

# iris

Stimulating Thinking on dementia policy and practice from the  
Dementia Services Development Centre at the University of Stirling

## 03. Voices and assets

### Dementia in black, Asian and minority ethnic communities

#### The importance of voice

**W**hat dementia means is different in different communities. These differences determine what people think and do.

Central to the DSDC work in London was the creation of the right conditions for open exchange between people in communities, both between each other and with others with different experiences and knowledge from outside the communities. This exchange was not limited to dementia but embraced many other sensitive issues around respect, faith, meaning, death, ageing and love. There is little evidence that this type of trusted space for conversation and exchange is being generated with any conviction in BAME communities (or even seen as necessary by planners or professionals who could help stimulate and support these conversations). Our work shows that local communities themselves have a real thirst for knowledge and that external agencies can have a role to play in helping encourage voices from across communities, all of which will play a role in making and sustaining change.

It is not difficult to see how an approach which promotes conversations resonates well with the way families, social spaces and communities actually work and evolve over time. Of course doing this properly can take time and is likely to appear, at least to professionals, as a messy, even unnecessary process. Professionals after all know what communities need to know about dementia, don't they? For them the issue is one of making these messages about how they "ought to" regard dementia culturally sensitive, isn't it? It often comes under the guise of awareness-raising. We argue that such an "awareness raising" approach is often not regarded as appropriate by BAME communities themselves and, more importantly, is unlikely to work as an agent for change.

*We all know dementia is a clear social and economic priority in the UK. So why is dementia in black, Asian and minority ethnic (BAME) communities still so widely ignored and marginalised? This Iris, based on recent work undertaken by DSDC<sup>1</sup>, argues that real change will only come through growing much greater understanding of what dementia actually means in each local community and through the development of those resources and assets around dementia which communities themselves decide will work for them.*

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<sup>1</sup> Dementia in South West London – Responses and Actions;  
Dementia Services Development Centre 2014

## Knowledge versus awareness

Our suggested approach is framed differently. It is based on absolute respect for the fact that trusted knowledge and local assets either already exist or need to be developed by communities themselves over time. This runs counter to the underlying philosophy of national policy implementation which is predominantly top-down, based on the rolling out of exemplar projects and seeks delivery of changes against aggressive, centrally-set deadlines. Of course there is some level of involvement of non-professional voices in elements of the national programmes, but local dialogue and support linked to genuine asset-based community development does not sit easily with such driven change. However it is the only way change of lasting value will actually happen and stick.

## One question

Our belief is that real effort has to be made to pursue a single primary question – *What is the meaning of dementia (to people in this community)?* For professionals this involves resisting any temptation to leap forward to “solutions” which come framed in professional language or even from advocacy organisations, if those solutions are imported from outside those communities. For communities it involves connecting, shaping and gathering together conversations and pulling different sorts of knowledge towards themselves.

## The meaning of dementia in communities

Understanding of dementia is shaped by complex cultural assumptions about ageing, family, faith and the nature of community. Understanding dementia means understanding cultural framing and ever-changing individual histories and shared experiences.

This is especially important in BAME communities. Although no general assumptions should ever be made, it is safe to assume that many BAME communities are enclaves within a dominant culture. The dominant culture’s understanding of such a complex psychological, physical and social condition can be imposed, but that framing of dementia is not sustainable because it does not change the minority culture. It is the process of exploring local meanings that anchors real change. It is also important to be alive to dangerous and counterproductive generalisations even as minority voices are gathered. The term “BAME communities” is probably unhelpful in capturing what are very different issues of development and aspiration of people from diverse backgrounds, cultures and experiences, but has some value when opening up these general principles with the dominant health and social care players.

## Overcoming stigma through conversation

Dementia is referred to more openly now than in the recent past in most communities but still carries a high level of stigma. BAME communities are no different in this respect. However, if they do have a familiar way of talking about it, it is often couched in terms that the dominant culture would abhor, such as “mad” or “senile”. Forbidding these familiar terms and frames of thinking leaves a vacuum if they are only replaced by vocabulary that is framed by public sector or third sector professional political correctness. This means that dementia tends to surface as an issue when it forms part of wider discussions about essential stages of life, rather than being a subject which people see in isolation or name as “dementia”.

So dementia is most likely to emerge in conversations about healing and coping; ageing and family relationships; death and dying. It links into shifting individual, faith and community histories and shared experiences. It is in these conversations that the meaning of dementia must be understood and actively engaged with. This is the foundation for community understanding and action. The critical issue is how you can do this.



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Stimulating Thinking  
on Dementia Policy

## Techniques and approaches

The national recent trend is for a generic “awareness raising” approach which is a largely passive act of exchange that is dominated by professionals, and includes tokenistic engagement or involvement, often through a model involving representatives of the community. A model which is more likely to succeed is one which is about “knowledge exchange” – a more messy one which is sensitive to how local communities already work, the assets they have and the complex way dementia may be described and engaged with in faith and community settings.

There are a number of different ways in which communities are likely to be engaging with dementia.

### Growing knowledge

Sometimes local faith communities simply want to know more about dementia. Specific incidents happen which bring the issue to the forefront of conversations. Statutory consultation on services may prompt the need to articulate what needs the community feels should be met and how. Commissioners and providers of services might reach into communities as part of routine engagement practices. Leaders or members of communities might become involved in discussions as part of governance arrangement. Local community initiatives may open up opportunities. Asset-mapping exercises may run.

In each of these examples it is unlikely that the primary question will be about what dementia means in that community. But in each case that should be the primary question – one framed by the dialogue in that community and respecting how and where dialogue takes place. An added focus and expertise around dementia or ageing or food or health in general is essential because technical questions will arise that need to be answered as the discussion goes along. External support for these discussions is vital to open access to objective information, but without forcing an external cultural view of what dementia is.

### The importance of conversations

DSDC usually use a combined workshop and conversation approach, working closely with a wide range of local people who are briefed and supported to seek to initiate conversations. Sometimes this might involve creative people from within the community who are not the “usual suspects” already leaning towards the issues of dementia and ageing, or health and care more generally. Each process is different and has to be shaped by the specific communities themselves. Initially this might include a small number of open questions designed to explore what dementia means and to surface local experiences. On others the research background of DSDC can be helpful in opening different discussions built around technical knowledge of dementia. What is common is the importance of external, respected agency – this can help move conversations forward and give a shape to where they go.

Recording and documenting is important as themes and questions recur and resurface in an interactive way which might get missed. Discussion is progressive and generative. For example over the length of projects a number of specific question areas keep recurring:

- what are the early symptoms and what to do when they are apparent
- where to get a diagnosis and access to medication
- how to delay the symptoms
- what to expect in terms of stigma and how to deal with it
- how to deal with anxiety and difficult behaviour
- how to move towards acceptance?



In parallel the value of open discussion between faiths and communities also becomes more apparent as the conversations and workshops develop momentum, revealing a lot of existing awareness of what effective community responses to dementia might look like including:

- preparing well in advance (years ahead)
- promoting activities which counter the effects of dementia
- gathering together people who have experience of dementia
- providing games, music, activities outside the home for people with dementia
- the befriending of families by others.

## The role of professionals

As our thinking has developed we have become less sure whether the dialogue around dementia actually needs to involve health professionals. (It does not use professional language for sure). It is likely to go beyond “dementia” and of necessity engage exploring what assets in those communities can be relied upon into the future, as the communities themselves see them and make them work. Given these histories it is hardly surprising that statutory services and health planners are largely irrelevant to the way people conceive of dementia and effective responses to it.

## Problems with current approaches

Increasing numbers of “state of the nation” reports<sup>2</sup> give the impression that positive progress is being made to address the social impact of dementia through top-down investment, a flurry of different initiatives and, above all else, the growth of dementia-friendly communities as a focus for action. The value of this activity remains largely outside formal or independent processes of evaluation and resistant to critical engagement. However recent work in London by DSDC and others, suggest that the Prime Minister’s Dementia Challenge has failed to reach into BAME communities in any meaningful way.

Apocalyptic data, which emphasises the scale of “the problem” of dementia’s future growth is still used to frame why dementia is a priority. This is off-putting to many local communities when it frames dementia as a tsunami and reinforces stigma and stereotype. It is likely that framing of dementia in terms of family and community responses to immediate challenges they face in their homes and communities will achieve more success.

The desire to develop a clear approach to what might work is no excuse for leaping to conclusions. The excellent 2014 Race Equality Foundation Report<sup>3</sup> concluded that dementia is misunderstood and highly stigmatised in BAME communities. They suggest one response is a single, culturally-appropriate dementia pathway from diagnosis to end-of-life. Professional language and framing is a real problem here. Dementia, a medical term, is not the term or even the concept used by many people in BAME communities to engage with dementia. And the idea of pathways (which are intended to provide coherence and clarity to statutory and third sector services) or even the idea of the importance of diagnosis, do not necessarily carry weight or have helpful resonances in many BAME communities.



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2 The Prime Minister’s Challenge on Dementia Annual Report

3 Better Health Briefing Paper 30 – Black, Asian and Ethnic Communities and Dementia – where are we now? David Truswell; November 2013; Mukadam N, Cooper C, Livingston G. A systematic review of ethnicity and pathways to care in dementia. *Int J Geriatr Psychiatry* 2011; 26:12–20

## Disconnected services

There is a fundamental disconnection between local communities and key gatekeepers such as local GPs. One conclusion of the DSDC report was to confirm that “professional services are widely distrusted and access to them is poor”. This is seemingly still not understood by those involved in the national, high-profile work which continue to build around a broken model of paternalistic provision. There is a tension between the idea of a pathway, which is a tramline into which you may be able to fit yourself, and the alternative idea of a map, with the help of which you can find the way that suits you through the tangled environment.

## Connecting communities?

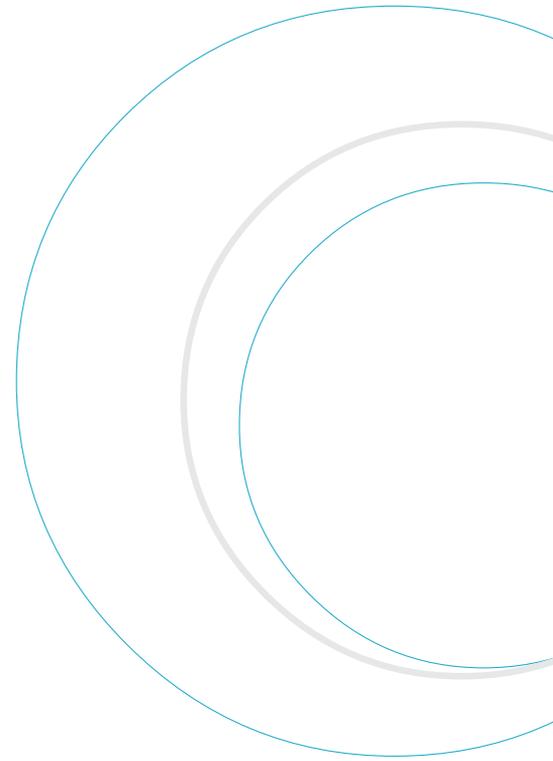
For example the Alzheimer’s Society, central to the development of Government policy on dementia, has secured government funding for a small London-based project called Connecting Communities. This should be good news at it is seeking to address dementia in BAME communities in London. In its own words this “will see volunteers from black, Asian and ethnic minority communities designing and delivering awareness raising activities that are culturally appropriate for their communities. Across eight London boroughs, Alzheimer’s Society aims to: raise awareness of dementia amongst diverse communities across different generations, highlight the importance of seeking an early diagnosis and how to do this locally; and build a local volunteer base that is reflective of the demographics of the area. Project findings will inform a black, Asian and minority ethnic commissioning toolkit for local authorities and volunteering best practice for the UK and London.”

The evidence of our work suggests that there are several problems with the way this is conceived and is being executed.

**Firstly** it is about “awareness raising”, which encompasses a sense of better-informed people telling the unenlightened what they think they ought to know. An alternative approach is to create space for exploring the understanding of dementia in the context of each community by genuine exchange and support.

**Secondly** it places undue emphasis on diagnosis. To be clear, diagnosis is extremely important for those who are comfortable with what is provided by the dominant culture. However, what value is a diagnosis if you don’t trust or have access to statutory services? How helpful is diagnosis if all it does is leave you with a label and a language that is alien to your culture?

**Thirdly** it talks of building a volunteer base. This seems to see this volunteer capacity as something new rather than recognising and building on the networks and activities that are already working in those communities. These may well not be about dementia but focussed on completely different issues – in some cases issues that are uncomfortable for the dominant culture. There is really nothing here about asset-based community development or recognition that the communities themselves are really the place to start.



## More national prescriptions

In 2013 the House of Commons All Party Parliamentary Group on Dementia published "Dementia does not Discriminate"<sup>4</sup> which sought to map out the issues relating to BAME communities and dementia. A set of actions, all made as recommendations for statutory and third sector bodies in the new English health landscape, promotes a cocktail of awareness-raising, behavioural change led by public health officials, dissemination of "good practice", improving access to services and improving staff knowledge and skills. In other words it offers another national top-down prescription which sees a number of agencies as the paternalistic drivers of change rather than starting with the communities themselves. The idea of assets and knowledge around dementia as being something which rightly resides in communities who own and develop them has no place here. It is easier so much easier to provide set agendas for agencies than it is to consider how to stimulate the right conditions where communities can focus on what they need, not what others think/know they need. This makes life easy for the agencies. It cuts out the voice of the communities themselves. Neat wins over messy.

## Assets under threat

During our work in London communities expressed a clear view that some of the core assets they rely on are under threat from changes which the communities themselves see as beyond their influence – for example funding decisions affecting local organisations, physical meeting spaces and community services and resources. Places where people have traditionally come together physically to interact are reducing – so where do you go now for difficult conversations?

## Conclusion

Dementia in BAME communities requires a fundamentally different approach than is being widely taken in the UK at this time.

A shift is needed from a paternalistic approach tied up in professional language and programmes of "awareness raising" to approaches which enable communities to grow knowledge, support responses and develop assets within their own communities in a way that each community itself determines will work best for them. This asset based community development approach resonates with other work in this area which argues that sustainability starts and ends with what is sustainable inside communities. It is not something which it should be assumed statutory institutions (the NHS, local community services or even the third sector bodies linked to government) automatically can play any really active or constructive role. It is certainly not something which can be imposed top-down as a part of national programme or as a response to a remote, "results-driven" political Challenge. But it is something where positive action can be supported in a way the DSDC report points towards:

*"There was a strong feeling from the workshops that communities themselves need to take responsibility for training their own dementia leaders and for pressing for more relevant and interactive information from statutory and third sector sources. There was also a clear feeling that the specification of what information was needed should be co-produced with "experts". The whole project revealed rich networks that already exist for social reasons. These seem fertile places for growing knowledge which would have credibility and relevance to local communities. The point that follows from this analysis is that it is not about adding to but about replacing some existing approaches to dementia awareness."*



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4 Dementia does not Discriminate – The experiences of black, Asian and minority ethnic communities; July 2013

The real challenge is about how communities can be supported to equip themselves with the knowledge they themselves need and to determine for themselves what dementia means for them. What is then needed as a result may well look very different from current top-down prescriptions. It is much more likely to actually help improve the lives of people on a continuing basis as this approach will place dementia as a live issue integral to the communities themselves and a natural part of conversations already taking place (as they always have been) about how those communities get through life.

There is much to be done but it starts and ends with what BAME communities themselves decide they need to know about dementia and what assets are developed as a result.

The Dementia Services Development Centre (DSDC) exists to improve services for people with dementia and their carers throughout the UK and beyond. We do this through research and teaching and by supporting workers and organisations that provide care for people with dementia. Our staff of academics, health and social care professionals, researchers and event organisers provide comprehensive dementia education and training, consultancy and research services. The Centre's flagship Iris Murdoch Building is a model for dementia friendly design. This open and welcoming environment provides inspiration for our team's work in designing and remodelling care homes for people with dementia. Research into understanding the needs of people and how to support them is central to our work. The Research Group are members of the University of Stirling who conduct research into our understanding of dementia and related matters. Their research projects help to improve the quality of life and services for people with dementia and their carers.

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