

Serving the needs of marginalised groups in dementia care: younger people and minority ethnic groups

SUMMARY OF KEY FINDINGS AND CONCLUSIONS

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Gavin Daker-White, Angela Beattie, Robin Means and Jane Gilliard

University of the West of England, Bristol and Dementia Voice, the dementia services development centre for South West England

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Availability of the full report

The full report of the study described in this summary is freely available as an Adobe Acrobat file on the world wide web:

http://www.dementia-voice.org.uk/Projects_Marginalised_Groups.htm

Alternatively, hard copies are available from Dementia Voice at the following address (please enclose a cheque for £5 – payable to 'Dementia Voice' – to cover postage, packing and administration):

Dementia Voice,
blackberry Hill Hospital,
Stapleton,
Bristol BS16 1DD

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SUMMARY OF KEY FINDINGS AND CONCLUSIONS

Aim - The aim of the study described in this report was to examine the needs and provision of services to people with dementia under 65 years of age and people with dementia from black and minority ethnic groups.

Scope - The bulk of this report is concerned with presenting the results of around 100 interviews with professionals, carers and people with dementia in the South West of England.

Methods – Qualitative interviews were conducted with professionals, users and carers living or working in Bristol, Gloucestershire and Cornwall. The study was framed by preceding literature reviews and a postal questionnaire survey of service providers.

Relevance - The range of people interviewed, and the use of different ‘case study’ local authority areas within the South West, should mean that results find resonance with users and providers of services throughout the United Kingdom.

Original Contribution - The main original contribution of this study relates to the inclusion of the views of people with dementia from marginalised groups (and their carers), whose voices have been largely absent from the literature to date.

Results – International Literature Review (Younger People) - The majority of the available literature concerning younger people in dementia care originated in the UK. However, aside from a few prevalence studies, and some exploratory work with small numbers of service users, little in the way of empirical work was available. The main recommendation concerning younger people in the dementia care literature was that specialist, age-appropriate services should be provided within a person-centred or tailor-made model of care (Beattie *et al.*, 2002, in press).

Results – International Literature Review (Minority Ethnic Groups) - Most of the literature concerning minority ethnic groups in dementia care had US origins. The main issues covered in the literature were the under-utilisation of services by minority ethnic groups; the prevalence of dementia in different ethnic groups; the experience of care giving in different racial groups and language as a factor in cognitive assessment. There was little consensus amongst the articles about

whether services should be provided specifically for different ethnic groups, reflecting a lack of evidence concerning the efficacy of different models of service provision (Daker-White *et al.*, 2002, in press).

Results – Postal Survey of Service Providers (Younger People) – Twenty-one (60.0%) health and social care organisations had not investigated the numbers of younger people with dementia in their catchment areas. In 1999 there were between 64 and 80 service users in the catchment area of one Bristol hospital, and an estimated 282 cases in the whole of Avon health authority. A similar exercise undertaken by an NHS Trust in Dorset suggested that there were 353 people with dementia aged 60-64 in that county. Only 2 specialist services for younger people with dementia were identified in the whole of South West England. Respondents were divided as to whether the needs of younger people with dementia were best served via specialist or generic service provision.

Results – Postal Survey of Service Providers (Minority Ethnic Groups) - When asked how their organisations responded in general to the needs of people from minority ethnic communities, 12/35 (34.3%) said that there were no specific services because the numbers of residents from minority ethnic groups were too low in their areas. The most common general service response mentioned for ethnic minorities was the availability of interpreting services (18/35 respondents, 51.4%), provided either in-house or via social services. Only one organisation said that they made use of services provided by a black community organisation. None of the organisations that responded to the survey had investigated the numbers of people with dementia from minority ethnic groups.

Results – Qualitative Interviews – 61 Professionals in South West England

- **Context:** Two fundamental structural factors emerged that were seen to affect the provision of services to marginalised groups in dementia care: budgetary constraints and issues in cross-boundary working in health and social care. Because of funding constraints, social care for people with dementia seems to be rationed, mainly via the use of complex bureaucratic procedures. Workers often have to “exaggerate to make a case” for providing services to an individual client. Problems of referral and working across geographical boundaries are compounded by the fact that different authorities will not all pay the same rates for the same services.

- **Access:** For members of marginalised groups, the fundamental issues in access relate to the small numbers of people involved, and their geographical dispersal. For younger people with dementia, the basic issue surrounds the age limits set by geriatric psychiatry or other 'elderly services' that have traditionally provided services to people with dementia. In the case of minority ethnic groups, access is mostly limited by virtue of the perceived cultural inappropriateness of services used almost exclusively by white people, a lack of awareness of mainstream provision, and the possible reluctance of some to engage in services perceived to have authoritarian and racist functions within a 'white officialdom.' However, marginalised groups in dementia care are also constrained by those access issues affecting everyone with dementia. Respondents from the main providers of dementia care in the region reported that those who are most successful at finding out about services tend to be articulate, middle class people with the skill and tenacity to navigate their way around the helping agencies. Younger people, as older people with dementia, tend to be 'slotted in' wherever there is a vacancy.
- **Service Provision (Younger People):** Across South West England, there is a scarcity of specialist care for people with dementia. The fieldworkers only identified two specialist services for marginalised groups with dementia in the whole of the region, both were for younger people and both were situated in urban areas.
- **Service Provision (Minority Ethnic Groups):** The fieldworkers only identified two day care centres specifically for minority ethnic groups, both in Bristol. When it comes to nursing or residential care, there was a similar dearth of specialist services for minority elders, including those with dementia. It is questionable whether people would find the very limited services available in most places relevant to their needs.
- **Waiting Time** for an assessment emerged as a major hurdle. One interviewee reported a 23-week waiting list for assessment for residential care.
- **Transport:** Some day centres reported that they were reliant on carers having their own transport. Transport was a particularly limiting factor in Cornwall, with people missing out on day care because relatives could not afford to pay the necessary transport costs.

- **Dementia Diagnosis:** An interesting tension was apparent in informants' accounts, between the desirability and benefits of an early diagnosis and referral to services in dementia, and the possible disadvantages of being labelled and treated as "beyond help." black people may be at increased risk of being misdiagnosed.
- **Groups Served:** Respondents pointed out that some services are most geared up for the management of risk and dealing with those in crisis. However, other services only seem prepared to work with people at particular levels or stages of dementia, usually the early stages. In the early or 'mild' stages of dementia, people can be cared for in generic services, which may or may not be suitable to the needs of marginalised groups depending on local circumstances.
- **Needs:** When asked about the needs of people with dementia in general, respondents' centred on the necessity of a secure and familiar environment coupled with a consistent, structured approach.
- **The Constraints of a Risk Management Approach:** Only one respondent in a nursing or residential home recognised, and made provisions for, people with dementia to 'wander'. For most staff in homes, wandering was rather viewed as a nuisance (for both staff and other residents) or a security risk. The bulk of informants seemed most concerned with managing risk in people with dementia.
- **Needs Assessment:** The numbers of different services needed in a care package (e.g. sitting services, respite, day care, home care, meals on wheels, personal care); the piecemeal nature in which services are provided; and the shortage of relevant or 'specialist' services exacerbates a situation where people are assessed repeatedly by different people. People with dementia were seen by some professional respondents as having very little insight into their own needs.
- **Staffing Issues:** The most common issues articulated about staffing centred on the low wages paid to care staff, and the need for staff to be trained specifically in dementia care. The basic argument advanced by managers in care homes was that low rates of pay for care staff mean that it can be difficult to fill vacancies; staff turnover is high; and, managers have to employ "the wrong kind of people". In addition to the reported difficulties of employing staff at all levels, a particular issue that emerged was a perceived shortage of

trained mental health nurses in two of the local authorities. In addition to workers not being paid at levels where they would feel valued, many organisations have insufficient staff numbers to provide even the most basic service. These staffing and skills shortages fundamentally undermine the possibilities of individualising or ‘tailor making’ services. As a result of these and other issues, users end up in services that cannot meet their needs or are even inappropriate.

- **Younger People in Services:** Many interviewees argued for the special case of younger people in services. The most interesting issue for services in practice seemed to be the ways in which younger people with dementia attending elderly services had tended to adopt caring roles (either willingly or by design of the care staff) towards other service users. This issue seems to relate to the fact that in services for older people, users are distinguished from staff by virtue of their age, and changing their role is apparently one way of making the service seem more appropriate. Other respondents could not see why services should be provided according to a person’s age. A dementia specialist questioned how the specialised, emotive needs of younger people could be justified when services (provided predominantly for older people) are “dire across the board.”
- **Arguments for Specialist Services for Younger People:** A fundamental reason for arguing for specialist services for younger people seemed to be the assumption that people of different generations should not mix with each other. Another argument in favour of segregated services for younger people (within the assumption that they have early stage dementia) is to protect them from the knowledge of how they might end up.
- **Black and Minority Ethnic Groups in Dementia Services:** Of the issues facing black and minority ethnic groups in dementia care, language was the major issue raised in the interviews. Racism is fundamental to any understanding of the position of black and minority ethnic groups in dementia services. black service users may also experience racism from white service users or their relatives.
- **Perceived Views of Black and Asian Service Users:** During the interviews, some staff articulated the ‘myth’ that ‘black people look after their own’. Another common view of black and Asian people was that they ‘tend to stay within their own communities.’ Another perceived issue was the stigma of dementia, and an associated unwillingness by family members to “wash their dirty linen in public.”

- **Meeting the Needs of Minority Ethnic Groups:** Many services do not know how to meet the needs of caring for these groups, as they have no experience. However, where services had such experience, it seemed as though they had learned from the experience and modified their approach. The essential question for seems to revolve around the ability of mainstream services to be responsive to individual's cultural and religious needs. In the context of these interviews, 'cultural needs' were understood to mean language, diet, bathing, hair care and skin care. Although specialist black agencies and community organisations exist, access to these services is often only when other organisations have failed. In addition, some black workers questioned the ability of these organisations to provide services to people with mental illnesses or dementia.
- Specific criticisms of services and manifestations of unmet need are detailed on pages 34-36 of the full report.
- Specific examples of flexibility and an individualised approach as identified by the fieldworkers are detailed on pages 55-57 of the full report.

Results – Qualitative Interviews – 14 Younger People with Dementia and 16 Carers in South West England

- **Interview Sample – Younger People with Dementia:** The ages of respondents with dementia ranged between 41 and 66 years, the mean being 59 years. The majority of the younger people interviewed with dementia (n=10) lived with their carers at home, 3 were living independently and 1 was living in a residential home. One was attending a day care centre for older people, 8 were attending specialist day care centres for younger people with dementia, 4 were not attending any service and 1 was in a residential home.
- **Dementia Diagnosis:** For the younger people with dementia, diagnostic testing was seen as 'baffling' and as leading to a sense of incompetence. Their accounts also raise issues around consent in dementia diagnosis, and the possible effects (deleterious or otherwise) of receiving a diagnosis. Informants' accounts suggest issues surrounding are complex. This may reflect the difficulties in recognising the signs and symptoms of early dementia, and possibly GPs' lack of experience, given the relative rarity of the condition in younger people. From accounts of the experiences of younger people, the cognitive assessment process and the 'news' of dementia can be a baffling, hurtful and frightening experience.

- **Specialist Services:** Age appeared to be a paramount concern for most of those interviewed. The majority of respondents commented that mixing with other younger people with memory problems was a positive experience. Care and services in older people's settings were viewed negatively. Thus, most respondents expressed the wish to be placed in age-appropriate services. Nine (64% of the total sample) younger people with dementia were receiving a limited dedicated specialist service. Most of the respondents who attended specialist day centres commented positively on them, and highly valued the opportunity to socialise with people with similar problems.
- **Knowledge about Services:** Generally, the perception of younger people with dementia in relation to what services were available was that most did not know of any, apart from the specialist day care service they were attending:
- **Service Needs:** It was evident from the majority of interviews that there was an overwhelming desire for purposeful activities that matched their level of fitness and capabilities. The ability to walk, go to the pub, go shopping, or do gardening, woodwork, art work, sculpting, were mentioned.
- **Loss of Self:** The theme of 'loss' was a central feature of the interviews with younger people with dementia. For some, the sense of having little or no independence or feeling 'invisible' came out in the interviews.
- **Interview Sample – Carers of Younger People with Dementia:** Sixteen carers (7 male, 9 female) of younger people with dementia were interviewed in their own homes.
- **Dementia Diagnosis:** Carers spoke of a 'journey' when talking about the diagnosis of dementia. For many this was a long and tortuous process. Many reported that it took "persistence," "badgering" and a "battle" to have their concerns taken seriously by their GP in the early stages of the disease. When a diagnosis was finally received, carers reported that this took between two and eight years. The possibility of misdiagnosis, in particular, where there was a history of mental illness, was another feature in some carers' accounts.
- **The Impact of Dementia and the Burden of Care:** The most central and consistent theme present in carers' accounts was the 'burden' of caring that many experienced. This was reported as a stressful and at times daunting experience. Most carers also spoke at length about how dementia affected their lives, families and their relationship with the wider community. Overall, there was a perception that their lives had been taken away, and, instead of this being 'their time', their life appeared to be placed on hold. Where carers

were coping with work it was evident that they were finding it difficult to cope. Moreover, feelings of guilt and not having enough patience were also a feature of these accounts. These carers raised questions around what support is available and how effective that support is in helping carers manage their 'burden' of care.

- **The Emotional Impact of Dementia:** Carers spoke of a range of emotions which their families had experienced. For example, feelings of pity, wanting to look after the person and at the same time 'not wanting to know' were mentioned. The fear of their partner or relative dying at a relatively young age, and the uncertainty of when this would occur, was also reported. This was further mediated by carers' perceptions that mental decline and death were likely to be more rapid. Dementia was placing their relationships under enormous pressure. The inability of partners to remember the past was deeply upsetting for some carers. Indeed, the sense of loss, in particular the loss of a 'living' partner and not having someone to share their lives with, was a recurrent theme.
- **Isolation:** Another feature of accounts was the sense of isolation, particularly at the beginning of the caring role and their perception of not having anyone to talk to.
- **Respite Care:** Many interviewees reported an overwhelming need for regular respite care. Only one carer expressed satisfaction with the respite care offered and reported that it met their requirements. According to most carers, respite care was primarily offered within an older person's environment and was generally viewed negatively. There were also tensions evident in carers' accounts of their need for respite and 'balancing' this with their feelings of guilt. It was evident that many carers were 'torn' and were aware of their partners' dislike of going into respite care.
- **Knowledge about Services:** Of the carers interviewed, knowledge regarding care and services for younger people was generally poor. Many expressed the view that it was "luck" that they had been referred to or accessed care for their relatives. Carers used metaphors such as "battle" or "struggle" when describing access to such support. Many commented that it was through other carers and voluntary organisations (Alzheimer's Society, Dementia Care Trust) that they had found out about specialist services.
- **Views of Services:** Overall, carers felt that care and services were uncoordinated and disparate with many professionals involved, yet no one person taking direct overall responsibility. Most carers' commented that

there was a need for support to be more responsive, flexible and less crisis led. For example, the ability for a carer to contact services for help and support if one was having a “bad day” (YC25) or in need of respite, without having to wait until the planned care date or service arrived. Some carers reported their belief that specialist day centres for younger people with dementia may help improve or maintain cognitive functioning for longer. Overall, the message from carers’ was the perception that care and services are *reactive* rather than *proactive*.

- **Service Accessibility:** Many carers felt that that had their relative been over 65 years, accessing support would not be so problematic. They spoke about the unwieldiness of assessment and benefit forms and the complexity of completing them. Some felt that the forms acted as a barrier, were like a “minefield” when attempting to claim various benefits and did not always reflect their position or the reality of caring for a younger person with dementia. Many expressed the desire for better preparation and help with these by the statutory authorities.

Results – Qualitative Interviews – one person with dementia from a minority ethnic group and 4 carers

- **Interview Sample:** Only a small number (3 Asian and 1 African-Caribbean) of people from minority ethnic groups were recruited and interviewed. The small numbers recruited reflects the general lack of awareness from professionals of dementia in minority ethnic groups, and their concomitant under-representation in the services where people were recruited for interview.
- **Burden of Care:** The majority of minority ethnic carers spoke of similar experiences to white carers when describing their caring roles.
- **Gender Issues for Carers:** The accounts of male Asian carers referred to how their culture prohibited them performing personal care for their female relative.
- **The Value of Older People in White Society:** Carers perceived that ageism was present, and that older people in mainstream white society were generally not valued.
- **Interpreters:** One carer commented on how difficult it was to secure an interpreter in an emergency situation, either at GPs’ surgeries or on hospital admission. Reports of having to book an interpreter in advance were also highlighted by another respondent. Communication problems were common

for these two carers. For example, when bathing, the words for hot and cold had been misinterpreted on one occasion. This account led to the comment: “If the care worker spoke the same language this would be a way forward.”

- **Visibility:** Comments that there were few paid minority ethnic care workers, and a general lack of visibility regarding minority ethnic people using services were also a feature of carers’ accounts.
- **Racism:** The issue of colour and racism was a central feature. One carer in particular, perceived that his colour acted as a barrier to receiving care and services, with the general feeling that he would not be believed and would be labelled as “lying”. The perception was that a white person would not encounter these obstacles.
- **The Value of Appropriate Services:** The introduction of specific minority ethnic services in Bristol had reportedly eased the situation for carers. One carer commented on how highly he valued a sitting service offered by one of these organisations, as it enabled him to go out independently and socialise where he had previously not been able to do.
- **Risk Assessment:** Similar issues surrounding the process of risk assessment arose during interviews with black carers as in the interviews with carers of younger people.
- **Good Practice:** Interviewees were satisfied with the specialist services they had received, where such services existed. Specific minority ethnic agencies in Bristol were generally highly valued. Dementia Care Trust was also singled out for providing care and services that matched (where possible) the ethnicity of the person with dementia. Examples highlighted were help with the preparation of appropriate diets and someone who could communicate with and understand their culture.

Conclusions and Recommendations

- Our first recommendation is that service planners and providers at all levels need to gather intelligence on younger people with dementia in the areas served by their agencies. In the absence of such intelligence, it is impossible for providers to effectively plan and organise appropriate care.
- The main message to service providers in relation to minority ethnic groups is the need to consult black people about service developments.
- An underlying theme emerging from the research seems to be the view that, in their current form, the bulk of health and social care services for people with dementia are unable to adapt their services to be flexible to the needs of

individual people. The ramifications of the structural, financial and organisational constraints to individualised care are wide reaching and affect all people with dementia, whether they are a member of a marginalised group or not.

- As one respondent to the questionnaire argued, younger people, as well as older people, are likely to gain most benefit from services which treat people as individuals, rather than invoking “arbitrary age cut off points” as criteria for accessing them. However, the younger people and carers interviewed for this study were clear that they wanted age-appropriate services and did not want to be, as they saw it, ‘lumped in’ with elderly people.
- One of the main challenges for service providers in dementia care seems to be how the needs of marginalised groups can be met in rural or sparsely populated areas.
- Our third recommendation is that one of the best ways for services to address the needs of marginalised groups in dementia care is by investing in overall improvements in care and services generally.
- Recognition and engagement with the needs of minority ethnic groups in dementia services should continue and expand. However, there comes a point where intelligence and vision must be translated into money and practice.
- Clearly identifiable training needs remain for staff throughout the health and social care system. Such training needs to focus on the effect of racism on service provision for black people, as well as fostering an increased awareness of the distinction between concepts like ‘nationality’, ‘race’ and ‘ethnicity’. Again, we are minded to state that as with younger people, the way to improve black people’s experiences of services is by fundamental systemic changes that would also benefit staff, carers, and everyone with dementia.
- The only advantages of an early diagnosis for potential service users seemed to be for younger people with dementia who lived near the only two regional specialist day care centres. This would suggest that there is little point in pursuing an early diagnosis where relevant services and follow-up care are not available. The research also questions whether cognitive assessment could be managed in more friendly and humane ways that are not seen to frighten, worry, or bewilder people with dementia and their carers.
- Notwithstanding the universal (and perhaps unsurprising) criticisms of the health and social care system, we would stress that the evident deficiencies are magnified for marginalised groups, and as such, it is these financial and

organisational issues (as well as ageism and racism) that fundamentally affect the provision and utilisation of dementia services in marginalised groups.

- The most clear and practical need to emerge from this study is the lack of flexible respite care, relevant to individual needs and the need for transport to be organised, provided and paid for by services. Once again, we can see how the key to improving services for marginalised groups lies in improving services for everybody with dementia and their carers.
- Services and professionals need to be made aware that contrary to popular belief, many people with dementia are able to recognise and articulate their needs, and do have opinions about services, including the sort of services they would like.
- Where specialist services have been provided for marginalised groups in dementia care, they have been highly valued by people with dementia and their carers.