

Refresh of Liverpool's Joint Dementia Strategy

BAME Communities Position Paper

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Background

Demographic data

Figures from the 2011 Census indicate that 15.2% of the Liverpool population is from a minority ethnic group, i.e. non-white British, equating to almost 71,000 residents. This is higher than the regional average (12.9%), but lower than England (20.2%). Between the 2001 and 2011 Census, the largest increase has been seen among the White Other group, followed by Black African and Indian. The change in numbers and age profile of these groups will impact on the need to provide culturally sensitive care for particular ethnic groups, with dementia likely to become a more significant problem as these populations age (Liverpool's Joint Strategic Needs Assessment (2013), Liverpool City Council).

The ONS 2011 Census identifies the top 5 ethnic minority groups in Liverpool as follows:

White Other	12,270
Black African	8,490
Chinese	7,980
White Irish	6,730
Arab	5,630

According to Public Health England Liverpool Dementia Profile (July 2017), there were 3,451 people in Liverpool with a diagnosis of dementia recorded for the period 2015/16.

LCCG Specification for the Dementia Champions (November 2016) stated:

Work is currently underway to establish a baseline for the dementia prevalence rate amongst BAME communities as there is underrepresentation within the local population.

Evidence of unmet need

Though significant progress has been made in terms of increasing the diagnostic rate, this increase has not been apparent within black Asian and minority ethnic (BAME) communities. The **Centre for Policy on Ageing** and **Runnymede Trust** applied well established dementia prevalence rates to census data and suggest that there are nearly 25,000 people living with dementia from BAME communities in England and Wales and this is expected to grow to 50,000 by 2026 and 172,000 by 2051 (**All Parliamentary Group on Dementia 2013**).

It is also likely that dementia is more common amongst BAME communities as people from these communities are more at risk of conditions like high blood pressure, diabetes, stroke and heart disease, all of which are common risk factors for dementia. These risk factors are potentially modifiable which means that the need to increase awareness within BAME groups is important in terms of disease prevention.

Although research in this area is scarce it suggests that there is under representation of BAME groups within services, lower awareness of dementia, higher levels of stigma attached to dementia and differing cultural understandings of dementia amongst these groups. Research suggests that people present later, therefore when dementia is more severe (**Knapp, M, Prince, M, Albanese, E et al (2007) *Dementia UK: The full report* Alzheimer's Society, London**)

A range of guidance has been produced;

- **National Dementia Strategy** (Department of Health, 2009)
- **Joint Commissioning Framework** (Department of Health, 2009)
- **Prime Minister's Dementia Challenge** March 2012
- **World Health Organisation (WHO) and Alzheimer's Disease International report** (World Health Organisation, 2012)
- **All Party Parliamentary Group (APPG) report** (All Party Parliamentary Group Report, 2012)
- **NICE** ten quality statements (NICE, 2013) which are aimed at supporting people to live well with dementia. These quality statements should also act as a benchmark for assessing the quality of care currently provided.
- **All Party Parliamentary Group (APPG) report *Dementia does not discriminate*** (2013)
- **Prime Minister's challenge on dementia 2020** February 2015

The **APPG Enquiry report on Dementia** (2013) significantly placed issues for black and minority ethnic communities and dementia at a national policy and political level not previously seen in the implementation of the National Dementia Strategy (2009).

Moriarty et al (Moriarty. J, Sharif. N and Robinson. J (2011) *BME people with dementia and their access to support and services*; Social Care Institute of Excellence, Research briefing March 2011) highlighted that despite the limited nature of the evidence base, a number of recurring themes emerge in research looking at people with dementia and carers from BAME communities. There are difficulties in accessing services and being able to choose care and support in the forms that people would like, due to lower levels of awareness about dementia and

greater levels of stigma among some communities. Dementia may be a new experience for some people, especially families that migrated to the UK who were of working age and did not bring older relatives.

Some languages, including some South Asian languages, do not have a word for dementia. Where there is a lower awareness of dementia and poorer literacy in English, this effectively reduces access to information and support services. Consequently, people from BAME communities tend to be diagnosed later. (APPG *Dementia does not discriminate* July 2013)

Projects are often short term and the most successful have been those building on links made by community development workers that have actively involved people from different communities. The SCIE study reports that commissioners need to be aware of the increase in the number of people from BAME communities likely to need dementia services.

It is essential that differing strategies are used to reach different communities as they may have different preferences for services; a range of ways of supporting people from BAME communities and their carers should be commissioned.

What we know about needs in Liverpool's BAME communities

A pilot project run by Liverpool PCT Community Development Workers in partnership with Mersey Care NHS Trust in 2012 developed and ran dementia awareness sessions within seven BAME communities in Liverpool. Phase two of the project involved employing two dementia champions to work within the Chinese community and with Somali elders, with the aim of building up culturally appropriate dementia support services in Liverpool.

This work continued until recently with champions from Chinese Wellbeing, Somali Elders, African Elders and Kensington Older People's Network supporting the needs of their respective communities through awareness raising, organising drop in sessions, peer support groups and outreach care and support.

The LCCG funding for the development of support services included 3 days intensive training delivered by Merseycare and ongoing mentoring support from the Care Navigators if required.

Two project evaluations were undertaken: Praxis (2012) BME Dementia Champions Project Evaluation; Abimbola, A, (2014) BME Dementia Champions Project: An

Evaluation Report

They highlighted the following:

Awareness-Raising

The dementia champions have established that the level of knowledge and understanding about dementia within the communities is generally low and there is little, if any, prior knowledge of what dementia services are available.

The project confirmed the prevalence of the cultural barriers identified in the research literature that act against individuals recognising dementia as an illness,

For both Chinese and Somali communities, families are concerned with the stigma associated with dementia. The outcome is that individuals or their family do not seek help.

Access and engagement

There are historic, cultural and social divisions that exist within communities that can act to limit access to particular groups, even for someone from the same ethnic background.

The identification and engagement of people at risk of dementia have proved difficult. It is more effective to work with people who may be in contact with more vulnerable individuals and can alert the dementia champion if they have a concern. Awareness-raising with carers and other family members can perform the same function.

Community events provide useful opportunities for building relationships and for awareness-raising. It is easier to organise such events through existing community and faith groups, than trying to organise these separately.

Information

Presenting information and concepts about dementia in accessible ways that are culturally sensitive is a challenge: information and materials that have been produced are often too complex and detailed. As well as translating this information, the champions have worked to produce simpler versions as literacy is an issue

- It remains the case that younger family members in both communities will often translate information and act as interpreters for their elders which can present difficulties

2012 BAME Strategy Development Event:

Extract from LCC Review Paper 2014 – Adults and Older People: Dementia

The BME Strategy Development Event was a one day conference where 120 older people from seven BME organisations met to brainstorm on the most effective ways of supporting older people around their dementia care needs within the community. The key findings and recommendations were:

Access to Services

From a total of 120 older people, 98 agreed that they have difficulty accessing their GP and Secondary Care services due mainly to language problems, cultural barriers and lack of awareness. They suggested local community based services are more welcoming and accessible due to the fact that they are nearer home and staff can communicate with them in their heart language.

Capacity Building

120 out of 120 agreed there was an urgent need for trained BME dementia champions and volunteers working in the community. Trained champions could also work effectively as interpreters because they also have both cultural competency and an appropriate knowledge base.

Information

50 out of 120 believed leaflets containing information on dementia should be available in local languages. Others believed word of mouth is more effective for older people within certain cultures due to inability to read the written format of their language.

Awareness Raising & Dementia Support Activities

80 out of 120 had participated in awareness raising workshops organised by Community Development Workers but they believe more should be done for early diagnosis through workshop sessions and activities supporting dementia.

Gender Specific Services

20 out of 120 (mainly women) expressed the need for gender specific services for women, especially women carers.

[End of extract]

Progress since current strategy

Liverpool CCG provided funding for Dementia Champions from **April 2016 to December 2017**

Aims and objectives of service

- a) To increase awareness of dementia within four BAME communities in Liverpool
- b) To provide support for people with a diagnosis and carers
- c) To provide culturally appropriate activities for improving wellbeing
- d) To liaise with Mersey Care and Care Navigators to promote closer working relationships and enable people to access post diagnostic support
- e) To provide opportunity for people with others who are living with dementia and carers to meet and gain support (peer support) via culturally appropriate dementia café type activities
- f) To promote healthy lifestyle activities and increase awareness of modifiable risk factors through information and activities provided
- g) To disseminate effective ways of working to other BAME communities through regular feedback to the Diversity subgroup within the Liverpool Dementia Action Alliance.

The BAME Dementia Champions provided the following services:

1. Awareness raising sessions

- o 24 Dementia café style drop in sessions, promoting awareness of dementia within the community
- o Contribute to the facilitation of a peer support network group

2. Provision of activities

- o Culturally appropriate activities for people with dementia/carers/those at risk of dementia in order to develop peer support and promote healthy lifestyles (1 per month per community)

3. Support

- o Signposting - encourage and promote access to primary and secondary care services as appropriate at weekly drop-ins, distributing NHS and other trusted information on dementia as appropriate
- o Operate an outreach service for those who have been newly diagnosed and require one to one support, offering to visit them at home, provide information and liaise with services on their behalf

4. Liaison/partnership working

- o Develop links with Mersey Care NHS Care Navigators to build relationships and increase awareness and understanding of the role of the care navigator service
- o If appropriate work with the care navigator to introduce to the person to post diagnostic support

Achievements

March 2016 – five Dementia Champions appointed within African, Chinese, Somali, Arabic and Faith communities. All received three days intensive training through Merseycare NHS.

April 2016 – The service was launched in four communities (Merseyside Yemeni Association did not participate in the final project)

Progress Summary

Criteria and Objectives	Outputs/Metrics	Totals for year 2016/17	Cumulative Totals 9 months 2017
Increasing awareness	Numbers of attendees in drop in sessions: Number of sessions run:	346 121	251 91
Monthly activity groups	Number of sessions: Number of attendees:	87 1658	70 1,133
Signposting to support	Numbers referred to care navigators:	10	3
People with dementia feel supported	Number of peer support sessions	40	57
Carers feel supported	Attendees peer support group:	275	213
Outreach support	1-1 support	52	44

Partnership working: referrals to other services including memory assessment:

Local GP
LCCG
Mersey Care – Memory Clinic
LCDS
Community Groups

LCC – Adult Social Services
Merseyside Fire Service
Benefit Max team
RSL's
Alzheimer's Society
Healthiness
Evergreen Wellbeing Club –CW
Care Home
PSS
HOP
Talk Liverpool
HIM Project
CAB
Whitechapel
other

Current situation

Withdrawal of funding

The LCCG withdrew funding in December 2017 following six months notice to terminate.

Impact on services: There is no longer a coordinated approach by the LCCG to developing dementia support services within Liverpool's BAME communities. The training and development of support services throughout the period have been terminated or substantially reduced. The outcome for each organisation and therefore respective communities will be different depending upon organisational structures and alternative funding streams available (if any).

Briefly, those currently providing limited dementia support services to their respective communities are as follows;

Chinese Wellbeing received Pioneer Funding from LCC to continue to deliver its dementia support services for one year: i.e. Tea House Reminiscence, post diagnostic support, one to one outreach, drop in information and advice sessions based in GP practice surgeries.

African Elders no longer promote the Dementia Champion services, although continue to provide a limited support service through their Luncheon Club.

Back to Life Liverpool (African Communities): the African Elders Dementia Champion has continued to operate a limited service by continuing to run a monthly peer support network group supported by Tesco, Park Lane.

Alive Believers (Kensington Older Persons Network): No longer has an active

Dementia Champion; however, it continues to provide limited support services through its Rainbow Centre.

Liverpool Somali Community no longer provides dementia support services.

Mary Seacole House operates a dementia support network for South Asian carers funded by DEEP.

Irish Community Care operates a dementia support memory group funded by DEEP.

Impact on communities

LCCG's original justification for funding the BAME Dementia Project remains valid today. Work needs to continue to break down the cultural barriers and reduce the social stigma through raising awareness and education. The Champions have developed a trust within their respective communities and this is evident from the number of attendees at activity sessions and peer support groups. The number of individuals and family members approaching the Champions on a one to one basis was steadily increasing directly as a result of the hard work from each of the Champions in promoting the support services available in ways which were culturally appropriate. It is apparent that the Champions were reaching individuals with dementia and their carers who were not accessing mainstream dementia services.

Some BAME communities, e.g. African Caribbean, are known to be at a high risk of dementia, particularly vascular dementia. With Liverpool's ageing BAME population, the city's dementia strategy needs to reflect the actions which LCC/LCCG will be taking to better understand the needs of its ageing BAME communities and prioritise action to address ethnic inequalities in its mainstream health services.

Implications for current strategy refresh

There is a high risk of disillusionment with public services; we can anticipate responses such as '*why bother/what is the point?*'

Whilst there is disillusionment with health services, there is a commitment from the Liverpool DAA Diversity Sub Group members and from the organisations hitherto involved in the Dementia Champions service, for people living with dementia and their family carers to be given the opportunity to have a voice in the consultation exercise.

The feedback from the 2012 BAME Dementia Consultation event remains valid today. It will be important to check out current views and highlight any new needs that may have emerged, although this may evoke a response of '*we've told you all*

this before’.

Next Steps

The LDAA has asked Chinese Wellbeing to co-ordinate engagement with the BAME groups in the city. Chinese Wellbeing has already made approaches to several organisations known to provide dementia support via peer support groups and therefore have direct access to people living with dementia and their family carers as follows:

Back to Life Liverpool (African Elders)
Irish Community Care
Mary Seacole House
Alive Believers

The above organisations are keen to assist with the engagement on behalf of their respective communities. Chinese Wellbeing will host a meeting to discuss our approach to the engagement about the strategy, given the particular sensitivities following withdrawal of funding to support the Dementia Champions.

There are a number of organisations that may be able to promote engagement through their networks to establish active participation from organisations that may be willing to coordinate this activity within their service user groups, as follows:

LCC Community Relations Unit
LCVS – Welfare and Wellbeing Organisations Network
Jewish Community Care
LCCG VCSE Engagement Panel
Liverpool Home Care Providers CIC
Registered Social Landlords
Liverpool Carers (Local Solutions)
Dementia Care Navigators (MerseyCare)