia currently experience"* [33]

In *What Makes a Dementia Friendly Community?* a dementia friendly community is defined as:

> *"… one in which it is possible for the greatest number of people to live a good life with dementia; where people with dementia are enabled to live as independently as possible and to continue to be part of their community, but at the same time are met with understanding and given support where necessary*" [34]

4.2 Aims of dementia friendly communities as suggested during the semi-structured conversations

This section of the report outlines the information gathered during the semi-structured conversations which relates to the question, what do dementia friendly communities aim to achieve?

During the semi-structured conversations the reduction of stigma was the most commonly cited aim of dementia friendly communities. One respondent described this aim as a need *"to fundamentally change the way people think about and the culture surrounding dementia"*. This aim was also phrased as a need to reduce discrimination towards individuals living with dementia.

The second most frequently mentioned aim of dementia friendly communities was to increase awareness. This included awareness about dementia and how to support those living with dementia.

It was common for respondents to mention the need to increase awareness in the context of reducing stigma, suggesting these aims are intertwined. As one respondent explained "*more understating creates compassion and also reduces stigma".*

The third most commonly referred to aim of dementia friendly communities was to create a community which would allow people with dementia to be active and included as part of their community.

In addition to the more commonly asserted aims outlined above individual respondents also suggested that dementia friendly communities aimed to:

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http://www.innovationsindementia.org.uk/projects_communities.htm (Accessed 1 August 2012) p.21

[33] Mitchell, Lynne (2012) Breaking New Ground: The Quest for Dementia Friendly Communities. Viewpoint No. 25, Housing LIN [Online] http://www.housinglin.org.uk/Topics/browse/HousingandDementia/Design/?parent=5091&child=8525 (Accessed 1 August 2012) p.1

[34] See Milton, Steve (2012) What makes a dementia-friendly community? *Journal of Dementia Care*, 20 (2), p.12

- Make communities, businesses and services more accessible to people living with dementia
- Allow people with dementia to remain independent, healthy and well
- Allow people with dementia and their carers to live with dignity
- Improve all aspects of the lives of people living with dementia

4.3 Summary on the aims of dementia friendly communities

The findings of both the literature review and semi-structured conversation can be grouped together under four headings which encompass all of the aims suggested during the project's research. It is therefore suggested that the key aims of developing dementia friendly communities are:

- To challenge stigma
- Increase understanding and awareness about dementia and how to support individuals with dementia
- To support individuals living with dementia to remain active and included members of their communities
- To support individuals living with dementia to maintain their independence for as long as possible

5. What factors need to be addressed in order to achieve the aims of dementia friendly communities?

Summary overview

- This section outlines the factors that need to be addressed in order to achieve the aims of dementia friendly communities
- The expression 'factors to be addressed' is used in this report to mean the tangible goals required to achieve the aims that were set out in section 4
- On the basis of the information gained during the literature review and the semi-structured conversations, the factors that need to be addressed in order to achieve the aims of dementia friendly communities are:
    - Supporting individuals living with dementia to engage in their community
    - Increasing understanding and awareness about dementia and the needs of those with dementia
    - Creating physical environments appropriate for people living with dementia
- The literature review and semi-structured conversations also yielded information relating to a number of factors that are relevant to the *process* of creating dementia friendly communities. These are:
    - The need for those with dementia to be at the centre of the process of developing dementia friendly communities
    - How to monitor the 'dementia friendliness' of organisations and the community as a whole
    - The role that local, regional and national networks play in the process of developing dementia friendly communities
    - How to address the costs associated with developing and maintaining dementia friendly communities

This section outlines the factors that need to be addressed in order to create a dementia friendly community. The expression 'factors to be addressed' is used in this report to mean the tangible goals required to achieve the aims that were set out in section 4. These aims are:

- To challenge stigma
- Increase understanding and awareness about dementia and how to support individuals with dementia
- To support individuals living with dementia to remain active and included members of their communities
- To support individuals living with dementia to maintain their independence for as long as possible

There is no authoritative guide as to what factors need to be addressed in order to develop dementia friendly communities.

This report groups together the information gained during the literature review and the semi-structured conversations under three broad headings that represent the three key factors that need to be addressed in order to create dementia friendly communities, these are:

- Supporting individuals living with dementia to engage in their community
- Increasing understanding and awareness about dementia and the needs of those with dementia
- Creating physical environments appropriate for people living with dementia

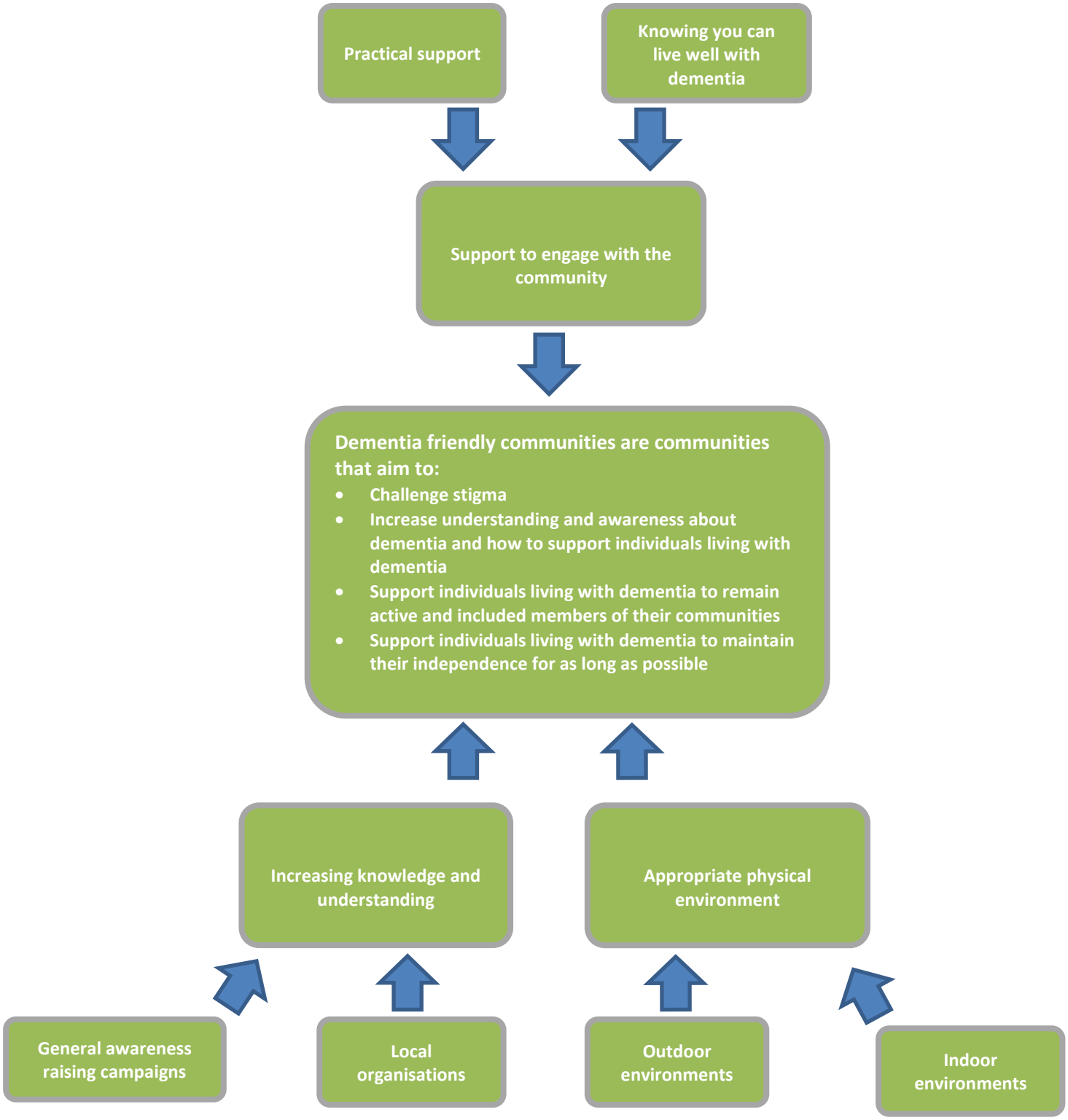
Existing knowledge of *how* to address each of the factors will be outlined in sections 6, 7 and 8.

The literature review and semi-structured conversations also yielded information relating to a number of factors that, while not the end goals of dementia friendly communities, are relevant to the *process* of creating dementia friendly communities. Information on these issues can be again grouped under four broad headings these are:

- The need for those with dementia to be at the centre of the process of developing dementia friendly communities
- How to monitor the 'dementia friendliness' of organisations and the community as a whole
- The role that local, regional and national networks play in the process of developing dementia friendly communities
- How to address the costs associated with developing and maintaining dementia friendly communities

Existing knowledge on each of these issues will be outlined in section 9.

Diagram detailing the aims of dementia friendly communities and the factors that need to be addressed in order to achieve those aims



6. Supporting individuals living with dementia to engage with their community

Section overview

- This section of the report outlines existing knowledge and examples of practice relating to the provision of support and other services for people living with dementia as this is one important factor that must be addressed when developing a dementia friendly community
- Information gained in the project's research suggested that there are two issues that need to be addressed to support individuals living with dementia to engage with their community, these are:
    - Supporting individuals living with dementia to understand that it is possible to live well with dementia
    - The need for support to assist individuals with dementia to practically engage with their community and access appropriate information about such services

This section of the report outlines existing knowledge and examples of practice relating to the provision of support for people living with dementia so that they can engage with their community. As noted in section 5 this is one of the factors that must be addressed in order to achieve the aims set out in section 4 and thereby create dementia friendly communities.

6.1 The importance of supporting individuals living with dementia to engage with their community

Both the literature review and respondents during the semi-structured conversations suggested that an important part of making a community dementia friendly is supporting individuals living with dementia to engage with their community.

According to the Innovations in Dementia report *Dementia Capable Communities: The views of people with dementia and their supporters,* individuals living with dementia had stopped doing a range of activities in their community, including:

- Pursuing hobbies and interests
- Going out
- Make use of local facilities
- Volunteering[35]

[35] Innovations in Dementia (2011) Dementia Capable Communities: The views of people with dementia and their supporters [Online} Available at: http://www.innovationsindementia.org.uk/projects_communities.htm (Accessed 1 August 2012) pp.19-20

The fact that many people living with dementia don't feel they are included in their community was highlighted by the Alzheimer's Society report *Dementia 2012: A national challenge* which suggested that 22% of individuals living with dementia did not feel part of their community and 38% feel part of their community only sometimes.[36] In addition the report highlighted the fact that 61% state they feel lonely in their communities.[37]

The importance of supporting individuals living with dementia to engage with their community was noted during the semi-structured conversations where one respondent stressed that it is not enough to address a community's physical environment and increase awareness and understanding as *"unless individuals with dementia are supported to interact with their community*" addressing these other factors "*would not achieve much*".

6.2 How to support individuals living with dementia to engage with their community

Information gained in the literature review and the semi-structured conversations suggested that there are two issues that need to be addressed in order to support individuals living with dementia to engage with their community, these are:

- Supporting individuals living with dementia to understand that it is possible to live well with dementia
- The need for support to assist individuals with dementia to practically engage with their community

This section of the report will look at each of these issues in turn.

While addressing these issues is important for developing dementia friendly communities, these goals also overlap with several of the objectives set out in the National Dementia Strategy.

6.2.1 Supporting individuals living with dementia to understand that it is possible to live well with dementia

The Innovations in Dementia research revealed that the most common reasons why individuals had stopped doing activities in their community were:

- The progression of their dementia and a fear about their ability to engage with the community
- A perception that people lack understanding about dementia.[38]

Quoting this research the Local Government Association report *Developing dementia-friendly communities: Learning and guidance for local authorities* commented "*people with dementia and carers almost exclusively cited dementia as the sole barrier to community engagement, rather than external barriers*".[39]

[36] Alzheimer's Society (2012). Dementia 2012: A national challenge. Alzheimer's Society: London p.40
[37] Ibid p.46
[38] Ibid p.17
[39] Local Government Association (2012) Developing dementia-friendly communities: Learning and guidance for local authorities [Online] Available at: http://www.local.gov.uk/web/guest/ageing-

During the literature review and the semi-structured conversations the diagnosis process was suggested as a key factor that shapes the perceptions of individuals living with dementia. This point was made in the Local Government Association report *Developing dementia-friendly communities Learning and guidance for local authorities* which commented that "*many people give up soon after getting their diagnosis"* because of "*the negative and insensitive ways in which they were given their diagnosis and the lack of advice, information and support made available to them at the time"*.[40]

The report goes on to recommend that in order to ensure that individuals living with dementia continue to feel that they can engage with their community the diagnosis process needs to include:

- Post diagnostic support that goes beyond the simple provision of information
- Peer group support to share knowledge and provide engagement with wider community[41]

Plymouth

As part of their work to make Plymouth a dementia friendly city the Plymouth Dementia Action Alliance is working to increase early diagnosis and improve the diagnosis process.

In order to achieve this aim a GP from the Plymouth Dementia Action Alliance is visiting every GP practice in the community in order to advise GPs and other staff involved in the diagnostic procedure on the importance of improving diagnosis rates and the diagnosis process.

6.2.2 Supporting individuals living with dementia to practically engage with their community

As well as the need to communicate the message that it is possible to live well with dementia the research for this project also highlighted a need for appropriate support that can assist individuals with dementia to practically engage with their community where such support is needed. It was also suggested that individuals need appropriate information about such services.

Respondents in the Innovations in dementia research suggested that what they wanted to help them engage with their community was "*low level 1-1 support by a volunteer or 'buddy'"*.[42]

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well/what-makes/-/journal_content/56/10171/3489459/ARTICLE-TEMPLATE (Accessed 1 August 2012) p.26

[40] Local Government Association (2012) Developing dementia-friendly communities: Learning and guidance for local authorities [Online] Available at: http://www.local.gov.uk/web/guest/ageing-well/what-makes/-/journal_content/56/10171/3489459/ARTICLE-TEMPLATE (Accessed 1 August 2012) p.13

[41] Ibid p.13

According to the Innovations in Dementia report *Dementia Capable Communities: The views of people with dementia and their supporters* "*friends, family, neighbourhoods and the broader community*"[43] all represented important sources of support. However there were a number of challenges that often meant people living with dementia found it difficult to get the necessary support for a number of reasons, including:

- The drifting away of family and friends following a diagnosis of dementia
- A loss of community as "*people keep themselves to themselves*"[44]
- Fear of driving new people away by appearing too needy[45]

The Innovations in Dementia report stated that local groups are "*the most common way that individuals with dementia stay connected to their communities*".[46] These groups included memory cafes and 'Singing for the Brain' groups.

Respondents during the Innovations in Dementia research also claimed that though support services, including mental health teams and NHS services, represented one of the key means by which they were able to remain in touch and involved with their community the respondent highlighted a number of concerns relating to these support services including:

- Problems accessing services
- Lack of services including day services and services for people in the early stages of dementia
- Problems resulting from a lack of understanding about dementia amongst those working in the services
- Lack of joint working between support services [47]

In order to improve the provision of support to help people with dementia remain included in their community the Innovation in Dementia report recommends that there is a need for:

- More information, and more accessible information about local services and facilities
- Support for local groups that assist individual's living with dementia and their carers[48]

In addition it was noted by one of the project's respondents during the semi-structured conversations that a formal diagnosis was an important preliminary factor. This was because it allows individuals living with dementia to know what their condition is and receive appropriate support and information about services that will allow them to continue to engage with their community.

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[42] Innovations in Dementia (2011) Dementia Capable Communities: The views of people with dementia and their supporters [Online} Available at: http://www.innovationsindementia.org.uk/projects_communities.htm (Accessed 1 August 2012) p.17
[43] Ibid p.9
[44] Ibid p.14
[45] Ibid pp.13-14
[46] Ibid p.15
[47] Ibid p.13
[48] Ibid p.3

The Debenham Project

The Debenham Project was launched in 2009 in Suffolk as a volunteer-led group which is inspiring the community of Debenham to "take responsibility for the welfare and support of those who are family carers looking after someone with dementia, and of meeting the health and social needs of those that they care for".

The Debenham Project currently has 80 volunteers offering their time to support individuals in the community living with dementia and their carers and has "developed a comprehensive range of local volunteer-based services which 'draws in' the best professional support".

The support services offered by the project include:

- Confidential telephone support line
- Activities and social support sessions
- Food 'n' Friends luncheon clubs
- Information and advice centre
- Medication and pharmacy support
- A Carers' Club and Info Café
- Local access to memory and clinical services
- Chair-based exercise therapy (Fit Club)

Information taken from the document 'This is: The Debenham Project' which is available on the home page of the project's website. Additional information and contact details are available at www.the-debenham-project.org.uk.

7. Increasing understanding and awareness about dementia and the needs of those with dementia

Section overview

- This section of the report outlines existing knowledge about and examples of work undertaken to increase understanding and awareness about dementia and the needs of individuals living with dementia
- There is a need to increase awareness and understanding amongst targeted organisations within the community as well as through wider awareness raising campaigns
- During the literature review and semi-structured conversations, increasing awareness and understanding about dementia and the needs of individuals living with dementia was the most commonly cited factor that needs to be addressed to develop dementia friendly communities
- During the literature review and the semi-structured conversations, a number of common themes emerged relating to how to increase awareness and understanding amongst local organisations, these were:
    - How to decide which local organisations to target
    - How to get local organisation to 'sign up' to become more dementia friendly
    - What is the most appropriate way to raise awareness amongst those working in local organisations

This section of the report outlines existing knowledge about and examples of work undertaken to increase understanding and awareness about dementia and the needs of those with dementia. This includes increasing awareness and understanding amongst targeted organisations within the community as well as wider awareness raising campaigns. As noted in section 5 this is one of the factors that must be addressed in order to achieve the aims set out in section 4 and thereby create dementia friendly communities.

7.1 The importance of increasing understanding and awareness about dementia and the needs of those with dementia

In both the literature review and the semi-structured conversations the need to increase awareness and understanding about dementia and the needs of individuals living with dementia was the most frequently cited factor that ought to be addressed in order to develop dementia friendly communities

The need for increased awareness and understanding was highlighted by the findings of the Local Government Association report which suggested that while members of a community "*are often willing to help individual's living with dementia*" these same individuals are often

unsure about "*what to do for the best*" due to "*fear and stigma around what dementia means*".[49]

The findings of the literature review and semi-structured conversations suggested that increasing awareness and understanding about dementia and how to support people with dementia not only helps individuals living with dementia at a practical level, such as when using local facilities but also plays an important part in reducing stigma. As explained by one respondent "*raising awareness and reducing stigma are both aspects of the societal and behavioural change that is needed to make communities' dementia friendly*".

Section 7.2 outlines knowledge and issues relating to the task of increasing awareness and understanding amongst local organisations and section 7.3 outlines information relating to more general awareness raising initiatives that target the community at large.

7.2 Raising awareness amongst local organisations

During the project's research there were numerous examples of initiatives that aimed to increase awareness and understanding about dementia amongst the staff of local organisations. While this included increasing awareness and understanding amongst those working in the field of health and social care, it was recognised that in order to create dementia friendly communities there is a need to go further and increase awareness and understanding amongst staff from a wider range of organisations. This intention was highlighted by one respondent who stated that it was their aim to see that "*every organisation, venue and individual a person living with dementia comes into contact with has a basic awareness of dementia and how to best act to support someone who has the illness*".

The importance of increasing awareness and understanding amongst local organisations was noted in *Developing dementia-friendly communities: Learning and guidance for local authorities* which explained that the main areas of concern for people living with dementia relates to the "*practicalities of everyday life*" including "*banking, understanding insurance and finance, paying bills and dealing with utility companies*".[50] While the physical design of these services play an important part in making such services dementia friendly the report claimed that for most people the largest determinant of how dementia friendly the services are is *"the attitude of the people with whom they came into contact"*.[51]

As well as examples of work that has been done to increase awareness and understanding so that individuals living with dementia will be able to use local facilities more easily, there are examples of initiatives that aim to increase awareness and understanding amongst local organisations so that they will be more aware of the needs of their own staff who may develop early onset dementia or may be caring for someone with dementia.

[49] Local Government Association (2012) Developing dementia-friendly communities: Learning and guidance for local authorities [Online] Available at: http://www.local.gov.uk/web/guest/ageing-well/what-makes/-/journal_content/56/10171/3489459/ARTICLE-TEMPLATE (Accessed 1 August 2012) p.29

[50] Ibid p.12

[51] Local Government Association (2012) Developing dementia-friendly communities: Learning and guidance for local authorities [Online] Available at: http://www.local.gov.uk/web/guest/ageing-well/what-makes/-/journal_content/56/10171/3489459/ARTICLE-TEMPLATE (Accessed 1 August 2012) p.29

Plymouth Naval Base

The Plymouth Dementia Action Alliance has worked to increase awareness amongst the city's naval base. The Plymouth Dementia Action Alliance has "*provided awareness sessions for members of Naval Families Service and Naval Base staff to raise awareness of the difficulties some of their staff face in maintaining caring duties alongside their work responsibilities. As a result of this and a business case by the Naval Base, Human Resources have re-structured their HR policies to reflect the needs of carers within the workforce and Naval Personal and Family Service have made it a priority to ensure that servicemen and women deployed on tours of duty are assured that their loved ones in need of care will be given the support that they require*".

Quote taken from: Sherriff, Ian and McFarlane, Helen (2012) Building a Dementia Friendly Community Checklist (Unpublished)

During the literature review and the semi-structured conversations, a number of common themes emerged relating to how to increase awareness and understanding amongst local organisations, these were:

- How to decide which local organisations to target
- How to get local organisation to 'sign up' to become more dementia friendly
- What is the most appropriate way to raise awareness amongst those working in local organisations

Each of these issues will be addressed in turn in the remainder of section 7.2

7.2.1 Deciding which organisations to target

The project's semi-structured conversations revealed that communities had adopted different approaches when deciding which organisations to target or prioritise.

In some communities respondents described an intention to engage with every organisation within their area.

Alternatively a respondent in another area explained that they did not have a definite strategy as to which organisations to approach. Instead the respondent was using local networks to engage with organisations with which they had a personal connection. As the respondent explained "*we started by asking, who do we know?"*. The respondent commented that while this was done for practical reasons it was hoped that once contact was made with the first group of organisations these organisations would in turn be able to introduce further contacts.

Yet another respondent described plans to 'map out' the organisations most used and valued by individuals living with dementia in their area. This mapping was then to be used to guide decisions about which organisations to prioritise.

East Sutherland

In East Sutherland a group of individuals have come together to make the county more dementia friendly. The group began by selecting a single village that would act as "*a beacon 'Dementia Friendly Community' that will provide the inspiration for other towns and villages in East Sutherland to follow*".

When deciding which organisations to engage with in the village the group identified "*the key partners, services, activities and businesses*" in the village to "*develop a local map of 'the people and the place'*"

Information taken from 'A Carers Voice' website which can be accessed at: http://www.acarersvoice.com/dementia-friendly-community/dementia-friendly-communities/

7.2.2 How to get local organisation to 'sign up' to become more dementia friendly

The literature review and semi-structured conversations suggested that although there may be many organisations who sign up to become more dementia friendly because of a shared belief in the importance of creating dementia friendly communities there may be others who, due to the pressures of running a business or otherwise, may be more hesitant.

The 'Dementia-Friendly Hampshire Toolkit'[52] provides guidance on how to explain to local businesses and facilities the benefits and importance of becoming dementia friendly. The document 'Why do we need to be dementia friendly?'[53] lists a number of reasons why organisations may want to become more dementia friendly, these reasons include:

- Being dementia friendly will allow businesses to maintain existing customers and attract new customers who are living with dementia
- Being dementia friendly will be an advantage to those businesses that "*have a community charter or community benefit component to them*"[54]
- Being dementia friendly will help businesses to comply with their obligations under the Equality Act 2010

[52] Innovations in Dementia (2012) Dementia-Friendly Hampshire Toolkit [Online] Available at: http://www.innovationsindementia.org.uk/DementiaFriendlyCommunities/DementiaFriendlyCommunities_ToolkitIntroduction.pdf (Accessed 1 August 2012)

[53] Innovations in Dementia (2012) Why do we need to be dementia-friendly? [Online] Available at: http://www.innovationsindementia.org.uk/DementiaFriendlyCommunities/Why%20do%20we%20need%20to%20be%20dementia%20friendly.pdf (Accessed 1 August 2012)

[54] Ibid p.3

- The fact that "*staff who are unsure how to help customers with dementia may be hesitant causing delays to themselves, the customer with dementia and other customers*"[55]

The 'Why do we need to be dementia friendly?' tool also provides guidance for businesses on what actions they can take to make their businesses more dementia friendly and can be downloaded for free from the Innovations in Dementia website.[56]

Organisations may also be persuaded of the benefit of being dementia friendly by the Local Government Association's observation that, "*many of the techniques for responding to people with dementia are the basis of good customer care for all* [for example] *respect, patience* [and] *clear and jargon free communication*".[57]

Potential barriers to local organisations becoming more dementia friendly

Despite the benefits of becoming more dementia friendly highlighted above respondents during the semi-structured conversations suggested that there were still a number of factors that made local businesses reluctant to sign up to become more dementia friendly.

Firstly, it was noted by one respondent that "*local small business are shying away from the Dementia Action Alliance model as they fear attending 'committees' or groups and see them as ineffective*".

Secondly, it was felt that where there was a need for local businesses, as members of their local alliance, to sign up to national targets and there was a concern that smaller businesses were being put off by too much paperwork which could be cumbersome.

South West England

In South West England local alliances are approaching organisation in their respective communities and encouraging them to sign up to become more dementia friendly. They are doing this by emphasising the importance and benefits to them of being dementia friendly.

A representative working with the local alliances in the South West suggested that once the first group of businesses had signed up to become more dementia friendly this encouraged other local organisation to become involved. It was suggested that this was a result of the idea being spread by word of mouth and also the pressures of local competition which meant that businesses were conscious of what their competitors were doing.

[55] Ibid P.3

[56] www.innovationsindementia.org.uk/

[57] Local Government Association (2012) Developing dementia-friendly communities: Learning and guidance for local authorities [Online] Available at: http://www.local.gov.uk/web/guest/ageing-well/what-makes/-/journal_content/56/10171/3489459/ARTICLE-TEMPLATE (Accessed 1 August 2012) p.22

North West England

There are currently plans in the North West of England to ensure that "*every organisation, venue and individual a person living with dementia comes into contact with has a basic awareness of dementia and how to best act to support someone who has the illness*".

"*So for example if a person living with dementia goes out to buy a newspaper and get their hair cut… a minimum of one person on duty at any one time in each of these shops has had dementia awareness training, the same for bus drivers, taxi companies, milk men etc*".

There are also plans to train volunteers to perform tasks such as checking premises and signage to ensure they are dementia friendly and then make recommendations for any improvements that local organisations can make in order to make their premises more dementia friendly.

Work is currently underway to target individual areas at the sub council ward level and bring together volunteers in those areas who can publicise local meetings and 'awareness training sessions'.

Bradford

Bradford is currently piloting work to make the city more dementia friendly. A development worker is working intensively with a pilot group of eight local organisations including businesses, community organisations and faith organisations.

The eight organisations are given a briefing sheet which explains the importance of staff attitude and understanding and suggests that a quiet space be provided where people with dementia can talk to staff and also stresses the importance of clear signs and good lighting. The briefing sheet also highlights the need for employers to be aware that their staff may be a carer for someone with dementia.

The development worker provides the organisations with check lists and other information and support to help the organisations review their service and facilities. The development worker is also helping the organisations to draw up

7.2.3 What is the most appropriate way to raise awareness amongst those working in local organisations?

During the project's research a number of respondents discussed the importance of ensuring that the level of information provided to local organisations was appropriate.

A representative from the Torbay Dementia Action Alliance stressed that:

> *"the words 'Dementia Aware' are very important as we are certainly not a training consultancy firm nor profess to be so… All I am asking is if every business in Torbay will agree to sign up to this and let us do the hard work for them. We will provide the information, we will provide the badge and we can also supply the "Including People with Dementia What Works Cards" which they can either buy for a very small fee of £3.00 or even download free from the internet. The training officers or health and safety reps* [could] *include this information in their induction training and also include it in the yearly review they do with the staff"*

The representative from the Torbay Action Alliance stressed that the focus on awareness raising rather than in-depth training was the most appropriate approach as "*many businesses will be put off by talk of costs, training and the like*".

The need to avoid 'overwhelming' organisations was echoed by a number of respondents. One respondent claimed that in-depth training was not appropriate as customer-facing staff in local facilities were not expected to be able to diagnose people with dementia, instead the aim was to increase awareness so that staff will be mindful that customers may have dementia and will act in a dementia friendly manner to all customers.

Despite a common commitment to 'awareness raising' rather than in-depth training the exact way in which information was delivered varied between localities. In some areas representatives were providing hardcopy information for dissemination amongst staff while in other localities it was felt that short presentations were more appropriate. In one area a volunteer arranged with local businesses to speak to their staff for 10-15 minutes as it was felt that businesses would be "*unwilling to allow staff to come off the floor for any longer*". Another respondent had suggested that they were planning on producing a training DVD for local organisations as it was felt that this was would be the most convenient option for busy organisations.

Guidance for organisations seeking to increase awareness and understanding amongst their staff has been provided in the *Dementia-Friendly Hampshire Toolkit*. This toolkit includes the document '*Help-Pack for customer-facing staff*' which is designed to help staff to "*support customers who might have dementia*".[58] The Toolkit also includes the document '*Dementia awareness raising options for staff*' which details options for further training including existing face to face training options, online training and printed materials.[59]

[58] Innovations in Dementia (2012) Help-Pack for customer-facing staff [Online] Available at: http://www.innovationsindementia.org.uk/DementiaFriendlyCommunities/DementiaFriendlyCommunities_Help%20Pack%20for%20Customer%20Facing%20staff.pdf (Accessed 1 August 2012)

[59] Innovations in Dementia (2012) Dementia awareness raising options for staff [Online] Available at: http://www.innovationsindementia.org.uk/DementiaFriendlyCommunities/Dementia%20Awareness%20raising%20options.pdf (Accessed 1 August 2012)

It was explained by one of the project's respondents that their preliminary research had shown that that there is a need to take awareness training sessions to local businesses rather than expecting companies to travel.

See also section 9.3.1 of this report for details relating to the cost of providing training or awareness raising sessions to local organisations.

Wales

The Alzheimer's Society in Wales has launched its dementia friendly communities programme through which the Society aims to support and give public recognition to villages, towns, cities and national organisations who are taking steps towards being more inclusive of people with dementia and their families.

An awareness event was held by Alzheimer's Society Abertawe Bro Morgannwg and was attended by a wide cross section from the community, including people living with dementia, city centre managers, GP's, bus companies, Health and Social care managers and members of the Women's Institute amongst others. The Lord Mayor and mayors, as well as the council leader also accepted the invitation and in total 137 people attended the event.

The meeting ended with 110 attendees pledging their support to the idea of dementia friendly communities.

Following the enthusiasm expressed at the Awareness event Alzheimer's Society Abertawe Bro Morgannwg are looking to work with various partners to form a steering group to take forward the ambition of becoming dementia friendly in Neath Port Talbot, Swansea and Bridgend. The Alzheimer's Society Abertawe Bro Morgannwg are working to maintain contact with the people who signed up to the idea at the awareness raising event, encouraging them to become involved in the process and are also liaising with local businesses to encourage their involvement.

7.3 General awareness raising initiatives

As well as targeting customer-facing staff in local organisations a number of respondents also stressed the need to increase awareness and understanding amongst the community more generally.

The need to for general awareness raising campaigns was mentioned less commonly than awareness raising initiatives that targeted local organisations and the research revealed few details about general awareness raising initiatives.

Plymouth

The Plymouth Dementia Action Alliance is working to increase awareness and understanding about dementia amongst the citizens of Plymouth. The local football team is running an awareness raising advert in their match programme and taking part in memory walks. In addition the local basketball team have also dedicated a full page of their weekly match programme to detail information about dementia.

The Plymouth Dementia Action Alliance is seeking to use the local media to raise awareness by providing them with stories about the work that is being done in the area.

8. Creating physical environments appropriate for people living with dementia

Section overview

- This section of the report outlines existing knowledge about the role that physical environments, both indoors and outdoors, can play in developing dementia friendly communities and what physical environments are most appropriate for individuals living with dementia
- The section highlights two key sources that have, in light of the Prime Minister's Challenge on Dementia, summarised existing knowledge relating to the creation of physical environments appropriate for people living with dementia
- The *Checklists for dementia-friendly environments* report suggest that the most important factors to be considered when designing internal environments appropriate for individual's living with dementia are the signage, lighting, flooring, seating and navigability
- The *At a Glance: a Checklist for Developing Dementia Friendly Communities* report suggests that the key principles to be considered when designing appropriate outdoor spaces for individuals living with dementia are that such spaces should be familiar, legible, distinctive, accessible, safe and comfortable

This section of the report outlines existing knowledge about the role that physical environments play in developing dementia friendly communities and what physical environments are most appropriate for individuals living with dementia. As noted in section 5 this is one of the factors that must be addressed in order to achieve the aims set out in section 4 and thereby create dementia friendly communities.

Section 8 details existing knowledge relating to the physical environment of both indoor and outdoor spaces.

8.1 The importance of dementia friendly physical environments

The importance of a community's physical environment was explained in the Innovation in Dementia report *Dementia Capable Communities: The views of people with dementia and their supporters* which stated that "*good design and attention to orientation can make a significant difference to a person with dementia's ability to navigate their surroundings*".[60]

[60] Innovations in Dementia (2011) Dementia Capable Communities: The views of people with dementia and their supporters [Online} Available at: http://www.innovationsindementia.org.uk/projects_communities.htm (Accessed 1 August 2012) p.29

The importance of a community's physical environment was echoed in the Local Government Association report *Developing dementia-friendly communities: Learning and guidance for local authorities* which stated:

> *"The physical environment, from streetscape down to individual shops and facilities within it, play a key role in determining the extent to which people with dementia will find their community dementia friendly".*[61]

However these claim should be understood in the context of the observation made in *What makes dementia friendly communities?* that while "*the physical environment is a factor"* that influences how dementia friendly a community is "*attitude is far more important*".[62]

A recommendation common to the literature on both indoor and outdoor environments was the need to *"build on the potential for people with dementia in advising on access issues*".[63] This insight was echoed in *Developing dementia-friendly communities: Learning and guidance for local authorities* which stated the importance of involving *"people with dementia in the planning of new developments or redesigns to the built environment"* as well as the need for local organisations to *"talk to people with dementia about how they found using a place".*[64]

8.2 Literature relating to the development of dementia friendly physical environments

During the research the need for appropriate physical environments was highlighted as an important part of creating a dementia friendly community in all of the literature surveyed. By contrast the role physical environments play in developing dementia friendly communities was only briefly mentioned by two respondents during the semi-structured conversations. Consequently this section of the report will outline information gained during the literature review.

Section 8.2.1 outlines the key factors to be addressed when making the internal environments of local businesses and facilities more dementia friendly. Section 8.2.2 sets out the factors that determine the dementia friendliness of outdoor public spaces.

Although there is a large body of literature that details the factors that should be considered by those designing dementia friendly environments much of it has been summarised in two key documents that review and condense the existing literature in light of the Prime

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[61] Local Government Association (2012) Developing dementia-friendly communities: Learning and guidance for local authorities [Online] Available at: http://www.local.gov.uk/web/guest/ageing-well/what-makes/-/journal_content/56/10171/3489459/ARTICLE-TEMPLATE (Accessed 1 August 2012) p.28

[62] Milton, Steve (2012) What makes a dementia-friendly community? *Journal of Dementia Care*, 20 (2), p.13

[63] Innovations in Dementia (2011) Dementia Capable Communities: The views of people with dementia and their supporters [Online} Available at: http://www.innovationsindementia.org.uk/projects_communities.htm (Accessed 1 August 2012) p.29

[64] Local Government Association (2012) Developing dementia-friendly communities: Learning and guidance for local authorities [Online] Available at: http://www.local.gov.uk/web/guest/ageing-well/what-makes/-/journal_content/56/10171/3489459/ARTICLE-TEMPLATE (Accessed 1 August 2012) p.28

Minister's Challenge on Dementia. These documents are *Checklists for dementia-friendly environments* [65] and *At a Glance: a Checklist for Developing Dementia Friendly Communities.*[66]

As these documents have summarised existing literature on the design of the physical environment sections 8.2.1 and 8.2.2 will draw exclusively on the summaries provided in these publications. However outlined below is some of the literature that informed these summaries.

Key sources cited in *Checklists for dementia-friendly environments* and *At a Glance: a Checklist for Developing Dementia Friendly Communities* include:

- **Neighbourhoods for life: Designing dementia-friendly outdoor environments**[67]

  This document details recommendations for the design of dementia friendly outdoor environments

- **Building Dementia and Age-Friendly Neighbourhoods**[68]

  Produced by Alzheimer's Australia NSW this report contains the Dementia and Age-Friendly Outdoor Design Checklist which lists issues relevant to the design of both indoor and outdoor dementia friendly environments

- **Checklist of Essential Features of Age-Friendly Cities**[69]

  The checklist was produced by the World Health Organisation and is based on their Global Age-Friendly Cities project. While age and dementia are not interchangeable concepts the majority of individuals living with dementia are 65 and many of the principles listed in the checklist will be of assistance to individuals living with dementia

- **Dementia Design Checklist: Design checks for people with dementia in healthcare premises**[70]

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[65] Innovations in Dementia (2012) Checklists for dementia-friendly environments [Online] Available at http://www.innovationsindementia.org.uk/DementiaFriendlyCommunities/Dementia-friendly%20Environmental%20checklists.pdf (Accessed 1 August 2012)

[66] Porteus, Jeremy (2012) At a Glance: a Checklist for Developing Dementia Friendly Communities. Viewpoint No. 25, Housing LIN [Online] http://www.housinglin.org.uk/Topics/browse/HousingandDementia/Design/?parent=5091&child=8525 (Accessed 1 August 2012)

[67] Oxford Centre for Sustainable Development (2004) Neighbourhoods for life – Designing dementia-friendly outdoor environments [Online] Available at: http://www.housinglin.org.uk/Topics/browse/HousingandDementia/Design/?parent=5091&child=6988 (Accessed: 1 August 2012)

[68] Alzheimer's Australia NSW (2011) Building Dementia and Age-Friendly Neighbourhoods [Online] Available at: http://www.fightdementia.org.au/common/files/NSW/DementiaFriendlyNeighbourhoodsWebVersion.pdf (Accessed 1 August 2012)

[69] World Health Organisation (2007)Checklist of Essential Features of Age-Friendly Cities [Online] Available at: http://www.who.int/ageing/publications/Age_friendly_cities_checklist.pdf (Accessed 1 August 2012)

Although intended for use by those involved in the design of healthcare environments the document, which was developed by Stirling University Dementia Services Development Centre and NHS Scotland, "*still has much of application to other indoor environments*"[71]

8.2.1 Dementia friendly indoor environments

The *'Checklists for dementia-friendly environments'* which is part of the *'Dementia-Friendly Hampshire Toolkit'* can be downloaded from the Innovations in Dementia website[72] and lists the small scale changes recommended to make environments, particularly indoor environments, more accessible for individuals living with dementia. This summary is reproduced below.

Signage:

- Signs should be clear, in bold face with good contrast between text and background
- There should be a contrast between the sign and the surface it is mounted on
- Signs should be fixed to the doors they refer to – not on adjacent surfaces
- Signs should be at eye level and well-lit
- The use of highly stylised or abstract images or icons as representations on signage should be avoided
- Think about placing signs at key decision points for someone who is trying to navigate your premises for the first time
- Signs for toilets and exits are particularly important
- Ensure that glass doors are clearly marked

Lighting:

- Entrances should be well-lit and makes as much use of natural light as possible
- Pools of bright light and deep shadows should be avoided

Flooring:

- Avoid highly reflective and slippery floor surfaces
- Changes in floor finish should be flush

Seating:

- In larger premises – a seating area especially in areas where people are waiting
- People with dementia prefer seating that looks like seating – so for example a wooden bench rather than an abstract metal Z-shaped bench

[70] Stirling University Dementia Services Development Centre and NHS Scotland (2007) Dementia Design Checklist – Design checks for people with dementia in healthcare premises [Online] Available at: https://dementia.stir.ac.uk/files/DementiaDesignChecklist.pdf (Accessed 1 August 2012)

[71] Innovations in Dementia (2012) Checklists for dementia-friendly environments [Online] Available at http://www.innovationsindementia.org.uk/DementiaFriendlyCommunities/Dementia-friendly%20Environmental%20checklists.pdf (Accessed 1 August 2012) p.2

[72] www.innovationsindementia.org.uk

Navigation:

- Research shows that people with dementia use "landmarks" to navigate their way around, both inside and outside. The more attractive and interesting the landmark (which could be a painting, or a plant) the easier it is to use as a landmark[73]

8.2.2 Dementia friendly outdoor environments

Breaking New Ground: The Quest for Dementia Friendly Communities[74] surveys the existing literature on the design of outdoor spaces and summarises the key principles in the document *At a Glance: a Checklist for Developing Dementia Friendly Communities*.[75] This summary is reproduced below.

The most useful design principles and recommendations currently available include:

- Familiar environments which people with dementia recognise and understand
- Legible environments which give clues to help people with dementia understand where they are, what is expected of them in that space and which way they need to go
- Distinctive environments, spaces and features help capture people's attention and concentration and enhance their living environment while helping them to find their way around
- Accessible environments that enable people to reach, enter, use and move around the places and spaces they need or wish to visit, regardless of any physical, sensory or cognitive impairment
- Safe environments so people can independently use, enjoy and move around places and spaces freely without fear of coming to harm plain paving, raised beds, seating and shelter, flat topography and no trip hazards
- Comfortable environments so people feel at ease and are able to visit, use and enjoy places and spaces of their choice without physical or mental discomposure[76]

[73] Innovations in Dementia (2012) Checklists for dementia-friendly environments [Online] Available at http://www.innovationsindementia.org.uk/DementiaFriendlyCommunities/Dementia-friendly%20Environmental%20checklists.pdf (Accessed 1 August 2012) pp.4-5

[74] Mitchell, Lynne (2012) Breaking New Ground: The Quest for Dementia Friendly Communities. Viewpoint No. 25, Housing LIN [Online] http://www.housinglin.org.uk/Topics/browse/HousingandDementia/Design/?parent=5091&child=8525 (Accessed 1 August 2012)

[75] Porteus, Jeremy (2012) At a Glance: a Checklist for Developing Dementia Friendly Communities. Viewpoint No. 25, Housing LIN [Online] http://www.housinglin.org.uk/Topics/browse/HousingandDementia/Design/?parent=5091&child=8525 (Accessed 1 August 2012)

[76] Porteus, Jeremy (2012) At a Glance: a Checklist for Developing Dementia Friendly Communities. Viewpoint No. 25, Housing LIN [Online] http://www.housinglin.org.uk/Topics/browse/HousingandDementia/Design/?parent=5091&child=8525 (Accessed 1 August 2012) pp.1-3

9. Cross cutting themes that are relevant to the process of creating dementia friendly communities

Section overview

- This section outlines details about the four cross cutting themes relevant to the *process* of creating dementia friendly communities that were highlighted in section 5
- The project's research suggested that need for individuals living with dementia to be at the centre of the process of developing dementia friendly communities is important because:
    - It increases the likelihood that the community is responsive to the needs of individuals living with dementia
    - Individuals living with dementia have a right to be included in decisions that affect them
- The research highlighted a range of opinions regarding the most appropriate means of monitoring the 'dementia friendliness' of organisations and the community as a whole:
    - A number of areas are adopting an accreditation scheme however other respondents suggested that there may be a number of potential problems arising from such a scheme
    - The most commonly suggested form of monitoring 'dementia friendliness' is through the use of a peer review system
- Local, regional and national networks play an important role in the process of developing dementia friendly communities as they provide an important site for:
    - Allowing the voices of those with dementia to shape any work done to develop a dementia friendly community
    - Provide a platform for sharing ideas between local organisations and monitoring of progress through a process of peer review and feedback
    - Set local priorities specific to the needs of that particular community
- The potential costs associated with developing dementia friendly communities include:
    - Employing a coordinator/facilitator to encourage the creation of local groups and alliances and help local organisations become more dementia friendly
    - The provision of awareness raising sessions and materials
    - Providing support services and associated facility costs
- The potential sources of income for those developing dementia friendly communities, includes:
    - Contributions from local alliances and organisations
    - Charging for awareness raising sessions
    - Funding through city and parish councils and local authorities
    - Registering as a social entity in order to secure funding

This section of the report outlines information relating to the four cross cutting themes that were highlighted in section 5. These themes are:

- The need for those with dementia to be at the centre of the process of developing dementia friendly communities
- How to monitor the 'dementia friendliness' of organisations and the community as a whole
- The role that local, regional and national networks play in the process of developing dementia friendly communities
- How to address the costs associated with developing and maintaining dementia friendly communities

While these themes are not the end goals of dementia friendly communities they are relevant to the *process* of creating dementia friendly communities.

9.1 The need for those with dementia to be at the centre of the process of developing dementia friendly communities

The importance of ensuring that individuals who are living with dementia are at the centre of the process of developing dementia friendly communities was highlighted in the document, *Finding out what a dementia friendly community means to people with dementia and carers,* which stated:

> *"Dementia-friendly communities need to be responsive to what people want, but perhaps more importantly, people with dementia should have the right to have a sense of ownership, investment, responsibility and of connectedness to their own communities"*[77]

As noted in section 4 one of the aims of developing dementia friendly communities is to ensure that individuals living with dementia are included in their community. Involving individuals living with dementia in the process of developing dementia friendly communities is an important means of achieving this aim.

Including individuals living with dementia in the process of developing dementia friendly communities also has a practical importance as this involvement increases the likelihood that communities will be responsive to the specific needs of individuals in the community living with dementia.

The *Finding out what a dementia friendly community means to people with dementia and carers*[78] toolkit can be downloaded from the innovation in dementia website[79] and provides useful guidelines on how to engage with people with dementia on the issue of dementia friendly communities. This includes tools for one to one conversations, group discussions,

[77] Innovations in Dementia (2012) Finding out what a dementia friendly community means to people with dementia and carers [Online] http://www.innovationsindementia.org.uk/DementiaFriendlyCommunities/DementiaFriendlyCommunities_engagement.pdf (Accessed 1 August 2012) p.4

[78] Innovations in Dementia (2012) Finding out what a dementia friendly community means to people with dementia and carers [Online] http://www.innovationsindementia.org.uk/DementiaFriendlyCommunities/DementiaFriendlyCommunities_engagement.pdf (Accessed 1 August 2012)

[79] www.innovationsindementia.org.uk

guideline questionnaires and details on alternative techniques for identifying the opinions of individuals in the community living with dementia. This document also provides references to further reading on this subject.

9.2 How to monitor the 'dementia friendliness' of organisations and the community as a whole

The literature review and semi-structured conversations revealed a range of opinions about what is the most appropriate means of monitoring the dementia friendliness of individual organisations and the community as a whole.

Section 9.2 outlines:

- Information regarding the use of an accreditation scheme as a means of monitoring 'dementia friendliness'
- Problems arising from the use of an accreditation scheme as a means of monitoring 'dementia friendliness'
- Alternative means of monitoring 'dementia friendliness'

The importance of monitoring the 'dementia friendliness' of organisations and communities was noted by one respondent who claimed, "*there is a need to be more than a talking shop and those who sign up must complete the actions they sign up to"*. This principle was expressed by another respondent who stated that

> "*Businesses who sign up need to understand that they are signing up have an affect…we don't want it to be just about collecting names, the businesses need to deliver on their commitments however great or small those commitments are*"

9.2.1 Information regarding the use of an accreditation scheme as a means of monitoring 'dementia friendliness'

A number of respondents explained they are, or are planning to, use an accreditation scheme to identify which organisations are dementia friendly. An example of this can be seen in Torbay where the Torbay Action Alliance is distributing badges to show which organisations are dementia friendly. The badges can be displayed in the windows of local organisations and are given *"once awareness has been raised amongst all staff*".

According to one respondent the accreditation scheme incentivises businesses to take part through the possibility of positive publicity and potentially increased custom. In addition it was suggested the scheme raises awareness about dementia and provides a guide as to which organisations in the area offer the best service for people living with dementia and their carers.

The '*Making Hampshire Dementia Friendly Toolkit'* includes the document '*Thinking about a "memory aware" high street scheme'*. This document outlines guidance on developing a 'kitemark' which can be displayed in "shops and facilities" in order to demonstrate that they are dementia friendly. The guidance advises that:

"*It is important to establish a shared meaning about what this might mean, both for businesses signing up, and for people with dementia who might want to use it*"[80]

It is suggested in the document that failure to do so risks businesses and individuals in the community living with dementia losing faith in the scheme.

The document claims that the essential elements to be considered when developing a dementia-friendly accreditation scheme are:

- It must be grounded in what people living with dementia say they want
- It must be grounded in what is possible and realistic from the perspective of local businesses
- It must involve a commitment by businesses to, as a minimum requirement, provide awareness raising for staff
- It must be "owned" by an organisation or alliance of organisations willing to support both businesses and people with dementia in its use
- It must involve businesses signing up to a charter, or "dementia declaration" that may be aspirational, but which commits them to reviewing the ways in which they support customers with dementia[81]

9.2.2 Problems arising from the use of an accreditation scheme as a means of monitoring 'dementia friendliness'

A number of respondents suggested that there may be several potential problems that arise from the use of an accreditation scheme. It was claimed by one respondent that a particular challenge is the fact that developing dementia friendly communities "*does not lend itself to quantification"* and therefore it is difficult to ascertain a 'cut off' point at which it was possible to say that an organisation or a community has become sufficiently dementia friendly, or dementia friendly enough to justify accreditation.

The respondent denied that the lack of an accreditation would make the concept "*too vague*". Instead the respondent explained that while they did not think that there is a clear cut off point at which an organisation become dementia friendly, they did feel that it was possible to set goals and monitor improvements and progress. The respondent claimed "*while it is not possible to say an organisation is dementia friendly, it is possible to say that an organisation is getting more dementia friendly*".

Another respondent dismissed the use of a formal accreditation scheme stating that the creation of dementia friendly communities is about "*more than a sign it's a movement*". The respondent suggested that developing dementia friendly communities is about changing attitudes and behaviour and a scheme that focused on "*ticking boxes and collecting badges misses the point*".

[80] Innovations in Dementia (2012) Thinking about a "memory aware" high street scheme [Online] Available at http://www.innovationsindementia.org.uk/DementiaFriendlyCommunities/Memory%20aware%20high%20street.pdf (accessed 1 August 2012) p.2

[81] Ibid pp.2-4

Torbay

Volunteers from the Torbay Action Alliance are approaching local businesses to encourage them to become more dementia friendly. The organisations they are approaching include, "*banks, supermarkets, cafes, local shops, bus companies, post offices, coach companies, hotels, bed and breakfasts, hairdressers, barber shops, social clubs and everywhere that people visit during their everyday lives*".

The volunteers provide the organisation with three documents, two short documents entitled 'A Guide to the Symptoms of Dementia' and 'What is Dementia' as well as a copy of the Torbay Dementia Action Alliance logo and explain that "*all we want them to do is to make sure that they and all their staff read the documents* [and] *understand them*". The volunteers also provide the phone number of the Alzheimer's Society Hot line and the phone number of the local office of the Alzheimer's Society in case the organisations have any further questions.

The Torbay Action Alliance volunteers revisit the organisation within two to three weeks, depending on the size of the business, and if there is an increased awareness amongst the organisation's staff the establishment receives a badge to display in their window which states they are 'Dementia Aware'. Any organisation that is able to demonstrate that they are 'dementia Aware' will also be included on a dedicated website (http://www.palm.fm/p/whats-on/dementia-awareness).

As of August 2012 the Torbay Action Alliance had given out almost three hundred badges.

9.2.3 Alternative means of monitoring 'dementia friendliness'

The most commonly suggested means of monitoring 'dementia friendliness' was through the use of a peer review scheme, in which stakeholders and in particular individuals living with dementia, will be encouraged to monitor and feedback on how dementia friendly local organisations are. It was suggested that the formation of a local alliance would assist with the monitoring process as it could provide a space for feedback and the sharing of ideas "*in a positive way that promotes the good work of the businesses and supports them to change where further work is needed*".

It was suggested that such monitoring should be done openly and the project's respondents were cynical about the idea of a 'mystery shopper' scheme. One respondent explained that the idea of "catching people out" through a mystery shopper scheme would make the process too negative and would therefore be likely to put off local organisations.

9.3 The role that local, regional and national networks play in the process of developing dementia friendly communities

The creation of local, regional and national networks was highlighted as being a useful part of the process of developing dementia friendly communities during both the literature review and the semi-structured conversations.

At the local level networks respondents stressed the importance of forming 'local alliances' made up of individuals in the community living with dementia as well as businesses, facilities and other local stakeholders from the public and voluntary sectors.

During the semi-structured conversations respondents suggested that the formation of local alliances or groupings were useful for the creation of dementia friendly communities because local alliances can:

- Bring together those who live with dementia and those who are able and willing to shape how dementia friendly the community is therefore allowing the voices of those with dementia to shape any work done to develop a dementia friendly community
- Provide a platform for sharing ideas between local organisations and monitoring of progress through a process of peer review and feedback
- Set local priorities specific to the needs of that particular community

The benefit of creating local networks was described in the Local Government report *Developing dementia-friendly communities: Learning and guidance for local authorities* which stated that local networks are:

- *Effective in sharing understanding of how well people will dementia are living in the community*
- *Practical in helping to identify or create new solutions to problems which occur*
- *Inclusive in that they cross organisational and sector boundaries and do not over professionalise*
- *Discreet in that they understand how to respect confidentiality, whilst creating a network of support*[82]

In some areas regional alliances were proactively involved in the creation of local alliances. By contrast in other areas it was claimed that local alliances had arisen 'organically'.

The semi-structured conversations also revealed that regional networks are beneficial for the creation of dementia friendly communities because, like local alliances, they provided a platform for the sharing of ideas and feedback. In addition the semi-structured conversations suggested that in many areas regional alliances provided support and information for local alliances.

[82] Local Government Association (2012) Developing dementia-friendly communities: Learning and guidance for local authorities [Online] Available at: http://www.local.gov.uk/web/guest/ageing-well/what-makes/-/journal_content/56/10171/3489459/ARTICLE-TEMPLATE (Accessed 1 August 2012) p.30

East Midlands

In the East Midlands the Dementia Action Alliance model is being used to support the work being undertaken around dementia friendly communities.

There is a regional East Midlands Dementia Action Alliance Board for organisations that cover all of the East Midlands or more than one county. The regional alliance aims to support organisations and towns to become dementia friendly.

There are also local Dementia Action Alliances which are specific to a county and for organisations that operate in that county. Local alliances have been set up in Leicestershire, Northamptonshire, Nottinghamshire and Lincolnshire. There are plans to establish a local alliance in Derby in September/October 2012.

To be involved in a local or regional alliance an organisation needs to complete an action plan that details how they will be working to achieve the outcomes listed in the Dementia Declaration until 2014. Alliance members must work towards their action plans as well as attending alliances meetings in order to update others on their progress, and share information and best practice.

South West England

The South West region is currently focusing on helping Dementia Action Alliances to get started at a local level. A South West Steering Group has been established to assist, inform and monitor the strategic development of the Local Dementia Action Alliances across the region, keeping the person with dementia at the centre of this work.

A starter pack has been developed to provide guidance to individuals or groups looking to create a local alliance. It includes advice on managing meetings, recruiting members, involving the local media and funding opportunities. There are also a number of other resources being developed and made available to help these local alliances to increase awareness about dementia in their community, these include:

- Basic dementia awareness raising presentations
- 'Top 10 tips' for local organisations
- Guidance and tool kits for businesses/organisations to create dementia friendly communities

The aim is for Local Dementia Action Alliances to come together in self-defined communities, made up of businesses, organisations, community groups, local services and identify priorities through consultation with local people living with dementia, that they can use to inform their local alliance action plan. In the South West the emphasis for local alliances is on local action. As such an alliance must have an action plan of activities that will take place to improve lives for people in that community living with dementia, for example increasing awareness and understanding of dementia by all employees/staff. Alliances will also register their local alliance on the national website and encourage members where possible to sign up to the National Dementia Declaration.

It is expected that the alliances will take ownership of their own action plan and with guidance from the South West Steering Group, take responsibility for their own monitoring of this work. It is the intention that Local Dementia Action Alliances can be used as vehicles for communities to become dementia friendly.

9.4 How to address the costs associated with developing and maintaining dementia friendly communities

This section outlines the information gained during the literature review and semi-structured conversations which relates to the issue of how to address the costs associated with developing and maintaining dementia friendly communities.

9.4.1 Costs associated with the development of dementia friendly communities

This section outlines the potential costs associated with developing a dementia friendly community. The list of costs highlighted here do not represent a comprehensive list of expenditure associated with the development of dementia friendly communities but merely those costs that were discussed by the project's respondents.

Employing a coordinator

One potential cost associated with the development of dementia friendly communities that was discussed by a number of respondents was employing a coordinator who could set up local alliances and support businesses to become more dementia friendly. The level of this cost was questioned by one respondent who felt that this expenditure need only be temporary. The respondent explained that while a regional coordinator could help to "*get the ball rolling*" this needn't be a long term expense as "*once things are running and the word has got out the responsibility can be handed over to the local alliance who would have an interest in keeping it going forward and could be collectively responsible for maintaining it*".

Providing awareness raising sessions

Another potential cost that respondents thought could arise from the development of dementia friendly communities was the provision of awareness raising sessions or other training for local organisations. It was suggested by one respondent however that the provision of such sessions could be relatively "cost effective" as the respondent's organisation already possessed awareness raising resources.

The costs associated with awareness raising sessions will vary depending on the method used. As discussed in section 7.2.3 there is a number of ways in which raising awareness can be approached and the document '*Dementia awareness raising options for staff*'[83] describes a range of existing awareness raising possibilities for businesses including awareness raising possibilities that are free.

Providing support services

An additional cost suggested by the project's respondents was the expense of providing support services for individuals living with dementia so as to ensure that they are supported to remain included within their community. It was suggested by one respondent that the cost of providing such support could be lowered through the use of existing community facilities and volunteer networks.

9.4.2 Sources of income for the development and maintenance of dementia friendly communities

No common source of funding was mentioned during the project's research. This section of the report outlines the possible sources of funding that were discussed by the project's respondents. The possible sources of funding outlined in this section is not a comprehensive

[83] Innovations in Dementia (2012) Dementia awareness raising options for staff [Online] Available at: http://www.innovationsindementia.org.uk/DementiaFriendlyCommunities/Dementia%20Awareness%20raising%20options.pdf (Accessed 1 August 2012)

list of all possible sources of funding and is instead limited to those highlighted by the project's respondents during the semi-structured conversations.

Contributions from alliance members

It was suggested by one respondent that contributions from those organisations that sign up to local and regional alliances could provide a useful source of funding. This view was however questioned by a number of other respondents who felt that this approach could deter organisations from joining local alliances. As noted by one respondent *"creating dementia friendly communities is about behavioural change not fundraising*".

It was also suggested that in some situations it may be more appropriate for organisations to give resources in kind.

Charging for training and awareness raising sessions

An alternative suggestion for funding was that some training or awareness raising sessions could be profit making ventures. It was suggested that the amount charged for training should vary depending on the audience for example it was felt that professions such as solicitors could be charged at a higher rate than health and social care and charitable organisations. There is however the potential that charging for these sessions will deter some local organisations.

Alternative sources of funding

Some of the projects respondents stated that they had secured funding from sources such as city and parish councils and local authorities. A number of respondents discussed the need for research into the 'business case' for dementia friendly communities so as to secure future funding however they were not aware of any such research having been conducted. In addition another respondent explained that their community group had registered as a social enterprise in order to secure funding.

9.4.3 Maintaining the momentum and funding over time

A common theme amongst the project's respondents was the need to maintain the momentum and funding for dementia friendly communities over time and avoid it becoming "*a fad*" or a "*flash in the pan*".

One respondent was optimistic about maintaining the drive to make communities more dementia friendly and explained that while "*many projects start off with funding and then wither away once the funding has stopped, the fact that this project started as a grass roots movement based on good will is positive for the future*".

A particular issue noted during the semi-structured conversations was the difficulty of maintaining project's that are reliant on the good will of a small number of volunteers. In response to this issue one respondent said that they were trying to ensure that the momentum was maintained by "embedding the behavioural changes into the life of the community". The respondent explained their believed that once there was an initial push to change attitudes and behaviour this would become an accepted and sustained minimum standard.

10. Work to develop dementia friendly communities in the North East

Section overview

- This section of the report highlights the work currently being undertaken to develop dementia friendly communities in the North East of England
- This information is based solely on the written responses to a request for information about work that is being undertaken to develop dementia friendly communities in the North East of England
- Based on the action plans of the localities in the North East of England it is likely that the localities not represented in this section are undertaking work to develop dementia friendly communities however as this has not been verified it has not been possible to include the information here
- The localities detailed in this section are:
    - Northumberland
    - Redcar
    - Stockton-on-Tees
    - Sunderland

This section of the report highlights the work currently being undertaken to develop dementia friendly communities in the North East of England. This information is based solely on the written responses to a request for information about work that is being undertaken to develop dementia friendly communities in the North East of England. This request was made through the North East Dementia Alliance members and the dementia leads in each of the localities within the region.

The information contained in this section is not necessarily comprehensive as it is restricted to those localities that were able to respond to the project's request. Based on the dementia action plans of the different localities it is likely that the localities not represented in this section are undertaking work to develop dementia friendly communities however as this has not been verified it has not been possible to include the information here.

10.1 Regional initiatives

During the project's research respondents identified a number of initiatives that are taking place at a regional level. Respondents stated that:

- A number of Acute Hospital Trusts across the North East have started to make their physical environments more dementia friendly. This has included using better signage and making use of colour to help with orientation. This follows funding by

the North East Strategic Health Authority to deliver training on the design principles promoted by Stirling University[84]

- Three Best Practice Facilitator training programmes have been delivered by the University of Stirling in the North East with over 100 staff becoming registered facilitators and rolling out the 6 month, reflective programme within their organisations

10.2 Northumberland

In Northumberland the Ballinger Trust Northumberland Dementia Initiative is a 3 year programme of work in Northumberland comprising of a number of discreet projects aimed at transforming the lives of people living with dementia and their carers. One of the initiative's aims is to support communities to become dementia friendly.

The Northumberland Dementia Initiative is undertaking projects to raise awareness about early diagnosis and acute care post diagnosis. The Northumberland Dementia Initiative is also undertaking projects that aim to provide information giving services and improve wellbeing in the wider community through dementia advisors and community champions.

10.3 Redcar

Although not yet operational there is currently a plans to link the work on dementia friendly communities with another initiative called 'Safer Communities'. The Safer Communities project aims to provide safe havens which offer protection for people who are victims of hate crimes. This scheme will involve designating certain public buildings and shops as safe havens where individuals can go if they feel threatened until help can be summonsed. Staff in these safe havens may receive training in dementia awareness so they could provide support to people with dementia. The safe havens would provide somewhere that individuals could go and be helped or wait while the police are called.

The intention is to extend this scheme to include other vulnerable members of society who could go to the same places in the knowledge that they would receive help if needed.

10.4 Stockton-on-Tees

In Stockton-on-Tees there is a café called Fusion for individuals living with dementia and their carers and creates a social space where the effects of dementia are understood and accepted. Those who attend Fusion are also involved in fundraising events that are raising awareness of dementia, for example by participating in local and national sports events.

Stockton-on-Tees partners host an annual dementia awareness week in order to provide advice, information and support. In 2012 this was hosted by Stockton Library Services in a number of library branches and in previous years the main hub was situated in a shopping mall, capturing the attention of the passing public.

[84] Stirling University Dementia Services Development Centre and NHS Scotland (2007) Dementia Design Checklist – Design checks for people with dementia in healthcare premises [Online] Available at: https://dementia.stir.ac.uk/files/DementiaDesignChecklist.pdf (Accessed 1 August 2012)

Other activities taking place during the dementia awareness week included:

- 'Book chat', a demonstration of how people with memory loss can still enjoy books at Stockton Central Library
- 'Communication issues in dementia care', an information session delivered at the George Hardwick Foundation carers centre
- 'Mindful of Music', a session that engages people with dementia and their carers in musical activity hosted at the local art centre the ARC
- Fusion dementia café session hosted by a local Alzheimer's charity, Clevearc
- The launch of an intergenerational project that introduces the concept of memory loss through story
- Information sessions on communication, for service users, carers, their extended family, friends and care staff

Stockton also has a friendship group called "Young at Heart" for people with dementia and their carers, to discuss things of interest to them and give their time to talk about their experiences, participate in recruitment or provide evidence for the local Joint Strategic Needs Assessment.

In addition there are "Live at Home" schemes run by Methodist Homes and Avalon's sitting service which provides valuable time for carers to have a break from their caring role.

10.5 Sunderland

The work to create dementia friendly communities in Sunderland includes the provision of memory cafes, including peer support and other related activities. In addition there are efforts to raise awareness of dementia.

11. Conclusion

Those seeking to develop dementia friendly communities face a number of challenges. Of particular significance is the lack of an authoritative definition and the scarcity of research and literature on the subject.

Although it was not the aim of the 'Knowing the Foundations of Dementia Friendly Communities for the North East' project to produce recommendations on how any particular community can become dementia friendly it is expected that the project's findings will provide a useful starting point for anyone seeking to develop dementia friendly communities.

This report has outlined existing knowledge relating to:

- The aims of dementia friendly communities
- The factors to be addressed in order to achieve the aims of dementia friendly comities
- The cross-cutting themes relevant to the process of creating dementia friendly communities

This report has suggested that the key aims of developing dementia friendly communities are:

- To challenge stigma
- Increase understanding and awareness about dementia and how to support individuals with dementia
- To support individuals living with dementia to remain active and included members of their communities
- To support individuals living with dementia to maintain their independence for as long as possible

In addition the report has noted that although the priorities of different communities may vary, the factors that most commonly need addressing in order to achieve the aims of dementia friendly communities are:

- Supporting individuals living with dementia to engage in their community
- Increasing understanding and awareness about dementia and the needs of those with dementia
- Creating physical environments appropriate for people living with dementia

In particular the report suggests that the key issues to be considered during the process of developing dementia friendly communities are:

- The need for those with dementia to be at the centre of the process of developing dementia friendly communities
- How to monitor the 'dementia friendliness' of organisations and the community as a whole
- The role that local, regional and national networks play in the process of developing dementia friendly communities
- How to address the costs associated with developing and maintaining dementia friendly communities

12. References

All-Party Parliamentary Group on Dementia (2012) Unlocking Diagnosis: All Party Parliamentary Group Report 2012 [Online] http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1583 (Accessed 1 August 2012)

Alzheimer's Australia NSW (2011) Building Dementia and Age-Friendly Neighbourhoods [Online] Available at: http://www.fightdementia.org.au/common/files/NSW/DementiaFriendlyNeighbourhoodsWebVersion.pdf (Accessed 1 August 2012)

Alzheimer's Society (2012). Dementia 2012: A national challenge. Alzheimer's Society: London

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

Department of Health (2011) Commissioning Pack for Dementia [Online] Available at: http://dementia.dh.gov.uk/dementia-commissioning-pack/ (Accessed 1 August 2012)

Department of Health (2011) NHS Operating Framework 2012–13. Department of Health: London

Department of Health (2010) Quality outcomes for people with dementia: building on the work of the National Dementia Strategy. Department of Health: London

Department of Health (2009) Living well with dementia: a National Dementia Strategy. Department of Health: London

Innovations in Dementia (2012) Dementia-Friendly Hampshire Toolkit [Online] Available at: http://www.innovationsindementia.org.uk/DementiaFriendlyCommunities/DementiaFriendlyCommunities_ToolkitIntroduction.pdf (Accessed 1 August 2012)

Innovations in Dementia (2012) Finding out what a dementia friendly community means to people with dementia and carers [Online] http://www.innovationsindementia.org.uk/DementiaFriendlyCommunities/DementiaFriendlyCommunities_engagement.pdf (Accessed 1 August 2012)

Innovations in Dementia (2012) Why do we need to be dementia-friendly? [Online] Available at: http://www.innovationsindementia.org.uk/DementiaFriendlyCommunities/Why%20do%20we%20need%20to%20be%20dementia%20friendly.pdf (Accessed 1 August 2012)

Innovations in Dementia (2012) Help-Pack for customer-facing staff [Online] Available at: http://www.innovationsindementia.org.uk/DementiaFriendlyCommunities/DementiaFriendlyCommunities_Help%20Pack%20for%20Customer%20Facing%20staff.pdf (Accessed 1 August 2012)

Innovations in Dementia (2012) Dementia awareness raising options for staff [Online] Available at:

http://www.innovationsindementia.org.uk/DementiaFriendlyCommunities/Dementia%20Awareness%20raising%20options.pdf (Accessed 1 August 2012)

Innovations in Dementia (2012) Thinking about a “memory aware” high street scheme [Online] Available at http://www.innovationsindementia.org.uk/DementiaFriendlyCommunities/Memory%20aware%20high%20street.pdf (accessed 1 August 2012)

Innovations in Dementia (2012) Checklists for dementia-friendly environments [Online] Available at http://www.innovationsindementia.org.uk/DementiaFriendlyCommunities/Dementia-friendly%20Environmental%20checklists.pdf (Accessed 1 August 2012)

Local Government Association (2012) Developing dementia-friendly communities: Learning and guidance for local authorities [Online] Available at: http://www.local.gov.uk/web/guest/ageing-well/what-makes/-/journal_content/56/10171/3489459/ARTICLE-TEMPLATE (Accessed 1 August 2012)

Innovations in Dementia (2011) Dementia Capable Communities: The views of people with dementia and their supporters [Online} Available at: http://www.innovationsindementia.org.uk/projects_communities.htm (Accessed 1 August 2012)

Milton, Steve (2012) What makes a dementia-friendly community? *Journal of Dementia Care*, 20 (2), pp. 12-13.

Mitchell, Lynne (2012) Breaking New Ground: The Quest for Dementia Friendly Communities. Viewpoint No. 25, Housing LIN [Online] http://www.housinglin.org.uk/Topics/browse/HousingandDementia/Design/?parent=5091&child=8525 (Accessed 1 August 2012)

Oxford Centre for Sustainable Development (2004) Neighbourhoods for life – Designing dementia-friendly outdoor environments [Online] Available at: http://www.housinglin.org.uk/Topics/browse/HousingandDementia/Design/?parent=5091&child=6988 (Accessed: 1 August 2012)

Porteus, Jeremy (2012) At a Glance: a Checklist for Developing Dementia Friendly Communities. Viewpoint No. 25, Housing LIN [Online] http://www.housinglin.org.uk/Topics/browse/HousingandDementia/Design/?parent=5091&child=8525 (Accessed 1 August 2012)

Sherriff, Ian and McFarlane Helen (2012) Building a Dementia Friendly Community Checklist (Unpublished)

Stirling University Dementia Services Development Centre and NHS Scotland (2007) Dementia Design Checklist – Design checks for people with dementia in healthcare premises [Online] Available at: https://dementia.stir.ac.uk/files/DementiaDesignChecklist.pdf (Accessed 1 August 2012)

World Health Organisation (2007)Checklist of Essential Features of Age-Friendly Cities [Online] Available at:

http://www.who.int/ageing/publications/Age_friendly_cities_checklist.pdf (Accessed 1 August 2012)

13. Appendices

Appendix 1: Case studies

South West England

The South West region is currently focusing on helping Dementia Action Alliances to get started at a local level. A South West Steering Group has been established to assist, inform and monitor the strategic development of the Local Dementia Action Alliances across the region, keeping the person with dementia at the centre of this work.

A starter pack has been developed to provide guidance to individuals or groups looking to create a local alliance. It includes advice on managing meetings, recruiting members, involving the local media and funding opportunities. There are also a number of other resources being developed and made available to help these local alliances to increase awareness about dementia in their community, these include:

- Basic dementia awareness raising presentations
- 'Top 10 tips' for local organisations
- Guidance and tool kits for businesses/organisations to create dementia friendly communities

The aim is for Local Dementia Action Alliances to come together in self-defined communities, made up of businesses, organisations, community groups, local services and identify priorities through consultation with local people living with dementia, that they can use to inform their local alliance action plan. In the South West the emphasis for local alliances is on local action. As such an alliance must have an action plan of activities that will take place to improve lives for people in that community living with dementia, for example increasing awareness and understanding of dementia by all employees/staff. Alliances will also register their local alliance on the national website and encourage members where possible to sign up to the National Dementia Declaration.

It is expected that the alliances will take ownership of their own action plan and with guidance from the South West Steering Group, take responsibility for their own monitoring of this work. It is the intention that Local Dementia Action Alliances can be used as vehicles for communities to become dementia friendly.

For further information please contact: carol.clifford@alzheimers.org.uk

Plymouth

As part of their work to make Plymouth a dementia friendly city the Plymouth Dementia Action Alliance are encouraging local organisations to sign up to join the alliance and become more dementia friendly. So far this has included, amongst other:

- Plymouth Naval Base
- Dartmoor Rescue Service
- Plymouth City Council
- Plymouth City Centre Manager
- National Farmers Union
- Women's Institute

In order to increase awareness and understanding about dementia and the needs of individuals living with dementia the local football and basketball teams are running a weekly advert in their match programmes which includes information about dementia and the Plymouth Dementia Action Alliance.

In addition Plymouth Dementia Action Alliance are seeking to use the local media to raise awareness by providing them with stories about work that is being done in Plymouth to make the city more dementia friendly.

The Plymouth Dementia Action Alliance is working to increase early diagnosis and improve the diagnosis process. In order to achieve this aim a GP from the Plymouth Dementia Action Alliance is visiting every GP practice in the community in order to advise GPs and other staff on the importance of the diagnosis process and improving diagnosis rates.

Torbay

Volunteers from the Torbay Action Alliance are approaching local businesses to encourage them to become more dementia friendly. The organisations they are approaching include, "*banks, supermarkets, cafes, local shops, bus companies, post offices, coach companies, hotels, bed and breakfasts, hairdressers, barber shops, social clubs and everywhere that people visit during their everyday lives*".

The volunteers provide the organisation with three documents, two short documents entitled 'A Guide to the Symptoms of Dementia' and 'What is Dementia' as well as a copy of the Torbay Dementia Action Alliance logo and explain that "*all we want them to do is to make sure that they and all their staff read the documents* [and] *understand them*". The volunteers also provide the phone number of the Alzheimer's Society Hot line and the phone number of the local office of the Alzheimer's Society in case the organisations have any further questions.

The Torbay Action Alliance volunteers revisit the organisation within two to three weeks, depending on the size of the business, and if there is an increased awareness amongst the organisation's staff the establishment receives a badge to display in their window which states they are 'Dementia Aware'. Any organisation that is able to demonstrate that they are 'dementia Aware' will also be included on a dedicated website (http://www.palm.fm/p/whats-on/dementia-awareness).

As of August 2012 the Torbay Action Alliance had given out almost three hundred badges.

Yorkshire and Humber

The Yorkshire and Humber Dementia Action Alliance is encouraging organisations from across the region to commit to becoming more dementia friendly this includes businesses, voluntary, community and private sector organisations and educational institutions from across the region. Organisations will have to produce action plans detailing how they are going to work towards the aims of the National Dementia Declaration.

The Yorkshire and Humber Dementia Action Alliance is producing an information pack for local organisations who sign up to the regional alliance describing what the Dementia Action Alliance is and its objectives. The information pack will also contain guidance on producing action plans.

Organisations that sign up to the Yorkshire and Humber Dementia Action Alliance will be expected to report their progress towards achieving their aims. The Yorkshire and Humber Dementia Action Alliance is also working to create a monitoring framework to track progress over time and it is possible that this could be based on a peer review system.

The Yorkshire and Humber Dementia Action Alliance is planning to develop a website for sharing information and good practice and it is hoped the website will provide a space to celebrate the achievements of the alliance members. The alliance produces a regular E-Bulletin which is used to keep organisations in contact with each other and maintain momentum for the project.

The Yorkshire and Humber Dementia Action Alliance is planning a launch event to encourage organisations to commit to the alliance and produce action plans. The event will take place in autumn 2012

York

The Joseph Rowntree Foundation is currently funding a project entitled 'Dementia Without Walls' which aims to bring together local stakeholders, including individuals living with dementia, in order to identify how it is possible to make York a dementia friendly city.

The project draws on the experiences of individuals living with dementia as well as local, national and international examples of best practice. This information is used to promote innovative thinking about how to make York a better place for individuals living with dementia.

The project is looking at changes that can be made beyond the traditional confines of health and social care and this includes exploring how "housing, shopping, leisure and transport" can be improved to make the city more dementia friendly.

The findings of the project will be released on 21st September 2012.

Bradford

Bradford is currently piloting work to make the city more dementia friendly. A development worker is working intensively with eight local organisations to make them more dementia friendly. This pilot group includes businesses, community organisations and faith organisations.

The eight organisations are given a briefing sheet which explains the importance of staff attitude and understanding and suggests that a quiet space be provided where people with dementia can talk to staff and also stresses the importance of clear signs and good lighting. The briefing sheet also highlights the need for employers to be aware that their staff may be a carer for someone with dementia.

The development worker provides the organisations with check lists and other information and support to help the organisations review their service and facilities. The development worker is also helping the organisations to draw up action plans.

Leeds

Work to develop dementia friendly communities in Leeds is being led by the Community Dementia Forum which is run by the local branch of the Alzheimer's Society and attended by representatives from the public sector, voluntary sector groups and individuals living with dementia and their carers.

The group is currently planning to approach local supermarkets and transport facilities with the intention of encouraging them to become more dementia friendly by increasing staff awareness and tackling practical issues relating to the physical environment such as seating.

The group are using established contacts to target local organisations.

Further information on plans to create a dementia friendly Leeds can be found in the local dementia strategy '*Living Well With Dementia in Leeds'* which can be accessed at:
http://www.leeds.nhs.uk/Downloads/Have%20your%20say/Living%20well%20with%20dementia%20in%20Leeds%20-%20draft%20strategy%20for%20consultation.pdf

North West England

There are currently plans in the North West of England to ensure that "*every organisation, venue and individual a person living with dementia comes into contact with has a basic awareness of dementia and how to best act to support someone who has the illness*".

"*So for example if a person living with dementia goes out to buy a newspaper and get their hair cut… a minimum of one person on duty at any one time in each of these shops has had dementia awareness training, the same for bus drivers, taxi companies, milk men etc*".

There are also plans to train volunteers to perform tasks such as checking premises and signage to ensure they are dementia friendly and then make recommendations for any improvements that local organisations can carry out to make their premises more dementia friendly.

Work is currently underway to target individual areas at the sub council ward level and bring together volunteers in those areas who can publicise local meetings and 'awareness training sessions'.

For more information please contact: Helen.Foster@alzheimers.org.uk

East Midlands

In the East Midlands the Dementia Action Alliance model is being used to support the work being undertaken around dementia friendly communities.

There is a regional East Midlands Dementia Action Alliance Board for organisations that cover all of the East Midlands or more than one county. The regional alliance aims to support organisations and towns to become dementia friendly.

There are also local Dementia Action Alliances which are specific to a county and for organisations that operate in that county. Local alliances have been set up in Leicestershire, Northamptonshire, Nottinghamshire and Lincolnshire. There are plans to establish a local alliance in Derby in September/October 2012.

To be involved in a local or regional alliance an organisation needs to complete an action plan that details how they will be working to achieve the outcomes listed in the Dementia Declaration until 2014. Alliance members must work towards their action plans as well as attending alliances meetings in order to update others on their progress, and share information and best practice.

The Debenham Project

The Debenham Project was launched in 2009 in Suffolk as a volunteer-led group which is inspiring the community of Debenham to "take responsibility for the welfare and support of those who are family carers looking after someone with dementia, and of meeting the health and social needs of those that they care for".

The Debenham Project currently has 80 volunteers offering their time to support individuals in the community living with dementia and their carers and has "developed a comprehensive range of local volunteer-based services which 'draws in' the best professional support".

The support services offered by the project include:

- Confidential telephone support line
- Activities and social support sessions
- Food 'n' Friends luncheon clubs
- Information and advice centre
- Medication and pharmacy support
- A Carers' Club and Info Café
- Local access to memory and clinical services
- Chair-based exercise therapy (Fit Club)

Information taken from the document 'This is: The Debenham Project' which is available on the home page of the project's website. Additional information and contact details are available at www.the-debenham-project.org.uk.

East Sutherland

In East Sutherland a group of individuals have come together to make the county more dementia friendly. The group began by selecting a single village that would act as "*a beacon 'Dementia Friendly Community' that will provide the inspiration for other towns and villages in East Sutherland to follow*".

When deciding which organisations to engage with in the village the group identified "*the key partners, services, activities and businesses*" in the village in order to "*develop a local map of 'the people and the place'*".

The group have been approaching hospitals, dentists, shops, coops, banks, swimming pools churches and businesses and providing ten minute training sessions to increase understanding and awareness and challenge stigma and myths about dementia.

The group are currently developing a dementia friendly community website that will go online in 2012.

Quotes taken from 'A Carers Voice' website which can be accessed at: http://www.acarersvoice.com/dementia-friendly-community/dementia-friendly-communities/

For further information please contact Ann Pascoe at: ann@acarersvoice.com

Wales

The Alzheimer's Society in Wales has launched its dementia friendly communities programme through which the Society aims to support and give public recognition to villages, towns, cities and national organisations who are taking steps towards being more inclusive of people with dementia and their families.

An awareness event was held by Alzheimer's Society Abertawe Bro Morgannwg and was attended by a wide cross section from the community, including people living with dementia, city centre managers, GP's, bus companies, Health and Social care managers and members of the Women's Institute amongst others. The Lord Mayor and mayors, as well as the council leader also accepted the invitation and in total 137 people attended the event.

The meeting ended with 110 attendees pledging their support to the idea of dementia friendly communities.

Following the enthusiasm expressed at the Awareness event Alzheimer's Society Abertawe Bro Morgannwg are looking to work with various partners to form a steering group to take forward the ambition of becoming dementia friendly in Neath Port Talbot, Swansea and Bridgend. The Alzheimer's Society Abertawe Bro Morgannwg are working to maintain contact with the people who signed up to the idea at the awareness raising event, encouraging them to become involved in the process and are also liaising with local businesses to encourage their involvement.

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