# SUPPORT AND CARE FOR PEOPLE LIVING WITH DEMENTIA FROM MINORITY COMMUNITIES

Produced for the North East Dementia Alliance

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The North East Dementia Alliance are happy for this report to be used to improve the support and care of people living with dementia from minority communities but ask that the North East Dementia Alliance and the author, Peter Prior, be acknowledged.

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# Contents:

Executive summary..... 6

1. Introduction..... 8

1.1 Background to the project..... 8

1.2 Aims of the project..... 9

1.3 What is meant by 'minority communities'?..... 9

1.4 Methodology and sources of information..... 10

1.5 Structure of the report..... 11

1.6 Acknowledgements..... 11

2. Policy context.....12

2.1 Living well with dementia: A National Dementia Strategy.....12

2.2 National Dementia Strategy: Equalities Action Plan.....13

2.3 Dementia: Supporting people with dementia and their carers in health and social care..... 13

2.4 The Equality Act 2010..... 14

3. Black and minority ethnic, religious minority and Gypsy and Traveller communities..... 15

3.1 Introduction..... 15

3.2 Policy context..... 17

3.3 Issues relevant to the provision of appropriate support and care..... 18

3.3.1 Diagnosis..... 18

3.3.2 Awareness and understanding of dementia and the services available to people living with dementia..... 20

3.3.3 Stigma..... 23

3.3.4 Services and staff that can meet people's cultural and religious needs..... 24

3.3.5 Issues affecting carers..... 28

3.4 What type of organisations are best placed to deliver support and care?.....29

3.5 What support and care services are available in the North East?..... 32

3.6 Recommendations..... 35

**4. Younger people living with dementia**..... 37

4.1 Introduction ..... 37

4.2 Policy context..... 38

4.3 Issues relevant to the provision of appropriate support and care for younger people living with dementia..... 38

4.3.1 Diagnosis..... 38

4.3.2 Understanding where responsibility lies in relation to diagnosis and on-going support and care..... 39

4.3.3 The type of support and care provided..... 41

4.4 What type of organisations are best placed to deliver support and care?..... 44

4.5 What services are available in the North East?..... 46

4.6 Recommendations..... 47

**5. Lesbian, gay and bisexual communities and transgender communities**... 48

5.1 Introduction ..... 48

5.2 Policy context..... 49

5.3 Issues relevant to the provision of appropriate support and care.....50

5.3.1 Experiences of discrimination.....51

5.3.2 Recognising that people from LGB communities are using support and care services..... 52

5.3.3 Creating an environment in which people can be open about their sexual orientation or gender identity and ensuring that services provide support and care appropriate for people living with dementia from LGBT communities..... 53

5.4 What type of organisations are best placed to deliver support and care?..... 59

5.5 What services are available in the North East?..... 60

5.6 Recommendations..... 61

**6. People with learning disabilities and dementia**..... 63

6.1 Introduction ..... 63

6.2 Policy context..... 64

6.3 Issues relevant to the provision of appropriate support and care..... 65

6.3.1 Diagnosis..... 65

6.3.2 Issues relevant to the provision of appropriate support and care for people with learning disabilities and dementia..... 67

6.4 What type of organisations are best placed to deliver support and care?..... 70

6.5 What support and care services are available in the North East?..... 71

6.6 Recommendations..... 75

**7. Conclusion**..... 76

**8. Bibliography**..... 77

**Appendix A: Recommendations**..... 82

**Appendix B: Acknowledgements**..... 88

# Executive summary

The project 'Support and Care for People Living with Dementia from Minority Communities' was commissioned by the North East Dementia Alliance as part of their programme of work around dementia within minority communities for 2013-2014.

The project aimed to make suggestions and recommendations of what the North East Dementia Alliance could further develop and influence in relation to the support and care to people with dementia from minority communities in the North East.

The minority communities that formed the focus of the research were:

- Black and minority ethnic communities
- Gypsy and Traveller communities
- Lesbian, gay and bisexual communities
- Transgender communities
- Religious minority communities
- Individuals with learning disabilities and dementia
- Younger people with dementia

The project's research included an in-depth literature review of current policy and existing research as well as semi-structured interviews with service providers from across the UK and community representatives in the North East.

The report is organised into seven sections.

- Section 1 provides an overview of the project's aims and methodology
- Section 2 outlines the policy context that is relevant to the support and care of people living with dementia from all minority communities
- Section 3 details the findings of the research relating to the support and care of people living with dementia from black and minority ethnic communities, religious minority communities and Gypsy and Traveller communities
- Section 4 outlines issues relevant to the support and care of younger people living with dementia
- Section 5 looks at issues relevant to the support and care of people from lesbian, gay and bisexual communities as well as people from transgender communities
- Section 6 outlines issues relevant to the support and care of people with disabilities living with dementia.
- Section 7 provides a conclusion on the key themes highlighted in the report

Appendix A provides a summary of the recommendations made throughout the report.

## Summary of the key findings of the research

| | Particular issues regarding the community's support and care | What services are valued and best able to deliver support and care | Support and care already available in the North East |
|---|---|---|---|
| **BME, religious minority and Gypsy and Traveller communities** | • More likely to receive no diagnosis or receive a diagnosis at a later stage<br>• Lack of awareness about dementia and the services that are available<br>• Stigma attached to dementia in some communities<br>• Services need to be delivered in a culturally appropriate manner<br>• There is a need to provide support to unpaid carers | • Day care and respite services particularly valued<br>• Difference in opinion about whether specialist services needed as responses varied between communities | • Non-dementia specific community groups that support specific BME or religious communities<br>• Support worker for hard to reach groups in Stockton |
| **Younger people living with dementia** | • Difficulties and delays experienced during the diagnostic process<br>• Difficulty in identifying who is responsible for on-going care and support and what services are available to young people living with dementia<br>• The need to meet the specialist care and support needs of younger people living with dementia, including:<br>  • Age appropriate activities<br>  • Support with the particular financial and legal issues faced by younger people living with dementia<br>  • Practical and emotional support for family members including dependent children and older relatives | • The research emphasised the importance of specialist services tailored to meet the needs of younger people living with dementia | • Tees, Esk and Wear Valley NHS Trust young onset dementia team<br>• Northumberland, Tyne and Wear NHS Trust young onset dementia services<br>• Alzheimer's Society roaming day club |
| **Lesbian, gay and bisexual communities and Transgender communities** | • Previous experiences of discrimination can shape how people from LGBT communities engage with care and support services<br>• To provide appropriate care and support services it is necessary that services:<br>  • Recognise that people from LGB communities are using support and care services<br>  • Make it clear that they respect and work to accommodate the needs of people living with dementia from LGBT communities<br>  • Develop appropriate policies and procedures to prevent discrimination and protect confidentiality<br>  • Employ appropriately trained staff<br>  • Recognise the family and other social relationships of people from LGBT communities<br>  • Ensure that services are informed by people from LGBT communities | • Focus on ensuring that mainstream services are delivered in a manner appropriate for people living with dementia from LGBT communities<br>• Advice, information and advocacy from LGBT community groups is seen as important | • There are a number of community groups providing advice, support and information to people from LGBT communities<br>• There are some community groups specific to older people but not specific to people living with dementia |
| **People with learning disabilities and dementia** | • Issues around diagnosis including:<br>  • Recognising the early symptoms of dementia among people with learning disabilities<br>  • The specialist assessment process often required to deliver a diagnosis<br>  • Providing post-diagnostic information and support in an appropriate manner<br>• Issues relevant to on-going support and care including:<br>  • The effect of the person's dementia on people around them including other service users<br>  • Issues relating to the physical design of support and care services<br>  • Staff training to develop appropriate knowledge and skills | • Maintaining people in existing support and care services following diagnosis seen as preferable<br>• If necessary to move then desirable to move to specialist dementia and learning disabilities service | • Middlesbrough learning disabilities dementia groups<br>• Specialist residential units for people with learning disabilities and dementia in Ponteland, Blyth and Coulby Newham |

# 1. Introduction

## Section summary

- The project 'Support and Care for People Living with Dementia from Minority Communities' was commissioned by the North East Dementia Alliance as part of their programme of work around dementia within minority communities for 2013-2014
- The project aimed to make suggestions and recommendations of what the North East Dementia Alliance could further develop and influence in relation to the support and care to people with dementia from minority communities in the North East
- The minority communities that formed the focus of the research were:
    - Black and minority ethnic communities
    - Gypsy and Traveller communities
    - Lesbian, gay and bisexual communities
    - Transgender communities
    - Religious minority communities
    - Individuals with learning disabilities and dementia
    - Younger people with dementia
- The project's research included an in-depth literature review of current policy and existing research as well as semi-structured interviews with service providers from across the UK and community representatives in the North East

## 1.1 Background to the project

The North East Dementia Alliance commissioned the project 'Support and Care for People Living with Dementia from Minority Communities' as part of their programme of work around dementia within minority communities for 2013-2014. This report details the findings of the research stage of the project.

In 2011 *Dementia: A North East Perspective*[1] outlined the need for more detailed data on the numbers of people living with dementia from minority communities in the North East. In response to

[1] Smith, D. (2011) Dementia: A North East Perspective [Online] Available at: http://www.nr-foundation.org.uk/wp-content/uploads/2011/08/Dementia-A-North-East-Perspective.pdf (Accessed 24 January 2013)

this observation the North East Dementia Alliance commissioned the report *Dementia in Minority Communities in North East England.*[2] This report, which was released in September 2012, provides estimates of the number of people living with dementia from minority communities in the North East.

In Spring 2012 the North East Dementia Alliance commissioned a local theatre company; Open Clasp, to write, perform and film a piece of work tackling issues around people with dementia from minority communities which will be used as a training DVD.

The project 'Support and Care for People Living with Dementia from Minority Communities' builds on the work already commissioned by the North East Dementia Alliance and further informs their programme of work for 2013-2014.

## 1.2 Aims of the project

The aim of the project 'Support and Care for People Living with Dementia from Minority Communities' was to make suggestions and recommendations of what the North East Dementia Alliance could further develop and influence in relation to the support and care to people with dementia from minority communities in the North East.

In order to develop these suggestions and recommendations, the project aimed to identify information relating to:

- What support and care services are valued by people living with dementia from minority communities?
- What issues, if any, affect the support and care of people living with dementia from minority communities?
- What types of organisations are best able to deliver support and care to people living with dementia from minority communities?
- What services currently exist for people living for people living with dementia from minority communities in the North East?

## 1.3 What is meant by 'minority communities'?

The meaning of minority communities in this work reflects the understanding outlined in the report *Dementia in Minority Communities in North East England* where the term is used to mean "*those groupings… that are identified through their age, ethnicity, their sexual orientation, their gender reassignment, their religious beliefs or their level of disability*".[3] These categories are based on the

[2] Jackson, M (2012) Dementia in Minority Communities in North East England [Online] http://www.nepho.org.uk/uploads/doc/vid_16758_Dementia%20in%20Minority%20Communities%20in%20North%20East%20England%20Aug%202012.pdf (Accessed 6 January 2013)

[3] Jackson, M (2012) Dementia in Minority Communities in North East England [Online] Available at: http://www.nepho.org.uk/uploads/doc/vid_16758_Dementia%20in%20Minority%20Communities%20in%20North%20East%20England%20Aug%202012.pdf (Accessed 6 January 2013)

classifications employed by the Equality Act 2010[4] and enforced by the Commission for Equality & Human Rights in the UK.[5]

On the basis of this definition the research project focused on information relating to the care and support of people with dementia from seven communities these were:

- Black and minority ethnic communities
- Gypsy and Traveller communities
- Lesbian, gay and bisexual communities
- Transgender communities[6]
- Religious minority communities
- Individuals with learning disabilities and dementia[7]
- Younger people with dementia

## 1.4 Methodology and sources of information

The project's research included an in-depth literature review of current policy and existing research as well as semi-structured interviews with service providers from across the UK and community representatives in the North East.

The literature review included an analysis of research and reports that detail knowledge and examples of effective interventions relating to the support and care of individuals living with dementia from minority communities. The literature review also included an analysis of key policy documents relating to the support and care of individuals living with dementia from minority communities.

In addition the literature review was used to:

- Inform the subject matter of the semi-structured interviews
- Identify which local and national respondents to engage with during the semi-structured interviews
- Identify what resources already exist and which can be used in the North East to improve the care and support to individuals living with dementia from minority communities

The semi-structured interviews were in-depth and qualitative and were conducted with:

- Individuals across the UK (including the North East) who are knowledgeable about the care and support of people with dementia from minority communities
- Representatives from minority communities in the North East

[4] Great Britain. The Equality Act: Elizabeth II. Chapter 15 (2010) London: The Stationery Office

[5] www.legislation.gov.uk/ukpga/2010/15/contents

[6] The expression 'transgender communities' is employed in this report as this was the community used by the respondents spoken to and the documents reviewed during the literature however the expression 'trans communities' is used in the report *Dementia in Minority Communities in North East England.*

[7] The report *Dementia in Minority Communities in North East England* addresses the wider category of people living with dementia and disabilities, however this report is concerned exclusively with the needs of people with learning disabilities and dementia. This difference was requested by the North East Dementia Alliance.

The research also included a request for information about work that has already been undertaken to meet the support and care needs of people living with dementia from minority communities in the North East of England. This request for information was made to the North East Dementia Alliance members and the dementia leads in each of the localities within the region.

## 1.5 Structure of the report

This report contains information relating to the seven categories of minority communities highlighted in the report *Dementia in Minority Communities in North East England.* As the research implied an overlap in the support and care needs of particular communities (e.g. Issues around the support and care of people from black and minority ethnic communities were often referenced as being related to their minority religious beliefs) this report will, in some sections, group together information relating to two or more minority communities.

The report is organised into seven sections. Following this introduction the remaining section address:

- Section 2 outlines the policy context that is relevant to the support and care of people living with dementia from all minority communities
- Section 3 details the findings of the research relating to the support and care of people living with dementia from black and minority ethnic communities, religious minority communities and Gypsy and Traveller communities
- Section 4 outlines issues relevant to the support and care of younger people living with dementia
- Section 5 looks at issues relevant to the support and care of people from lesbian, gay and bisexual communities as well as people from transgender communities
- Section 6 outlines issues relevant to the support and care of people with disabilities living with dementia
- Section 7 provides a conclusion on the key themes highlighted in the report

## 1.6 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.

The author would also like to thank the North East Dementia Alliance for their oversight and advice throughout the project.

Please see Appendix B for a more complete list of acknowledgments.

# 2. Policy context

## Section Summary

- This section of the report outlines the English policy context relevant to the provision of support and care of people living with dementia from Minority communities
- Policy documents relevant to the support and care of people living with dementia from the minority communities discussed in this report include:
    - Living well with dementia: A National Dementia Strategy
    - National Dementia Strategy: Equalities Action Plan
    - Dementia: Supporting people with dementia and their carers in health and social care
    - The Equality Act 2010

This section of the report will outline the English policy context relevant to the provision of support and care of people living with dementia from Minority Communities.

The policy outlined in this section is restricted to those documents that are applicable to all of the minority communities addressed in this report. Policy documents relevant to specific communities only will be addressed in the section of the report which relates to that particular community.

## 2.1 Living well with dementia: A National Dementia Strategy[8]

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. The National Dementia Strategy set out 17 objectives that have shaped subsequent priorities in the provision of dementia services.

The National Dementia Strategy emphasises that it is "*designed to address the needs of all people with dementia, no matter of what type, age, ethnic origin or social status*".[9]

[8] Department of Health (2009) Living well with dementia: a National Dementia Strategy. London: Department of Health
[9] Ibid p.16

## 2.2 National Dementia Strategy: Equalities Action Plan[10]

The Equalities Action Plan "*sets out a series of planned actions in relation to the implementation of the National Dementia Strategy and the Dementia Commissioning Pack*".[11] The Equalities Action Plan has been produced in compliance with the requirements of the Equality Act and builds on the Equality Impact Assessment which was first published alongside the National Dementia Strategy in 2009 and 2010.

The Equalities Action Plan provides a detailed review of how the provisions set out in the *National Dementia Strategy* and the *Dementia Commissioning Pack* affect people on the basis of their disability, sex, race, age, gender reassignment (including transgender), sexual orientation, religion or belief and other identified characteristics.

## 2.3 Dementia: Supporting people with dementia and their carers in health and social care[12]

The clinical guidelines produced by the National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE) offer "*best practice advice on the care of people with dementia and on support for their carers".*[13] The amended guidelines published in 2011 affirm the need for health and social care staff to "*identify the specific needs of people with dementia and their carers arising from diversity, including gender, ethnicity, age (younger or older), religion and personal care*"[14] and should "*accommodate the preferences of people with dementia and their carers, including diet, sexuality and religion".*[15]

In relation to younger people living with dementia the guidelines recommend that "*younger people with dementia have special requirements, and specialist multidisciplinary services should be developed, allied to existing dementia services, to meet their needs for assessment, diagnosis and care*".[16]

In addition the guidelines suggest that "*people with learning disabilities and those supporting them should have access to specialist advice and support regarding dementia*".[17] The guidelines also

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[10] Department of Health (2011) National Dementia Strategy: Equalities Action Plan [Online] Available at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_128519 (Accessed 6 January 2013)

[11] Department of Health (2011) National Dementia Strategy: Equalities Action Plan [Online] Available at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_128519 (Accessed 6 January 2013) p.2

[12] National Collaborating Centre for Mental Health (2011) A NICE-SCIE guidelines on supporting people with dementia and their carers in health and social care. Nice clinical guidance 42 [Online] Available at: http://www.nice.org.uk/nicemedia/live/10998/30318/30318.pdf (Accessed 6 January 2013)

[13] Ibid p.5

[14] Ibid p.12

[15] Ibid p.13

[16] Ibid p.13

[17] Ibid p.13

recommend that *"health and social care staff working in care environments where younger people are at risk of developing dementia, such as those catering for people with learning disabilities, should be trained in dementia awareness".*[18]

## 2.4 The Equality Act 2010[19]

The Equality Act 2010 replaces previous discrimination laws and makes it illegal for public bodies to discriminate (both directly and indirectly), harass or victimise people on the grounds of their:

- Age
- Disability
- Gender reassignment
- Marriage or civil partnership
- Pregnancy and maternity
- Race
- Religion or belief
- Sex
- Sexual orientation

The Equality Act 2010 also brought the public sector equality duty into force. The public sector equality provision imposes an obligation on public bodies to:

> *"consider all individuals when carrying out their day to day work – in shaping policy, in delivering services and in relation to their own employees. It requires public bodies to have due regard to the need to eliminate discrimination, advance equality of opportunity, and foster good relations between different people when carrying out their activities".*[20]

In May 2012 the Home Secretary announced that a review would be undertaken of the public sector equality duty. The findings of this review are expected in April 2013.[21]

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[18] National Collaborating Centre for Mental Health (2011) A NICE-SCIE guidelines on supporting people with dementia and their carers in health and social care. Nice clinical guidance 42 [Online] Available at: http://www.nice.org.uk/nicemedia/live/10998/30318/30318.pdf (Accessed 6 January 2013) p.13

[19] Great Britain. The Equality Act: Elizabeth II. Chapter 15 (2010) London: The Stationery Office

[20] Information from the Home Office Website. Available at http://www.homeoffice.gov.uk/equalities/equality-act/ (Accessed 6 January 2013)

[21] Ibid

# 3. Black and minority ethnic, religious minority and Gypsy and Traveller communities

## Section summary

- This section of the report outlines issues relevant to the support and care of people living with dementia from black and minority ethnic (BME) communities, religious minority communities and Gypsy and Traveller communities
- Issues affecting the support and care of people living with dementia from BME and religious minority communities include:
    - The lower rates of diagnosis among people living with dementia from BME and religious minority communities
    - A lack of awareness about dementia and the services available to people living with dementia and their carers
    - The stigma attached to dementia among some BME and religious minority communities
    - The need for care and support services to be delivered in a culturally appropriate manner in order to be accessible to people from BME and religious minority communities
    - The need to provide more support for the carers of people living with dementia from BME and religious minority communities

## 3.1 Introduction

This section of the report will outline issues relevant to the support and care of people living with dementia from black and minority ethnic (BME) communities, religious minority communities and Gypsy and Traveller communities.

Although it is important to recognise that ethnicity and religion are distinct concepts, this section of the report will address the needs of people living with dementia from both BME and religious minority communities. Although these communities can be mutually exclusive, respondents and documents consulted during the research both highlighted the frequency with which a person's ethnicity and religion interact to shape their identity, culture and their care and support needs.

The inter-related nature of religion and ethnicity can be seen in the definition of ethnicity as a "*self-defined and fluid concept, which can embrace a number of features such as skin colour, national or*

*regional identity, cultural,* ***religion****, country of birth, language, dress and political affiliation as being inter-related*" [emphasis added].[22]

While the term BME may be inexact due to the diverse factors that contribute to a person's ethnicity the phrase BME will be used in this report to refer to individuals who do not define themselves as being white British.

The term religious minority will be used to refer to religions or beliefs that would not be defined as Christian.[23]

The grouping of BME and religious minority communities used in this report are a reflection of the terminology employed by respondents or documents analysed during the literature review. It should however be noted that umbrella terms such as Black African or South Asian disguise a myriad of cultural and religious differences and the North East Dementia Alliance would benefit from further research into the differences between these "*communities within communities*".[24]

Gypsy and Traveller communities have also been included in this section of the report due to the group's status as an ethnic minority.[25] The research revealed a relative lack of information specifically about dementia among Gypsy and Traveller communities. It has therefore been necessary to extrapolate from more generic resources relating to the health and social care needs of people from Gypsy and Traveller communities.

While every effort has been made to contact representatives from a range of relevant communities in the North East the information provided in this report cannot be assumed to be relevant to all BME and religious minority communities in the region.[26]

The report *Dementia in Minority Communities in North East England*[27] estimated that in the North East in 2012:

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[22] Katbamna, S. and Matthews, R. Ageing & Ethnicity in England: A Demographic Profile of BME Older People in England. London: Age Concern England. Quoted in Moriarty, J. and Manthorpe, J. (2012) Diversity in older people and access to services – an evidence review [Online] Available at: http://www.kcl.ac.uk/sspp/kpi/scwru/pubs/2012/reports/Moriarty-Manthorpe-2012-AgeUK.pdf (Accessed 6 January 2013)

[23] Definitions follow the guidance used in the report Jackson, M (2012) Dementia in Minority Communities in North East England [Online] http://www.nepho.org.uk/uploads/doc/vid_16758_Dementia%20in%20Minority%20Communities%20in%20North%20East%20England%20Aug%202012.pdf (Accessed 6 January 2013)

[24] Rauf, A. (2011) Caring for Dementia: Exploring good practice on supporting South Asian carers through access to culturally competent service provision [Online] Available at: http://www.meriyaadain.co.uk/Dementia%20guide%202011%20-%20ENGLISH%20-%2019may11.pdf (Accessed 6 January 2013) p.1

[25] See Great Britain. Race Relations Act: Elizabeth II. Chapter74 (1976) London: The Stationery Office

[26] In particular a representative from the Polish community was contacted as part of this research however they felt unable to contribute claiming *"most of the Polish migrants within the North East came to live in the area as recent economic migrants, between 22 to 50 years old and that is why I have little knowledge of dementia within the Polish community in the region".*

- 353 people living with dementia had have a non-white ethnic background,
- 175 people living with dementia had religious beliefs other than Christian
- 781 people living with dementia were likely to have no religious belief

The report also suggested that "*over the next fifteen years, the number of people with dementia from non-white ethnic backgrounds is likely to increase more rapidly than the numbers with white ethnic backgrounds due to the demographic structure of the communities*".[28]

## 3.2 Policy context

This section of the report will outline the policy context that is specifically relevant to the support and care of people living with dementia from BME and religious minority communities. This policy context should be considered in conjunction with the policy context outlined in section 2 of this report.

In 1998 the Department of Health published *They look after their own, don't they?*[29] This document "*challenged the myth that ethnic minority families support dependent family members and highlighted a number of service deficits*".[30]

The carers strategy *Recognised, valued and supported: Next steps for the carers strategy*[31] outlined the need for advice, information and other support to be personalised to meet the needs of carers from ethnic minorities. The document also highlighted the importance of reaching out to individuals from "*ethnic minority communities, where caring is seen as part of their family responsibilities*".[32]

In 2013 the All-Party Parliamentary Group on Dementia launched an investigation into the support of people living with dementia from minority ethnic communities in the UK. The inquiry will look at examples of effective work already being done to support people from Black, Asian and Minority Ethnic communities and make recommendations on how to improve the quality of care delivered to these communities.

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[27] Jackson, M (2012) Dementia in Minority Communities in North East England [Online] http://www.nepho.org.uk/uploads/doc/vid_16758_Dementia%20in%20Minority%20Communities%20in%20North%20East%20England%20Aug%202012.pdf (Accessed 6 January 2013)
[28] Ibid p.4
[29] Department of Health (1998) They look after their own don't they? Inspection of community care services for black and minority ethnic older people, London: Department of Health
[30] Seabrooke, V. and Milne, A. (2004) Culture and Care in Dementia: A Study of the Asian Community in North West Kent [Online] Available at: http://www.mentalhealth.org.uk/content/assets/PDF/publications/culture_care_dementia.pdf (Accessed 6 January 2013) p.10
[31] HM Government (2010) Recognised, valued and supported: Next steps for the carers strategy [Online] Available at: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_122393.pdf (Accessed 6 January 2013)
[32] Ibid P.41

## 3.3 Issues relevant to the provision of appropriate support and care

This section of the report will outline issues that need to be addressed in order to improve the support and care of people living with dementia from BME and religious minority communities. While many of the issues relevant to the support and care of people from BME and religious minority communities are the same as the issues important for people living with dementia from other communities, this section will focus on the support and care needs that are specific to people from BME and religious communities or support and care needs that may pose particular challenges in the context of people from BME and religious minority communities.

### 3.3.1 Diagnosis

Ensuring that individuals living with dementia have the opportunity to receive a timely diagnosis that is delivered in a suitable manner is of importance to all people living with dementia.[33] There is however a body of research which suggests "*BME people with dementia are less likely to receive a diagnosis or receive it at a later stage than their White British counterparts*".[34]

Receiving an early diagnosis provides individuals with an opportunity to prepare for the future and plan how they would like to be cared for. Receiving a diagnosis at an early stage may also allow people living with dementia to undertake preventative treatment that could slow the progression of their dementia.[35] Individuals living with dementia who are not diagnosed or are diagnosed at a later stage may lose these opportunities.

Late diagnosis may also have a negative effect on the life of people who care for individuals living with dementia. In particular it has been noted that carers and other key people can experience higher levels of stress and a poorer quality of life when looking after an individual whose dementia has not been diagnosed as compared to carers for people who have received a diagnosis.[36]

**Barriers to receiving an early diagnosis**

It has been suggested that members of BME and religious minority communities are more likely to receive no diagnosis of their dementia or receive the diagnosis at a later stage due to a number of inter-related factors. These factors include:

- A lack of awareness about dementia and an inclination to see it as a natural part of the ageing process (see section on awareness 3.3.2)

[33] See objective 2 of the National Dementia Strategy Department of Health (2009) Living well with dementia: a National Dementia Strategy. London: Department of Health

[34] Moriarty, J. Sharif, N. and Robinson, J. (2011) Black and minority ethnic people with dementia and their access to support and services [Online] Available at: http://www.scie.org.uk/publications/briefings/files/briefing35.pdf (Accessed 6 January 2013) p.3

[35] Moriarty, J. Sharif, N. and Robinson, J. (2011) Black and minority ethnic people with dementia and their access to support and services [Online] Available at: http://www.scie.org.uk/publications/briefings/files/briefing35.pdf (Accessed 6 January 2013) p.3

[36] Seabrooke, V. and Milne, A. (2004) Culture and Care in Dementia: A Study of the Asian Community in North West Kent [Online] Available at: http://www.mentalhealth.org.uk/content/assets/PDF/publications/culture_care_dementia.pdf (Accessed 6 January 2013)

- A reluctance among people who may be living with dementia and their families to discuss or acknowledge dementia (see section on stigma 3.3.3)
- The presence of language barriers that may make the diagnostic process and the provision of information about dementia more problematic[37]
- The cultural inappropriateness of standard diagnostic assessment tools
- The low level of GP engagement among some BME and religious minority communities
- The pressures of the average GP workload (which may exacerbate other issues affecting the diagnosis of BME and religious minority communities) [38]

The barriers making it difficult for people from BME communities to receive a diagnosis were explained by a respondent from the North East who commented that:

> *"Getting a diagnosis can be difficult for people from BME communities as the Mini Mental State Examination isn't culturally appropriate. The majority of the older population who originate from India/Pakistan have either not been educated or are illiterate, so asking them to write or draw shapes can be very unsettling and intimidating for them. Also GP's in the past have not put much emphasis on encouraging people who are concerned about their memory to get a diagnosis".*

The lack of culturally appropriate diagnostic tools was also discussed by a respondent from an African community who stated "*how do they know how I think or what is normal or not normal for me when I have a different culture*".

**For examples of work that has been done in Australia to develop culturally appropriate assessment tools see: http://www.fightdementia.org.au/understanding-dementia/culturally-appropriate-dementia-assessment-tools-1.aspx**

In the context of Asian communities it was explained in the report *Culture and Care in Dementia: A Study of the Asian Community in North West Kent*[39] that there is a need to increase awareness among GPs about dementia in Asian communities so that they can see beyond cultural barriers and distortions.

There is currently a lack of research into the reasons for the lower levels of dementia diagnosed among members of Gypsy and Traveller communities. In Scotland the Scottish Parliament's Equal Opportunities Committee reported that "*it is not clear whether the apparently rare occurrence of dementia amongst Gypsy/Travellers is because*

[37] Ibid p.8 see also Sachrajda, A. (2011) Dementia Care in London. London: Institute of Public Policy Research
[38] Ibid
[39] Seabrooke, V. and Milne, A. (2004) Culture and Care in Dementia: A Study of the Asian Community in North West Kent [Online] Available at: http://www.mentalhealth.org.uk/content/assets/PDF/publications/culture_care_dementia.pdf (Accessed 6 January 2013)

*of under-diagnosis (related to lack of engagement with GP services), low life expectancy, or genuinely low levels of the disease*".[40]

As well as the need to ensure that people have the opportunity to receive a diagnosis, the research also highlighted the importance of ensuring that a person's diagnosis is delivered in an appropriate manner. A representative from the Chinese community in the North East explained that the diagnosis process can be particularly traumatic for individuals who do not possess strong English language skills. The respondent emphasised the need for translation services to be provided during the diagnosis process and for post-diagnostic support and information to be delivered in a language that can be understood by the individual who has received the diagnosis.

### 3.3.2 Awareness and understanding of dementia and the services available to people living with dementia

A number of documents analysed as part of the literature review suggested that there is a lack of awareness and understanding about dementia among some BME and religious minority communities.[41]

In *Culture and Care in Dementia: A Study of the Asian Community in North West Kent* it was claimed that some members of Asian communities "*do not conceptualise the illness as an organic disease or treatable illness*" and that "*in its early stages, it is often regarded as a 'normal' part of ageing*".[42] A similar lack of awareness and understanding has been noted among Caribbean and Irish communities.[43]

Concerns about a lack of awareness among BME and religious minority communities were also expressed by respondents in the North East.

A respondent in the North East who works with the carers of people living with dementia from Muslim communities commented "*dementia is not traditionally recognised in Muslim and Asian communities*".

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[40] Scottish Parliament Equal Opportunities Committee (2012) 3rd Report (session 4) Gypsy/Travellers and Care [Online] Available at: http://www.scottish.parliament.uk/S4_EqualOpportunitiesCommittee/Reports/eor-12-03w-rev.pdf (Accessed 6 January 2013) p.10

[41] Ethnic Minority Dementia Advocacy Project (2009) Brining dementia out of the shadows of BME elders: a report on the Ethnic Minority Dementia Advocacy Project (EMDAP) [Online] Available at: http://dan.advocacyplus.org.uk/data/files/publications/EMDAP_Report_PDF.pdf (Accessed 6 January 2012)

[42] Seabrooke, V. and Milne, A. (2004) Culture and Care in Dementia: A Study of the Asian Community in North West Kent [Online] Available at: http://www.mentalhealth.org.uk/content/assets/PDF/publications/culture_care_dementia.pdf (Accessed 6 January 2013) p.8

[43] Brownfoot Associates (1998) The needs of people with dementia and their carers within three ethnic minority groups in Haringey: a report commissioned by Haringey Housing and Social Services and the London Regional Office of the Alzheimer's Disease Society. Social Services Department/Alzheimer's Disease Society: Haringey quoted in Moriarty, J. Sharif, N. and Robinson, J. (2011) Black and minority ethnic people with dementia and their access to support and services [Online] Available at: http://www.scie.org.uk/publications/briefings/files/briefing35.pdf (Accessed 6 January 2013)

A respondent who has researched the views of the Jewish communities in the North East stated:

> "*dementia is not a well-recognised or accepted condition. There needs to be greater recognition among the Jewish community that dementia is not the same as getting old and that the care needs of people living with dementia can sometimes go beyond what can be delivered by the family at home*".

Respondents from a number of Black African communities in the North East noted that they had little understanding of what dementia is and suggested that this low level of awareness and understanding was common among their communities.

The literature review and respondents in the North East both highlighted how a lack of awareness about dementia was one factor that contributed to the lower rate of diagnosis among BME and religious minority communities.[44]

The types of information respondents from BME and religious minority communities stated they would like to know included:

- What is dementia
- How does dementia affect a person
- What to do if you suspect a person has dementia
- What, if anything, can be done to lower your risk of developing dementia
- What support and care services are available for people living with dementia including culturally appropriate services
- Where to go to get further advice and information

### The barriers to accessing information

The research identified a number of barriers that make it harder for people from BME and religious minority communities to access information about dementia and the support and care services available for people living with dementia. These barriers included:

- The stigma associated with discussing dementia
- The fact that 'dementia', 'carer' and other concepts were not directly translatable into some languages making it more difficult to communicate important ideas
- Information provided in English may not be accessible to some members of BME and religious minority communities who have limited English language skills
- A shortage of translation services or a reluctance to use translation services due to unease about translators that are from a person's own community and related concerns about a lack of confidentiality
- The inability of some members of BME and religious minority communities who are unable to read and write

[44] See Nijjar, M (2012) Perspectives on ageing in South Asian families. York: Joseph Rowntree Foundation and Moriarty, J. (2008) The health and social care experiences of black and minority ethnic older people [Online] Available at: http://mighealth.net/uk/images/f/fe/Ref1.pdf (Accessed 6 January 2013)

- The low level of engagement with GPs among some communities
- A lack of understanding about local systems and the difficulty of navigating these systems to access information and care and support services

In the report *Perspectives on ageing in Gypsy families* it was advised that "*as many Gypsy people are not literate, information and communications need to be provided in an accessible format and with appropriate content".*[45]

**The Alzheimer's Society has produced dementia factsheets in a number of languages these are available at http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1004**

### Ways to increase awareness and understanding about dementia and the services that are available for people living with dementia

The report *Black and minority ethnic people with dementia and their access to support and services*[46] suggested that examples of effective intervention have included:

- *"Using neutral language in leaflets, such as 'memory problems' for dementia and 'looking after' instead of being a 'carer'. This avoids making assumptions that people understand what is meant by these terms"*
- *"Developing a multi-purpose leaflet instead of individual leaflets for each separate service. Such a leaflet should include information about memory problems and about what sort of help is available"*
- *"Holding 'road shows' at religious establishments and community centres"*
- *"Providing DVDs and videos about dementia. This approach is particularly useful where members of a community are neither literate in English or their mother tongue"*
- *"Publicising information on local radio stations"*
- *"Creating links with local communities in locations such as places of worship and community centres"*
- *"Appointing outreach workers who can work with local communities"*[47]

[45] Lane, P. Spencer, S. and McCready, M. (2012) Perspectives on ageing in Gypsy families. York: Joseph Rowntree Foundation p.11

[46] Moriarty, J. Sharif, N. and Robinson, J. (2011) Black and minority ethnic people with dementia and their access to support and services [Online] Available at: http://www.scie.org.uk/publications/briefings/files/briefing35.pdf (Accessed 6 January 2013)

[47] Moriarty, J. Sharif, N. and Robinson, J. (2011) Black and minority ethnic people with dementia and their access to support and services [Online] Available at: http://www.scie.org.uk/publications/briefings/files/briefing35.pdf (Accessed 6 January 2013) p.6

Many of these approaches were also highlighted by respondents in the North East as being methods that they had employed or would like to see trialled in order to increase awareness and understanding among BME and religious minority communities in the North East.

In the Teesside area one respondent working with people living with dementia from BME and religious minority communities explained that they had received an increase in referrals for their carer support services following the distribution of information through a local Muslim orientated radio station and community forum.

Another respondent in the Teesside area recounted how they had found using fact sheets and DVDs in different languages a useful way of increasing awareness among individuals who had low levels of English language skills.

The same respondent also suggested that, in order to overcome the language barriers that can prevent the communication of information, it may be useful to develop a translation service supported by volunteers. This proposal should however be balanced against the caution expressed by other respondents who felt that members of BME and religious minority communities may worry about translators breaching confidentiality. Respondents suggested that concerns about confidentiality would be particularly significant among communities in which there is a stigma associated with dementia.

### 3.3.3 Stigma

Both the literature review and respondents in the North East suggested that there is a stigma about dementia among some BME and religious minority communities.

The report *Black and minority ethnic people with dementia and their access to support and services* commented that:

> "*Religious beliefs may account for some stigma among Asian people. For instance, among those who believe in reincarnation, dementia may be seen as a punishment for behaviour in a past life. Research with Black Caribbean and Irish people suggests they are more inclined to see dementia as a 'mental illness', rather than the result of physiological changes in the brain. Among Eastern Europeans, stigma may relate to experiences of persecution and the need to 'keep face'*".[48]

The stigma about dementia among some BME and religious minority communities was remarked on by a number of respondents from the North East.

One respondent who works with BME and religious minority communities in the North East commented that "*the issue of dementia is a taboo subject among Muslim and Asian communities*" and explained that while stigma has declined over the past ten years there are still considerable

[48] Moriarty, J. Sharif, N. and Robinson, J. (2011) Black and minority ethnic people with dementia and their access to support and services [Online] Available at: http://www.scie.org.uk/publications/briefings/files/briefing35.pdf (Accessed 6 January 2013) p.6

cultural barriers that prevent people talking about the condition. The respondent went on to explain that "*there is still a trend towards seeking help from the Imam rather than medical professional*".

Speaking about the Jewish Community in the North East another respondent suggested "*there is a strong sense of shame. People would rather deal with it on their own*".

The issue of stigma was also reflected in the opinions of a representative from the Chinese community who indicated that many individuals within the community felt a reluctance to discuss issues relating to their mental health.

In order to overcome the stigma about dementia respondents said that there is a need to both increase awareness and understanding about dementia and to also use carefully chosen language when discussing dementia. In particular it has been suggested that among some groups the term "*medical services is more acceptable than 'mental health' or 'social care' services*".[49]

### 3.3.4 Services and staff that can meet people's cultural and religious needs

A further issue identified in the research was the need for support and care services to be delivered in a culturally appropriate manner. Cultural factors that were highlighted as being relevant to the provision of appropriate support and care included:

- Meeting a person's dietary requirements
- Speaking a person's language
- Providing gender appropriate carers
- Ensuring that service providers are dressed appropriately
- Ensuring staff are trained to help with prayers and related activities
- Creating an environment in which people could express their religious views and celebrate religious occasions
- Providing culturally appropriate activities

There is some evidence to suggest that placements in care and support services do not proceed because of an inability of services to meet these needs.[50]

Respondents in the North East highlighted a number of examples of services that have been unwilling or unable to meet the dietary requirements of individuals living with dementia from BME and Religious Minority communities. This included care homes that refused to provide Halal or

[49] Seabrooke, V. and Milne, A. (2004) Culture and Care in Dementia: A Study of the Asian Community in North West Kent [Online] Available at: http://www.mentalhealth.org.uk/content/assets/PDF/publications/culture_care_dementia.pdf (Accessed 6 January 2013) p.8

[50] Seabrooke, V. and Milne, A. (2004) Culture and Care in Dementia: A Study of the Asian Community in North West Kent [Online] Available at: http://www.mentalhealth.org.uk/content/assets/PDF/publications/culture_care_dementia.pdf (Accessed 6 January 2013) p.9

Kosher meals and an anecdotal account of a person who, because of their dementia, was unable to express their dietary preference and was fed culturally inappropriate food in a care home.

A further issue mentioned by respondents in the North East was a fear that services would be delivered in an overly 'medical' manner that failed to support a person's spiritual support needs. This concern led respondents to highlight the importance of ensuring care and support staff are trained to support people living with dementia to pray and complete related activities such as undertaking ablutions prior to prayers.

A respondent from the Jewish community explained that activities provided as part of a person's support and care services must be inclusive and observed that some activities common to care and support settings, for example watching TV or playing pool or cards, would exclude many members of the Jewish community.

Respondents from a number of communities emphasised the importance of ensuring that carers are of the same gender as the individual being cared for. It was also noted that when going into a person's home, carers should be dressed in a culturally sensitive manner. An example of this was provided in relation to the Jewish community where there is an expectation among some members of the community that visitors to their home, including carers, will cover their hair and wear long sleeves to cover their arms.

The inability of support and care staff to speak the language of members of BME and religious minority communities was seen by respondents from a number of communities as being another issue that could make support and care services inaccessible. It was further observed that this barrier can become increasingly problematic as a person's dementia progressed because individuals may at this point revert to their original language and lose their English language skills if English is not their first or predominant language.

The research suggested that not only does an inability to communicate prevent service providers from identifying the needs of people living with dementia but can also contribute to a feeling of isolation among individuals living with dementia from a BME or religious minority communities. This prompted one respondent to comment "*it is important to have front-line support that can communicate in a person's own language*".

**The Meri Yaadain Project in Bradford aims to reduce stigma among members of the South Asian communities in Bradford by overcoming language and increasing understanding of dementia**
**See: www.meriyaadain.co.uk/**

In relation to Gypsy and Traveller communities specific cultural requirements included the use of different bowls for different washing activities.[51]

Fears that support and care would not be delivered in a culturally appropriate manner were further compounded by the high turnover of staff working in care and support services. Respondents voiced a concern that that as soon as carers began to understand what was religiously and culturally appropriate they would leave and be replaced by new staff members who may not be culturally aware.

### Factors that may cause support and care services to be culturally inappropriate

One reason suggested why support and care services may not be delivered in a culturally or religiously appropriate manner was a "*lack of knowledge among service providers and managers about the lifestyles, health, religious and cultural needs*"[52] of BME and religious minority communities.

It was also suggested by a number of respondents that some private service providers were unwilling to invest in making their services culturally appropriate claiming that it was not financially prudent to expend time and money to meet the needs of a small number of potential clients. This view was however rebutted by one respondent who claimed "*if there was one good service in the area it would pull in people from all over. People from the Muslim community would also be willing to pay to ensure that their family got the right service*".

Additionally it was thought that the focus on equality emphasised by some service providers may make service providers blind to the different needs of people living with dementia from BME and religious minority communities. This point was made by a respondent who commented that:

> "*mainstream services claim 'we are open to everyone' but they are not really, what they mean is that they treat people equally. To provide support to people from BME communities you need to do some things differently. This isn't about giving us extra it's about plugging a gap*".

This point was articulated in the report *Hidden Shame* which stated "*Comments such as "Everyone is equally welcome here" assume that all people have the same needs regardless of cultural experience. Providing the same service for everyone when needs are different is not equitable as the outcomes will vary for users from different groups in the community*".[53]

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[51] Lane, P. Spencer, S. and McCready, M. (2012) Perspectives on ageing in Gypsy families. York: Joseph Rowntree Foundation p.11

[52] Seabrooke, V. and Milne, A. (2004) Culture and Care in Dementia: A Study of the Asian Community in North West Kent [Online] Available at: http://www.mentalhealth.org.uk/content/assets/PDF/publications/culture_care_dementia.pdf (Accessed 6 January 2013) p.9

[53] St John, T. (2004) 'Hidden shame: a review of the needs of Asian elders with dementia and their carers in a Kent Community', Journal of Integrated Care, vol 12, no 3, p.24

Respondents also highlighted concerns about the prevalence of stereotyped views regarding what members of BME and religious minority communities want. This led the report *Black and minority ethnic people with dementia and their access to support and services* to state "*research has suggested that if organisations and practitioners hold stereotyped ideas about BME people with dementia, and in particular the extent of family support or preferences for certain types of care, then this can be an important factor discouraging BME people with dementia and their families from using services*".[54]

In order to address this issue the report emphasised that an "*important starting point in achieving personalised approaches to services is the need to pay greater attention to the diversity and complexity that exists within the life stories of people with dementia".*[55]

Respondents felt that the consideration given to the needs of people living with dementia from BME and religious minority communities was relatively limited at the regional level and among service commissioners. It was believed that this might be a further factor contributing to a lack of culturally appropriate services. Moreover, respondents were concerned that the current review of the Public Sector Equality Duty may further limit the level of consideration given to the needs of people living with dementia from BME and religious minority communities. These worries led one respondent to comment:

> "*At a regional level there is need for commissioning to be informed by the views of BME and religious minority communities and this applies to all work and not just that work which is focused on BME communities. Equality and diversity needs to be a standing item on the agenda of regional bodies and community groups need play an important part in informing regional work*".

Another respondent also remarked that "*there needs to be more done to shape the market place. It's not good enough having personal allowances if people only have limited choice about how to spend their allowance*".

In addition to the above issues, a number of respondents highlighted the need for staff from support and care services to receive adequate training so that they are able to provide support and care in culturally sensitive manner. Respondents noted that while there are examples of individual practitioners who provide care and support in a suitable manner there were also examples of staff members who did not.

Respondents stressed that staff training on equality and diversity needs to go beyond "*piecemeal* training *that is tagged onto the end of training days*". Instead it was felt that it would be beneficial for staff to receive experiential training and it was suggested that visiting places of worship and BME community venues would give staff a much deeper understanding of the needs of people from BME and religious minority communities. A number of respondents from community groups expressed a willingness to work with service providers to help them address issues that may deter people living

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[54] Moriarty, J. Sharif, N. and Robinson, J. (2011) Black and minority ethnic people with dementia and their access to support and services [Online] Available at: http://www.scie.org.uk/publications/briefings/files/briefing35.pdf (Accessed 6 January 2013) p.8

[55] Ibid p.5

with dementia from BME and religious minority communities from using their services. It was also felt that developing a good relationship between service providers and community groups could help bridge the gap between universal services and what is "*actually going on at the ground level*". Furthermore, it was also felt thought that this relationship could help service providers make contact with people who are currently hidden from the view of mainstream services or whose needs are not being met.

A number of respondents commented that 'same culture caring' would be advantageous for service users and that it may be beneficial to train people from BME and religious minority communities because "*it is easier to train a person to understand the principles of health and social care rather than explain a whole culture to someone".*

### 3.3.5 Issues affecting carers

The research revealed a number of issues that affect the unpaid carers of people living with dementia from BME and religious minority communities.

Research has shown that carers from BME communities tend to seek professional assistance at a later stage than their White British counterparts.[56]

It was noted by respondents in the North East that many carers were "*suffering in silence*". In one example a respondent spoke of a carer who had spent thirteen years caring for an elderly family member without professional support.

Demographic changes and the pressure to move for work have "*resulted in the disruption of traditional sources of support*". However, the pressure to care for family members living with dementia at home remains an issue for many members of the BME and religious minority communities in the North East.

In the report *Black and minority ethnic people with dementia and their access to support and services* this trend was explained as resulting from people being "*unwilling to relinquish their caring role due to a commitment to family duty"*.[57] In relation to the Jewish community it was noted by one respondent that there is a "*strong emphasis on family responsibility and giving up the responsibility can be daunting after a family orientated life*".

In addition a respondent in the North East commented that because of the stigma attached to dementia many families from Asian communities would rather "*keep it in-house or deal with it in the family*".

Another respondent also explained that there was a stigma attached to the idea of encouraging a family member to attend a day centre or move into a care home. The respondent explained "*there is*

[56] Moriarty, J. Sharif, N. and Robinson, J. (2011) Black and minority ethnic people with dementia and their access to support and services [Online] Available at: http://www.scie.org.uk/publications/briefings/files/briefing35.pdf (Accessed 6 January 2013) p.7
[57] Ibid

*a lot of stigma attached to this. Many carers from these groups feel that they may be frowned upon*".

These issues led one respondent to claim that "*communities need further educating on the benefits of day centres/respite care/care homes in order to tackle stigma*".

Respondents also noted that there was a growing demand for support groups for carers. As suggested by one respondent "*female carers did highlight that they would like to attend a regular group or coffee morning session where they could meet other women in the same situation*". However it was noted that there may be a range of barriers preventing carers from BME and religious minority communities accessing carer support services. These barriers included:

- The stigma attached to asking for support
- The reluctance of some carers to attend mixed gender support groups

It was also mentioned by a number of respondents that culturally specific support groups would be more advantageous as it would give people a common frame of reference and a deeper understanding of the issues people face. Furthermore it was felt that culturally specific groups would avoid language barriers and help people to communicate more effectively.

## 3.4 What type of organisations are best placed to deliver support and care?

**What services are valued?**

Respondents indicated that the support and care services valued by people living with dementia from BME and religious minority communities were similar to the services wanted by members of other communities living with dementia. However, it was suggested that many people from BME and religious minority communities prioritise services that support people living with dementia to remain in the family home. This included respite care and day centres. Respondents implied that for some communities these services were valued due to the cultural importance placed on caring for family members at home instead of using long-term placements in care homes.

A number of respondents did, however suggest that the cultural importance of caring for family members at home may be changing due to:

- Changing family patterns

***"After working with South Asian Communities, I have found it is often the daughters in law who care for the elderly in the household. This can be very distressing as they have other duties to juggle. These carers have been reluctant to access outside support because of a fear of being portrayed as failing as a wife, mother and carer and concern about what other people, including family members, are going to say if they find out"***
**(Support worker in the North East)**

- The growing need for family members to move for work
- Changing values as younger generations are 'westernised'

As a consequence of these changes it was felt by some respondents that long-term placements in care homes would become more common among BME and religious minority communities, provided services were able to meet their cultural needs.

**Specialist or mainstream services?**

Respondents were divided over the issue of whether it was preferable to have specialist services exclusively for people living with dementia from BME and religious minority communities or whether it was instead beneficial to make generic mainstream services more culturally appropriate. For many respondents the end result of culturally appropriate services was considered to be the most important factor.

One respondent commented that "*I think people from the Muslim community would be happy to use mainstream services but there is a demand for specialist services because the mainstream service providers aren't meeting their needs*".

Another respondent also warned that focusing on specialist services could lead to higher levels of segregation between BME communities and the rest of the population and also between different BME groups. The respondent questioned "*where would it end*" and instead argued for the benefit of culturally sensitive services that could include all communities.

Despite these sentiments other respondents still felt that it was necessary that specialist services were provided.

One respondent speaking of the Jewish community remarked that while it may not be necessary for support and care staff to be from the Jewish community themselves, there was a strong view that support and care should be "*delivered in a Jewish environment*". The respondent noted that status was an important issue within Jewish communities and families would not want to lose this within generic services.

Other respondents noted that the use of generic services could lead to people feeling isolated where they are the only member of a BME or religious minority community. This point was however refuted by a respondent who, speaking about the Chinese community, commented "*services don't have to be specifically for members of the Chinese community however it helps if there are a few people from the community using the same service as it can make people feel more comfortable in the environment*".

The literature review also revealed a mixture of views on the question of specialist services. While some sources indicated that specialist services were particularly valued[58] other sources suggested a much more complicated picture.

[58] See Moriarty, J. Sharif, N. and Robinson, J. (2011) Black and minority ethnic people with dementia and their access to support and services [Online] Available at:

In the report *Black and minority ethnic people with dementia and their access to support and services* it was explained that:

> *"It has been suggested that different ethnic groups have different preferences for 'mixed' or culturally-specific dementia services. In Haringey, a study suggested that Black Caribbean and Irish people with dementia and their carers preferred 'mixed' services…. However, Gujarati Asians interviewed in the same study set more importance on having services in which care was provided by Asian staff".*[59]

In addition it has been observed that a community's preference for specialist or culturally appropriate services could be influenced by the social context. The report *Culture and Care in Dementia: A Study of the Asian Community in North West Kent* explained that with regard to Asian communities:

> *"What services are suitable depends on the context i.e. mainstream services may be appropriate where the Asian community existed for a long time".*[60]

Despite this complicated picture it was highlighted that there may be a role for both universal and specialist services. A respondent suggested that mainstream providers have the advantage of being able to offer services to a larger number of individuals while smaller community groups that support BME and religious minority communities, possess a level of local and cultural knowledge that could allow them to inform and influence the work of mainstream services.

The respondent explained that local specialist community groups that are "*clued up on the local context and the needs of a specific community*" could be used to tap into the "*the complexities of the issues facing people from BME communities*" and could provide a useful resource for specialist information for mainstream services.

The respondent noted that specialist community services often have short-term finite budgets and so there needs be an emphasis on ensuring that these projects are designed to both:

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http://www.scie.org.uk/publications/briefings/files/briefing35.pdf (Accessed 6 January 2013) p.9 and Seabrooke, V. and Milne, A. (2004) Culture and Care in Dementia: A Study of the Asian Community in North West Kent [Online] Available at: http://www.mentalhealth.org.uk/content/assets/PDF/publications/culture_care_dementia.pdf (Accessed 6 January 2013) p.12

[59] See Moriarty, J. Sharif, N. and Robinson, J. (2011) Black and minority ethnic people with dementia and their access to support and services [Online] Available at: http://www.scie.org.uk/publications/briefings/files/briefing35.pdf (Accessed 6 January 2013) p.9

[60] Seabrooke, V. and Milne, A. (2004) Culture and Care in Dementia: A Study of the Asian Community in North West Kent [Online] Available at: http://www.mentalhealth.org.uk/content/assets/PDF/publications/culture_care_dementia.pdf (Accessed 6 January 2013) p.9

- Meet the specialist needs of the current generation of BME and religious minority communities
- Have a long-term, positive effect on the way mainstream services operate

Moreover, it was felt that specialist services could train staff from BME and religious minority communities with the long-term goal of helping these staff members move into mainstream services where they would be able to influence the work of generic service providers.

In addition it was noted by another respondent that while specialist services may be desired by some communities at the moment it may be necessary to "*plug the gap*" for the current generation, segregated services may not be desirable or sustainable in the long run. This view was echoed in the report *Culture and Care in Dementia: A Study of the Asian Community in North West Kent* which in the context of Asian communities commented that "*although it is appropriate for new services to be integrated into existing provision, it may be necessary to provide separate services for the current generation of older Asians*".[61]

## 3.5 What support and care services are available in the North East?

This section of the report will detail the support and care services that are available for people living with dementia from BME and religious minority communities in the North East. This section includes only the services highlighted by respondents during the research. The information included in this section cannot therefore be assumed to be comprehensive however it may provide a useful guide to the type of services that are currently available and the work that has already been done.

This section does not include mainstream care services such as care homes that accommodate people from BME and religious minority communities.

The research suggested that there are currently a number of community groups that are providing support and/or care for people living with dementia from BME and religious minority communities. These groups are not exclusively targeted at providing support and care for people living with dementia however people living with dementia were supported as part of the wider community. These included:

- The Hindu Cultural Centre in Middlesbrough provides a range of services including a luncheon club for older members of the Hindu community
- Stockton Mosque is currently scoping the possibility of providing day centre services for older members from the Muslim community in Stockton
- The Sunderland Bangladeshi Community Centre provides support for the families of people living with dementia
- The organisation Zayis Raanon provides a day centre and home care for elderly and disabled people in the Gateshead Jewish Community

[61] Seabrooke, V. and Milne, A. (2004) Culture and Care in Dementia: A Study of the Asian Community in North West Kent [Online] Available at: http://www.mentalhealth.org.uk/content/assets/PDF/publications/culture_care_dementia.pdf (Accessed 6 January 2013) p.9

- BECON are currently undertaking work to develop and promote access to health and social care support services to BME carers and their families in Middlesbrough
- The George Hardwick Foundation in Stockton provides support to the carers of people living with dementia from BME and religious minority communities
- A respondent from the Chinese Community highlighted Westend Befrienders in Newcastle as being a group that was doing a lot to help members of the Chinese community living with dementia

The Alzheimer's Society employs a Dementia Support Worker to work with hard to reach communities in Stockton. The service aims to raise awareness about dementia and offer support and advice to a range of hard to reach communities, including BME and religious minority communities.

In 2010 the report *Look, Listen, Speak and Deliver – Voices of South Asian Black Minority Ethnic (BME) Ageing Population in Newcastle upon Tyne*[62] detailed the findings of a research project that aimed to identify the needs of Newcastle's South Asian ageing population.

The report suggested that

- While most South Asian elders wanted to remain living with their families the role of the family in the Asian communities is changing
- South Asian elders valued community-based support services and activities that addressed their health and social care needs
- South Asian elders are effectively denied access to mainstream social services due to the failure of service providers to address the cultural, religious and linguistic needs of South Asian elders
- South Asian elders had limited access to mainstream services due to a lack of knowledge about services
- South Asian elders had no voice or role in expressing their needs to local policy makers and need be involved in and have a voice in local policy making on health and social care issues
- Service commissioners need to include independent providers such as community and voluntary agencies in their procurement and commissioning processes
- It is necessary to take account of the support needs of family carers

The local dementia strategies for a number of localities within the North East have addressed the issue of support and care for people living with dementia from BME and religious minority communities.

In Gateshead the *Joint Commissioning Strategy 2009-2012*[63] sets out a commitment to undertake awareness raising campaigns with local priority groups including minority groups such as black and

[62] Mattu, P. and Akhtar, P. (2010) Look, Listen, Speak and Deliver – Voices of South Asian Black Minority Ethnic (BME) Ageing Population in Newcastle upon Tyne (Unpublished)
[63] Available at: http://www.phine.org.uk/social-care-north-east/resources/1839 (Accessed 6 January 2013)

ethnic minority communities. This provision is mirrored in the Joint Commissioning Frameworks for South Tyneside[64] and Sunderland.[65]

The Gateshead Joint Commissioning strategy also states an intention to "*explore specific issues for black and minority ethnic elders with regard to the early detection of mental illness*".

In Middlesbrough the *document Mental Health Services for Older People in Middlesbrough: Implementation Plan 2009-2014* includes a commitment to "*explore specific issues for black and minority ethnic elders with regard to the early detection of mental illness (functional and organic) and review the role of community development workers in helping to improve the delivery of services*".[66]

The *National Dementia Strategy Implementation Action Plan for Stockton-on-Tees* states an intention to "*explore specific issues for BME elders with regard to the early detection of mental illness (functional and organic)".* The document also sets out a commitment to "*address the needs of carers of people with dementia from BME communities*" and to identify the number of carers from BME communities in the locality.[67]

The *Redcar & Cleveland Implementation Plan of the National Dementia* Strategy outlines an aim to "*further develop the role of mental health community development workers to improve services and access for black and ethnic minority elders*".[68]

In Northumberland the *Joint Dementia Action Plan* proposes the need to "*produce revised joint communications plan between health and social care with specific reference to minority communities e.g. BME*"[69]

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[64] Ibid

[65] Ibid

[66] Available at: http://www.phine.org.uk/securefiles/130113_1733//Mental%20Health%20Services%20for%20Older%20People%20in%20Middlesbrough[1].pdf (Accessed 6 January 2013)

[67] Available at: http://www.phine.org.uk/securefiles/130113_1732//National%20Dementia%20Strategy%20Implementation%20Plan%20Stockton%202011[1].pdf (Accessed 6 January 2013)

[68] Available at: http://www.phine.org.uk/securefiles/130113_1734//National%20Dementia%20Strategy%20Redcar%20and%20Cleveland%20Implementation%20Plan[1].pdf (Accessed 6 January 2013)

[69] Available at: http://www.phine.org.uk/securefiles/130113_1731//Northumberland%20Int%20Plan%20September%202011.pdf (Accessed 6 January 2013)

## 3.6 Recommendations

### Further research

There is a need for:

- Further research to identity the specific needs of the full range of (BME and religious minority) 'communities within communities' in the North East
- Particular research to identify the support and care needs of people living with dementia from Gypsy and Traveller communities

### Improving diagnostic rates and the diagnostic process

There is a need for:

- Training to help GPs see beyond cultural distortions and reluctance to discuss dementia among BME and religious minority communities
- Increased knowledge about and use of culturally appropriate diagnostic assessment tools among professionals
- Appropriate translation and support services during and after the diagnosis process

### Reducing stigma and increasing awareness

There is a need to:

- Produce locally specific leaflets, fact sheets and DVDs that provide information about dementia and the services available to people living with dementia, this information should be provided in a range of languages and should use neutral terminology
- Work with local radio stations aimed at BME and religious minority communities to provide information about dementia and the services that are available for people living with dementia and their carers
- Forge close links with BME and religious community leaders so that community outreach workers can provide information or run workshops in 'safe places' such as community centres or places of worship
- Provide information to community leaders so that they can take the information to their communities
- Consider the use of translators to work with information providers. These services should be designed in a manner that maximises reassurance about confidentiality (this may take the form of a volunteer translator service)

### Developing culturally appropriate services

This could be done by:

- Encouraging mainstream service providers to ensure that support and care is:
    - Person centred and designed to meet the needs of individual and not cultural stereotypes

    - Delivered in a culturally appropriate environment where religious and cultural diversity are celebrated (i.e. not overly medical in character)
- Developing in-depth experiential training on cultural and religious diversity for frontline staff from care and support services
- Encouraging the development of relationships between BME and religious minority community groups and mainstream services so that specialist community groups can advise and inform mainstream services (this could take the form of a dedicated liaison officer)
- Encouraging service commissioners to work in collaboration with BME and religious minority groups when commissioning all support and care services (not just services aimed at BME and religious minority communities)
- Ensuring that BME and religious minority groups are included in regional bodies working in the field of dementia such as the North East Dementia Alliance
- Improving the training of support and care staff who are from BME and religious minority communities
- Considering the provision of culturally specific care and support services for particular communities
- Promoting the development of confidential and culturally sensitive support services for carers from BME and religious communities

# 4. Younger people living with dementia

## Section summary

- This section of the report outlines issues relevant to the support and care of younger people living with dementia
- Issues highlighted as being relevant to the support and care of younger people living with dementia include:
    - Difficulties and delays during the diagnostic process
    - Difficulty identifying who is responsible for on-going care and support and what services are available to young people living with dementia
    - The need to provide support and care services that meet the specific needs of younger people living with dementia, including the need for:
        - Age appropriate activities
        - Support to address the financial and legal issues faced by younger people living with dementia
        - Practical and emotional support for family members including dependent children and older relatives
        - Support to deal with the stigma associated with young-onset dementia
- The research suggested that younger people living with dementia value specialist services that are designed to meet their needs

## 4.1 Introduction

This section of the report addresses issues relating to the support and care of younger people living with dementia. The phrase younger people living with dementia will be used in this report to refer to people living with dementia who are under 65 years old. [70]

According to the report *Dementia in Minority Communities in North East England* there were estimated to be 694 younger people living with dementia in the North East of England in 2012 and this figure is expected to rise to 713 individuals by 2025.[71]

[70] This figure is taken from the Alzheimer's Society Website and can be accessed at http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=543

No information was submitted by respondents in the North East in relation to the support and care needs of younger people living with dementia. Consequently information about the needs of younger people living with dementia and the recommendations outlined in this section are drawn from national trends highlighted by the literature review and respondents from outside of the region.

## 4.2 Policy context

This section of the report will outline the policy context that is specifically relevant to the support and care of younger people living with dementia. This policy context should be considered in conjunction with the policy context outlined in section 2 of this report.

In 2005 the Royal college of Psychiatrists and Alzheimer's Society jointly published the document *Services for Younger People with Alzheimer' Disease and other Dementias*[72]. The paper outlines the needs of younger people living with dementia and sets out detailed recommendations of how services could be developed to meet the particular needs of younger people living with dementia.

## 4.3 Issues relevant to the provision of appropriate support and care for younger people living with dementia

This section of the report will outline the issues that were highlighted during the research as being relevant to the provision of support and care for younger people living with dementia.

### 4.3.1 Diagnosis

The importance of ensuring that people living with dementia have the opportunity to receive a timely diagnosis, if they choose to, is a theme that is relevant to all individuals living with dementia. A diagnosis gives individuals an opportunity to understand the medical consequences of living with dementia and provides people with a chance to plan forward and identify the support and care services that can meet their needs. The research conducted as part of this project suggested that there are a number of issues that are unique to younger people living with dementia that may affect and sometimes delay the process of receiving a diagnosis.

Delays in receiving a diagnosis may be attributed to a number of factors however one commonly cited issue is the comparative rarity of the condition and the resulting lack of awareness among GPs who may be insufficiently trained to recognise the signs of young-onset dementia.[73]

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[71] Jackson, M (2012) Dementia in Minority Communities in North East England [Online] http://www.nepho.org.uk/uploads/doc/vid_16758_Dementia%20in%20Minority%20Communities%20in%20North%20East%20England%20Aug%202012.pdf (Accessed 6 January 2013) p.6

[72] Royal College of Psychiatrists and Alzheimer's Society (2005) Services for younger people with Alzheimer's disease and other dementia [Online] Available at: http://www.rcpsych.ac.uk/files/pdfversion/cr135.pdf (Accessed 6 January 2013)

[73] Daker-White, G. Beattie, A. Means, R. and Gilliard, J. (2002) Serving the needs of marginalised groups in dementia care: younger people and minority ethnic groups [Online] Available at: http://www.dementia-voice.org.uk/Projects/summaryreport.pdf (Accessed 6 January 2013)

The research suggested that even where young-onset dementia is suspected by medical professionals at an early stage, receiving a diagnosis can take longer than it does for other groups. The diagnostic challenges were explained by one respondent who explained that the difficulty resulted from a combination of factors including:

- The prevalence of rarer forms of dementia among younger people living with dementia and the fact that medical professionals may be less familiar with these forms of dementia
- Neuropsychological assessments often produce less clear results among younger people living with dementia as compared to older people living with dementia
- The need for extra tests because of the above difficulties and the need for medical professionals to be confident before delivering a diagnosis of dementia

These difficulties have led one report to claim that for younger people living with dementia "*diagnostic testing was seen as baffling and as leading to a sense of incompetence*".[74] It has also been suggested that as well as the practical consequences of a longer diagnostic process, delays in the diagnostic process can result in younger people living with dementia facing increased emotional hardship. It was noted in the report *Serving the needs of marginalised groups in dementia care: younger people and minority ethnic groups* that because of these difficulties "*the cognitive assessment process and the 'news' of dementia can be a baffling, hurtful and frightening experience*".[75]

### 4.3.2 Understanding where responsibility lies in relation to diagnosis and on-going support and care

Respondents highlighted the confusion that can emerge when trying to ascertain which bodies are responsible for the diagnosis of younger people living with dementia. As explained by one respondent "*People get directed in all sorts of ways. Where do you they go? What is the point of access*?"

It has been further observed that:

> *"People with dementia are usually seen by an old age psychiatrist, but if the person is under 65, it may not be clear which specialist they should see. Will the local old age psychiatrist be willing to see the person or should it be the neurologist?"*[76]

In order to address these issues a number of localities across the UK have developed clear pathways to maximise diagnostic certainty and increase clarity for younger people living with dementia and practitioners.

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[74] Daker-White, G. Beattie, A. Means, R. and Gilliard, J. (2002) Serving the needs of marginalised groups in dementia care: younger people and minority ethnic groups [Online] Available at: http://www.dementia-voice.org.uk/Projects/summaryreport.pdf (Accessed 6 January 2013)

[75] Ibid p.8

[76] Information from the Social Care Institute for excellence, Dementia Gateway: Young onset dementia available at http://www.scie.org.uk/publications/dementia/young/diagnosis.asp (Accessed 6 January 2013)

**In Hammersmith and Fulham "*a clear, shared care protocol has been agreed, outlining the referral route from a GP to a named neurologist for assessment and diagnosis, and then on to the community mental health teams for older people for ongoing support including a support group and social events for relatives. This provides a more consistent referral pathway for GPs to follow, and a more comprehensive response for individuals and their families*"**

**Department of Health, Good Practice Guide and examples : http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Healthcare/Longtermconditions/Bestpractice/Recognitionanddiagnosis/DH_4104901**

Similar issues were highlighted with regards to accessing immediate post-diagnostic support and care services. It was noted that this is a particular issue in localities where there is no specific service for younger people living with dementia. It has been observed that:

*"Accessing services can… be complicated. Which social services team will be responsible for ongoing care management – one that deals with mental health among working age adults or one that works with older people with dementia? Can a younger person with dementia attend a day facility for older people?"*[77]

This is particularly problematic when it is considered that there can be issues "*around the age limits traditionally set by geriatric psychiatry or other 'elderly services' that have traditionally provided services to people with dementia*".[78]

Similar concerns were expressed in the report *Serving the needs of marginalised groups in dementia care: younger people and minority ethnic groups* which suggested that among the carers of younger people living with dementia there is a concern that accessing services would have been easier if their relative had been over 65.[79]

An additional difficulty faced by many younger people living with dementia and their carers is "*a poor knowledge regarding care and services for younger people with dementia*".[80] This sentiment was echoed in the comments of one respondent from outside of the North East who noted that, as compared to the services for older people living with dementia, information about services for younger people living with dementia was much more limited and harder to access.

[77] Information from the Social Care Institute for excellence, Dementia Gateway: Young onset dementia available at http://www.scie.org.uk/publications/dementia/young/key.asp (Accessed 6 January 2013)
[78] Daker-White, G. Beattie, A. Means, R. and Gilliard, J. (2002) Serving the needs of marginalised groups in dementia care: younger people and minority ethnic groups [Online] Available at: http://www.dementia-voice.org.uk/Projects/summaryreport.pdf (Accessed 6 January 2013) p.5
[79] Ibid
[80] Daker-White, G. Beattie, A. Means, R. and Gilliard, J. (2002) Serving the needs of marginalised groups in dementia care: younger people and minority ethnic groups [Online] Available at: http://www.dementia-voice.org.uk/Projects/summaryreport.pdf (Accessed 6 January 2013) p.11

**Young Dementia UK supports younger people living with dementia to engage in activities that they value. This ranges from "*long walks to rounds of golf, organising personal paperwork to a visit to the museum*"**

**See: www.youngdementiauk.org**

### 4.3.3 The type of support and care provided

The research indicated that the types of support and care valued by younger people living with dementia may be different from that wanted by older people living with dementia.

#### Age appropriate activities

The activities valued by younger people living with dementia can be different from the activities appropriate for older people living with dementia. As explained by one respondent "*young people living with dementia often have very different expectations of how to fill their day when compared to older people with dementia*".

During the research the greater levels of physical ability and energy possessed by younger people living with dementia, as compared to older people living with dementia, was a crucial factor that individuals felt needed to be reflected in the activities that younger people living with dementia were supported to engage with.

As the majority of people living with dementia are older than 65, mainstream support services for people living with dementia are often targeted at older people and are designed to be appropriate for people with more limited physical abilities. It was explained by a respondent that the provision of support to engage in physical activities is not only valued by many younger people living with dementia but may also have secondary benefits through the reduction of physical and psychological effects of a person's dementia. Examples of activities valued by younger people living with dementia included gardening groups, walking groups and kayaking. Further examples were also provided in the report *Serving the needs of marginalised groups in dementia care: younger people and minority ethnic groups* which stated that "*purposeful activities that matched their level of fitness and capabilities*" included "*the ability to walk, go to the pub, go shopping, gardening, woodwork, art work and sculpting*".[81]

The research also highlighted the need to consider the age appropriateness of activities that are not dependent on physical ability. This point was explained by a respondent who noted that while activities such as singing groups can provide a useful means of empowering people and building on existing skills the songs chosen must be age appropriate and gave the example that "*people in their forties are more likely to want to sing Queen songs than the White Cliffs of Dover*".

[81] Daker-White, G. Beattie, A. Means, R. and Gilliard, J. (2002) Serving the needs of marginalised groups in dementia care: younger people and minority ethnic groups [Online] Available at: http://www.dementia-voice.org.uk/Projects/summaryreport.pdf (Accessed 6 January 2013) p.9

## Support for carers and family members

As young-onset dementia affects people earlier in their life the person's responsibilities and relationships may differ from those of older people living with dementia. According to the Alzheimer's Society younger people living with dementia, are more likely to:

- Have a partner who still works
- Have dependent children
- Have ageing parents who they need to care for[82]

It was suggested by one respondent that these differences mean that the burden faced by the family carers of younger people living with dementia is substantially different from the challenges facing carers for older people living with dementia.

Respondents explained how carers can lose a lot of ambition in the early days of a loved one being diagnosed with young-onset dementia. The respondent, themselves a carer for a younger person living with dementia, explained that carers can often feel that their hopes for the future will not be realised and also recounted experiences of their social networks ebbing away as friends stopped inviting the individual living with dementia to social events. The respondent felt that this was due to a stigma or misconception about dementia. As one carer stated during the research "*you quickly lose friends. It's unexpected that someone will have dementia at that age, people are frightened and you don't get invited out to things anymore*".

Social contact is further limited by the fact that younger carers will often have to face the dual burden of caring for the person living with dementia while still being in employment. Carers can feel further social isolation as the individual who has developed dementia will eventually lose the ability to drive which can put extra pressure on the carer. This is particularly true where the individual living with dementia was the sole driver in the household and where the carer and person living with dementia are responsible for dependent children or aging parents in need of support.

The difficulties faced by carers led a number of respondents to stress the importance of making sure that there were specialist services for the carers of younger people living with dementia such as a carer drop-in centres that can provide support and information.

In relation to the provision of support for carers and family members it has been observed that:

> *"The kind of information and support that is required will depend on the age of the family member and their relationship to the person diagnosed. For example, the person's spouse will probably want to know what to expect and how best to cope. They may want to meet with other people in a similar position for support. Younger family members (say children or grandchildren) might appreciate a*

[82] Information from the Alzheimer's Society Website. Available at: http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=543 (Accessed 6 January 2013)

*book called It's me Grandma! It's me, by Eileen Mitchell, which explains what dementia is in terms that a 7–11 year old can understand."*[83]

### Financial and other practical support

Younger people living with dementia and their carers are more likely than older people living with dementia to:

- Have mortgage commitments
- Have dependent children to support
- Have a family carer who is in full time work
- Be made redundant
- Have their pensions affected as a result of developing dementia[84]

In order to support people with dementia to tackle these financial and legal issues the charity Young Dementia in Oxfordshire have done work to help people access solicitors or other advisors in order to improve access to information about benefits and other entitlements. The charity Young People with Dementia Berkshire West has developed a course for younger people with dementia and their carers which provides information about legal issues such as mortgage commitments, making wills and issues around power of attorney. The course also provides information about what other services are available and routes to accessing those services.

One respondent did however, note that providing information about benefits and legal matters can be difficult in larger geographical areas as the services and entitlements provided by each local authority can be slightly different and there is a need to make sure information is up-to-date and correct for every local authority.

A further issue that younger people living with dementia and their carers may need help with is in regards to being made redundant. It was suggested by one respondent that "*where it is possible to get in early it possible to help people get a medical retirement*" however it is was remarked that the law in this area is often poorly understood and it is important that younger people living with dementia and their carers are able to access accurate information at an early stage of a person's dementia.

### Addressing stigma and providing emotional support

The research revealed that a further issue facing younger people living with dementia is stigma. While stigma associated with dementia can affect people of all ages and from different groups the research suggested that among younger people living with dementia stigma can be a particular issue. This point was highlighted by the Social Care Institute of Excellence who noted that

*"Because dementia is so strongly associated with older people, younger people can feel extra stigma and discrimination. A younger person may not be believed*

[83] Information from the Social Care Institute for excellence, Dementia Gateway: Young onset dementia available at http://www.scie.org.uk/publications/dementia/young/services.asp

[84] Information from the Alzheimer's Society Website. Available at: http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=543 (Accessed 6 January 2013

*when they say they have been diagnosed with dementia. This attitude can add to a person's problems… Later, a younger person may feel and look out of place in a care home where most other people are in their 70s, 80s and 90s".*[85]

In order to address this it has been suggested by the Social Care Institute of Excellence that:

*"The person and their spouse may well need counselling or extra emotional support to cope with the diagnosis. Counselling is available on the NHS but a younger person with dementia would only be referred for this if they were showing signs of severe anxiety and/or depression, which they may well be. Some families may seek private counselling or perhaps more commonly turn to a charity like the Alzheimer's Society for emotional support…. There are a growing number of community-based services specifically for younger people with dementia, which provide emotional support".*[86]

## 4.4 What type of organisations are best placed to deliver support and care?

Respondents stressed that younger people living with dementia value specialist support and care services. It was noted that specialist services are valued not only because they provide support and care that is tailored towards the particular needs of younger people living with dementia and their carers but also because younger people living with dementia appreciate the opportunity to engage with people of their own age. The research highlighted that being diagnosed with dementia can be particularly difficult for younger people and this emotional burden can be made more challenging as a result of only being able to access services that are more commonly used by people a generation older than themselves. This point was emphasised in the report *Serving the needs of marginalised groups in dementia care: younger people and minority ethnic groups* which claimed that:

"*Age appeared to be a paramount concern for most of those interviewed. The majority of respondents commented that mixing with other young people with memory problems was a positive experience*"[87]

However, despite their benefit, specialist services can be difficult to access. Respondents suggested this difficulty results from:

- A shortage of specialist services
- The extra costs of providing specialist services

[85] Information from the Social Care Institute for excellence, Dementia Gateway: Young onset dementia available at http://www.scie.org.uk/publications/dementia/young/services.asp (Accessed 6 January 2013)
[86] Information from the Social Care Institute for excellence, Dementia Gateway: Young onset dementia available at http://www.scie.org.uk/publications/dementia/young/services.asp (Accessed 6 January 2013)
[87] Daker-White, G. Beattie, A. Means, R. and Gilliard, J. (2002) Serving the needs of marginalised groups in dementia care: younger people and minority ethnic groups [Online] Available at: http://www.dementia-voice.org.uk/Projects/summaryreport.pdf (Accessed 6 January 2013) p.9

- The limited recognition among local authorities that younger people living with dementia have specialist care and support needs making local authorities reluctant to pay for specialist services

In response to these issues a number of respondents highlighted the benefits of personal budgets that would allow younger people living with dementia to purchase support services that are appropriate to their needs and enable them to "*avoid having to use services that are targeted at older people".*

Respondents were divided over the issue of whether it was better to have regional specialists or whether it is more appropriate have smaller local services. While it was felt that regional services have the benefit of:

- Expertise
- Single point of access
- Being known to people

Conversely it was felt that regional services could be undesirable because they centralise specialist knowledge and prevent the up skilling of staff outside of that service. It was also suggested that in large rural communities the lack of a central base can be important as it encourages services to grow in a way that responds to the requirements of younger people living with dementia in that area.

The majority of respondents indicated that a compromise was most appropriate where regional specialists were complimented by 'patch workers' who could increase awareness about the needs of younger people living with dementia and encourage cross-learning among a range of service providers.

The issue of specialist services was addressed in the Royal College of Psychiatrists and Alzheimer's Society report *Services for younger people with Alzheimer's disease and other dementia* which recommended that localities should develop "*a specialist service for younger people with dementia… with a lead from a consultant in old age psychiatry*".[88]

In addition the research highlighted that *"because of the particular issues and risk factors facing younger people with dementia… younger people with dementia*

**The charity Young People with Dementia Berkshire West has worked in partnership with the NHS and pays for an occupational therapist to provide activities and services that would not normally be provided by the NHS. This includes walking, swimming and running a choir. These services are also designed to allow their carers respite and opportunity to socialise with other carers.**

[88] Royal College of Psychiatrists and Alzheimer's Society (2005) Services for younger people with Alzheimer's disease and other dementia [Online] Available at: http://www.rcpsych.ac.uk/files/pdfversion/cr135.pdf (Accessed 6 January 2013) p.18

*may need input from non-dementia specialist services such as generic counsellors and substance misuse services".*[89]

## 4.5 What services are available in the North East?

The Tees, Esk and Wear Valleys NHS Foundation Trust's Young Onset Dementia services provides diagnostic assessment, information, support and care co-ordination for people with dementia aged between 18-64 years old.

The Northumberland, Tyne and Wear NHS Foundation Trust provide support for people under 65 with dementia through integrated community mental health teams based in Newcastle and Sunderland.

The Alzheimer's Society in partnership with the Tees, Esk and Wear Valleys NHS Foundation Trust runs the Roaming Day Club for younger people with dementia. The club rotates between Middlesbrough, Stockton, Hartlepool and Redcar and Cleveland and provides peer support and age appropriate activities chosen by the service users.

A number of local dementia strategies for localities in the North East have addressed the issue of support and care for people living with young onset dementia.

In Middlesbrough the document *Mental Health Services for Older People in Middlesbrough: Implementation Plan 2009-2014* highlighted the work being done to achieve good quality early diagnosis and intervention for younger people living with dementia through the young onset dementia team. The document states *"the young onset dementia team provides an assessment, treatment and follow up service for people with early onset dementia. This is a multidisciplinary team, integrated with social care and working with the Alzheimer's Society".*[90]

As part of its commitment to ensuring good quality intervention and diagnosis *the National Dementia Strategy Implementation Action Plan for Stockton-on-Tees* highlights that "*the Young Onset Dementia Service provides timely and specialist assessment and diagnosis, information, support and care-co-ordination".*[91]

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[89] Information from the Social Care Institute for excellence, Dementia Gateway: Young onset dementia available at http://www.scie.org.uk/publications/dementia/young/services.asp (Accessed 6 January 2013)

[90] Available at: http://www.phine.org.uk/securefiles/130113_1733//Mental%20Health%20Services%20for%20Older%20People%20in%20Middlesbrough[1].pdf (Accessed 6 January 2013)

[91] Available at: http://www.phine.org.uk/securefiles/130113_1732//National%20Dementia%20Strategy%20Implementation%20Plan%20Stockton%202011[1].pdf (Accessed 6 January 2013)

## 4.6 Recommendations

### Improving the diagnostic process

- Increase awareness and understanding of young onset dementia among GPs
- Ensure clear diagnostic pathways are developed in all the localities in the North East in order to minimise uncertainty about who is responsible for diagnosis and reduce unnecessary delays in the diagnostic process for younger people living with dementia

### Improving access to care and support services

- Develop a clear care pathway that outlines responsibility for on-going care and support
- Improve information about the services available to younger people living with dementia

### Provide support that meets the specific needs of younger people living with dementia by:

- Promoting the further development of services specifically for younger people living with dementia that include age appropriate activities to build on the services already provided in some areas of the North East
- Developing support services for the carers and families of younger people living with dementia
- Providing information for younger people living with dementia and their carers on financial, legal and employment issues (this could be through a dedicated advisor or education courses for younger people living with dementia and their carers)
- Promoting the development of community services that can provide emotional support and or counselling to younger people living with dementia and their carers and family
- Promoting the development of care homes for younger people living with dementia or other bespoke environments that avoid reliance on services aimed at older populations living with dementia
- Promoting good inter-service working with non-dementia specialist services including genetic counselling and substance misuse services in order to provide the full range of support which is valuable to younger people living with dementia

# 5. Lesbian, gay and bisexual communities and transgender communities

## Section summary

- This section of the report outlines issues relevant to the support and care of people living with dementia from lesbian, gay and bisexual (LGB) communities and transgender (T) communities
- The research highlighted the fact that previous experiences of discrimination can make people living with dementia from LGBT communities reluctant to disclose their sexual orientation or gender identity and can sometimes make people avoid using formal care and support services
- In order to provide care and support appropriate for people living with dementia from LGBT communities it is necessary that service providers:
    - Recognise that people from LGBT communities are using support and care services
    - Make it outwardly clear that services respect and work to accommodate the needs of people living with dementia from LGBT communities
    - Develop appropriate policies and procedures to prevent discrimination and protect confidentiality
    - Ensure all staff providing support and care are appropriately trained
    - Recognise the family and other social relationships of people from LGBT communities
    - Ensure that services are informed by people from LGBT communities
- The research suggested that people from LGBT communities emphasised the importance of ensuring mainstream services are appropriate as opposed to the development of specialist services
- LGBT community groups were highlighted as important sources of advice, advocacy and peer support

### 5.1 Introduction

This section of the report addresses issues relating to the support and care of people living with dementia from lesbian, gay and bisexual (LGB) communities and transgender (T) communities.

This report does not seek to overlook the differences between LGB and T communities. As highlighted in the report *Issues facing Older Lesbian, Gay Men and Bisexuals* "*sexuality and gender identity are distinct and… each faces its own set of legal and social issues*". [92] These two communities have however been included together in this section as a number of documents analysed during the literature review addressed issues relating to the support and care of both communities. In addition, a number of community groups approached during the research provided support to people from both LGB and T communities.

The importance of recognising the unique support and care needs of people living with dementia from LGBT communities has become more pressing. As explained by one respondent working for a community group supporting people from LGBT communities, the legal and attitudinal changes that have taken place during the last fifty years have led to more, though not all, people feeling comfortable discussing their sexual orientation or gender identity. The respondent stated that this has resulted in "*an aging 'out' population*" and an increased understanding of the need to provide appropriate support and care for people from LGBT communities. In addition it has also been noted that "*we are only now seeing the first generation of trans people who have taken hormone therapy for 30 years or more, and who are living with gender reassignment performed using the very different techniques of the 1960s and 1970s"*.[93]

The report *Dementia in Minority Communities in North East England* estimated that in 2012 there were between 540-756 people living with dementia who were lesbian, gay or bisexual and 5 people living with dementia who were transsexual. [94]

The literature review produced a relatively small amount of information relating to the support and care of people living with dementia from LGBT communities. Consequently the literature review was extended to include information relating to the support and care of older people from LGBT communities and literature regarding the provision of support and care to members of LGBT communities who have mental health support needs.

## 5.2 Policy context

This section of the report will outline the policy context that is specifically relevant to the support and care of people living with dementia from LGB and T communities. This policy context should be considered in conjunction with the policy context outlined in section 2 of this report.

In 2011 the Home Office set out the actions that the government will take in order to achieve its commitment to achieving equality for people from LGBT communities. These actions were set out in

[92] Age Concern (2002) Issues facing Older Lesbian, Gay Men and Bisexuals [Online] Available at: http://www.openingdoorslondon.org.uk/resources/Age_Concern_Issues_facing_older_LGB.pdf (Accessed 6 January 2013)

[93] Age UK (2011) Transgender issues in later life [Online] Available at: http://www.openingdoorslondon.org.uk/resources/AgeUK_Transgender_issues_in_later_life.pdf (Accessed 6 January 2013)

[94] Jackson, M (2012) Dementia in Minority Communities in North East England [Online] http://www.nepho.org.uk/uploads/doc/vid_16758_Dementia%20in%20Minority%20Communities%20in%20North%20East%20England%20Aug%202012.pdf (Accessed 6 January 2013) p.4

the document *Working for Lesbian, Gay, Bisexual and Transgender Equality: Moving Forward.*[95] To improve equality of access to health and social care services the document outlined the following actions:

- Work with the NHS to increase awareness of LGB&T health issues and how medical staff can work more sensitively with their LGB&T patients and their carers
- Develop a national network of LGB&T "champions"
- Support NHS providers to appropriately collect data on sexual orientation
- In partnership with LGB&T groups, ensure that evidence on LGB&T health issues is used to influence public health strategies and policies
- Consider what further action could be taken to support the health and social care needs of older LGB&T people
- Engage with transgender communities to identify specific health issues faced by this group
- Work with the Equality and Human rights Commission to analyse the current process for commissioning and service provision for gender identity services and identify best practice[96]

Since the Civil Partnership Act 2004[97] it is important for service providers to understand that "*same-sex couples in civil partnerships must be treated the same as married couples and any policies or practices should reflect this*".[98]

In 2011 the Home Office published *Advancing transgender Equality: A Plan for action.*[99] This document outlines the actions that the government will take to improve equality in a number of areas of public life including health and social care.

The Gender Recognition Act 2004[100] makes provisions for people to apply to the Gender Recognition Panel to receive a Gender Recognition Certificate which, if awarded, will certify that the person has legally changed their gender. The Gender Recognition Act makes it an offence for a person who, in an official capacity, has acquired information about a person's change of gender to disclose that information to another person without the consent of the person who has changed their gender.

## 5.3 Issues relevant to the provision of appropriate support and care

This section of the report outlines the particular support and care needs of people living with dementia from LGBT communities. Although many of the issues relevant to the support and care of

[95] H M Government (2011) Working for Lesbian, Gay, Bisexual and Transgender Equality: Moving Forward [Online] Available at: http://www.homeoffice.gov.uk/publications/equalities/lgbt-equality-publications/lgbt-action-plan?view=Binary (Accessed 6 January 2013)

[96] H M Government (2011) Working for Lesbian, Gay, Bisexual and Transgender Equality: Moving Forward [Online] Available at: http://www.homeoffice.gov.uk/publications/equalities/lgbt-equality-publications/lgbt-action-plan?view=Binary (Accessed 6 January 2013) p.7

[97] Great Britain. Civil Partnership Act: Elizabeth II. Chapter 33 (2004) London: The Stationery Office

[98] Taylor, J. (2012) Working with older lesbian, gay and bisexual people: A Guide for Care and Support Services [Online] Available at: http://www.stonewall.org.uk/documents/older_people_final_lo_res.pdf (Accessed 6 January 2013) p.4

[99] H M Government (2011) Advancing transgender Equality: A Plan for action [Online] Available at: http://www.homeoffice.gov.uk/publications/equalities/lgbt-equality-publications/transgender-action-plan?view=Binary (Accessed 6 January 2012)

[100] Great Britain. Gender Recognition Act: Elizabeth II. Chapter 7 (2004) London: The Stationery Office

people from LGBT communities are the same as other communities, this report will focus on support and care needs that are specific to people from LGBT communities or support and care needs that may pose particular challenges in the context of people living with dementia from LGBT communities.

### 5.3.1 Experiences of discrimination

Research has shown that many members of LGBT communities have reported direct or indirect discrimination while using support services. The report *Not Safe for Us Yet* found that 41% of respondents from LGB communities using mental health services had:

> "*Reported being subjected to homophobic remarks from professionals and discriminatory behaviour, with a slightly smaller percentage noting mockery and verbal abuse and disclosure of sexual orientation without permission*"[101]

In addition:

> *"60% had witnessed other service users talking negatively about LGB people in general, and 45% had witnessed discriminatory or negative behaviour towards another. 77% reported experiencing discriminatory behaviour, 66% verbal abuse and 44% violence from other service users on account of their sexual orientation."*[102]

A theme highlighted throughout the research was the manner in which previous experiences of discrimination, such as those outlined above, have led some members of LGBT communities to be cautious about engaging with formal support and care services or reluctant to disclose their sexuality or gender identity to the staff of care and support services.[103] Moreover, experiences of discrimination or an inability to be open about their sexuality or gender identity has been linked to greater levels of social isolation among some members of LGBT communities.[104]

The research suggested that the fear of discrimination, resulting from previous negative experiences may be a particular issue where social care is provided in a person's home. It has been noted that *"having a stranger come into their home may impact on older gay people's ability to be*

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[101] Wintrip, S. (2009) Not safe for us yet: The experiences and views of older lesbians, gay men and bisexuals using mental health services in London [Online] Available at: http://www.openingdoorslondon.org.uk/resources/Not%20safe%20for%20us%20yet.pdf (Accessed 6 January 2013) p.5

[102] Ibid

[103] Musingarimi, P. (2008) Social Care Issues Affecting Older Gay, Lesbian and Bisexual People in the UK: A Policy Brief. London: International Longevity Centre – UK

[104] Ibid p.6.

*themselves"*[105] and may "*lead many older LGB people to avoid seeking access to social care services which might improve their quality of life*".[106]

### 5.3.2 Recognising that people from LGB communities are using support and care services

In relation to people from LGB communities, an issue frequently highlighted during the research was the assumption of heterosexuality among service providers.[107] This issue was described by one respondent as "*hitting the heterosexual barrier*". The respondent explained that the failure of service providers to consider whether people using their service are lesbian, gay or bisexual has meant that issues relevant to the support and care of people form LGB communities were often marginalised.

Although a person's identity as lesbian, gay or bisexual cannot be reduced to their sexuality, the research did indicated that the tendency of service providers to neglect the role that sexuality plays in the identity, lifestyle and corresponding care and support needs of all older people is one factor that contributes to the failure of service providers to recognise that people from LGB communities are using their services.

It has been noted that:

> "*one of the biggest single barriers to good practice in care for older people in general – not just care for lesbian, gay or bisexual people – is the prevalent ageist assumption that older people are no longer sexual beings…sexuality and intimate relationships are topics that are often avoided or disregarded. It is not uncommon for sexual needs never to be mentioned in a care plan apart from where they are perceived as problematic; and very rarely is sexuality presented as a positive aspect of a person's* individuality".[108]

In the report *The Whole of me… Meeting the needs of older lesbians, gay men and bisexuals living in care homes and extra care housing* it was suggested that the reluctance of service providers to consider a service user's sexuality can result from *"the attitude that someone's sexual orientation is a private matter"*[109]. The report goes on to highlight that *"our own anxieties about asking personal*

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[105] Taylor, J. (2012) Working with older lesbian, gay and bisexual people: A Guide for Care and Support Services [Online] Available at: http://www.stonewall.org.uk/documents/older_people_final_lo_res.pdf (Accessed 6 January 2013)

[106] Musingarimi, P. (2008) Social Care Issues Affecting Older Gay, Lesbian and Bisexual People in the UK: A Policy Brief. London: International Longevity Centre – UK

[107] While this issue was only highlighted in relation to LGB communities it may be possible that it also relates to people from T communities

[108] Knocker, S. (2006) The whole of me: Meeting the needs of older lesbians, gay men and bisexuals living in care homes and extra care housing. England: Age Concern p. 19

[109] Ibid

*questions can also sometimes prevent professionals from finding out whether someone identifies as lesbian or gay"*[110].

While the marginalisation of older people's sexuality is an issue that can apply to all older service users it was indicated during the research that given the cultural biases and assumption of heterosexuality, an inability to discuss issues relating to sexuality can disproportionately affect older people who are lesbian, gay and bisexual as it can reinforce the prevalent assumptions of heterosexuality.

Failing to consider the sexual orientation of service users can lead service providers to marginalise the needs of people from LGB communities and reduces the impetus of service providers to make their services more appropriate for people from LGB communities. This may in turn increase the concerns people from LGB communities have about using formal support services or disclosing their sexuality to the service and thereby reinforcing the default assumption of heterosexuality prevalent among some service providers.

As well as taking steps to make it easier for people to be open about their sexuality it has been suggested that it would be helpful for service providers to monitor the sexuality and gender identity of people using their services in order to make services more aware that people from LGB communities are using their services.[111] As one respondent commented "*are they monitoring sexual orientation? Without data sets how can we convince the services*?"[112]

It should be noted however that monitoring the sexual orientation of service users can only be effective where steps are taken to:

- Create an environment in which people feel open about their sexual orientation
- Staff are appropriately trained to handle such matters in a suitably sensitive manner[113]
- Guarantee confidentiality for service users

### 5.3.3 Creating an environment in which people can be open about their sexual orientation or gender identity and ensuring that services provide support and care appropriate for people living with dementia from LGBT communities

It is essential that support and care services are person centred and respond to the particular needs of the individual using those services. Achieving this aim may however be problematic in the context of LGBT communities who may feel an inability to disclose their sexual orientation or gender identity

[110] Ibid

[111] Opening Doors London (2010) Lesbian, Gay, Bisexual and Transgender people: A checklist for social care providers. London: Camden Age UK and Opening Doors London. p. 2

[112] For further guidance see the Stonewall Workplace guide: Cowan, K. (2006) Monitoring: How to monitor sexual orientation in the workplace. London: Stonewall

[113] Opening Doors London (2010) Lesbian, Gay, Bisexual and Transgender people: A checklist for social care providers. London: Camden Age UK and Opening Doors London.

and related support and care needs. It is therefore important that service providers create an environment in which people can be open about their sexual orientation and gender identity.

Conversely however, it may be that people from LGBT communities will not feel comfortable being open about their sexual orientation and gender identity unless they observe that a service provider is meeting the support and care needs of people from LGBT communities.

Consequently the need to create an environment in which people are able to be open about their sexual orientation or gender identity is inter-twined with the aim of ensuring that support and care services respond to the needs of people living with dementia from LGBT communities who are using those services. This section of the report will outline a number of factors that service providers need to address in order to ensure that their services meet the needs of people living with dementia from LGBT communities. These factors are:

- Making it clear that services respect and work to accommodate the needs of people living with dementia from LGBT communities
- Developing appropriate policies, procedures and practices to prevent discrimination and protect confidentiality
- Ensuring that front-line staff are trained to provide appropriate support and care for people from LGBT communities
- Recognising and involving the family and other relationships of people from LGBT communities
- Ensuring service users are able to shape the care and support they receive (or where appropriate liaising with LGBT groups who may be able to advise)

### Making it clear that services respect and work to accommodate the needs of people living with dementia from LGBT communities

Research has suggested that making it clear to service users and potential service users that support and care is provided in a respectful and non-discriminatory manner is an important factor in making service users feel more comfortable about being open about their sexual orientation or gender identity.[114]

In order to achieve this aim it was been recommended that service providers:

- *"Use LGBT media… to let LGBT communities know you are friendly"*[115]
- *"Include lesbian, gay and bisexual people in… promotional literature and information packs"*[116]

[114] Wintrip, S. (2009) Not safe for us yet: The experiences and views of older lesbians, gay men and bisexuals using mental health services in London [Online] Available at: http://www.openingdoorslondon.org.uk/resources/Not%20safe%20for%20us%20yet.pdf (Accessed 6 January 2013) suggests that 41 % of respondents believed that if there was greater LGB visibility in publicity material they would feel more comfortable disclosing their sexual orientation.

[115] Opening Doors London (2010) Lesbian, Gay, Bisexual and Transgender people: A checklist for social care providers. London: Camden Age UK and Opening Doors London. p.3

- Review the language used in publicity materials so that it is inclusive[117]
- *"Include LGBT reading matter in [the] reception area, centre or homes"*[118]
- *"Advise the organisation to 'come out' first e.g. publish the anonymised diversity data of the staff group"*[119]
- *"Allow transgender people access to appropriate single-sex facilities which are in-line with their gender identity"*[120]

**Developing appropriate policies and procedures to prevent discrimination and protect confidentiality**

The research indicated that in order to meet the needs of people living with dementia from LGBT communities and create an environment in which they feel able to be open about their sexuality and gender identity, it is vital that service providers develop clear and effective policies to prevent discrimination and to ensure confidentiality.[121]

In relation to anti-discrimination policies it has been recommended that service providers possess clear "*policies which set out how you handle discrimination and anti-gay bullying*"[122] and "*residents know about any codes of conduct that include sexual orientation, discrimination and can complain if necessary*".[123]

In addition it is essential that in order to prevent discrimination service providers need to ensure "*all policies or working practices about relationships need to apply to same sex relationships*"[124] in the same manner as heterosexual relationships.

Policies regarding confidentiality should also take into account the privacy of transgender people which has been protected by section 22 of the Gender Recognition Act 2004 which makes "*it a*

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[116] Taylor, J. (2012) Working with older lesbian, gay and bisexual people: A Guide for Care and Support Services [Online] Available at: http://www.stonewall.org.uk/documents/older_people_final_lo_res.pdf (Accessed 6 January 2013) p.12

[117] Information taken from the Alzheimer's Society website available at : http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1100 (Accessed 6 January 2013)

[118] Opening Doors London (2010) Lesbian, Gay, Bisexual and Transgender people: A checklist for social care providers. London: Camden Age UK and Opening Doors London. p.2

[119] Ibid p.3

[120] Ibid p.7

[121] Information taken from the Alzheimer's Society website available at : http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1100 (Accessed 6 January 2013)

[122] Taylor, J. (2012) Working with older lesbian, gay and bisexual people: A Guide for Care and Support Services [Online] Available at: http://www.stonewall.org.uk/documents/older_people_final_lo_res.pdf (Accessed 6 January 2013) p.12

[123] Ibid

[124] Opening Doors London (2010) Lesbian, Gay, Bisexual and Transgender people: A checklist for social care providers. London: Camden Age UK and Opening Doors London. p.3

*criminal offence with a fine of up to £5000 for any individual who has obtained the information in an official capacity to disclose that a person has a Gender Recognition Certificate*".[125]

Despite the importance of developing policies to prevent discrimination and preserve confidentiality, it was noted by one respondent that "*it is not just about following the policies and procedures but the LGBT friendly attitude needs to be engrained into the environment and the way people behave*".

### Appropriately trained staff

A theme repeatedly highlighted in the research is the need to ensure that staff providing services to people from LGBT communities are suitably trained and possess an appropriate attitude and approach when providing support and care.

The importance of this was emphasised in the report *Not Safe for us Yet* which commented that "*over a third of respondents felt that the behaviour of mental health professionals towards them on account of their sexual orientation had made their problems worse".*[126]

Despite the importance of good practice by staff it has been noted that there are inconsistencies both between and within care and support services.[127]

In order to promote good practice among care and support staff the report *Lesbian, Gay, Bisexual and Transgender people: A checklist for social care providers* has suggested that there needs to be strong and consistent messages from the management of support and care services. The report also recommended that the recruitment process for care and support staff "*must include an assessment of the attitudes of potential staff around equality issues including LGBT people*".[128]

While it is has been observed that not everyone will want to discuss their sexual orientation[129] it has been noted that staff can play an important role in facilitating an environment that allows someone to feel able to disclose their sexual orientation if they so choose. The report *Working with older lesbian, gay and bisexual people: A Guide for Care and Support Services* advises care and support staff to:

- Avoid assuming that people you care for are heterosexual

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[125] Age UK (2011) Transgender issues in later life [Online] Available at: http://www.openingdoorslondon.org.uk/resources/AgeUK_Transgender_issues_in_later_life.pdf (Accessed 6 January 2013)

[126] Wintrip, S. (2009) Not safe for us yet: The experiences and views of older lesbians, gay men and bisexuals using mental health services in London [Online] Available at: http://www.openingdoorslondon.org.uk/resources/Not%20safe%20for%20us%20yet.pdf (Accessed 6 January 2013

[127] Musingarimi, P. (2008) Social Care Issues Affecting Older Gay, Lesbian and Bisexual People in the UK: A Policy Brief. London: International Longevity Centre – UK

[128] Wintrip, S. (2009) Not safe for us yet: The experiences and views of older lesbians, gay men and bisexuals using mental health services in London [Online] Available at: http://www.openingdoorslondon.org.uk/resources/Not%20safe%20for%20us%20yet.pdf (Accessed 6 January 2013

[129] Knocker, S. (2012) Perspectives on ageing: lesbians, gay men and bisexuals. York: Joseph Rowntree Foundation

- Ask people open questions about their life and who is important to them
- In everyday conversation talk about gay people or issues in a non-judgemental way
- Don't force people to talk about their sexual orientation if they don't want to
- Ask older gay people you care for how you can help, for example, by putting them in touch with a local gay group[130]

It has also been noted that "*not all older people may feel comfortable with the phrases lesbian, gay or bisexual*" and it is therefore recommended that staff employ the terminology favoured by the service user.[131]

In relation to the support and care of people from transgender communities the report *Lesbian, Gay, Bisexual and Transgender people: A checklist for social care providers* has advised that support and care staff be aware that:

> "*transgender people may have specific personal care needs and handle these sensitively. For example trans women who have transitioned later in life may still need to shave regularly. Trans people who have personal care needs require support from workers who understand that their body may not match their gender identity*".[132]

Furthermore, the report emphasises that "*transgender people should be recognised as (and treated according to) the gender they have spent their lives expressing*".[133]

A further factor highlighted as being important for ensuring that services are delivered by appropriate staff is the need to offer people living with dementia from LGBT communities the opportunity to control which front-line staff they receive care and support from. As noted in the report *Lesbian, Gay, Bisexual and Transgender people: A checklist for social care providers "it is important to listen when people want to change staff, homophobic attitudes can be very pervasive, but hard for a service user to make a specific complaint about*".[134]

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[130] Taylor, J. (2012) Working with older lesbian, gay and bisexual people: A Guide for Care and Support Services [Online] Available at: http://www.stonewall.org.uk/documents/older_people_final_lo_res.pdf (Accessed 6 January 2013) p.9

[131] Information taken from the Alzheimer's Society website available at : http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1100 (Accessed 6 January 2013)

[132] Taylor, J. (2012) Working with older lesbian, gay and bisexual people: A Guide for Care and Support Services [Online] Available at: http://www.stonewall.org.uk/documents/older_people_final_lo_res.pdf (Accessed 6 January 2013) pp 7-8

[133] Ibid

[134] Opening Doors London (2010) Lesbian, Gay, Bisexual and Transgender people: A checklist for social care providers. London: Camden Age UK and Opening Doors London. p.5

## Recognising the family and other social relationships of people from lesbian, gay and bisexual communities

A further issue highlighted in the research was the importance of ensuring service providers "*don't assume that just because someone has never been married they have never had an intimate partnership*".[135]

Research into the family and social relationships held by older people from LGB communities has suggested that:

- Gay and bisexual older men are three times more likely to be single than heterosexual men
- 41 per cent of lesbian, gay and bisexual older people live alone compared to 28 per cent of heterosexual older people
- Lesbian, gay and bisexual older people are less likely to have children and less likely to see biological family members on a regular basis – just a quarter of men and half of women see their children compared to nine in ten heterosexual men and women[136]

People from LGBT communities do however often possess "*networks made up of partners and friends who act as family".*[137] These networks are sometimes referred to as 'families of choice'.

It has however been observed that the assumptions of service providers or experiences of discrimination and victimisation may make some older LGB people uncomfortable about informing service providers about the important role they play in their lives. The consequences of this were highlighted in the report *Social Care Issues Affecting Older Gay, Lesbian and Bisexual People in the UK* which commented that "*by not consulting 'families of choice' in the care plans of an older LGB person, this may impact on the quality of care that individual receives*". [138]

Consequently it is essential that service providers take steps to ensure that people living with dementia from LGB communities feel safe using their services and implement measures that promote the inclusion of families of choice to the same extent as other forms of family.

In addition it has been recommended that service providers "*ensure people are given an opportunity to nominate their next of kin and that this can include friends as well as partners or family*"[139] and

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[135] Information taken from the Alzheimer's Society website available at : http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1100 (Accessed 6 January 2013)

[136] Taylor, J. (2012) Working with older lesbian, gay and bisexual people: A Guide for Care and Support Services [Online] Available at: http://www.stonewall.org.uk/documents/older_people_final_lo_res.pdf (Accessed 6 January 2013) pp 2-3

[137] Musingarimi, P. (2008) Social Care Issues Affecting Older Gay, Lesbian and Bisexual People in the UK: A Policy Brief. London: International Longevity Centre – UK

[138] Musingarimi, P. (2008) Social Care Issues Affecting Older Gay, Lesbian and Bisexual People in the UK: A Policy Brief. London: International Longevity Centre – UK. p.4

[139] Opening Doors London (2010) Lesbian, Gay, Bisexual and Transgender people: A checklist for social care providers. London: Camden Age UK and Opening Doors London.p.3

**Anchor Housing have established a Lesbian, Gay, Bisexual and Trans tenant group which helps to inform the work of the organisation and make their services more appropriate for people from Lesbian, Gay, Bisexual and Trans communities**

"*make same-sex partners feel welcome by allowing private time for couples and the sharing of rooms*".[140]

**Ensuring that services responds to the needs of people from LGBT communities**

The importance of ensuring that support and care services are person centred and built around a person's values and needs is a theme relevant to the provision of social care to all individuals and consequently it is vital that **"***all service providers… regularly involve older gay people in decisions about how their services are run*".[141]

In the context of people living with dementia from LGBT communities there may be particular barriers due to the fact that service users may not feel comfortable talking about care and support needs that relate to their sexual orientation or gender identity.

As well as addressing the factors that may make people reluctant to discuss support and care needs related to their gender identity or sexual orientation, it has been suggested that service providers could work with members of LGBT communities in order to inform the manner in which they provide support and care services.

One respondent suggested that services and service users would benefit from establishing strong links between LGBT community groups that could advise on how services can be delivered in a manner more appropriate for people from LGBT communities. It has also been suggested that service providers could appoint a dedicated liaison officer from their staff who could work to build trust between LGBT community and support and care services and work to address issues regarding the service provision.[142] In addition it has been recommended that service providers "*appoint an LGBT champion on* [their] *boards and advisory or user groups*".[143]

## 5.4 What type of organisations are best placed to deliver support and care?

The research appeared to emphasise the importance of ensuring that mainstream care and support services are delivered in a manner and environment appropriate for people from LGBT communities as opposed to developing specialist services for people from LGBT communities.

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[140] Taylor, J. (2012) Working with older lesbian, gay and bisexual people: A Guide for Care and Support Services [Online] Available at: http://www.stonewall.org.uk/documents/older_people_final_lo_res.pdf (Accessed 6 January 2013)

[141] Taylor, J. (2012) Working with older lesbian, gay and bisexual people: A Guide for Care and Support Services [Online] Available at: http://www.stonewall.org.uk/documents/older_people_final_lo_res.pdf (Accessed 6 January 2013)

[142] Opening Doors London (2010) Lesbian, Gay, Bisexual and Transgender people: A checklist for social care providers. London: Camden Age UK and Opening Doors London.p.2

[143] Ibid p.7

A number of sources consulted during the research highlighted the importance of personal budgets that would enable people from LGBT communities to use the services they felt were most appropriate. [144]

The role of community and voluntary organisations for people from LGBT communities were also highlighted as being important sources of support, information and advice for people living with dementia from those communities.[145] There was no suggestion in the research that dementia specific community groups were valued.

It was also suggested that the voluntary and community sector could provide an important role in informing the work of service providers, commissioners and policy makers.

One respondent suggested that by providing advocacy services for people living with dementia from LGBT communities and educating people on their rights while at the same time informing services and policy makes, LGBT community groups can play an important role in improving the appropriateness of care and support services provided to people living with dementia from LGBT communities.

## 5.5 What services are available in the North East?

The research suggested that people living with dementia from LGBT communities put a greater emphasis on ensuring that mainstream support and care services were delivered in an appropriate manner rather than wanting specialist services specifically for people from LGBT communities. It is beyond the scope of this research to review the extent to which all mainstream care and support services in the North East meet the needs of people from LGBT communities. It is therefore not possible to outline which mainstream support services in the North East are suitable for people living with dementia from LGBT communities.

The research highlighted a number of community groups in the North East that provide peer support and advice to people from LGBT communities. These were not specific to people living with dementia. These groups included Gay Advice Darlington and MESMAC North East. There are also a number of community groups specifically for people from LGBT communities who are over 50. These included:

- 'Tea with Dorothy' a social group for people from LGBT communities who are over fifty. These groups operate in Newcastle, Sunderland and North Tyneside

[144] Age UK (2011) Transgender issues in later life [Online] Available at: http://www.openingdoorslondon.org.uk/resources/AgeUK_Transgender_issues_in_later_life.pdf (Accessed 6 January 2013)

[145] Wintrip, S. (2009) Not safe for us yet: The experiences and views of older lesbians, gay men and bisexuals using mental health services in London [Online] Available at: http://www.openingdoorslondon.org.uk/resources/Not%20safe%20for%20us%20yet.pdf (Accessed 6 January 2013)

- Age UK County Durham run the EngAge 50+ LGBT group which "*meets monthly to socialise, discuss current issues and help to inform the development of local services and policies that impact on their lives*"[146]

None of the dementia action plans for the localities within the North East explicitly addressed the support and care of people living with dementia from LGBT communities. Each of the action plans do however make reference to 'minority communities' and it is possible that this includes people from LGBT communities.

## 5.6 Recommendations

### Increasing recognition that people from LGB communities are using support and care services

- Encourage local authorities or service providers to consider how they could monitor the sexual orientation of people living with dementia using support and care services
- Support local authorities or service providers to develop the necessary conditions to implement a monitoring procedure, namely:
    - A safe environment in which people feel able to be open about their sexual orientation
    - Staff are appropriately trained to handle such matters in a suitably sensitive manner
    - Guarantee confidentiality for service users
- Support service providers to better understand sexuality as an aspect of person's identity and train staff to engage in conversation about the subject in an appropriate manner

### Making it clear that support and care services respect and work to accommodate the needs of people living with dementia from LGBT communities

Encourage support and care providers to:

- Ensure that same-sex and transgender people are included in service promotional material and that all such materials employ inclusive language
- Use local media (particularly LGBT media) to highlight that the service is suitable for people from LGBT communities
- Provide LGBT orientated image and reading materials in public areas of the service

[146] Information taken from the MESMAC website: http://www.mesmacnortheast.com/lgbt-groups/older-people/ (Accessed 6 January 2013)

## Ensuring support and care services have appropriate policies and procedures to prevent discrimination and protect confidentiality

Encourage support and care providers to:

- Develop clear policies on discrimination, victimisation and confidentiality that relate explicitly to the needs of people from LGBT communities
- Ensure that the policies are clearly displayed or easily accessible and ensure staff and service users are aware of the content of the policies
- Ensure that service users are aware of how to make a complaint if they feel they have been the victim of discrimination, victimisation or a breach of confidentiality

## Ensuring that the staff from support and care services have appropriate knowledge and skills

Encourage support and care providers to:

- Train staff to avoid assuming people are heterosexual and encourage the use of open, non-judgemental language when discussing relationships and sexuality
- Don't force people to discuss their sexual orientation or gender identity if they do not wish to do so
- Include attitude to equality and diversity in the recruitment process
- Ensure staff are aware of the law surrounding equality and diversity and how this relates to their support and care of people living with dementia from LGBT communities
- Ensure that managers deliver strong consistent messages with regards to the support and care of people from LGBT communities
- Ensure that service users have the opportunity to determine which members of staff they work with
- Ensure staff are have an understanding of how to sensitively meet the needs of transgender people living with dementia

## Ensure support and care services recognise and involve the families of people from LGBT communities and their other social networks

- Ensure people are given an opportunity to nominate a next of kin who can be family or friend
- Include same-sex partners in planning a person's care (where it is the wish of the service user)

## Ensure that support and care servicers respond to the needs of people LGBT communities

- Allow service users from the LGBT community to inform their care and support so that it is person centred and responds to their needs as an individual
- Establish an LGBT user group to provide feedback on the service received

- Work with local community groups for people from LGBT communities to inform the work of service providers and help them develop more responsive and appropriate services
- Encourage organisations to establish a liaison officer who can build trust between the service provider and the LGBT community and address potential issues arising out of the care and support provided
- Support people living with dementia from LGBT communities to access LGBT community groups for information about their rights and peer support
- Involve community groups for people from LGBT communities in regional policy making and commissioning bodies

# 6. People with learning disabilities and dementia

## Section summary

- This section of the report outlines issues relevant to the support and care of people living with dementia and learning disabilities
- Issues highlighted as being relevant to the support and care of people with learning disabilities and dementia include:
    - Issues around diagnosis including:
        - The difficulty of recognising the early symptoms of dementia among people with learning disabilities
        - The specialist assessment process often required to deliver a diagnosis
        - The manner in which post-diagnostic information and support is delivered
    - Issues relevant to the provision of on-going support and care for people with learning disabilities and dementia. These issues include:
        - The effect of a person's dementia on people around them including other service users
        - Issues around the physical design of support and care services
        - Staff training to develop appropriate knowledge and skills
- The research suggested that it is preferable to support a person with learning disabilities to remain in their existing environment following a diagnosis of dementia

## 6.1 Introduction

This section of the report outlines issues relevant to the support and care of people living with dementia and learning disabilities.

People with learning disabilities are at a greater risk of developing dementia as compared to people who do not have a learning disability.[147] Among people living with a learning disability those with

[147] Information from the Alzheimer's Society factsheet *Learning Disabilities and dementia.* Available at: Information from the Social Care Institute for excellence, Dementia Gateway: Learning Disabilities available at

Down's Syndrome are at particular risk of developing dementia.[148] People living with learning disabilities are also at increased risk of developing dementia at a younger age[149] with research suggesting that one in three people with Down's Syndrome develop dementia in their fifties.[150] As a result of these trends and the increased life expectancy of people with learning disabilities there is now a growing number of people living with learning disabilities and dementia.[151]

Drawing on existing evidence the report *Dementia: A North East Perspective* suggests that in 2010 there were 88 people in the North East with Down's Syndrome and dementia.[152]

## 6.2 Policy context

In 2001 the Government published the white paper *Valuing People: A new strategy for learning disabilities for the 21st century*[153]. The paper sets out what the Government aimed to do in order to enable people with learning disabilities to *"live full and independent lives as part of their local communities".*[154] In particular the paper outlines a commitment to promoting the rights, independence, choice and inclusion of people with learning disabilities.

The paper recognises the specialist needs of people with learning disabilities who develop dementia and states the Government's desire for "*learning disability services to work with the specialist mental health services to ensure that, between them, appropriate supports are provided for younger people with learning disabilities suffering from dementia*".[155]

*Valuing People: A new strategy for learning disabilities for the 21st century* was updated in the document *Valuing People Now: a new three-year strategy for people with learning disabilities*[156] which set out the government's three year plan to improve the lives of people living with learning

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http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=103asp (Accessed 6 January 2013)

[148] Information from the Social Care Institute for excellence, Dementia Gateway: Learning Disabilities available at http://www.scie.org.uk/publications/dementia/environment/ld.asp (Accessed 6 January 2013)

[149] Department of Health (2001) *Valuing People: A new strategy for learning disabilities for the 21st century* London: The Stationery Office p.104

[150] Information from the Alzheimer's Society factsheet *Learning Disabilities and dementia.* Available at: Information from the Social Care Institute for excellence, Dementia Gateway: Learning Disabilities available at http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=103asp (Accessed 6 January 2013)

[151] Wilkinson, H. Diana Kerr, D, and Rae, C.(2004) Home for Good? Preparing to support people with learning difficulties in residential settings when they develop dementia [Online] Available at: http://www.jrf.org.uk/sites/files/jrf/1841961272.pdf (Accessed 6 January 2013)

[152] Smith, D. (2011) Dementia: A North East Perspective [Online] Available at: http://www.nr-foundation.org.uk/wp-content/uploads/2011/08/Dementia-A-North-East-Perspective.pdf (Accessed 24 January 2013) p.19

[153] Department of Health (2001) *Valuing People: A new strategy for learning disabilities for the 21st century* London: The Stationery Office

[154] Ibid p.2

[155]Department of Health (2001) *Valuing People: A new strategy for learning disabilities for the 21st century* London: The Stationery Office p.104

[156] Department of Health (2009) Valuing People Now: a new three-year strategy for people with learning disabilities. London: Department of Health

disabilities and their families. *Valuing People Now* stresses the importance of ensuring that the Valuing People agenda works for everyone including those people with more specialist needs and emphasises the importance of providing "*high-quality specialist health services where these are needed*".[157]

## 6.3 Issues relevant to the provision of appropriate support and care

This section of the report will outline the particular support and care needs of people with learning disabilities and dementia. While many of the issues relevant to the support and care of people with learning disabilities and dementia are the same as other communities this report will focus on support and care needs that are specific to people learning disabilities and dementia or support and care needs that may pose particular challenges in the context of people with learning disabilities and dementia.

### 6.3.1 Diagnosis

People with learning disabilities face a number of challenges throughout the diagnosis process, consequently people with learning disabilities *"are less likely to receive a correct or early diagnosis of dementia."*[158] Particular issues highlighted during the research include:

- The difficulty of recognising the early symptoms of dementia among people with learning disabilities
- The specialist assessment process often required to deliver a diagnosis
- The manner in which post-diagnostic information and support is delivered

**Recognising the early symptoms of dementia in someone with a learning disability**

Recognising the early signs of dementia among people with learning disabilities can be problematic. It has been stated that "*without a thorough process of diagnosis, it is more likely that the person's difficulties will be attributed simply to their learning disability. Or the problems may be explained away by the fact that the person is getting 'older' or is being 'uncooperative'*".[159] In particular it was suggested that difficulties such as memory problems, poor concentration, difficulty with daily living skills, communication problems and poor orientation may all be misdiagnosed as resulting from a person's learning disabilities.[160]

Recognising the early symptoms of dementia in a person with learning difficulties may be further complicated by the fact that:

[157] Ibid P.9

[158] Information from the Alzheimer's Society factsheet *Learning Disabilities and dementia.* Available at: http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=103 (Accessed 6 January 2013)

[159] Information from the Social Care Institute for excellence, Dementia Gateway: Learning Disabilities available at http://www.scie.org.uk/publications/dementia/environment/ld.asp (Accessed 6 January 2013)

[160] Ibid

> *"People with a learning disability – particularly those with Down's Syndrome… often show different symptoms in the early stages of dementia* [and] *… may experience a more rapid progression of dementia"*[161]

Given the difficulty of recognising the early signs of dementia in a person with learning disabilities it is necessary that staff working with people with learning disabilities are trained to recognise the early signs of dementia.[162] In addition it has been recommended that individuals working with people with learning disabilities are trained to keep good records in order to monitor changes over a long time-frame and "*build up a picture that will inform the process of assessment and diagnosis*".[163]

In addition it has been suggested that *"people with Down's syndrome should have regular assessments from age 30 as this will help doctors to identify changes in their behaviour or personality over time that could be due to dementia".*[164]

**The diagnosis process**

Standard assessments are often inadequate to diagnose dementia among people with a learning disability. It has been explained that:

> "*assessment tools for dementia in the general population are not appropriate for people with learning disabilities. For example, widely-used tools such as the Mini Mental State Examination… assume the pre-morbid level of functioning to have been within the average range*."[165]

While there is "*no single battery of assessments universally used by learning disabilities teams in the UK*" a number of assessment tools have been developed which include, *"the application of a questionnaire to a close carer, relative or friend"* [166] and *"the exclusion, through a detailed history, clinical examination, and the undertaking of appropriate investigations, of other causes of dementia or of other disorders that might mimic dementia".* [167]

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[161] Information from the Alzheimer's Society factsheet *Learning Disabilities and dementia.* Available at: http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=103 (Accessed 6 January 2013)

[162] Wilkinson, H. Diana Kerr, D, and Rae, C.(2004) Home for Good? Preparing to support people with learning difficulties in residential settings when they develop dementia [Online] Available at: http://www.jrf.org.uk/sites/files/jrf/1841961272.pdf (Accessed 6 January 2013)

[163] Information from the Social Care Institute for excellence, Dementia Gateway: Learning Disabilities available at http://www.scie.org.uk/publications/dementia/environment/ld.asp (Accessed 6 January 2013)

[164] Information from the Alzheimer's Society factsheet *Learning Disabilities and dementia.* Available at: http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=103 (Accessed 6 January 2013)

[165] Royal College of Psychiatrists (2009) Dementia and People with Learning Disabilities: Guidance on the assessment, diagnosis, treatment and support of people with learning disabilities who develop dementia [Online] Available at: http://www.rcpsych.ac.uk/files/pdfversion/cr155.pdf (Accessed 6 January 203) p.23

[166] Mukherji , S. (2012) Filling the gap for learning disabled people with dementia [Online] Available at: http://www.communitycare.co.uk/articles/22/05/2012/118231/filling-the-gap-for-learning-disabled-people-with-dementia.htm (Accessed January 6 2013)

[167] Holland, D. (2004) Down's Syndrome and Alzheimer's Disease: A guide for Parents and Carers. [Online] Available at: http://www.downs-syndrome.org.uk/images/documents/1090/DS_and_Alzheimers.pdf (Accessed 6 January 2013)

**Delivering post diagnostic support and care**

A further difficulty faced by people with learning disabilities is that, following a diagnosis of dementia, they may have difficulty understanding and coming to terms with the diagnosis and might require additional "*specific support to understand the changes they are experiencing and to access appropriate services after diagnosis and as dementia progresses*".[168]

In response to this issue it has been advised that there is a need for "*careful thought and planning [to ensure] that terms familiar to the person are used by all family and care staff to explain changes*".[169]

**The British Institute of Learning Disabilities have produced advice to help people with learning disabilities understand their dementia diagnosis. This resource is titled About Dementia: For People with Learning Disabilities**

## 6.3.2 Issues relevant to the provision of appropriate support and care for people with learning disabilities and dementia

This section of the report will outline issues relevant to the support and care of people with learning disabilities following their diagnosis of dementia. These issues include:

- The effect of the person's dementia on people around them, including other service users
- Issues around the physical design of support and care services
- Staff training to develop appropriate knowledge and skills

**The effect of the person's dementia on people around them, including other service users**

The importance of considering the impact of a person's diagnosis on those around them was highlighted in the research as an important but often overlooked issue.[170] In particular it was noted that in many instances a person with learning disabilities will, prior to the development of dementia, be using support and care services or living in a supported living environment. Consequently it is necessary to consider how the diagnosis of dementia in a person with learning disabilities may affect other individuals using the same care and support services, or people living in the same supported living environment.

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[168] Information from the Alzheimer's Society factsheet *Learning Disabilities and dementia.* Available at: Information from the Social Care Institute for excellence, Dementia Gateway: Learning Disabilities available at http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=103 (Accessed 6 January 2013)

[169] Ibid

[170] Royal College of Psychiatrists (2009) Dementia and People with Learning Disabilities: Guidance on the assessment, diagnosis, treatment and support of people with learning disabilities who develop dementia [Online] Available at: http://www.rcpsych.ac.uk/files/pdfversion/cr155.pdf (Accessed 6 January 203) p.43

The importance of supporting other service users to understand the needs of a person diagnosed with dementia was explained by the report *Dementia and People with Learning Disabilities: Guidance on the assessment, diagnosis, treatment and support of people with learning disabilities who develop dementia* which explained that:

> *"Helping peers to understand dementia can reduce their distress and help them to be more considerate and understanding of the changes occurring with the person with dementia, in some cases helping to prevent placements breaking down".*[171]

The report *Growing older with a learning a learning disability and dementia also* explained that while "*fellow residents have an understanding and high level of acceptance of the implications of dementia*" they can also experience "*anxiety and distress due to the disturbing behaviours of those with dementia, such as shouting, banging, kicking and night time activity*".[172] However, the report added that "*levels of understanding and tolerance were higher among residents when the reasons for the behaviour or disruption had been explained*".[173]

Resources such as *About my friend; for friends of people with Down's syndrome and* dementia[174] may be used to help explain the person's changes to fellow service users with dementia. It has also been shown that short courses developed for people with learning disabilities who are living with an individual who has been diagnosed with dementia can be a useful means of increasing understanding and acceptance.[175]

This approach was echoed in the report *Findings: Support for people with learning difficulties in residential settings who develop dementia* which emphasised the need for services that provide support and care for people with learning disabilities to have "*a policy to support and educate fellow residents on the needs of the person with dementia (which should take account of the fact that some people may object to others knowing the diagnosis)."*[176]

The report also recommended that services seek "extra support staff for the residents without dementia, releasing time for permanent staff in the home to give to the person with dementia".[177]

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[171] Ibid p.41

[172] Wilkinson, H. (2004) Growing older with a learning a learning disability and dementia [Online] Available at: http://www.crfr.ac.uk/reports/rb17.pdf (Accessed 6 January 2012) p.1

[173] Ibid p.1

[174] Dodd, K. Turk, V. and Christmas, M. (2002) About dementia series: About my friend; for friends of people with Down's syndrome and dementia. Worcester: BILD Publications

[175] Royal College of Psychiatrists (2009) Dementia and People with Learning Disabilities: Guidance on the assessment, diagnosis, treatment and support of people with learning disabilities who develop dementia [Online] Available at: http://www.rcpsych.ac.uk/files/pdfversion/cr155.pdf (Accessed 6 January 203) p.43

[176] Joseph Rowntree Foundation (2004) Findings: Support for people with learning difficulties in residential settings who develop dementia [Online] Available at: http://www.jrf.org.uk/sites/files/jrf/614.pdf (Accessed 6 January 2013)

[177] Ibid

**Issues around the physical design of support and care services**

A number of sources affirm that "*the design of the built environment is important for someone with a learning disability: this becomes even more critical if the person develops dementia*".[178] In particular it has been observed that "*the most important things we can do to improve the care environment are to ensure that it makes sense and is calm, familiar, predictable and suitably stimulating*".[179]

In light of the difference that the physical environment can make to the provision of support and care of people living with learning disabilities and dementia the Joseph Rowntree Foundation report *Findings: Support for people with learning difficulties in residential settings who develop dementia* recommends that there needs to be an increased "*understanding by service providers of the impact of the built environment on people with dementia so that it informs building design*" and increased "*awareness by Care Commissioners of the complexities of providing dementia appropriate environments*".[180]

**Staff training to develop appropriate knowledge and skills**

A further issue relevant for the provision of appropriate support and care to people living with dementia and learning disabilities is the need to ensure that staff experienced in providing support and care to people with learning disabilities receive training that will allow them to support an individual diagnosed with dementia.

A number of resources have been developed to help staff better understand how to provide support and care to people with learning disabilities and dementia. These resources include:

- *Supporting Derek - a new resource for staff working with people who have a learning difficulty and dementia*[181]
- *Down's syndrome and dementia: a resource for carers and support staff*[182]
- *Tips: supporting someone with learning disabilities and dementia*[183]
- *Do you recognise pain in someone with a learning difficulty and dementia?*[184]

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[178] Information from the Social Care Institute for excellence, Dementia Gateway: Learning Disabilities available at http://www.scie.org.uk/publications/dementia/environment/ld.asp (Accessed 6 January 2013)
[179] Information from the Social Care Institute for excellence, Dementia Gateway: Learning Disabilities available at http://www.scie.org.uk/publications/dementia/environment/ld.asp (Accessed 6 January 2013)
[180] Joseph Rowntree Foundation (2004) Findings: Support for people with learning difficulties in residential settings who develop dementia [Online] Available at: http://www.jrf.org.uk/sites/files/jrf/614.pdf (Accessed 6 January 2013)
[181] Watchman, K. et al (2010) Supporting Derek - a new resource for staff working with people who have a learning difficulty and dementia. Joseph Rowntree Foundation
[182]Dodd, K. Turk, V. and Christmas, M. (2005) Down's syndrome and dementia: a resource for carers and support staff.: British Institute of Learning Disabilities
[183] Produced by the Alzheimer's Society. Available at: http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=103 (Accessed 6 January 2013)
[184] Wilkinson, H. Kerr, D. and Cunningham, C. (2008) Do you recognise pain in someone with a learning difficulty and dementia? Joseph Rowntree Foundation

The report *Dementia and People with Learning Disabilities: Guidance on the assessment, diagnosis, treatment and support of people with learning disabilities who develop dementia* suggests that support and care staff should, as a minimum have training on:

- What is dementia?
- Types, signs and symptoms of dementia
- Working with people in a person-centred way
- Using accessible information formats for person-centred plans and health action plans
- Lifestory work
- Use of medication in dementia
- Communication skills
- Roles of different health and social professionals
- Safeguarding adults
- Palliative care approaches[185]

In addition the report highlights the fact that external services and "*staff with specialist skills need to be identified to ensure that people with learning disabilities and dementia have excellence in care*".[186]

It has also been emphasised that training should be provided to support staff for people with learning disabilities prior to any service users developing dementia so that they are aware of the symptoms and are able to provide consistently appropriate support.[187]

## 6.4 What type of organisations are best placed to deliver support and care?

In response to the fact that many people living with dementia may already be living in supported environments or using support and care services, the literature suggests that there are three possibilities for how support and care can be provided for people living with dementia and learning disabilities. They are:

- To continue with the same support and care provider
- To move on to specialist support and care providers for people living with dementia and learning disabilities
- To move into generic services for people living with dementia[188]

[185] Royal College of Psychiatrists (2009) Dementia and People with Learning Disabilities: Guidance on the assessment, diagnosis, treatment and support of people with learning disabilities who develop dementia [Online] Available at: http://www.rcpsych.ac.uk/files/pdfversion/cr155.pdf (Accessed 6 January 203) p.59
[186] Ibid
[187] Wilkinson, H. Diana Kerr, D, and Rae, C.(2004) Home for Good? Preparing to support people with learning difficulties in residential settings when they develop dementia [Online] Available at: http://www.jrf.org.uk/sites/files/jrf/1841961272.pdf (Accessed 6 January 2013)
[188] Janicki M. and Dalton A. (1999) Dementia and Aging Adults with Intellectual Disabilities: A Handbook. Routledge

**Continuing with the same care and support provider**

The sources analysed during the research suggested that in certain situations this would be the preferable option as it will allow an individual to "*stay with familiar people (family, peers, familiar carers) and in an environment that they know*". [189]

It was noted however that achieving this aim may require "*environmental changes and adaptations to support the person, increases in staffing levels and careful thinking about the supports required*"[190] in order to provide high quality support and care as a person's dementia progresses.

It may however not be possible in all cases to maintain a person's current support and care services due to the fact that "*making the necessary environmental modifications may not be possible, staff may not be trained in dementia care and there may be a negative impact on other users*".[191]

**Moving into specialist care for people with learning disabilities and dementia**

Where a person has to move to other support and care services the research suggested that the most preferable option is that the person moves to a specialist service for people with learning disabilities and dementia. It has however been noted that "*there is a marked scarcity of such specialist services*".[192]

**Moving into generic services for people with dementia**

The option of moving into generic services for people living with dementia was generally regarded by the literature as being the least preferable option. Despite this, it has been suggested that such placements remain relatively common place due to the lower costs associated with this option.[193]

## 6.5 What support and care services are available in the North East?

Specialist services for people with learning disabilities and dementia in the North East include:

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[189] Royal College of Psychiatrists (2009) Dementia and People with Learning Disabilities: Guidance on the assessment, diagnosis, treatment and support of people with learning disabilities who develop dementia [Online] Available at: http://www.rcpsych.ac.uk/files/pdfversion/cr155.pdf (Accessed 6 January 203) p.43

[190] Ibid

[191] Mukherji , S. (2012) Filling the gap for learning disabled people with dementia [Online] Available at: http://www.communitycare.co.uk/articles/22/05/2012/118231/filling-the-gap-for-learning-disabled-people-with-dementia.htm (Accessed January 6 2013)

[192] Ibid

[193] Mukherji , S. (2012) Filling the gap for learning disabled people with dementia [Online] Available at: http://www.communitycare.co.uk/articles/22/05/2012/118231/filling-the-gap-for-learning-disabled-people-with-dementia.htm (Accessed January 6 2013)

- Specialist residential dementia unit for people with learning disabilities provided by the charity Self Unlimited in Ponteland
- Specialist residential dementia unit for people with learning disabilities at Tynedale House in Blyth
- Specialist residential dementia unit for people with learning disabilities provided by BUPA in Coulby Newham
- Middlesbrough Learning Disabilities Dementia Group (Team EDIN) which provides support for carers of people who have a learning disability and dementia

In 2008 Skills for People were commissioned by the Care Services Improvement Partnership to identify what people with learning disabilities in the North East thought should be include in the National Dementia Strategy. The consultation included speaking to 76 people in three sessions which took place in Newcastle upon Tyne, North Tyneside and Middlesbrough.

Respondents during the consultation suggested they wanted:

- People with learning disabilities to be actively involved in the progression of the Strategy
- Awareness raising about dementia and learning disabilities
- Training for professionals
- Early diagnosis so that people can access a variety of services and support to remain independent
- The development of new assessment materials which clearly define the differences between having a learning disability, and dementia
- Regular checks of skills and abilities, which will help to make sure that any changes in the future, due to dementia are not mistaken for part of a learning disability
- The development of good quality accessible information made available in a variety of mediums as well as support and advice
- The development of specialist teams in hospitals, with senior leads and well trained staff and good planning when people are leaving hospital
- Early planning with people when they have the capacity about their future values wishes and beliefs should they get dementia
- Commissioned independent person centred planning teams from the voluntary sector
- Care homes designed by people who have experience of dementia
- Person centred respite services and people involved in planning their holiday
- Good support to stay living in their own home and retain independence
- Person centred planning tools implemented across all services from early diagnosis through to end of life to create a seamless service for people[194]

In 2010 Middlesbrough Council, NHS Middlesbrough and NHS Redcar and Cleveland published the report *South Tees Learning Disability: Dementia Development Report* which details how it is possible

[194] Skills for People (2008) National Dementia Strategy: Report of consultation with people with learning disabilities in the North East: What we think about the Government's plan [Online] Available at: http://www.nepho.org.uk/securefiles/130124_1542//Skills%20for%20People%20Consultation%20on%20National%20Dementia%20Strategy%20Aug%202008.pdf (Accessed 24 January 2013

to achieve the aims of the National Dementia Strategy for people living with dementia and learning disabilities.[195]

Work undertaken in Northumberland in order to improve the support and care of people with learning disabilities and dementia has included:

- Regularly updating the list of clients known to have Down's syndrome
- Carrying out health checks as part of the routine assessment of people with learning disabilities
- Offering a carers assessment following a diagnosis of dementia

In addition members of the Down's Syndrome and Dementia group have attended the learning disabilities care manager's team meetings in Northumberland to discuss:

- The use of the Disability Distress Assessment Tool following diagnosis in order to record the appearance and behaviour of people who cannot vocalise whether they are content or distressed
- The possibility of a routine screening for dementia in people with Down's Syndrome

A number of local dementia strategies within the North East have addressed the issue of support and care for people living dementia and learning disabilities.

In Gateshead the *Joint Commissioning Strategy 2009-2012*[196] sets out a commitment to undertake awareness raising campaigns with local priority groups including minority groups such as people with learning disabilities. This provision is mirrored in the Joint Commissioning Frameworks for South Tyneside[197] and Sunderland[198]

The Gateshead Joint Commissioning strategy also set out an aim to *gather evidence* in order to achieve their goal of using national best practice in long term care to inform commissioning. This includes gathering evidence on homes registered for people with Learning Disabilities.

In Middlesbrough the document *Mental Health Services for Older People in Middlesbrough: Implementation Plan 2009-2014* highlights how they are working towards the aim of achieving good quality early diagnosis through the development of a care pathway and a register of those at risk.[199]

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[195] Baker, J. (2010) South Tees Learning Disability: Dementia Development Report [Online] Available at: http://www.nepho.org.uk/securefiles/130113_2348//South%20Tees%20LD%20Dementia%20Report%202010.pdf (Accessed 6 January 2013)

[196] Available at: http://www.phine.org.uk/social-care-north-east/resources/1839 (Accessed 6 January 2013)

[197] Ibid

[198] Ibid

[199] Available at: http://www.phine.org.uk/securefiles/130113_1733//Mental%20Health%20Services%20for%20Older%20People%20in%20Middlesbrough[1].pdf (Accessed 6 January 2013)

The document also states that in order to improve community personal support services "*the specialist mental health service will work with …learning disability services… to deliver an integrated service".*

The National Dementia Strategy Implementation Action Plan for Stockton-on-Tees highlights that the needs of people with learning disabilities will be met by the Learning Disability Team with advice and support from the Young Onset Dementia Team if requested. [200]

The North Tyneside Dementia Action Plan sets out a target to gain a greater understanding of the services available and to improve service provision for people with learning disabilities and dementia.[201]

In Northumberland the Joint Dementia Action Plan[202] proposes to produce a revised joint communications plan between health and social care with specific reference to learning disabilities.

The Northumberland Joint Dementia Action Plan also sets out a commitment to achieve "greater understanding of the needs of individuals with both learning disabilities and dementia, the services currently available and provide an identified care pathway. The document states that the pilot of the Northumberland Dementia Care Pathway for people with Down's Syndrome was completed and a new care pathway introduced in October 2008 and evaluated in July 2010. The document also outlines plans to develop an easy to read guide on dementia and plans to distribute it via Learning Disability Partnership Boards.

[200] Available at: http://www.phine.org.uk/securefiles/130113_1732//National%20Dementia%20Strategy%20Implementation%20Plan%20Stockton%202011[1].pdf (Accessed 6 January 2013)

[201] Available at: http://www.phine.org.uk/securefiles/130113_1731//North%20Tyneside%20Dementia%20Action%20Plan%20Feb%202011.pdf (Accessed 6January 2013)

[202] Available at: http://www.phine.org.uk/securefiles/130113_1731//Northumberland%20Int%20Plan%20September%202011.pdf (Accessed 6 January 2013)

## 6.6 Recommendations

### Improving the diagnostic process

- Develop training resources to help staff supporting people with learning disabilities to recognise the early signs of dementia or encourage the adoption of existing training
- Train staff working with people with learning disabilities to keep appropriate records that can be used to monitor changes over a longer time-frame
- Develop resources that can be used to explain a diagnosis of dementia to people with learning disabilities

### Improving the support and care of people with learning disabilities and dementia

- Develop, or encourage the use of existing, resources that can be used to explain a person's dementia to fellow services users who may also have learning disabilities
- Support service providers to develop clear policies regarding the provision of information to fellow service users following a person's diagnosis of dementia including how this can be done without breaching a person's confidentiality
- Encourage service providers to consider the use of extra staff to allow more experienced or specialist staff to support service users diagnosed with dementia
- Improve understanding among service providers about the importance of the built environment and provide resources that can help service providers understand appropriate changes they can make to benefit people with learning disabilities and dementia
- Ensure staff providing support to people with learning disabilities are trained to meet the support and care of a person living with learning disabilities
- Ensure staff training is delivered prior to any service users developing dementia
- Encourage the development of specialist services for people living with dementia and learning disabilities to avoid placements in generic services for people living with dementia if a person can't be supported to remain in their current environment

# 7. Conclusion

The principles of person centred care are paramount to the provision of high-quality care and support for people living with dementia. Adopting a person centred approach to care means that the "*emphasis should always be on the person as an individual. In a person centred approach the unique qualities of the individual as determined by their life history and experiences, likes and dislikes, are their defining characteristics*"[203]. The adoption of a person centred approach is particularly important with regards to the provision of support and care for people living with dementia from minority communities as the needs of these individuals may well differ from the majority of the population living with dementia.

The research has however, suggested that on its own the adoption of person centred approaches is insufficient to address all the care and support needs of people living with dementia from minority communities. It is essential that service providers, GPs, commissioners, policy makers, regional bodies and community groups all take pro-active steps to support people living with dementia from minority communities and to overcome the barriers that currently prevent some members of these communities accessing appropriate support and care.

While some of the needs of the minority communities addressed in this report are unique there are also a number of common themes that emerged throughout the research. One such theme is the need for minority communities to be represented among policy makers, commissioning bodies and regional groups such as the North East Dementia Alliance. This representation should come from individuals who understand the needs of particular communities such as community groups or community representatives.

A second theme common to the minority communities addressed in this project, other than lesbian, gay, bisexual and transgender communities, is the difficulties faced in relation to accessing and receiving a diagnosis. The particular reasons why diagnosis is an issue does vary between the communities researched.

A third theme highlighted throughout the research was that while equality is a key principle that should guide the provision of support and care of people living with dementia, this equality should be an equality of outcomes not an equality of treatment. To ensure that people receive high-quality care and support it is essential that the differences in people's needs are recognised and responded to. What constitutes appropriate support and care varies between communities, however this project has sought to provide details of the issues faced by each community.

[203] National Care Forum Older People and Dementia Care Committee (2007) Key Principles of Person Centred Dementia Care: Statement of Best Practice [Online] Available at: http://www.nationalcareforum.org.uk/content/Key%20principles%20of%20person-centred%20dementia%20care.pdf (Accessed 6 January 2013)

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# Appendix A: Recommendations

## Recommendations to improve the support and care of people living with dementia from black and minority ethnic communities and religious minority communities

### Further research

There is a need for:

- Further research to identity the specific needs of the full range of (BME and religious minority) 'communities within communities' in the North East
- Particular research to identify the support and care needs of people living with dementia from Gypsy and Traveller communities

### Improving diagnostic rates and the diagnostic process

There is a need for:

- Training to help GPs see beyond cultural distortions and reluctance to discuss dementia among BME and religious minority communities
- Increased knowledge about and use of culturally appropriate diagnostic assessment tools among professionals
- Appropriate translation and support services during and after the diagnosis process

### Reducing stigma and increasing awareness

There is a need to:

- Produce locally specific leaflets, fact sheets and DVDs that provide information about dementia and the services available to people living with dementia, this information should be provided in a range of languages and should use neutral terminology
- Work with local radio stations aimed at BME and religious minority communities to provide information about dementia and the services that are available for people living with dementia and their carers
- Forge close links with BME and religious community leaders so that community outreach workers can provide information or run workshops in 'safe places' such as community centres or places of worship
- Provide information to community leaders so that they can take the information to their communities
- Consider the use of translators to work with information providers. These services should be designed in a manner that maximises reassurance about confidentiality (this may take the form of a volunteer translator service)

### Developing culturally appropriate services

This could be done by:

- Encouraging mainstream service providers to ensure that support and care is:
    - Person centred and designed to meet the needs of individuals and not cultural stereotypes
    - Delivered in a culturally appropriate environment where religious and cultural diversity are celebrated (i.e. not overly medical in character)
- Developing in-depth experiential training on cultural and religious diversity for frontline staff from care and support services
- Encouraging the development of relationships between BME and religious minority community groups and mainstream services so that specialist community groups can advise and inform mainstream services (this could take the form of a dedicated liaison officer)
- Encouraging service commissioners to work in collaboration with BME and religious minority groups when commissioning all support and care services (not just services aimed at BME and religious minority communities)
- Ensuring that BME and religious minority groups are included in regional bodies working in the field of dementia such as the North East Dementia Alliance
- Improving the training of support and care staff who are from BME and religious minority communities
- Considering the provision of culturally specific care and support services for particular communities
- Promoting the development of confidential and culturally sensitive support services for carers from BME and religious communities

## Recommendations to improve the support and care of for younger people living with dementia

### Improving the diagnostic process

- Increase awareness and understanding of young onset dementia among GPs
- Ensure clear diagnostic pathways are developed in all the localities in the North East in order to minimise uncertainty about who is responsible for diagnosis and reduce unnecessary delays in the diagnostic process for younger people living with dementia

### Improving access to care and support services

- Develop a clear care pathway that outlines responsibility for on-going care and support
- Improve information about the services available to younger people living with dementia

### Provide support that meets the specific needs of younger people living with dementia by:

- Promoting the further development of services specifically for younger people living with dementia that include age appropriate activities to build on the services already provided in some areas of the North East
- Developing support services for the carers and families of younger people living with dementia
- Providing information for younger people living with dementia and their carers on financial, legal and employment issues (this could be through a dedicated advisor or education courses for younger people living with dementia and their carers)
- Promoting the development of community services that can provide emotional support, and or counselling to younger people living with dementia and their carers and family
- Promoting the development of care homes for younger people living with dementia or other bespoke environments that avoid reliance on services aimed at older populations living with dementia
- Promoting good inter-service working with non-dementia specialist services including genetic counselling and substance misuse services in order to provide the full range of support valuable to younger people living with dementia

## Recommendations to improve the support and care of people living with dementia from lesbian, gay and bisexual communities and transgender communities

### Increasing recognition that people from LGB communities are using support and care services

- Encourage local authorities or service providers to consider how they could monitor the sexual orientation of people living with dementia using support and care services
- Support local authorities or service providers to develop the necessary conditions to implement a monitoring procedure, namely:
    - A safe environment in which people feel able to be open about their sexual orientation
    - Staff are appropriately trained to handle such matters in a suitably sensitive manner
    - Guarantee confidentiality for service users
- Support service providers to better understand sexuality as an aspect of person's identity and train staff to engage in conversation about the subject in an appropriate manner

## Making it clear that support and care services respect and work to accommodate the needs of people living with dementia from LGBT communities

Encourage support and care providers to:

- Ensure that same-sex and transgender people are included in service promotional material and that all such materials employ inclusive language
- Use local media (particularly LGBT media) to highlight that the service is suitable for people from LGBT communities
- Provide LGBT orientated image and reading materials in public areas of the service

## Ensuring support and care services have appropriate policies and procedures to prevent discrimination and protect confidentiality

Encourage support and care providers to:

- Develop clear policies on discrimination and victimisation and confidentiality that relate explicitly to the needs of people from LGBT communities
- Ensure that the policies are clearly displayed or easily accessible and ensure staff and service users are aware of the content of the policies
- Ensure that policies include service users are aware of how to make a complaint if they feel they have been the victim of discrimination, victimisation or a breach of confidentiality

## Ensuring that the staff from support and care services have appropriate knowledge and skills

Encourage support and care providers to

- Train staff to avoid assuming people are heterosexual and encourage the use of open, non-judgemental language when discussing relationships and sexuality
- Don't force people to discuss their sexual orientation or gender identity if they do not wish to do so
- Include attitude to equality and diversity in the recruitment process
- Ensure staff are aware of the law surrounding equality and diversity and how this relates to their support and care of people living with dementia from LGBT communities
- Ensure that managers deliver strong consistent messages with regards to the support and care of people from LGBT communities
- Ensure that service users have the opportunity to determine which members of staff they work with
- Ensure staff are have an understanding of how to sensitively meet the needs of transgender people living with dementia

### Ensure support and care services recognise and involve the families of people from LGBT communities and their other social networks

- Ensure people are given an opportunity to nominate a next of kin who can be family or friend
- Include same-sex partners in planning a person's care (where it is the wish of the service user)

### Ensure that support and care servicers respond to the needs of people LGBT communities

- Allow service users from the LGBT community to inform their care and support so that it is person centred and responds to their needs as an individual
- Establish an LGBT user group to provide feedback on the service received
- Work with local community groups for people from LGBT communities to inform the work of service providers and help them develop more responsive and appropriate services
- Encourage organisations to establish a liaison officer who can build trust between the service provider and the LGBT community and address potential issues arising out of the care and support provided
- Support people living with dementia from LGBT communities to access LGBT community groups for information about their rights and peer support
- Involve community groups for people from LGBT communities in regional policy making and commissioning bodies

## Recommendations to improve the support and care of people with learning disabilities and dementia

### Improving the diagnostic process

- Develop training resources to help staff supporting people with learning disabilities to recognise the early signs of dementia or encourage the adoption of existing training
- Train staff working with people with learning disabilities to keep appropriate records that can be used to monitor changes over a longer time-frame
- Develop resources that can be used to explain a diagnosis of dementia to people with learning disabilities

### Improving the support and care of people with learning disabilities and dementia

- Develop, or encourage the use of existing resources that can be used to explain a person's dementia to fellow services users who may also have learning disabilities
- Support service providers to develop clear policies regarding the provision of information to fellow service users following a person's diagnosis of dementia including how this can be done without breaching a person's confidentiality

- Encourage service providers to consider the use of extra staff to allow more experienced or specialist staff to support service users diagnosed with dementia
- Improve understanding among service providers about the importance of the built environment and provide resources that can help service providers understand appropriate changes they can make to benefit people with learning disabilities and dementia
- Ensure staff providing support to people with learning disabilities are trained to meet the support and care of a person living with learning disabilities
- Ensure staff training is delivered prior to any service users developing dementia
- Encourage the development of specialist services for people living with dementia and learning disabilities to avoid placements in generic services for people living with dementia if a person can't be supported to remain in their current environment

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