

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

FINAL REPORT

May 2002

*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

DEMENTIA



VOICE



University of the  
West of England

**A programme of original research funded by Community Fund**

**COMMUNITY  
FUND**

*Lottery money making a difference*

## Contents

Acknowledgements	4
Availability of this report	4
<b>Summary of key findings and conclusions</b>	<b>5</b>
<b>Chapter 1 – Introduction, research methods and initial results</b>	<b>18</b>
<i>Results of a postal survey of service providers</i>	
- A: People under 65 years of age	19
- B: People from minority ethnic groups	21
<b>Chapter 2 - The views of professional carers and service providers, Gavin Daker-White</b>	<b>23</b>
<i>Fieldwork methods</i>	23
<i>Introduction One: The structural and institutional contexts of service provision</i>	24
<i>Introduction Two: Accessing care</i>	26
<i>Introduction Three: Dementia diagnosis, disease progression and user's needs</i>	29
<i>The assessment of need system</i>	32
<i>Unmet needs and criticisms of existing provision</i>	34
<i>Staffing issues</i>	36
<i>Specific issues facing younger people in dementia care</i>	39
<i>Issues facing black and minority ethnic groups in dementia care</i>	49
<i>Examples of flexibility and an individualised approach in service delivery</i>	55
<b>Chapter 3 - The views and experiences of younger people with dementia, Angela Beattie</b>	<b>58</b>
<i>Introduction</i>	58
<i>Methodology</i>	58
<i>The views of younger people with dementia</i>	60
<i>Dementia diagnosis</i>	62
<i>Service provision and specialist service provision for younger people with dementia: is age an issue?</i>	65
<i>The needs of younger people with dementia</i>	69
<i>The family context for younger people with dementia</i>	71
<i>Models of good practice: alternative, more 'individual' services?</i>	71
<i>Reflecting on the interview process with younger people with dementia</i>	72
<i>Interviewing younger people with dementia in the more advanced stages</i>	72
<i>Accessing younger people with dementia</i>	73
<i>Issues of interpretation</i>	74
<b>Chapter 4 - The views and experiences of carers of younger people with dementia, Angela Beattie</b>	<b>75</b>
<i>Fieldwork methods</i>	75
<i>The 'burden' of caring: the subjective experiences of caring for a</i>	

<i>younger person with dementia</i>	75
<i>Family dynamics and how caring for a younger person     with dementia impacts upon the family</i>	78
<i>The role of caring: isolation and loss</i>	80
<i>Having younger children: how dementia impacts upon the family</i>	81
<i>Dementia diagnosis</i>	82
<i>Carers' Needs</i>	84
<i>Respite: the position of younger people with dementia in an older     person's context</i>	86
<i>Accessing care and services: carers' knowledge regarding services</i>	87
<i>Accessing care: age issues</i>	88
<i>Accessing care: benefits and barriers</i>	89
<i>Carers' unmet needs</i>	90
<i>Carer satisfaction</i>	90
<i>Examples of co-ordinated 'individual' and valued services</i>	92
<i>Recommendations for future care / models of good practice</i>	92
<i>Stigma, labelling and powerlessness</i>	93
<i>Risk and the management of risk</i>	94
<i>Methodological and conceptual issues</i>	95
<b>Chapter 5 – The views and experiences of minority ethnic carers of people with dementia and one person with dementia, Angela Beattie</b>	96
<i>Fieldwork methods</i>	96
<i>Burden of care</i>	96
<i>Duty of care and cultural obligations: "They look after their own"</i>	96
<i>Communication and language barrier issues</i>	98
<i>Services and service provision for minority ethnic people     in mainstream services</i>	99
<i>The issue of colour</i>	99
<i>Need</i>	101
<i>Risk assessment</i>	102
<i>Good practice</i>	103
<i>Results from the interview with a minority ethnic person     with dementia</i>	103
<i>Interpretation issues</i>	104
<b>Chapter 6 - Conclusions and recommendations</b>	106
References	114
Appendix 1 - Questionnaire used in the postal survey of service providers	115
Appendix 2 - Feedback from service providers at a stakeholder conference held at Dartington Hall, September 2000	118
Appendix 3 - Final topic guides used in depth interviews	122

## **Acknowledgements**

This study was funded by Community Fund (formerly National Lottery Charities Board). We would like to thank Charlie Sheldrick, Jo Moriarty, Wendy Smith and Paul Burton, who acted as external advisors and provided valuable comment and guidance. The study would not have been possible without the assistance of those professionals, carers and people with dementia who agreed to be interviewed, filled in questionnaires, attended workshops, or supported the project in other ways. We hope we have represented their views fairly. We would like to thank Leigh Taylor, Deb Joy, Sandy Green and others, who transcribed interviews and provided other support to the study.

## **Availability of this report**

This report is freely available as an Adobe Acrobat file on the world wide web:  
[http://www.dementia-voice.org.uk/Projects\\_Marginalised\\_Groups.htm](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

Bristol, May 2002

## **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 this 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.

## **Chapter 1 – Introduction, research methods and initial results**

The aim of the study described in this report was to examine the needs and provision of services to groups of people with dementia who may be marginalised within the care system. Whilst we chose to focus on people with dementia under 65 years of age, and people with dementia from black and minority ethnic groups, it should be stressed that there are many other groups who are marginalised because of the ways in which services are accessed and provided.

The bulk of this report is concerned with presenting the results of around 100 interviews undertaken with professionals, carers and people with dementia in South West England. The range of people interviewed, and the use of different 'case study' local authority areas within the South West, should mean that our results find resonance with users and providers of services throughout the United Kingdom. The main original contribution of our 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.

The study was preceded by a comprehensive, international, English language literature review, that examined all of the available studies relating to marginalised groups in dementia care (Beattie *et al.*, 2002, in press; Daker-White *et al.*, 2002, in press). Interestingly, the majority of the available literature about younger people in dementia care originated in the UK (69 of 74 relevant articles identified). 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). On the other hand, most of the literature concerning minority ethnic groups in dementia care had US origins (44 of 67 papers retrieved). 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).

Following the literature reviews, the research team undertook a postal questionnaire survey of service providers in South West England. The questionnaire used is reproduced in Appendix 1. The questionnaire was sent to chief executives of health authorities (n=11) and NHS Trusts (n=30), and directors of social service departments (n=22). A covering letter stated that the questionnaire should be completed by someone with knowledge of dementia care within the organisation. The organisations targeted included all those within the South West regional office of the NHS Executive, plus those in the Isle of Wight, Hampshire, Jersey and Guernsey.

The questionnaire was first sent out in April 2000 with a second mailing undertaken in June 2000. Thirty-five organisations completed the questionnaire (55.6%). A greater response rate was obtained from NHS trusts (63.3%) when compared with social services departments (50.0%) and health authorities (45.5%).

Respondents had a range of functions including directorate, team and unit managers; chief executives; consultant physicians and psychiatrists; senior 'EMI' ("Elderly Mentally Infirm") nurses; an outreach nurse; a social worker; a project officer (for a Primary Care Group); commissioning officers; and a local authority and health authority partnership officer. The results of the postal survey are summarised below.

*Results of a postal survey of service providers – A: People under 65 years of age*

- Twenty-one (60.0%) organisations had not investigated the numbers of younger people with dementia in their catchment areas. Two of these reported that there were no plans to investigate this issue, whilst five said that the issue should or would receive priority in the future. Two organisations suggested that they extrapolated figures from work undertaken in other areas, but provided no results. Seven organisations had recorded the numbers of younger people attending services. A health authority reported that the numbers were "considerably less than research statistics would suggest" and a social services department similarly reported that there were "very few [cases] known to us". Two island social services departments each reported that they knew of four people with dementia under the

age of 65 years. One health authority had investigated the numbers of people with Huntington's chorea only. The Memory Clinic in Swindon recorded that 82 younger people with dementia were referred between 1994 and 1999.

- The most comprehensive assessment of the incidence of early onset dementia was undertaken in Avon and West Wiltshire Mental Health Care NHS Trust, although this work was unusual in that all cases under 70 years of age were classified as younger people. A variety of methods were used, including analysis of health service records and estimates based on published literature. The results suggested that 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 the South West: one in Swindon and one in Kingswood, Bristol (actually located within the boundary of South Gloucestershire). However, a respondent from one health authority said that social services provided tailor-made care packages for people with dementia under 65 in their area. An NHS trust also referred to individualised care plans. Cornwall had a specialist centre for people with Huntington's chorea, although this was not specifically for under-65s.
- Respondents were divided as to whether the needs of younger people with dementia were best served via specialist or generic service provision. Eighteen (51.4%) respondents thought that specialist services were necessitated by the special needs of this group as they do not "fit" in elderly services. One of these felt that a locally accessible generic service would be better than a distant specialist one would. Nine (25.7%) people felt that generic service provision was the only practical way to provide services given the small numbers of younger people with dementia in their catchment areas. Three people did not express an opinion either way, one felt either that a mixture of service provision was called for, whilst four argued that services for all people with dementia should be provided on the basis of individual need rather than - as one of these people put it - "arbitrary age cut-off points."

*Results of a postal survey of service providers – B: People from minority ethnic groups*

- When asked how their organisations responded in general to the needs of people from minority ethnic communities, twelve respondents (34.3%) said that there were no specific services because the numbers of residents from minority ethnic groups were too low in their areas. However, four of these people said that their organisations would respond to needs on an individual basis.
- The most common general service response mentioned for minority ethnic individuals was the availability of interpreting services (18 respondents, 51.4%), provided either in-house or via social services. Swindon social services department had established two minority ethnic outreach service posts, although the posts were both vacant when the questionnaire was completed. Other service responses mentioned were leaflets or information sheets translated into different languages (3 respondents) and specialist minority ethnic “engagement” or outreach workers (3 organisations). Only one organisation said that they made use of services provided by a black community organisation. Poole social services department was the only responding organisation that reported providing staff training around cultural issues.
- The only specialist services identified that could be used by people with dementia in the South West were a Polish residential home in Devon and a residential home for African-Caribbean people in Bristol.
- None of the respondent organisations had investigated the numbers of people with dementia from minority ethnic groups.
- Of the 25 respondents who expressed an opinion, 10 (40.0%) felt that the needs of minority ethnic groups were best served via the provision of specialist services and 14 (60.0%) felt that generic services were more suitable or practical.

The results of the international literature reviews and the questionnaire survey were presented to dementia care professionals in September 2000. Following feedback from the conference (see Appendix 2), and discussion in the study’s advisory group, the following local authority areas were selected for in-depth fieldwork: Bristol,

Gloucestershire and Cornwall. Supplementary interviews were undertaken in other parts of the region. The fieldwork methods used are described in the four results chapters below.

## **Chapter 2 - The views of professional carers and service providers, Gavin Daker-White**

### *Fieldwork methods*

The purpose of this chapter is to present the results of discussions with professional carers and service managers about marginalised groups in dementia care in South West England. Between September 2000 and November 2001, 58 interviews were held with people working in dementia care in the three local authority areas (Bristol, Gloucestershire, and Cornwall). A further 3 interviews were conducted with people working in Swindon and South Gloucestershire because the only specialist services for marginalised groups with dementia were based in these local authorities. However, several interviews involved more than one professional, so the actual number of interviewees was larger.

In each local authority case study site, informants were recruited from:

- Social services departments
- Day care centres for older people
- Specialist organisations for older people
- Specialist services for people with dementia and their carers (including statutory services in health and social care, and voluntary groups)
- Generic carers groups
- Specialist black and minority ethnic services working with older people or people with mental health problems, including advocacy groups
- Residential homes and nursing homes, whether operated by social services departments, charitable trusts or the private sector

Furthermore, different groups of workers were targeted to incorporate the views of people with both strategic and front-line caring functions. In the case of residential and nursing homes, all known homes in each authority were contacted, although many declined to participate after having the purposes of the study explained to them. Thus, the fieldworkers tried to identify those homes that either had clients from marginalised groups in their care at the time, or who had had them in the past. All of the interviews were conducted by the second and first authors of this report,

using an interview schedule which was developed and piloted in the initial interviews, taking on board feedback from the study's advisory group (appendix 2).

The objective of this chapter is to present a descriptive account of what was covered during these interviews. Thus, the aim of this chapter is not to analyse or 'deconstruct' what interviewees said. Neither is this chapter supposed to represent 'the reality' of service provision. Rather, the aim is to present the issues of marginalised groups in dementia care from the point of view of those working in services (including volunteers). Our main concern here is to highlight the main themes that emerged during the interviews, and to present the range of views considered. Reflection on this material is reserved largely for the final chapter of this report.

Following transcription, interview contents were thematically indexed using a computer software package designed for the analysis of interview data, called *Atlas.ti*. The software was used mainly for coding or labelling the interview data as the study progressed. An initial analysis of the first dozen interviews was used to refine the structure of the indexing system. This process was effected in discussion with members of the study's advisory group. The main data analysis of the professional interviews was undertaken by GD-W, although the results were checked by all of the authors of this report. The majority of the interviews (n=50) were analysed *en masse* towards the end of the data collection phase. The final dozen interviews with professionals were analysed supplementarily, partly as a reliability check on the main analysis. In this chapter, a referencing system is used to describe the origin of excerpts from interviews (e.g. 49:59–906:951) which reflects the way that *Atlas.ti* handles interview data: (interview id number : quotation number – line number start : line number finish).

### *Introduction One: The structural and institutional context of service provision*

During the interviews, 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. Thus, one social worker interviewed argued that a Community Mental Health Team was not in fact located 'in the community' but rather within medical psychiatry. One perceived effect of the medicalisation of dementia care is that within the mental health system, people with dementia have to be "mad, bad and sad" before their needs will be

funded (17:29–355:359). For marginalised groups in dementia care, ‘normal’ funding problems were compounded by the fact that the numbers of people presenting to services are tiny compared with the numbers of older and / or white people.

Moves towards more extensive joint-working in health and social services were proceeding in all three local authority areas where interviews took place, and although some social workers saw this as “joint working within a medical model” (17:6–39:49), others pointed to the ways that partnership monies could help to fund creative care packages. This was seen to have worked especially well in Cornwall, although it was recognised that the need to better co-ordinate services across sectors remained:

“It’s a bit hit and miss as to where you get your service from, and you could have one person from one area—you know, health will pay for their day centre placement—and somewhere else it will be social services. ... Sometimes social services don’t know what health are doing, and the other way round.”  
(49:59–906:951)

On the basis of the self-reported experiences of professional interviewees, it would seem as though financial constraints are a ubiquitous feature of social care provision. However, it is nevertheless important to stress that this perennial state of financial crisis militates against meeting the needs of people with dementia and their carers. Furthermore, financial aspects are exacerbated by those structural factors already mentioned:

“Down at the point where users come into services, the issue of who pays for what is still in some areas something that we need to sort out. ... There are occasions where the systems pervert ... what the [user’s] need is at the beginning. [For example,] often [at the] point of discharge from hospital, if the real consideration is, ‘This person must leave hospital because we need the bed,’ then that may be a very strong influence about where people go. ... And if ... social services ... are having big problems with their community care budget, and it’s going to be delayed ... suddenly it becomes a health care need’ ”  
(15:8–272:404)

An interesting tension arose in professional accounts, between the well recognised aim of maintaining people with dementia in their own homes, and social services departments’ inability or unwillingness to pay for some community care packages. One interviewee theorised that once an individual’s community care package costs more than £200 a week, they will then be placed in residential care, as this is

cheaper. However, this was not verified as an official or unofficial policy or practice by other respondents.

Financial shortages mean services are rationed to those users or carers who are in varying degrees of crisis. Resources are not available for everyone's needs (9:7–72:74). Even where money for creative care packages was available, it was reported that some “rarer” needs couldn't be met “on the grounds of costs” (50:7–122:124). ‘Normal’ budgetary constraints, coupled with a perceived under-funding of mental health services for older people (“dementia is not a very sexy illness,” 29:13–134:137), also means that there are no resources for service development. Government initiatives such as the Mental Health National Service Framework (Department of Health, 1999) come “with a very small amount of money” (41:8–121-124) and other grants are so difficult to obtain that organisations “don't bother” attempting (37:35–722:837), partly because of resources. Perhaps as a result of working in a ‘crisis culture’ one person argued that dementia services *need* a “controlled crisis,” to promote public awareness and government monies (41:32–576:580).

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 (17:27–303:334). 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.

### *Introduction Two: Accessing care*

The ‘career’ of a person with dementia is crucial to any understanding of service access, as people may require services at different stages in the illness. However, 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 in service access surrounds the age limits set by geriatric psychiatry or other ‘elderly services’ which 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.

Across South West England, there is a scarcity of specialist care for people with dementia. One of the main providers of specialist services in both Bristol and Gloucestershire is the Dementia Care Trust, who provide mainly a sitting and counselling service for carers (they also run a small day centre). Similar services are provided to carers in small pockets by Crossroads Care and the Alzheimer's Society. Typically, these services may be either contracted by social services as part of a package of care, or purchased individually by people with dementia and their families. No similar services were identified in Cornwall, although carers of people with dementia were receiving some support from generic sitting services.

The fieldworkers only identified two specialist services for marginalised groups with dementia in the whole of the South West: a day centre in Kingswood, South Gloucestershire and one in Swindon. Both were for younger people. Given the 'economies of scale' involved in providing specialist services to marginalised groups, it is perhaps no co-incidence that both services were situated in urban areas. In Cornwall, there was also a 27-bed specialist residential unit for people with Huntington's disease, which took people from all over the south of England. At least one nursing home in Cornwall that specialises in care for people with dementia was also known to include a specialist Huntington's unit. There was also a specialist hospital-based assessment facility for people with Huntington's in Plymouth, again outside of the main case studies considered in this study.

Non-specialist day care centres for older people might be deemed appropriate for someone with dementia. However, individual centres vary in their willingness to take people with dementia, particularly if the course of the illness is advanced or a person's behaviour is viewed as non-compliant or aggressive. 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 is a similar dearth of specialist services for minority elders or people with dementia.

The unavailability of services in all sectors surfaced as a major issue especially in Cornwall and Gloucestershire, where inequalities in access in different areas of these counties were linked to the way that services had been organised in the past (in the case of Gloucestershire) or population and transport issues (in Cornwall). A shortage of specialist and respite care beds emerged as a particular issue in Gloucestershire. However, whether marginalised groups would fit into these limited services is questionable.

Users' knowledge of services (or rather a lack of it) was raised by professionals in relation to minority ethnic groups. Thus, it was suggested that members of minority ethnic groups rely on "word of mouth" about services and "won't go through the system" (10:23–148:149). However, other groups, such as middle class white people, might also choose not to engage with the bureaucracy of publicly funded care, although for different reasons. 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 to helping agencies.

For people reliant upon access to care via the statutory sector, waiting time for an assessment emerged as a major hurdle. Waiting lists were reported as being lengthy in two case study authorities (Typically 6 to 8 weeks, although one interviewee reported a 23 week waiting list for assessment for residential care).

Transport was also an important issue in professional accounts of service access. Some day centres reported that they were reliant on carers having their own transport. One respondent at a centre which had its own buses said, "If we stopped transport we would lose half our members" (28:4–36:39). Despite an awareness that services need extended opening hours in order to meet the needs of carers who may be working (especially in younger people), only two day care centres defined themselves as offering "extended" day care, but this was limited in one to between 8am and 6pm during weekdays. The only day care centres with weekend opening hours (9 to 5 every Saturday and Sunday) were two dedicated day centres for people with dementia in Cornwall (59:19–953:990) and Bristol. The only other service identified as able to offer any flexibility in terms of access hours was Dementia Care Trust's relief (home-based)

care service. Many clients travelled to one specialist service for younger people by taxi, which was seen to increase anonymity for service users and avoid stigmatisation (51:12–584:600). However, a different respondent suggested that money spent on taxi fares might be better spent on providing individualised services in the home (52:31–1575:1585). 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 (57:34–1725:1731).

Whilst the expectation and rhetoric of the NHS and Community Care Act, 1990, was that people would have care fitted to their individual needs, the reality – especially for marginalised groups – was seen as being that people were fitted to services (35:30–464:484). Perhaps more importantly, people with dementia generally were not seen to ‘mix’ or ‘fit’ with other groups of service users. However, because of a shortage of suitable services, unsuitable services may be the only ones available. Furthermore, the unsuitability of the available services (e.g. in day care) is seen to extend to other groups of service users with specific needs:

“It’s a setting where it’s one large room. I mean there are lots of reasons why it doesn’t work for people with special needs, and not just people with dementia. People with hearing loss, etcetera, a whole range of people that the setting doesn’t work well for.” (46:5–187:205)

In the context of a general absence of appropriate services for people with dementia, the problem with setting-up specific services for specific groups of people is that by default these services will be inaccessible to other groups of users who do not fit the categories served.

### *Introduction Three: Dementia diagnosis, disease progression and user’s needs*

An interesting tension was apparent in the accounts of professionals, 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” (44:6–587:612). The diagnosis of dementia is difficult in both younger people (where the condition is rare) and in people whose first language is not that of the person assessing cognitive function. Another interesting inconsistency arose in that whilst respondents generally criticised GPs (general practitioners) for not picking up dementia and

referring to services in the early stages, few examples were given of where a medical diagnosis was necessary to access the available services. Some services were more geared up to the management of risk and dealing with those in crisis:

“Often it just feels like we’re answering the urgent cases and almost, if somebody rang us to say, ‘I’ve just been diagnosed with dementia, can I see you?’ Or, ‘Can I have some advice? Can you tell me what service is available in the future?’ We’re not going to rush out to see that person, you know, we’ve got so-and-so down the road leaving the gas on, who we’re far more concerned about.”  
(33:51–1274:1309)

As with other conditions in mental health, black people may be at increased risk of being misdiagnosed. Thus, one respondent claimed that black people with dementia would be more likely to be labelled as “mentally ill” and treated accordingly, e.g. with (inappropriate) medication (24:18–261:279).

Other services only seem prepared to work with people at particular levels or stages of dementia, usually the early stages. The problems with this approach should be evident given that access to services is dependent upon crisis management, and users or carers who are ‘in crisis’ are, by definition, less likely to be experiencing the earlier stages of dementia.

In the early or ‘mild’ stages of dementia, people can be cared for in generic services that may or may not be suitable to the needs of marginalised groups depending on local circumstances. One reason given for not putting people with early or mild dementia into services with people with moderate to severe dementia, was that it is distressing for people to see how they might themselves end up. Another reason related to the difficulties of organising group activities with people of different abilities:

“[When I visited a day centre] I could see there was a very clear difference in ability between the people there. And some of the people who had very mild dementia were getting very irritable with those who had quite severe dementia. And I can see that with all the best will in the world, people do need services more tailor made. I mean to be doing a word game—which they were at one point in the morning—for example. And the woman with mild dementia could actually answer a very large number of the questions. Hardly anybody else in the room could, and in the end she just crossed her arms and said, ‘Well I’m not answering any more. I’m answering them all,’

and, you know, 'I'll let somebody else do it now.' But nobody else really was up to it." (32:38–817:843)

The fieldworkers found two nursing homes (of around a dozen that they visited) that provided dual facilities for general nursing care combined with provision for those with dementia (such homes are still commonly referred to as “Elderly Mentally Infirm (EMI) homes”). One such home was organised into four separate units based around the progression of the disease and the perceived degree of need (53:3–106:114). This model of care enabled people to move to the more specialist unit(s) as their dementia progressed, whilst maintaining familiar surroundings. However, in a similar setting that also offered day care, mixing day users with residents was seen to have a downside:

“I think we found that giving day care in the main unit ... can prove quite distressing, because in the day unit they're people with quite a mild level of dementia, and when they come into the main unit the actual noise levels are higher. Though we've got very mobile people you can get confrontation, and they can find that quite distressing ... When we have people in for respite as well, they become very, very anxious because they actually see their companions coming to the day centre [and] they ... can be aware of visitors leaving and they don't understand why they aren't going with them, if that's been their normal pattern. So it's almost [as if] having them both within the building can have negative sides.” (47:10–182:208)

Another respondent at a specialist service mentioned the problems of mixing people with dementia of different aetiologies, e.g. pick's disease and Huntingdon's (55:17–845:871).

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 (box 1, below). 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. In one specialist unit, it was reported that people with dementia were having wandering or aggression 'treated' with undisclosed 'prescribed medication'. Attempting to leave a home has serious implications for service users, as many respondents in homes said that they would not take people who

were known to try and leave. There was also one reported instance of the punitive use of sectioning powers against people with dementia (“He might become non-compliant with care or medication and they would have to section him again”). However, the attitude of the following respondent contrasted with the bulk of informants who seemed most concerned with managing risk:

“Our philosophy is very much considered risk taking, allowing people to exercise independence for as long as they possibly can” (55:10–508-511)

**Box 1 - Professional views of the needs of people with dementia: overview of issues covered in the interviews**

- The need for a break - either for the carer from the person with dementia, or for the person with dementia from (unsupportive) families
- To have services that they can fit into
- A stable and consistent environment
- A structured routine
- Communication (touch, speech, smiling)
- To a care attendant or worker who they prefer
- To have support to live life to the full and maintain a sense of well-being
- To have choices in service provision
- Personal care

*The assessment of need system*

It was in the area of needs assessment that differences between the three study areas (Bristol, Gloucestershire and Cornwall) were most apparent. However, the basic message from the majority of respondents in all areas was of a care system replete with ‘blockages,’ largely resulting from the financial and organisational backdrops described in previous sections of this chapter.

We have already seen the problems faced by marginalised groups in terms of meeting the eligibility criteria for services, accessing services, and then “fitting in” with what is available. Their “further marginalisation” by the assessment system (10:11–76:89) is partly because of the “complex” care packages which may be needed by

marginalised groups, and by people with dementia in general. In this context, “complex” means a care plan involving “two or more agencies or disciplines” (15:6–142:202).

People with dementia may be assessed in different ways by different people at different times, depending on the services that they need. Some carers do not wish to engage with this assessment system. Typically, each agency providing a service will want to undertake its own assessment. It was suggested that choices are easier for people who are self-funded and not dependant upon waiting to find out what social services or health can or are prepared to pay for. However, for those who require state funding for specialist social care, or secondary and tertiary medical services, access to the formal system – via GPs, social workers or CPNs (Community Psychiatric Nurses) – is a prerequisite of receiving care. However, in the case of people with mental health problems, they may also be forced into the assessment system because they are deemed a risk to themselves or others. This report is written from the assumption that people want and need caring services, but we accept that this may not always appear to be the case from the point of view of the person with dementia all of the time.

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. Different agencies go about assessing the needs of people with dementia in different ways. In general, people working in social services recognised the necessity of consulting with people with dementia about the services they would like, but there was little evidence that this was actually taking place. One social worker reported:

“I can’t think of one CPA [Care Programme Assessment] where the user has been invited into the meetings. The consultant will be there. It is difficult to ascertain whether the family have been given a diagnosis or not.”

(17:7–51:55)

These issues also reflect the view that people with dementia were seen as having “very little insight [in]to their own needs” (33:34–659-675). In contrast, when people working in residential homes described the assessment process for people wishing to

enter care, the person with dementia would normally be visited by a social worker to ascertain their needs. Assessment by a social worker was seen as the key for a user wishing to access the full range of services.

Accounts of assessment by social services and access to care were different in one of the local authorities where the model of assessment was seen as having streamlined the assessment system and eradicated waiting lists:

Respondent: We have a system that...’s been quite foresighted in ... that we have got case co-ordinators attached to every GP practice throughout [the authority]. For everybody who lives in [the authority], if they have an accident or something should happen and they should need the Social services. There would automatically be a case co-ordinator attached to their surgery. So if you know who your family GP is you automatically know who the case co-ordinator is and the case co-ordinator does about 80% of the assessments.

Interviewer: Would that be for everything across the board, or?

Respondent: Well for community care they would, yes.”

(49:38–423:622)

However, another respondent who worked with carers rather criticised this system as variable between different areas of the local authority, and “quite bureaucratic and ... hierarchical” (60:14–695:740).

### *Unmet needs and criticisms of existing provision*

#### **Unmet needs**

- Services rarely ask minority communities or people with dementia what they define as their own needs (Bristol, Gloucestershire, Cornwall)
- Extra work is needed in monitoring the numbers of people with dementia, including marginalised groups (Cornwall)
- “We have recognised and accepted that we are not providing the service[s] that we should be ... across the board, to black and minority ethnic communities.” (3:12–324:348. Similar in 8:17, 8:25, 11:24, 17:22, 41:28, 46:11)
- A need for more services: ‘One Stop Shops’ for the elderly (Bristol and Cornwall), day care, including luncheon clubs for carers (in Bristol and the Cotswolds), day centres for minority ethnic groups (Gloucester), domiciliary care (Cotswolds), nursing home beds (Gloucestershire & Cornwall), ‘EMI’ beds (Gloucestershire),

specialist services for younger people with dementia (Gloucestershire), interpreting services (Gloucestershire), a memory clinic and day hospital (Cornwall)

- A need for more rapid assessments by Social services (Bristol and Gloucestershire)
- More publicity is needed about the available services
- “Sitting services need to be mainstream funded and provided in a consistent way across counties” (15:22–928:1015, also a need for night sitters in Cornwall)
- Carers are not getting enough breaks (Gloucestershire and Cornwall)
- More activities in services for people with dementia
- Awareness about memory loss and dementia needs to be raised throughout society (49:41–662:681)
- Information about services needs to be provided locally, not nationally
- “I’d love to develop the service as they are in [a neighbouring authority], which is aimed more at people with dementia [rather than carers], and stimulating aids, and going into people’s houses and providing activities, and taking people out and so on. I mean that would be wonderful, but I think that’s a few years on.” (32:25–594:606)
- “I think that the Polish population’s an issue in Bristol ... I mean we forget them and there are large groups of Polish first generation individuals, who in many ways, if you ask them, I think would want to be with other Polish people and have some of the cultural things available” (34:29–1202:1326).

### **Criticisms of existing provision**

- “In general, there are no high quality services” (9:3–16:25)
- There is no flexibility or creativity in service provision (37:64–1857:1916, 40:20–693:704, 3:19–477:482)
- “Services have to be people led if [they] are going to be satisfactory” (2:15–243:254)
- Hospital care is not culturally-sensitive (23:23–273:274)
- “The myth [that] ‘black people look after their own,’ is a view for not delivering any service[s]” (24:22–319:336)
- “There is a belief that people with advanced or moderate to late stage [dementia] cannot be rehabilitated” (29:72–1236:1261)
- “It is hard to get care staff to recognise there [are] quality of life issues present” in people with dementia (1:15–199:200): “It is a person with dementia. We can’t do

anything. They've gone back to being a child. They are just a problem.” (1:16–205:211)

- “If people want to play bingo, why are we setting up day centres to play bingo? Why don't we make it possible for them to go to a bingo hall and play bingo? What is it? Is it transport? ... What is it that prevents people engaging in the normal social activities and the normal social life that the rest of us take for granted?” (46:12–345:455)
- “[In one local authority] what you have is lots of different organisations doing a little bit of it, but they are not really talking to the next organisation that does the next bit. So the sort of process for people with dementia can be very disjointed instead of a continual service” (61:4–170:184).

### *Staffing issues*

The most common issues articulated about staffing centred on the low wages paid to care staff in homes and day centres, 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” (19:38–1150:1206). 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 case study 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 again end up in services that can only partially meet their needs or are even completely inappropriate.

In spite of this backdrop, some services were managing to develop new and creative ways of working, where conscientious and committed care staff could better meet the needs of people with dementia and uphold their quality of life. Examples of creative and innovative ways of working are considered in the final part of this presentation of the views of professional interviewees. In light of the criticisms of social

services assessment procedures, it is important to point out that social services departments also suffer from staff shortages. The amount of work that they can do is also limited by a lack of resources.

‘Individualised care,’ by definition (perhaps especially within the limits of the ‘economies of scale’ faced by marginalised groups) needs higher staffing ratios or even one-to-one care. This may seem infeasible for people working in day care centres or residential or nursing homes. However, one informant argued that providing one-to-one care outside of a day care setting can be cheaper than sending someone to a day centre (33:29–570:579). However, workers at day centres would argue that the whole point of going to a group setting is for group interaction.

Paradoxically for workers in mainstream dementia care, specialist services (such as the few for younger people) tend to have higher staffing ratios, which may foster resentment (34:34–1374:1396). The experience of flexibly meeting the needs of younger people with dementia in mainstream services was that it could be a drain on staff resources:

“I mean if we had the staff then [a younger person with dementia] would benefit from going out. But now she would need 2 people with her. We used to be able to take her out with one person, but ... one person wouldn’t be able to restrain her [if she wanted to cross the road] ... [*Later, during the same interview*] ... With the group she’s all right because there’s more people. It’s like having a fractious child, the more people you can pass them around to, the less of a burden it is. The staff, I have to say are not over the moon at the thought of taking her for a walk because it’s not a pleasurable experience. She’s no road sense at all, absolutely none.

(42:17–296:314 & 42:30–665:697)

Clearly, staff numbers is one issue here. More importantly, this excerpt once again highlights the tension between meeting need and minimising risks and burdens for care workers.

Another issue that emerged in the interviews was the ways in which the services that eventually reach the user are to a large measure dependent on the personalities of individual staff:

“Perhaps you get one nurse on or one carer on, and they just don’t seem to bring out the best in residents ... I think it’s perhaps sometimes the way, you know, people talk to someone and approach them. (14:13–318:344)

A different respondent similarly remarked that “some of the staff can hold the place back by bringing their negativity in” (26:33–169:170, similar in 57:29–1470:1475). The issue of staff personalities also arose in relation to the difficulties of effecting change in organisations like social services:

“I don’t think things like this change overnight, particularly where you’re talking about moving budgets around ... I do see things moving, the sad thing is, it only seems to be where you’ve got somebody who is prepared to be creative and go out ... on a limb ... So it’s finding the right person in each organisation that can do that.”

(35:36–578:588. Similar in 44:8–1043:1052)

As far as training for staff in dementia was concerned, the interviewers found some variability in the training given to care staff. Typically, organisations relied on a mixture of in-house ‘on the job’ training and external study days provided by such organisations as Dementia Voice, the Alzheimer’s Society, the Dementia Care Trust or health authorities. Of the different forms of training used, ‘on the job’ training seemed the most comprehensive training described, although once again stress seemed to be put on managing risk and challenging behaviours:

“As I’m the only mental health nurse [here], I’m the only nurse on the unit. All my staff are untrained staff, although they are well inducted and trained by myself ... [Later] ... I do specialise on communication, challenging behaviour. I will be doing [a session] on sexuality this year, incontinence, wandering. So really, all the things that can come up that aren’t really a problem for the client but could be a problem for the staff.”

(18:18–881:1004)

Whilst managers of nursing homes seemed happy to advertise external training, it was not clear in the interviews whether staff would be paid to attend these courses, or whether they would have to take time off and / or pay for the training themselves (19:13–286:315; 12:7–105:123 & 12:14–216:239). A care worker in a day centre criticised this ‘voluntary’ approach to training, however, and argued that courses on listening, communication skills and counselling should be compulsory (26:38–207:214). A respondent in one organisation told how when individual staff go away on

courses, when they get back they always feedback to the other staff (38:24–444:475) so that the benefits are spread. A manager in one nursing home reported that they wished they had money to pay for a full-time trainer (39:25–761:851). Homes that were part of large national management structures were able to make use of in-house training provided by the companies.

*Specific issues facing younger people in dementia care*

Interviewer: I suppose the first question I would ask is ... is there any difference in caring for someone who's under-65, as opposed to someone who's over-65? Or is it the same?

Respondent: No, there is a difference isn't there. (12:1–11:15)

Outside of the two specialist services provided for younger people with dementia there was very little awareness of people with dementia under 65 years of age. Even a dementia specialist remarked, "I can count on one hand the number of younger people I've become involved with in the last six years in post" (34:5–75:95). However, this is hardly surprising given that the existing services are mainly set up to cater for older people. Furthermore, because dementia is more difficult to diagnose in younger people, they are more likely to be managed in the community without a diagnosis. More importantly, few efforts have been made to date to determine the prevalence of dementia in younger people. Of course this affects service provision, for as one respondent remarked, "We don't know enough to know whether we need a specialist service for them" (22:14–111:113).

One reason why younger people might not be known to services is because they are more likely to be in the earlier stages of their dementia, and thus not yet at the sort of 'crisis point' that normally precipitates service utilisation. Indeed, when some respondents spoke about the needs of younger people with dementia, they rather referred to the needs of people with early dementia. Notwithstanding the difficulties of disentangling these categories in informants' accounts, box 2 (below) summarises professionals' views about the ways in which younger people are distinct from older people in services. Many interviewees articulated responses such as those in box 2 (below), and thereby 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 services for older people 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

**Box 2 - Views of the specific needs of younger people in dementia when compared with older people, as articulated by respondent interviewees**

- Fitter / more active
- Look 'normal' (i.e. not like they have dementia)
- Have more energy
- Need more social interaction
- Less likely to have a speedy diagnosis
- Their dementia is likely to progress more quickly
- More likely to be working (along with their carers)
- More likely to be sexually active
- More likely to have school age children
- Family may resent intrusions by home care staff
- Have more affinity with (younger) care staff than with (older) service users
- Need a higher staff ratio and more activities

of their age, and changing their role is apparently one way of making the service seem more appropriate, as in the following example:

Respondent: And her husband was in his late fifties, 57 or 8 I think she said he was. Well he had been diagnosed and the way that they got around it was that he was going in to elderly resident day care but his wife and everybody had told him that he was going in to help and he was like helping with the tea and washing up the dishes, but he was actually going in for day care.

Interviewer: Right, so he was?

Respondent: But there wasn't anywhere, she couldn't, there wasn't nowhere to put him with younger people, so to get round it he went in, as he thought, on a voluntary basis, to help with serving the teas and washing the dishes and helping the patients (sic.) although he was the one who was being helped.

Interviewer: Yes, and did this person, because I've come across this, this is something that's struck, that's beginning to strike me, because I have come

across this situation during this research. So was the person with dementia aware that he was going in as a volunteer, um, or was, you know, were?

Respondent: He wasn't aware, no, he definitely was not aware that he was going in as a patient (*Sic.*).

Interviewer: No, so he was going, do you think?

Respondent: Because he wouldn't have gone, his wife said he wouldn't have gone, because it was all old people and why would he want to go to a place like that? Because he wasn't bad, there was nothing wrong with him. You see, that's another thing you come up against, isn't it?

(58:10–429:469)

Other respondents could not see why services should be provided according to a person's age.

As was noted following our literature review of younger people in dementia care (see Beattie *et al.*, 2002, in press), an unfortunate side-effect of stereotyping younger people is the assumptions that are made about older people in the process, for example that they do not have sexual needs. More importantly, dementia is viewed as 'normal' in older people ("It's almost more acceptable to have dementia if you're older" 34:26–1061:1158), and cognitive decline is a more emotive issue in younger people (evidenced in 19:14–325:355). 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" (34:25–1044:1056).

One person suggested that the main reason that age is an issue in services is because of the way that services are funded:

"The 65 boundary, you know, the older on younger, is totally artificial ... In an ideal world, it wouldn't matter, people would get the care that their needs required and people should be able to work across boundaries. But as long as funding comes from different areas and ... is separate, then I can't see that happening ... Funding should be related to the [user] and I guess probably funding is the key issue in all of this."

(31:24–749:757)

Other interviewees referred to the arbitrary nature of the '65 years' cut-off in services. One respondent questioned why services would have a specific policy for meeting the needs of people under-65 with dementia when there's no policy for over-65s either.

Similarly, “If we’re presented with it, we’ll deal with it, but there’s no strategic plan I don’t think” (34:4–28:95). As we have discovered, younger people, as older people with dementia, tend to be ‘slotted in’ wherever there is a vacancy within the ‘rationed to crises’ care system.

A fundamental reason for arguing for specialist services for younger people seemed to be the assumption that people of different generations find it hard to mix with each other. For example:

“If you have dementia your short-term memory might be gone, but your long-term, with everything that has happened in the past, [might still be there]. When you are the same age as [the] group, everything has happened like that and you can relate to people.”

(39:35–1314:1348)

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:

“Generally, younger people with dementia have insight, particularly in the early stages, into their problems, and are able to recognise similarities and differences between elderly patients and themselves ... A sense of fear about not wanting to become like [older people] is present, but equally an awareness that that is where they will be going.”

(1:7–87:100)

A minority of respondents who spoke about the issue, argued that there was no problem in mixing people of different ages. The more important issue (related in part to the issues of *stage* of dementia already considered above) in mixing related to people’s abilities, rather than their ages. A worker at one of the specialist services for younger people admitted that segregation according to age was not ideal, but was needed in practice:

“I don’t like segregation, but I also find that integration is very hard working with some of the people who are younger. Having them go to [a hospital-based service] and seen the reaction on their faces and saying, ‘I would like to go now,’ not even trying to spend half a day there, ... then it doesn’t seem to be working either ... Quite often in the early stages there is lots of work that can be done to help maintain their memory [and] [generic dementia services] struggle to provide that when they have got quite a

heavy caseload of people who also have advancing physical needs.”  
(29:66–963:999)

However, it does seem as though arguments for specialist services are fundamentally about the competition for finances and resourcing in a system where it is perceived that there is not enough care available to meet everybody’s needs.

During the interviews, professionals described a small number of case studies of younger people whom they had known in services. These six cases are presented in Boxes 3 to 8 (below), to highlight how the sorts of issues raised in this section affect individuals with dementia.

*Box 3 - Case Study 1 - The problems of fitting younger people in services*

“I had a man that I was working with last year that we placed in one small home that we thought would work. And it was totally inappropriate. After 6 weeks we had to move again and that was because he was [a] younger man and the behaviour he was displaying towards other residents was not acceptable. The other residents became frightened and it was distressing for him, for his family, for the staff, ... you know it’s not an effect [on] just one person. It’s the effect that that person has on the whole of the group, and it’s also trying to keep that person is his own personality and his own needs. Trying to keep that focused—what their needs are—and it can be really difficult when you’ve got such limited resources for them. But I think. I don’t know what the research is why it is that there’s more younger people. But it definitely seems to be that we are trying to find resources for our younger people with dementia.”

(40:27–850:889, excerpt)

*Box 4 - Case Study 2 - Devastation for the carer and needs for information, counselling and flexibility in services*

“I remember vividly having a phone call from a woman in [somewhere]. She rang me up one day completely out of the blue and her husband had just been told, she had just been told with him. He was 37, they had three young children. Just like that. She wasn't working. He was in quite a high-powered job and he'd been off sick for the previous three months, and then wasn't ever going to go back. And she rang me up because she'd just been given this diagnosis and she was utterly, utterly devastated, as she would be, and she didn't know what to tell her kids ... She didn't know what would happen with their finances. She just didn't know where to begin. ... I think that day there'd been a news item in the press and she'd seen my name and rang up and I think her utter sense of, 'I know there are things out there and people have tried to help me but it's just so big and I need to just sit with it for a month, and now I'm ringing you. And now I want to take on board this information.' And I'm not sure there's room in the services for that, in a way. It's like, 'You either have this now when we're ready to give it to you, or you won't get it at all.' But for her, she, and then she had two-and-a-half hours. I mean I ended up, I cancelled an appointment, you know I said, 'Look I need to ring you back,' and I felt that I couldn't just walk away and say, 'I know you're not in my service but there's nothing I can do for you.' ... [Later] ... What was coming across for her was that, '... It wasn't that I was just abandoned [by services]. People did try to give help but I couldn't deal with it then, because all I had was this “dementia” word and “old people” and “mad” and “crazy” and that's what was going round and round my head. And yes, all these forms and numbers. They were being given to me but I couldn't engage myself at the time. it was just too much. And now I'm ready to deal with this, and now where do I go, because I couldn't remember all that [back] then?' So, you know, and that was a very powerful memory and that will stay with me when I'm dealing with people at that point.”

(34:21–629:754, excerpts)

*Box 5 - Case Study 3 - Younger people in care homes*

Respondent: She's quite difficult. She's young and fit and strong and very busy and she's on the move all the time, from morning until night, and sometimes all night depending on the night she has. She's in and out. She's very repetitive with her speech and tends to say the same things all the time. She just goes round and round and round, and sometimes she's talking so fast that the words just tumble over each other. It's doubtful whether she knows her husband anymore. He comes in regularly. Social[ly], she doesn't recognise any of her friends, and she doesn't seem to have a particular rapport with any member of staff. ... *[Later, during the same interview]* ... She goes round the unit, she lies on everybody's bed and you cannot get her to do anything for more than a minute at a time. Her food is eaten on the run. So she'll sit down, take it with her, come back, take it off again. Yesterday though, we were doing some activities in the unit. And [while the others] were painting and having their nails painted as well, we had a foot spa there and I asked her if she wanted to go in the foot spa. Because she is often on her own there, and that was the longest she['s] lasted at anything.

Interviewer: And how do you manage that? Because it's quite different from somebody in their 80s. How do actually manage her?

Respondent: It used to be, six months or a little bit longer ago, she went through a destructive phase where we had a few elderly clients who were quite mobile, and she's always been a forceful character, and she would take them into the garden. Once they were in the garden she would forget all about them and abandon them there. So they couldn't find their way back in, and for that reason we had to have an alarm put on the door so we knew every time it was opened. So somebody would just keep a watch that it was just [the younger person with dementia] who went out and she didn't have anybody else in tow with her.

(42:13–193:215, 42:14–217:248, 42:15–250:273)

*Box 6 - Case Study 4 - The detailed 'career' of a younger woman with dementia*

Respondent: There was a younger woman I worked with who was forty-six and she had [a] diagnosis of vascular dementia brought on by mini-strokes, etc. She was becoming more and more at risk in the community because she was doing things. People saw her as being a little bit mad in the neighbourhood where she lived because being a young woman and going out, she would do things like borrow money, go knocking on people's doors not completely dressed. So she was seen as being a bit promiscuous, and there was lots of issues around kids picking on her and sort of people abusing her in the street. And she wanted to stay at home. When I became involved she wanted to stay at home, and I'll never forget knocking on the door and opening the door, because she literally. She opened the door and she had to pull the door over all the post. So there was something like a foot of post behind the door that she had never dealt with. And the first thing I had to do was to delve through all the post, talking mother ... just to break the ice and talk with her. And fortunately enough for myself she was amenable, you know, she said, 'I'm having problems,' so she had enough insight to know that she was having problems. Um. She'd got two sons, 21 and 23 ... that's a young age to sort of have the difficulty of knowing that your [mum] had got dementia, which of course at the time they didn't know. Going ... even further into the case ... [Later] ... a long time into working with her and sort of having home care packages. You're probably aware of [a service]. Well I was very lucky in that I actually got two of the first eight users into [that service]. ... [Later] ... so I got her into there and along with a great deal of support she had an absolutely superb home care assistant that completely understood her. And ... the main difficulty [I've had] ... is that she was only forty, as I said forty-six or forty-seven. She was still sexually active. Her young son rang me absolutely horrified because [he] ... came in one night and had to chase a man out of his mothers' bedroom. Now this did raise anxieties for him and the slightly older brother. And I had a meeting with them and I don't think anybody was really wanting to face this issue of what was going on for mum because there was also a candle on the window ledge that she had told the home care assistant not to remove, right. And I can still remember it now that the social workers on my team thought it was hilarious that I had to tackle this. And I said, 'Well, what else do you do? She's still vulnerable to become pregnant, she's still susceptible to ... diseases.' I said, 'And she still, she might not be able to remember things,' I said, 'But her body is still functioning.'

Interviewer: Yes.

Respondent: So, I mean it was a very sensitive meeting with the two young sons and mum. And wanting to know whether they both wanted to be separate while the meeting went on or they wanted to be together as a family while we talked about it. And they wanted to stay as a family which was nice, um. And we did resolve how we were going to sort the issues out. Albeit, it wasn't going to [mean] much personal contact for her. But we resolved how she was going to meet some of those desires that she'd still got. And my colleague did say that Social services should be funding really, an escort for her. But I don't think that went down too well. I don't think the service manager would have provided funding for that. ... [Later] ... What we did about resolving her sexual urges, if you like, was we actually purchased a vibrator for her ... and she was absolutely chuffed to bits. ... It actually did help alleviate some anxieties that she'd had, and that the family had had. They didn't have any more problems with people coming round the house, so I think [the woman with dementia] was ... getting company from the day centre, company from the homecare assistant and the use of the vibrator for

other things ... [*Later, during the same interview*] ... Going back to [the woman] who was forty-eight. She had another stroke. She survived at home with home care, three days a weekday care, me popping in and her sons supporting her. She survived for another nine months and then had another stroke and was took into hospital. She ended up having to wear head helmets because of falling over and knocking herself, because the stroke had almost taken the whole of her one side. So she was really unsteady on her feet and she was also at risk. The other thing I forgot to tell you was that she smoked and she was so very careless with the cigarettes. And she went into [a] hospital because of her dementia, into which ward do you think she went.

Interviewer: The old, the elderly ward.

Respondent: The elderly ward and I am not ageist but I am saying she was 48 ... and she went into the elderly ward with people of 70, 80 and 90 ... She was in hospital for four months before they actually, 'Medically fit for discharge,' but of course, 'Medically fit for discharge to a nursing home,' they said. Well, have you ever tried finding a nursing home for a 48-year-old person with dementia, other than in an elderly person's nursing home? There isn't one. Well if you know of one then you have better resources than I have. But she didn't want a nursing home, she wanted to go home. She was still adamant that she wanted to go home. And it was the most difficult task I've ever had, but I stood up to the medics and I said, 'If you can place her in a nursing home to meet her needs, you go ahead and do it,' but I said, 'But I can't find one to meet her needs and I'm not prepared to do it.' They hated me, they absolutely hated me. ... [*Later*] ... She wanted to go home and ... she couldn't go home because of her physical disability ... So her accommodation wasn't suitable, so even before we could think about getting her home she needed to be re-homed. So you can imagine the battle. ... That was the other thing, she needed twenty-four hour care this time ... Took us nine and-a-half months, but she went home with twenty-four hour care. ... [*Later*] ... What we did was we had £200 worth of social services care, we applied for the independent living fund which gave us a top-up of £501, then with some crafty work we managed to get the department to pay the bill, which means we were exempt of that, which enabled us another £90 of care ... and then ... we got some health money. ... [*Later*] ... To me she was absolutely brilliant from day one when I started working with her. She'd got a smashing personality and she, although she had got all the confusion and couldn't cope ... she had still got that spirit there about what she wanted to do. So, and she even wanted male carers, and she wore out three wheelchairs and three male carers while she was at home ... [*Later*] ... as I said she had another massive stroke and went into hospital, because this time then she'd moved out of area because I had moved her house ... she went into hospital and [was] placed in a nursing home because it had got to the stage when she would not have been able to go home. She had had a massive stroke and she only lasted for three weeks in there, which was a massive god send really.

(45:8–223:534, 45:10–705:784, 45:11–795:857; 45:13–900:915)

*Box 7 - Case Study 5 - Difficulties maintaining independence within care management*

Respondent: Another gentleman I worked with was 51 and unfortunately, they didn't say it was a Korsikov's type dementia, but it was definitely memory impairment due to alcohol. And he'd been a bachelor all his life, he'd floated in and out of different bed-sits, different hostels, um back to his mum and dad's and [a town]. The day that he was due to leave [a hostel] they had given him a bottle of whisky as a goodbye present. Which in the first two days destroyed his, probably twelve months worth of work and a lot of co-operation from a lot of people. Because his parents were in their eighties so they couldn't do anything. His sisters were all very committed to seeing him. None of them wanted to take responsibility. He desperately didn't want to be in residential care, and he desperately wanted to [continue] controlled drinking. But it was only because he wanted that that he had actually succeeded, because he couldn't remember how much money he had. He couldn't remember where he had gone when he went out, what he had done with his money. He couldn't remember what forms he had filled in. It was just everything down to basic tasks that he could not remember to do. And after an awful lot of work we actually ended up re-housing him ... in a really lovely flat because he's still active, he was still mobile. There was actually nothing wrong with that at all. So none of that side of his life had been impaired, it was just his memory.

Interviewer: Yeah.

Respondent: So along with an agency and a very, again, a very good community care worker, we got care set up for him. And I took him out, and the community care worker. He picked everything for his flat. The difficulty was if he had money in his pocket he would buy [alcohol].

Interviewer: Right.

Respondent: So we had to make sure that everything was provided for him, including three pounds a day personal allowance to buy [alcohol]. Which was an awful thing because we had given him independence in one way, but taken [it] away in another. We had a really good agency that went into him that provided him with that everyday. Now we couldn't get that to them everyday. We tried um to keep a little cash box. We even tried hiding it in the place, because we were frightened of [him] having people in – alcoholics that knew he was very vulnerable – into the flat. So we thought we've got to lock it and hide it, but [he] knew where it was and one day they went in and he had broken into it. Now, bearing in mind that there was about £50 in there and all he's turned round and said that he only took the pound coins. He did try running up a [slate] with the off license. But we refused permission and went down with him and had a chat with the off license. It was about involving him even where perhaps he couldn't remember. It was about involving him in some of the decisions around his own life. And as far as I'm aware, ten years down the line he's still in his own flat and he loves it. He loves it, but there was a whole lot of issues there around him wanting to be independent, desperately wanting to be independent, but there just needed to be that support there.

(45:8–223:534)

*Box 8 - Case study 6 - The difficulties of managing complex care packages in the community*

“She had ... severe memory impairment but didn’t recognise that she had an alcohol problem. So she was a woman, as I said 41, two young children, a husband. And every time the house was empty she would be into the sherry. She was dreadfully underweight, to the [point] that she had been into hospital and been drip-fed on two occasions and absconded through the hospital window because she wanted to get to the alcohol. ... I think one of the main problems there was that the husband ... There was a husband and two children, the one young son had got insulin diabetes and also attention deficit disorder ... The other child, the little girl, was ten and so there [were] a great deal of concerns about dad [working] shift work. So he was out of the house at six o’clock in the morning, so getting the children up for school was difficult. Making sure that the lad had his insulin was difficult, because she would not remember from one day to the next if she had eaten. Monitoring her medication was difficult because she couldn’t remember what medication she’d taken. She’d put washing in, she wouldn’t be able to remember if she had put it on or not, and she wouldn’t remember to do ironing. The only thing she always ... did remember to do, and it was really strange but I suppose, and that was to check her son’s blood. I don’t know why, something in her mind latched on, but she always remembered to do his check. And of course there was the other end of the day when he was on late shift. It was children coming home from school unescorted. Finding people to actually escort the eight-year-old home, because of him not only having the diabetes, but making sure because of his attention deficit disorder. Making sure he didn’t eat chocolate biscuits as every eight-year-old would want to do. And of mum then in the middle of the day, after being at home all day, not able to function in the house, not being able to keep it clean and tidy. The house was in a complete shambles. The husband did as much as he could in the fact that he did all the shopping, he did all the cooking, like he’d left meals prepared for the family before he went out to work or when he came back in. He was sort of doing sort of the majority of washing and ironing and keeping the house as he could and providing entertainment for the two children. But unfortunately with that case ... the marriage was over recognisably within six months of my involvement there, and he was very much providing a caring role that was walking towards the door. And I mean we had care workers going in, homecare going in. And again, there you see the difficulty was who was going to provide which service. Homecare staff didn’t take children to school, right. Then you get the childcare staff saying, ‘Well, we can’t [do] that on a long term commitment.’ Although you can have homecare on a long-term commitment, right, you couldn’t have childcare on a long-term commitment. So there was always difficulties about collecting the children, well the younger one to school and home from school. And fortunately enough the husband managed to set someone up to bring the child home from school, and we managed to work it that twisted the rules if you like. And we actually said mum and the young child were being escorted to school, so mum is going out to do some shopping on the way back, so that’s that we.”

(45:9–552:638)

*Issues facing black and minority ethnic groups in dementia care*

The results of our fieldwork mirrored our literature review (Daker-White *et al.*, 2002) in that language was the major issue raised in the interviews. Outside of black organisations and services in inner-city areas, there was little experience or knowledge of minority ethnic groups in dementia care. This was particularly the case in the

residential and nursing home sectors (13:2–7:26). Furthermore, statutory agencies have not yet assessed the prevalence or needs of these groups, although work is beginning (see earlier discussion).

Racism is fundamental to any understanding of the position of black and minority ethnic groups in dementia services:

“You can’t talk about black carers and service users if you don’t talk about race equality. Yet there’s no one talking about that, you know. We’ve got a Race Equality Council, but they’re not doing that stuff.”

(8:27–536:542)

However, “This is not about a specific set of needs for a specific group of people” (8:25–508:514). Racism can lead to minority ethnic groups being viewed as a “drain on resources” (8:17–434:499) and was also mentioned as a factor in the misdiagnosis of black people with mental health problems:

“black people [are] over-represented in the statutory end of mental health services. And it’s at the acute end, it’s never at the primary care end ... It’s as though black people don’t have depression. What you seem to find is that black people have schizophrenia ... [Later] ... It is widely acknowledged that over 60% of [black] people are misdiagnosed, so you have some very sane people in the system.”

(24:6–67:100 & 24:17–257-287)

The same respondent mentioned racism in the provision of care packages too:

“You [to interviewer] have a package for service users that would be monitored and all that. You’re less likely to have that with a black person. Somehow the package never seems to work or it’s not in place”

(24:20–289:309)

black service users may also experience racism from white service users or their relatives (37:41–892:910, 26:35–185:189, 13:16–337:374). However, whether or not black service users experience overt racism from other residents, workers at specialist minority ethnic day care centres questioned the ability of white-dominated services to provide appropriate care. As one worker put it, “In other day centres they seem to be a bit lost ... It’s really difficult for them to join in any other day centre where they’re just not understood” (20:6–38:42). Similarly, another respondent said, “In a white place

they would just sit there and say nothing for fear of being misunderstood” (21:18–115:117). Much of this relates to language, but part of this is also about ownership of services, with black users “reluctant to use these services because they think that that service is nothing to do with us” (37:9–99:105). Instances of accounts of the possibility or actuality of racism (towards either service users or staff) arose especially in Cornwall, where it was perceived that older people have very little experience of contact with black people (55:25–1287:1309, 56:15–745:758, 57:24–1237:1248).

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 issue was the perceived stigma of dementia, and an associated unwillingness by family members to “wash their dirty linen in public” (20:30–196:206). Other responses pointed to a non-medicalised view of dementia, for example when a worker at a black organisation said it’s “not an illness because it comes with ageing” (37:25–382:410).

Views of services as being inappropriate or having racist and authoritarian functions, coupled with a reluctance to approach for help because of the stigma of dementia, exacerbates the situation where many services do not know how to meet the needs of caring for these groups, as they have no experience. However, where services had experience of caring for people from minority ethnic groups, it seemed as though they had learned from the experience and modified their approach:

Interviewer: Have you any experience of people from minority ethnic groups in here?

Respondent: ... And then you come across the problems where they can’t always make themselves understood, and we can’t always obtain the food that they’re actually used to. So the family used to ... bring a lot of food in for her. But she’s the only patient we’ve ever had.

Interviewer: So, if I asked you what you would do with ... a person from a minority ethnic group in this home?

Respondent: Well I think you learn from previous experience. I mean since she was here we’ve actually devised two ... sheets to go in the care plan, one of which is a life history and [the] other which is a food preference chart, so foods that are actually liked and disliked. We’ve got a full-time catering manager in who’s very experienced and she’s worked in

several nursing homes, so she's actually used to ... cooking for various minorities. So we would, obviously, you know, speak to the families and actually, you know, obtain information from them with regard to preference[s] for diet and ... order food in especially for them. And I think we would probably—if there are difficulties with communication, which obviously there were—we would actually, you know, look towards a translator or an interpreter or, you know. (19:15–359:408)

Of all the mainstream caring services visited, only one reported offering “bilingual, trained, minority group staff” (10:15–109:110).

We have already seen that ‘the community’ is a problematic place to serve people with dementia because of the stigma attached to the illness. In discussion with an interviewer, one worker also mentioned that the term ‘black community’ is sometimes used by people to articulate the false view that black people think alike, do things alike, and all live in the same places (24:12–130:158). Another problem with having services dependant upon ‘the community’ of an individual in question, as raised by some respondents, is that some people would rather not have a person of their own culture involved (39:33–1181:1188). However, existing and previous specialist groups had been dependent upon ‘community support’ for their ongoing success, and it was perceived that there is currently a vogue for talking about “developing services with the [minority ethnic] communities” (11:27–530:549). Where such initiatives had failed, some respondents claimed it was because of disagreement between different groups or sections of the community, also highlighting the dangers of assuming homogeneity in minority ethnic groups (22:24–283:318).

The fact that the standard of service provision for minority ethnic groups is unacceptable was recognised by statutory authorities themselves (3:12–324:348, 9:11–94:97, 11:24–464:466, 17:22–188:197, 45:25–1150:1166). The essential question 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. Fundamentally, people from minority ethnic groups do not enjoy the same choice when it comes to services as their white counterparts, even though they pay the same rates and taxes (24:28–483:498, 25:14–194:204, 37:64–1857:1916, 48:7–310:371, 48:8–350-371). To reiterate, these issues were not seen to be specific to dementia care: “It’s not that

they're not accessing our service, they aren't accessing any service[s]" (10:12–91:120). Furthermore, it was reported that some black or minority ethnic people did not want to use exclusive services (26:22–112:113), or could not tolerate the food offered in specialist services (22:28–391:429). More importantly, white service users were also using a specialist minority group day centre. However, pressure on the service from people living far away where no specialist services exist, was likely to lead to the exclusion of these local white people. The manager wanted to see the centre re-focused as a 'day centre for people from the local community' whatever their ethnic origins, and added, "It's nice to have everybody here and cater for everybody's needs" (20:11–56:60, 20:12–62:86, 20:33–217:232).

Although specialist black agencies and community organisations exist, access to these services is often only when other organisations have failed (8:17–434:499). In addition, some black workers questioned the ability of these organisations to provide services to people with mental illnesses or dementia. However, one worker stressed why such services were needed:

Interviewer: [Asks whether people would travel to use a specialist black service]

Respondent: There shouldn't be a need for separate services, that's for starters.

Interviewer: Right.

Respondent: That is a starting point, there shouldn't be a need for separate services. If the people who deliver service was delivering the service in a way that was sensitive and appropriate to [the] needs of the clients that they're delivering the services to, you wouldn't be talking about black and white. But in the real world, because racism plays a part in how black people are treated, that is why there is a call for specific service. Or acknowledgement of cultural needs. That is the problem. So it's not black people saying they want separate service, it's out of desperation that they're saying this. (24:25–409:429)

The interesting thing about specialist minority ethnic group services is that they are not seen (according to some respondents) as a part of statutory, mainstream, provision, but as "bolted on" to the existing services, and often based in the voluntary sector. Thus, one interviewee was critical of one such project:

“They set up the black Mental Health project as a bolt-on to mainstream services. ... The project decided that they didn’t want to be a project anymore and was renamed ‘team’. I am amazed that they want an exclusive black team. The group will play the colonising game so white people don’t get employed in it. Mainstream services are much better. The voluntary sector is always poor.”  
(17:23–199:227)

Through this interview, and that of another respondent in the same authority, it appeared that black workers in the specialist black team had not been trained to the same standard as workers in other mental health teams. Thus, it was claimed that some were not qualified to be a client’s key worker under the council’s risk assessment policy. However, it was reported that these training deficiencies were being addressed at the time of the interviews (16:20–711:811).

These apparent training deficiencies may be associated with a perception that specialist black services are under-funded, under-resourced and perhaps even “set up to fail” (24:13–160:174). Even though the black workers interviewed worked in voluntary-sector based ‘specialist’ organisations, they all shared a desire (based on social justice) to see the needs of minority ethnic groups met within mainstream service provision. This seems important given the current attention given to meeting the needs of black people ‘within black communities’ rather than within services and society as a whole. However, responses from staff in minority ethnic projects also suggested that they felt that their organisations were being funded in a short-term and unstable manner. For example:

“We have to hold them accountable and we don’t want everything in the voluntary sector, we want mainstream [so] we can ... feel safe. We want to say to them that we want quality, because in the voluntary sector again it depends on how much people, what the budget is, what the purse strings is. And so we want to hold them accountable, because we pay the taxes. We are the citizens of the country, and I wouldn’t mind If they said to me that they will put up more tax and we are going to help more elderly people. I would say, ‘Good’, ‘Make the world better’, ‘Improve more.’ I would say, ‘Good,’ because I want that for them, and I want that for myself, but that’s not the case. So sometimes the ... elderly women, they get very angry.”  
(37:64–1857:1916)

#### *Examples of flexibility and an individualised approach in service delivery*

One of our initial objectives was to collect material, cases or examples of policy or care that would constitute ‘best practice’ in dementia services. Unfortunately, when

questioned about what constituted best practice in dementia care, many respondents articulated the sort of idealised responses ('flexible, tailor made services) found in the practice literature. Because many services were not currently providing services to either minority ethnic groups or younger people with dementia, discussions about best practice tended to be hypothetical ones. However, during the course of the interviews, isolated examples of the ways that creative care had been managed flexibly in meeting the needs of people with dementia from marginalised groups were identified. Furthermore, in the particular case of dementia services, it may seem premature to be talking about 'best practice' when the opinion of many professional respondents was that services are not yet serving the basic needs of people with dementia in general. Nevertheless, we hope that these few examples will encourage others to think about creative ways of meeting the needs of marginalised groups in dementia care.

*1 - In care packages*

"Let's say somebody was 55 and taken into [a psychiatric assessment unit]. Living in their own accommodation, single, no carer, ... they've got variant CJD ... this is almost a true scenario ... can't return to his own home. We have a couple of choices ... It would be a good idea to assess him because he was sectioned under section one, one seven and for him to [be] placed in a nursing home. What we actually did was worked with him and his family and he's back with his wife now ... His wife was still involved with his care, but she was long-arming him because of his odd behaviour ... She was seeing very odd behaviour and she was scared. He's now been discharged under section 32 to his wife's home, a CPN, a social worker and the family involved. That chap could have been in long-term care with an annual review. We think it's good, we think it's proactive, we think it's innovative, yet it hasn't cost us so much money ... It doesn't feel like so much effort because we're not fighting for funds and we're using existing resources and the clients' existing strengths within their own lives. And the family's strengths, because families often feel very disempowered when a nurse, a social worker, a doctor, decide that their family member needs residential nursing care and takes them away." (16:11–275:321)

### *2 - Services provided in users' own homes*

“Within our ethnic minority groups, ... their needs are very much tailored to what they actually want within their cultural and religious needs. We have been finding that the care that has been delivered from Social services is excellent in its own right, and we all know that they do a really good service with the finances and the availability of staff that they have got. But what we tend to do is go and see the family ... and actually ask them what they want. Because often with bathing and dressing their cultural needs are so different. They may need somebody to cleanse their body first before they have a bath. They may have to have a certain lotion, which is not always able to be done by agency, because of time maybe. Because maybe that's not a role that they see themselves in. Whereas our care attendants are very skilled in building up relationships, trying to fill the needs very much. I know that within our families, when we first went in, being mainly a white organisation, we were very conscious about that. But that's not been a problem, it's actually not got anything to do with it. It's about the quality of service that you deliver, not the care attendants' colour. Or ... they don't actually always want somebody of their own culture. They ... want the service they want, whether it's delivered by a white care attendant or a black care attendant.”

(39:11–267:298)

### *3 - Day care centres*

“There have been some excellent pockets of day care working flexibly. I mean there's a couple of local authority residential homes that I know both offer to two [of] my service users flexible day care ... One is a lady who's routine is so chaotic that one day she'll turn up. A whenever she turns up they'll provide a meal for her. And she just goes in to have a chat or whatever, and the next day she might not turn up, but they're so good in providing her with a meal ... And another lady in another authority home, it's a carer and she's actually quite young ... So when she wants to go swimming, or something, for two hours, she'll drop her husband off. And the residential homes are perfectly okay with that, but it's often [more about the] personalities that work within those homes that are able to accommodate that flexibility and work with that.”

(33:64–1645:1667)

“If we build up a relationship with someone, then we will follow them into residential care.”

(10:28–166:179)

*4 - Nursing and residential homes*

“What I try to do on assessment when I actually go to see the client before they come in, I like to try and find as much about the person as possible. ... We do personal biographies, so we get to know a great deal about them before they even set foot in the door. And also when the clients actually arrive, we do operate a key worker system here so ... two care assistants are sort of seconded to them. And I also get the care assistants to fill out a post biography as well, so they’re asking them questions and finding out about the client and what they like to do and, you know, what activities they did when they were younger, what they can do now.” (18:8–149:229)

Respondent: Staff didn’t feel comfortable with it, it was, the spontaneity of just, right this is the day, it’s sunny today, why sit in? Why not go out, visit a garden. They actually took two ladies to the museum, and it was quite stressful, but they actually got a lot out of that day. I think it’s this thing about being responsible. I think within the confines of this unit staff know that their are managers there, whereas when they take people out in some ways, they then have that responsibility and I think that’s the bit that frightens them really.

Interviewer: So how do you get around that, because obviously you do?

Respondent: We’ve actually talked about ensuring that they know what medication [the] person is on; any factors that might arise; any behavioural factors; any medical things they need to be aware of. One lady, you know, in a closed environment, will hyperventilate, so therefore they need to know that. It’s about knowing the people and looking at maybe, they should ... go out with mobiles so they can phone back for advice. So they have got that reassurance there. And maybe initially not going too far away until staff do build up their confidence. But it’s nice, I mean if somebody needs clothes or needs stuff for their room, I mean why not take them out? Sometimes that could be a base of activity, somebody needs clothes so care staff will take two residents out to choose their clothes.

(47:21–585:625)

### **Chapter 3 - The views and experiences of younger people with dementia, Angela Beattie**

#### *Introduction*

The purpose of this chapter is to present a descriptive account of the results of interviews with younger people with dementia and to highlight the main themes that emerged in the interviews. All the individuals described in this chapter have fictitious names to protect their real identity. In some instances, place names, geographical descriptors and certain additional details have also been changed to ensure anonymity and confidentiality. The study methodology and sample are described and a thematic overview of the findings is followed by recommendations for the development of future care and services.

#### *Methodology*

Data were collected from 14 younger people with dementia over a six-month period (April-October 2001). Purposive sampling<sup>1</sup> and snowballing<sup>2</sup> were used to recruit people under 65 years of age who were using services, and had received a diagnosis of dementia. Their carers were also approached (see chapter 5, below). Recruitment took place via specialist and non-specialist day centres for younger people with dementia. Potential respondents were initially approached via staff gatekeepers, who distributed a general information sheet giving details about the project, covering letter and reply slip. The majority of people with dementia were interviewed separately from their carers, with the exception of two interviews where respondents requested to be interviewed jointly. A topic guide, shaped in part by the literature review and discussions with the research team, was used (see Appendix 3). All interviews were audio taped, with permission. For younger people with dementia (and the two joint interviews), 8 interviews took place at specialist day centres, 5 in interviewees' homes and 1 in a residential care setting. Interviews lasted between 15 minutes and one hour. Written, verbal and ongoing consent was sought throughout the interviews from all respondents. Ten gave written and verbal consent, 3 gave verbal consent, and in 1 respondent for whom it was difficult to assess if verbal consent was given, the

---

<sup>1</sup> i.e. the interviewer sought out respondents from marginalised groups

<sup>2</sup> A method of sampling common in qualitative research, where subjects are recruited through the chains of networks resulting from initial fieldwork contacts

*Table 1 - Characteristics of the interview sample: younger people with dementia*

<b>Interviewee</b>	<b>Sex</b>	<b>Age</b>	<b>Attending specialist day care?</b>	<b>Attending services in older settings?</b>	<b>Residential care?</b>	<b>Living independently?</b>	<b>Co-resident carer?</b>
YP 19	F	64	n	n	y	n	n
YP20	M	64	y	n	n	n	y
YP21	M	66	y	n	n	y	y
YP22	F	62	y	n	n	n	y
YP23	M	61	y	n	n	n	y
YP24	M	62	y	n	n	n	y
GL3	F	60	n	y	n	n	y
SW1	M	64	y	n	n	n	y
SW2	F	51	y	n	n	y	n
SW3	M	56	y	n	n	n	y
SW4	M	41	y	n	n	y	n
CU3	F	65	n	n	n	n	y
CU4*	M	61	n	n	n	n	y
CU6*	M	55	n	n	n	n	n

M=Male, F=Female, y=yes, n=no; \*Joint interviews

principles of seeking ongoing verbal consent were employed. Their ages 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 younger person with dementia had a part-time job, whilst the majority had taken early retirement due to memory problems. 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 (see table 1, above).

### *The views of younger people with dementia*

“When people say, ‘Oh I know how you must feel,’ or, ‘I know how you feel,’ How the bloody hell can they tell if they have never experienced it?” (YP23)

“[Dementia] is a thing, it’s hard, difficult sometimes for people to understand.” (SW3)

These quotations reflect the perceptions of younger people with dementia and illustrate how difficult it is for other people to understand their experiences. Of particular note in the interviews were issues surrounding *diagnosis*, *powerlessness* and *risk assessment*, which will be discussed at length in this chapter. Most respondents demonstrated remarkable insight into their memory problems and how others perceived them as a result. For example, in response to the interviewer asking, “Can you tell me about your experiences with memory problems?” the account below illustrates how forthright and direct one respondent felt about having his train pass taken away by statutory authorities:

Respondent: “You know I couldn’t believe it, you know they just took it away, [my train pass] ‘You don’t want that anymore,’ you know. Funny enough about a week ago, I thought I[d] love to go back down to on the train, but I can’t, I’m not gonna jump out the train or anything. I mean it really. I know I was ill early before but I still wouldn’t do ...

Interviewer: No not at all.

Respondent: I didn’t know what to do or say. They’ve taken it from me what can I do? ‘You don’t want to go anymore,’ or ‘You have to go with somebody or somebody ought to take you.’ I mean, I know what I am doing. I mean I know am older now, I am 66 years, I’m not daft, or perhaps I am?” (YP21)

More detailed accounts of the reality of living with dementia are offered below. What is of interest is the insightfulness of younger people with dementia and the personal biographies that are reflected in these accounts:

Respondent: “[My memory] ... you know has gone a bit wonky but occasionally it comes back to me.

Interviewer: Right and what comes back to you, what do you remember?

Respondent: Just things that I’m trying to work on saying, where is a place. Previously I would have walked straight into it, knowing it, but now I’ve got to, uh, which one? (laughter) It’s uh, apart from that there’s, I can still read, write and do other things, you know.” (YP20)

“It feels like I know what death is like. It’s ... as well that’s me finished now”. [*Later in same interview*] I said, ‘Don’t go shouting because people would begin to think you’re not of sound mind’, I was advising him. It’s not very nice life sometimes, you think you are complaining for nothing.” (YP23)

“People, like when you begin to get frail and unstable walking wise, other people don’t want to know [you] because you look funny. Probably it’s just what I think as well, but you’re just shoved away, you start to say something and they go, ‘Just keep quiet X,’ and that hurts, that hurts as well.” (YP23)

“I do forget things sometimes, but that’s part of the illness.” (SW3)

“It (will) affect[s] my memory because I do forget things.” (SW4)

“I just get, minds racing all the time, you know, just thinking.” (SW4)

Perhaps the sense of forgetting “getting everything wrong” is best reflected in the account below:

Interviewer: “Is that how it feels, Fred? [you’re finding it difficult to cope not being able to work anymore].

Respondent: “ Yes, that’s how it feels, you know. Sometimes I think what’s life all about? And, you know, because I get everything wrong now, like, you know. Then the tears start to flow. I try to do things right. I don’t like to do anything wrong, you know. I’ve always been conscientious, if that’s the word, whatever job I’ve worked in. I worked, you know, the best I could for them and couldn’t do any more, no.” (CU5)

With regard to the changing nature of dementia, this respondent’s account captures the reality of living with dementia and what it feels like to experience problems with memory: “I did get all muddled and I get good days and bad days, like.” (CU5). This world, which, by these accounts, appears to be a frightening and bewildering place, is compounded by respondents’ insight and awareness that their memory is deteriorating.

### *Dementia diagnosis*

A central theme that emerged was dementia diagnosis, the time it took to receive one, and the manner in which it was given. Many respondents' commented on the 'long journey' taken and the uncertainty involved before finally receiving a diagnosis.

"I went to [mentions 4 different hospitals] and had the scans. I went there last November and I went last January, this year, and I should have heard from in June this year I should have went but I haven't heard anything off them at all, right.

Interviewer: What is it, you know, what has the doctor said is the problem?

Respondent: Well, I don't know, personally." (YP24)

Moreover, the diagnostic testing was seen as 'baffling', engendering a sense of incompetence. For example:

" 'I'm going to ask you so and so,' like you might have said to me that the cat was crossing the road to follow a dog. Now an hour went by and he asked me something and I said, 'What was you on about then?' He said 'Can you remember what I told you?' Well, I couldn't remember it straight away. I couldn't react to it, because he was going on so much to baffle me that I couldn't go back to that sentence, then." (YP24)

The manner in which the diagnosis was given was perceived as a negative and almost 'casual' experience for one respondent:

"It was very blunt, yeh. It was brutal that's the only word for it." (CU6)

When the interviewer prompted for further clarification the following account was offered:

Respondent1: "It [diagnostic assessment] was brutal, but worse than that in some respects is that it was just all over the place too, wasn't it? It wasn't, it didn't even have a structure. If you knew it was going to be absolutely brutal then you, you can deal with that because you know it's gonna be absolutely brutal, but this was that and all over the place.

Respondent 2 [carer]: Very casual, wasn't it?

Respondent1: Yeh, casual. It went from being casual to an extreme." (CU6, CC2)

There was also the sense of respondents being unprepared for the receipt of potentially distressing news on the day of the clinic visit. According to some respondents, there

appeared to be a lack of information as to what was likely to happen or what the diagnostic tests involved. Moreover, the clinic location led one respondent to comment that this was the 'old work house' and as such held frightening connotations. The remaining three respondents (SW3, SW4, CU3) who spoke about their diagnoses commented upon the tests but did not perceive their overall experience as negative. Nonetheless, the following respondent suggests that the manner in which the diagnosis is given, how prepared people are for it, and the follow-up offered, are areas that are important to younger people with dementia (as indeed one would imagine to all people with dementia). These issues would appear to warrant further investigation, both from a research and practice perspective.

Respondent 2 (Carer): "We assumed that having done these tick box tests, that it would have to go away somewhere and be marked or whatever and that we weren't expecting a diagnosis" (CC2).

Respondent 1 (User): "Well I had no idea what the thing was about. I'll go on a bit further later on in a much more positive way, but that afternoon was very very badly, um, organised and dealt with and absolutely hopeless and if I was scoring them, they may as well pack up now. I'd like them to tell me what was gonna happen, um, what the choices were, um, "Would you like to ask, any questions about that particular thing?" Um, what is the purpose of the exercises, um, and the sort of strange, I mean, if you go into take an exam or whatever, or set up an exam to be done in school or whatever, you would give people an idea about what they were gonna do, why they were doing it, etc. Nothing like that at all." (CU6)

It is recognised that part of the diagnostic testing for dementia involves no prompting or rehearsing (Folstein & Folstein, 1975). However, considering the above accounts, it would seem timely to consider diagnostic procedures and communication in dementia. Keady & Nolan (1999) suggest that for younger people, the 'usual' practice of informing close family members of the suspected diagnosis, and leaving disclosure to the discretion of the family as to when, and if, to tell the person concerned, are questionable. The main reason given for this is that a younger person with dementia may experience a more rapid progression and loss of competence. For some younger people interviewed for this study, their accounts raise issues around consent in diagnostic testing:

"He [consultant] kept coming in and out of the door which, of course, you never do. I mean if I was dealing with parents or whatever and did that then I would be in big trouble. I would never do a thing like that. It's just so unprofessional. [Later] 'I

thought what on earth are these people doing, you know', they're not telling me, why they want to do it, or what purpose it is." (CU6)

In order to give a sense of 'balance' as to the negativity of the above respondent's experiences at a memory clinic, another respondent in a different geographical location and with a dedicated specialist service for younger people with dementia spoke very positively of his experiences.

"The research centre is quite good, the tests that you do up there for the memory tests and that are quite good as well." (SW3)

In sum, issues surrounding diagnosis in younger people with dementia appear 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. What is of note however, are the differences in respondents' accounts of the cognitive assessment process. What emerges from these accounts is the difficulties apparent in sharing the diagnosis as sensitively and as soon as possible, especially when it is recommended that younger people might benefit from an earlier diagnosis given their increased likelihood of rapid deterioration. Future work might usefully examine the outcomes, benefits and costs (including possible 'costs' to people with dementia) of the diagnosis process in early onset dementia. Pertinent questions might include: What do individual's need to know? What are the consequences of knowing (or not)? And, when is the best time and what is the best manner in which to impart potentially devastating news? 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. Furthermore, one wonders how it is possible to gain informed consent for a procedure (cognitive diagnostic testing) that is only said to work when sprung on people unawares.

*Service provision and specialist service provision for younger people with dementia: is age an issue?*

"I'd rather come here than go somewhere with more elderly people..." (SW2)

"Well I think it's better you stick with people of your own age." (SW3)

Age appeared to be a paramount concern for most of the younger people with dementia interviewed. The majority of respondents commented that mixing with other younger people with memory problems was a positive experience. Care and services in older person's settings were viewed negatively. Thus, most respondents expressed the wish to be placed in age-appropriate services. For example:

Interviewer: "And I was just interested because you've just said, something you said, just something there that you don't belong, [in an older person's day care setting] you know. Do you feel [like] that?"

Respondent: I do, I feel that in, I don't because I'm so much younger than they are all of them, you know, so why should they put me there? I don't know.

Interviewer: Why, so do you know why you go down there?

Respondent: No. I don't." (GL3)

In the present study, 9 (64% of the total sample) younger people with dementia were attending the specialist day care services. They lived mainly in the urban areas where the services were located.

Most of the respondents, attending specialist day care centres commented positively on them, and highly valued the opportunity to socialise with people with similar problems. For example:

Interviewer: "Because I was wondering, if you could sort of put yourself in someone like a similar age to you but didn't have this club to come to, you know, I wonder how they'd feel?"

Respondent: "They'd probably just sit at home all the time then, at least you have this club, [specialist day centre] you get out your house and you get a chance to meet other people. I think if you just sat at home, I mean I find on a Saturday I'm sat in front of the television because there's no club on a Saturday, so my wife's gone to work and I'm sat at home sitting watching television, and it's quite boring really. So at least when you've got your club you come to, you meet other people and you know they're people that you can talk to and you know they've all got the same sort of problems as you, everybody gets on with each other." (SW3)

For many respondents, the specialist service represented a place to meet new friends, socialise and generally be with people that were similar. There was an overwhelming sense of the centre providing social support and friendship both with other clients and the staff there. Many valued pursuing 'ordinary' events, like going to the pub for lunch and being given the opportunity to attempt new skills. Most of the respondents valued

the individual approach and the flexibility of being able to choose (or not) to join particular activities. It was evident that on some days the respondents were not able to join in a particular activity. However, choices were offered, and this was highly valued by respondents.

“I liked the layout, the people, the helpers and I couldn’t wish for anything better. They’re such, anything I want, it’s done. And they’re free and they’re helpful.” (YP24)

“It’s nice coming here because it’s company.” (SW2)

“There’s some interesting things go on here really you know. You get opportunities to do things that you wouldn’t normally get to do, so busy sawing away at a concrete block to get the shape you know, so it will be interesting to see how it comes out in the end.” (SW3)

“It’s the company and that, having people to talk to because I’m at home on my own.” (SW4)

Moreover, one respondent who was slightly ambivalent about the specialist day centre commented “ Well I don’t know if it’s helping me, but it isn’t making it worse, I don’t think.” (YP21). Not surprisingly, many respondents referred to the desire to attend the specialist services more frequently:

“I don’t think there’s any way they could improve on what they’re doing already. I mean more days ... would be better because there’s somewhere to go everyday then but that’s difficult there’s other people that have their needs as well. I think that’s the problem is there’s not just enough people to look after everybody but I mean I would come here more days of the week if they were available.” (SW3)

When respondents were asked, “What are your views on these [specialist services] and what is good about them?” Most respondents attending specialist services commented positively about the service and the staff:

“That’s another good thing about the club here they do a lot of art work and material work, you know, woodwork, I mean I was sawing a concrete block this morning and that’s another good thing about this club too, because they have different things to do, which makes life a bit more interesting, so I turn a hand to anything that’s going.” (SW3)

“I like to come, it’s nice, because the people here are lovely. Yes, they do help, help for everybody.” (YP22)

“Well obvious reasons is that it gets me out of the house and somewhere nice to go, the meals are cooked for me.” (YP23).

Perhaps the final words regarding levels of satisfaction with specialist care and services should go to a respondent who succinctly summarises this issue:

“But we all know we’ve all got the same problem, so I mean if people stumble a bit over words and that you know, it’s nothing, you don’t make anything of it, we’re all in the same boat.” (SW3)

When the interviewer asked what was “not so good” about the services their responses further demonstrated an overall consensus of satisfaction:

Interviewer: “So what, I mean I was going to say we talked about the club and what’s good about it, so what, is there anything, you don’t like or maybe you’d like to do?”

Respondent: “The clubs okay actually, they seem to have got it at the right level I think, there’s nothing too, there’s nothing boring about it, they seem to have it at the right level I think, and all the people who go to it seem to enjoy it.” (SW3)

Despite the positively glowing accounts above, one respondent reflected that mixing with younger people with dementia in a specialist day care service could also be ‘irritating’. For example, the constant talk from one client was troubling to this respondent, and the fact that one or two clients who expressed feelings of being cold despite the temperature being very warm were reluctant to allow ventilation:

“Eleven people sat in a room you’ve got a big (atmosphere?) two of them puts their coats on when they’re in there, mind, with the door shut, wants the door shut. And I said to them this morning, when they kept on, I said “Here, leave that door alone, it’s too hot in here. Let some air come in here.” “I’m cold,” and she puts her coat back on again. She doesn’t worry about the people around her. So long as she’s got her corner to keep warm, but it ain’t cold in there, no way, not if you’ve got 11 people sat in there.” (YP24)

“I just got a good friend nothing further or nothing worse you know but there’s others there [at the specialist day centre] that just don’t like this, don’t like that, got any fags for me, have you got this, have you got that, can I borrow this, can I borrow that ... he goes round to people getting cigarettes.” (YP20)

These examples highlight that providing care to individuals in a group setting is a complex endeavour, despite the obvious benefits, more so when people have a

cognitive impairment. The management of these needs, and considerations of individuality and difference are a challenge for service providers.

Interestingly, one respondent commented that being with clients of similar age might prevent cognitive decline. Whereas, the perception was, that if one mixed with older clients the opposite would occur:

“But most of them are the same, roundabout the same age group and I think you relate better that way, but I think if you are with people who are older than you and who are in a lot worse condition, you’d probably tend to deteriorate, whereas coming here, you’re mixing with people roughly of the same age group, or a little bit younger, you tend to more of less stay the same or improve. I mean, I’ve found it quite good coming here, it’s only twice a week but it’s, it helps. It’s nice to have other people to meet rather than being stuck at home all the time. I think you’d soon get very bored sitting at home in front the television or on your own.” (SW3)

When asked by the interviewer about being placed with people older if there were no alternative services, one respondent commented:

Interviewer: “So, Mary, in terms of the club here you’ve talked about company, can you tell me a little bit about that ...?”

Respondent: Yes, yes. I mean if I was sat at home every day I’d get fed up. It just gets me out to see people so I come three times a week, like Monday, Tuesday and Friday.

Interviewer: Yes, yes. And if the club wasn’t here what do you think you might do?

Respondent: Well I won’t be going many places at all I don’t think.

Interviewer: I mean I know sometimes there are places but, and they’re usually with people of a lot older age in day centres. Have you got any feelings about that, would you be happy? How do you feel about if you had to go there?

Respondent: No, I’d rather stay in my own house all the time.” (SW2)

Another respondent drew the analogy of looking after elderly parents and now having to face the possibility of being placed in the same home:

“...But I don’t want to be in a ... [older person’s home] not like where your mum was.” (CU5)

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:

Interviewer: Right. Can I ask you, Sean, in terms of thinking of what's available for people with memory problems as young as yourself, do you have any views on that in terms of what services are available, what help is available?

Respondent: As far as I know there isn't, I don't really know much of what's ...[*Later*]

Interviewer: Right. But in terms of helping you to live your life and like, for example, coming to the club.

Respondent: For people with memory problems this is about the only place I know, isn't it? (SW4)

### *The needs of younger people with dementia*

When respondents were asked about the needs of people with memory problems, some commented on the desire to be treated as 'normal' or as 'ordinary people' (SW3) and not as "zombies" (YP24). It was evident from the majority of interviews with younger people with dementia that there was an overwhelming desire for purposeful activities that matched their level of fitness and capabilities. For example, the ability to walk, go to the pub, go shopping, or do gardening, woodwork, art work or sculpting. For one respondent, the important thing was to keep busy:

Interviewer: Right. So Sean, if I was to ask you in terms of what do you think are the needs [of younger people with memory problems]?

Respondent: I kind of got written off when I had the depression.

Interviewer: Really. But just to sort of stay in this for a moment, in terms of thinking about the needs, people with memory problems, particularly younger people what would you say?

Respondent: "... I think they've [younger people with dementia] got quite a few needs haven't they really?

Interviewer: Such as? Can you give me some examples?

Respondent: I think they like things to do don't they?

Interviewer: Like things to do?

Respondent: I mean they're all doing that breeze blocks today.

... Even though they do, some of them might have trouble remembering it... [*Later*] I think it's better to keep busy, myself I think it's better to keep busy you know." (SW4)

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. For example, it appears that tensions may exist between professionals' risk assessment and needs to balance independence and safety in younger people with dementia. In particular, as outlined earlier, one respondent described his experiences of how 'they' (statutory authorities) "took" away his train pass as it was deemed 'at-risk' and unsafe:

“And that annoyed me because they think I gonna jump out the car, train or something, I don’t know what they think but I can’t use that now they took it away. [Later] That’s a bit, that’s what they said. And I just can’t understand that at all. Because I’ve got a bike. I could go down on the bike and it’s a darn sight, if I went on me bike it would take me a longer time and with all the roads, is worst than going on the train, it’s crazy.” (YP21)

It is important to acknowledge that younger people with dementia are by definition a vulnerable group, and to this end there will always be tensions between managing risk and maintaining safety. The questions to consider are: for whose benefit is risk assessment performed? Is it always in the client’s interests? More importantly, who makes these decisions and how are these decisions taken, and are they a ‘one off’ assessment or based on a continual assessment?

Interviewees’ themselves reported feeling invisible, or uninvolved in decisions surrounding their care:

“Of course you know these meetings with the family and the carers and all that they leave the room sometimes where they have been so... and I hate that, because I am sat in there like a lemon and its my life, I am the one that is dying” (Later). ... but you’re just shoved away, you start to say something and they go ‘Just keep quiet X’ and that hurts, that hurts as well.” (YP23)

“I kind of got written off when I had the depression.” (SW3)

Many interviewees complained about having their drivers’ licence taken away from them and expressed feelings of sorrow at not being able or allowed to drive:

“The only problem is that I don’t drive anymore, they took my licence away from me and sold my car so I’m relying on [my partner] all the time.” (GL3)

“I can’t drive, I had to give up driving because I, and I miss that a bit.” (CU3)

“Well, it hurt at the time when they said that you ... they revoked my licence and I thought, ‘Well, that’s that’.” (CU5)

The loss of paid work and for some, enforced early retirement was also featured across respondent interviews. A feeling of losing one’s identity and self-esteem was also apparent:

“[I] retired early because of my memory problems, so I wasn’t sort of, with memory problems at work you’ve got to be really on top you know, so I retired.” (SW2)

“... I enjoyed my work and if I was allowed to I’d be doing it now, but I’m not.” (YP20)

### *The family context for younger people with dementia*

For some respondents, especially those with younger dependent children, accounts of how the family was attempting to come to terms with the diagnosis of dementia were of particular note. For one respondent the experience of the children, “Both of the kids [teenagers] so far have blanked it completely,” (CU6) was a particularly difficult experience. A carer’s account of her son (young teenager) experiencing difficulties with bad behaviour at school as a result of his inability in accepting his fathers’ dementia serves as an example and provides insight into how dementia affects other members of the wider family. What was apparent from these interviews was the sense of ‘strain’ that dementia places upon relationships within the family, particularly when it appears at a younger age:

“What its [dementia] doing, see, is stretching our relationship to a very thin cotton, something is going to snap.” (YP23)

Having young dependent children appeared to compound this ‘strain’ still further.

### *Models of good practice: alternative, more ‘individual’ services?*

A central objective of this study was to identify models of good practice. A service highly valued by one respondent in Bristol, offered a facility, where a social service worker discussed with the younger person with dementia and what his or her expressed wish was on that day e.g. drive to a garden centre, lakes or to the pub, and these wishes were respected as much as possible. For this respondent the service gave him the freedom to leave his house and pursue activities with another person.

Another example of good practice identified was the provision of respite care for younger people with dementia set within an elderly person’s home. A specially designated ‘focus worker’ was available exclusively for the younger people with dementia. This worker would come in for two hours on a one-to-one basis and take the younger people with dementia out if that was their expressed wish, to the pub or for a

drive. The particular respite care service is 'attached' to the specialist day centre for younger people with dementia thus there are opportunities to visit the home and become familiar with the respite care.

### *Reflecting on the interview process with younger people with dementia*

A central dimension of these interviews was the ethical, and communication dynamics between respondents and the interviewer. Due to the nature and aims of the interviews, which were to explore the views and experiences of younger people with dementia surrounding 'key' issues regarding their needs for care and services, respondents, with the exception of two, were articulate and forthright in their expressed views. Seeking and securing consent from younger people with dementia (verbal, written and on going) was a major consideration for the interviewer. This aspect proved challenging throughout. It was unquestionably easier to gain consent from people in the earlier stages of dementia. Of the 14 younger people with dementia interviewed, 10 gave written and verbal consent, 3 gave verbal consent, and in 1 respondent where it was difficult to assess if verbal consent was given, the principles of seeking on going verbal consent were sought. For example, regular checks were made throughout the interview to ensure the respondent was happy to talk to the interviewer. For two respondents (YP24, SW4), despite feeling emotional during the interview, both expressed a wish to carry on. For these individuals, this was the first opportunity they had been given to talk to someone about their experiences.

### *Interviewing younger people with dementia in the more advanced stages.*

Of the fourteen respondents, two were in the more advanced stages of dementia, although Pat (YP22) was talkative and expressed satisfaction and pleasure in being interviewed. However Jenny (YP19) proved to be a very challenging interviewee in that both her husband and her care manager thought she was 'locked in her own world' and that the interviewer would be unsuccessful in communicating with her, but gave their permission for me to try. It was difficult to assess exactly how much Jenny understood. The approach and strategy was an informal approach, with the interviewer walking with Jenny, (who was a keen walker as informed by her husband during the carer interview) and essentially following Jenny's lead. The conversation was monosyllabic and left the interviewer reflecting on the challenges interviewers face when attempting to communicate with and 'enter the world' of people with dementia in

the more advanced stages. For example, when the interviewer asked Jenny what she liked her response was, “Nothing” and a smile. Nonetheless, it was a goal worth pursuing in order to inform the practice and research debate regarding alternative methods when communicating with younger people with dementia in the more advanced stages.

### *Accessing younger people with dementia*

Accessing younger people with dementia proved challenging. Some carers, when asked if it was possible to speak to their partners, commented, “She [younger person with dementia] is too far gone, had you come five years ago she could have talked to you...you won’t get anything out of her” (YC7, YC4, YC12). Only one carer (YC12) agreed to the interviewer visiting his wife in long-term care, the remaining carers declined. Indeed, this carers’ perception proved to be accurate as “Jenny” (YP19) proved to be relatively uncommunicative (see above). However, these issues raise concerns around the role of ‘gatekeepers’. For example from a practical, as well as an ethical and moral basis, carers’ wishes must be respected. However, this may cause ‘tensions’ between what the younger person with dementia may want, and their decision to participate with research, with those of their carers. On a methodological level, this poses questions as to how to gain access to younger people with dementia if carers and professionals are making these decisions on behalf of people with dementia? Who is the ‘right’ person to do this? Attempts should be made to ask the younger person with dementia about their views and wishes and whether or not they wish to take part in research. The question appears to be is how far will researchers’ be allowed to secure the views of the younger person with dementia and will the carer (once having negotiated all the professional gatekeepers) be the ultimate gatekeeper? These are complex, challenging, ethical and moral questions. It was the practice of this research to respect carers’ and professional judgements regarding who the interviewer could speak to. The overall sense is that the younger person with dementia is in danger of being ‘invisible’ (as indeed one could argue could apply to all people with dementia) and may be perceived as being ‘incapable’ of making decisions on their own.

### *Issues of interpretation*

The interviewer was aware that the interpretation of the user and carer accounts was in part, shaped by biographical experiences, intuitions and theoretical

“hunches” gained from the systematic literature review in addition to respondent accounts. Thus, detailed reflexive field notes helped the interviewer reflect upon the interviews, which in turn assisted and highlighted opaque areas during this iterative process. For instance, at times it was difficult to ‘hold’ some respondents in the discussion (YP22, GL3). For example, Pat’s (YP22) memory problems were quite restrictive and the ensuing conversation was on some levels quite superficial. Therefore, it was difficult engaging with Pat in terms of asking her what she liked and thought. Subsequently, devising a coding framework for this particular interview was challenging. Equally for Nora (GL3), who from the outset made it clear that she did not have memory problems, conducting the interview and analysing the data was again challenging and complex. Overall, the interviewer was mindful of ‘not rushing’ respondents and allowing them time to express their views without over interpretation.

## **Chapter 4 - The views and experiences of carers of younger people with dementia, Angela Beattie**

“This should have been our time now.” (CC4)

“I feel our lives are finished really, we’ve no plans or nothing you know, I mean when you come 70, 80 maybe you quieten down a bit then but we had a lot of living to do still and now there isn’t no living to do.” (SW5)

“I didn’t know what was ahead of me but emotion, emotionally I went to hell and back.” (YC26)

These words were spoken by carers of younger people with dementia and reflect the overall sense of caring, which for many was perceived as untimely, unwelcome and a role for which many were unprepared.

### *Fieldwork methods*

Sixteen carers (7 male, 9 female) of younger people with dementia were interviewed in their homes. Of these, five were working part-time, two full-time, one voluntary, seven had taken early retirement and one carer was currently unemployed (see table 2, below). Three of the carers’ spouses had a diagnosis of Huntington’s disease (HD). During the data collection period the spouses of two carers died. Carer interviews lasted between 55 minutes and 4 hours, the mean interview duration was 80 minutes. All were audio taped with permission, except for one carer who did not wish to be tape recorded and for whom interview notes were taken. Written, verbal and on-going consent was sought throughout the interviews.

### *The ‘burden’ of caring: the subjective experiences of caring for a younger person with dementia*

“You’re watching someone very slowly die.” (YC25)

“I suppose my life’s on hold for awhile.” (SW5)

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

Table 2 - Characteristics of carers of younger people with dementia sample

<b>Interviewee</b>	<b>Sex</b>	<b>Attending specialist day care?</b>	<b>Attending services in older settings?</b>	<b>Paid work?</b>	<b>Early retirement?</b>
YC4	M	y	n	n	y
YC6	F	y	n	y P/T	n
YC7	M	y	n	n	y
YC8	M	y	n	y F/T	n
YC9	F	y	n	y F/T	n
YC10^	F	n	n	unemployed	n
YC11^	F	n	y	voluntary	y
YC12	M	n	n	n	y
YC25	F	y	n	y P/T	n
YC26	F	y	n	y P/T	n
GL1	M	y	n	n	y
GL2	M	n	y	n	y
SW5	F	y	n	y P/T	n
CC8^	M	n	n	n	n
CC2*	F	n	n	y P/T	n
CC4*	F	n	n	n	y

M=Male, F=Female, y=yes, n=no; \*Joint interviews; ^ Carers of people with Huntingdon's Disease

times daunting experience. Most carers spoke at length about how dementia affected their lives, families and the wider community. One respondent spoke of hoping against

hope that it was not Alzheimer's causing her husband's change of personality but rather pressure of work (CC2). Others gave a vivid account of the 'reality' of living and caring for a younger person with dementia. For example:

"I could scream sometimes. Questions, questions, questions, all the time, so you have to keep explaining and then two minutes after, 'What did you say the time is?' and then I say, 'Well you're not blind, look', and then I think, no, you can see he's looking but it's not, and I do think, 'Now he can't help it, don't get mad'. Well then a few minutes later,  
 'What day is it today?  
 Tuesday.  
 Well why is it Tuesday'?  
 'Cos it is'.  
 'Well I thought it was Sunday'.  
 I say, 'No Sunday's gone'..." (CC4)

"I was getting up at four in the morning and starting to get things ready and leaving Zoe on her own, but I had to set things out for her, she couldn't do a lot at that time and going to work. [Later] Unless you are caring for someone with Alzheimer's, I don't care who they are, outside the family, your children, no one knows. Within these four walls [is] what it's like. Even the doctors, it's so traumatising and traumatic, you've got no life my life has been taken away because I love Zoe. We've been together now for 48 years, I don't know when the time's going to be to let go." (YC4)

"I was really going down at one time, I even felt suicidal I did." (SW5)

These graphic and harrowing accounts reflect their feelings about caring for a younger person with dementia. Overall, there was a perception that their lives had been taken away, and, instead of this being 'their time' (CC4), their life appeared to be placed on 'hold'. Not all were completely pessimistic. One carer reported that despite the caring role being "hard work, it's a full time job, tiring" (YC7) he also found caring "rewarding in a way". It must be stressed that most carers did not share this experience. Where carers were coping with work it was evident that they were finding it difficult to cope.

"It is hard work. I do shift work I was getting stressed out I am still working." (YC8)

"I think it's awful, it's a nightmare, it really is. It's just such hard work all the time, really is, just never ending job, you know and I go out to work and like I come, I do part-time now and I come back home and then my job starts here then." (SW5)

Moreover, feelings of guilt and not having enough patience were also a feature of carers' accounts of their experiences of caring:

“I mean there was times when I did mind, I wasn’t as good as gold, you know, there’s times when I did, when I have shouted at him and lost my rag but on the whole, you know, I just tried and managed the humour about it, you know.” (YC10)

In contrast, one carer [male] stated that he was not prepared to “ruin my life and spend 24 hours a day locked in this house”[caring for a younger person with dementia] (YC12). This raises questions around what support is available and how effective that support is in helping the carer manage his or her ‘burden’ of care. From this latter account, it seems as though some people will not be prepared (or able) to manage the burden of care, no matter what support is offered.

*Family dynamics and how caring for a younger person with dementia impacts upon the family*

Carers spoke of a range of emotions experienced by families. 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. These feelings were further exacerbated by carers’ perceptions that mental decline and death were likely to be more rapid. Indeed, comparisons were made between older people with dementia and younger people in relation to their longevity, the perception being that younger people had generally less time:

“It’s the most single element that is the biggest thing isn’t, it is how long have you got of worthwhile life? And if you knew that you could organise around it.” (CC2)

“It’s so hard, it’s really very, very hard and that is the worst part of the disease it’s, in fact I would go so far as to say it’s worse than caring for someone that I know is going to die. [Later] All that to me is so hard to cope and the whole family, you know, they’re all devastated over it, they’ve all their different emotions, one, part of them is full of pity, another is they’ll help to look after him all they can, and then another part of them don’t want it, you know they don’t want to see him like that every single day... [Later] ... It’s quite bad, it really is quite bad this disease because physically and mentally... this is a horrible disease. You wouldn’t really wish it on your worst enemy especially this one, you know with the Alzheimer’s disease, you know, they [people with Alzheimer’s] can get physically, it don’t seem to affect them quite so much mentally, you know, they can go on for ten, twenty years and physically they’re okay. ... This one’s [referring to her husband’s dementia Pick’s disease] a bad one and they said it’s a lot quicker, you know, very quick.” (YC25)

It is interesting to note this carers’ perception of Alzheimer’s, and the belief that physically and mentally, people with Alzheimer’s Disease are generally better off than a

person with Pick's disease. What this account suggests is the possible influence of lay beliefs surrounding dementia and how the differing social and psychological contexts between younger people and older people with dementia may influence carers' perception.

Some carers reported difficulties with their relationships and indicated that dementia was placing these under enormous pressure. For example:

"I've gone through such a lot of different stages of feelings and I mean like this time last year I could have really walked out on him, I could have walked out on my marriage." (YC26)

Similar difficulties were reported by a younger person with dementia (YP23) (unrelated to the above carer account), who indicated that their relationship was being pulled to a "thread" and suffering "strain" because of dementia. Another carer spoke of how dementia destroys relationships:

"The person I'm living with and looking after is not the person I married 35 years ago." (L2)

For one carer, the lack of an emotional relationship and loss of sexual contact was central.

"I've been dying to say in my conversations [with health and social care professionals] you know, but mind you I never felt like that then, but I'm feeling I want a bit of loving now. [*Later*] It scares me in a way because you don't know, because being young you don't know if you meet somebody along the way and it does scare me but there again you know, I long to be loved by somebody, I really do, and I mean you know not being loved for 4 years it's awful, it's horrible." (SW5)

The whole issue surrounding sexuality and people with dementia appears to be a neglected area in the literature and, in particular, how to express sexual needs appropriately. For example, a carer of a person with Huntington's disease (HD) spoke of the relative youth of her husband (late 40's) and how his expression of sexual needs and sexuality was perceived by health professionals in a mainstream setting as 'challenging and inappropriate behaviour'. In this particular case, medication was allegedly used to suppress his sexual needs:

“He had thoughts and they were of a sexual nature, and bear in mind he’s only a 48 year old man, and he would express these thoughts to people and, um, she’d [health professional] say, you know, ‘Don’t say that Sam,’ but he couldn’t think, couldn’t see anything wrong with it I don’t think. Anyway he went in to give her a bit of a break to [names hospital] and I’m sorry to say this but they absolutely ruined him, ruined him, they just did not know, they did not know anything about Huntingdon’s Disease and they got him on medication that just put him into bed like a zombie and, you know, totally confused him and he was still having these thoughts and of course saying things to the nurses, all this kind of thing and then he went into, um, [names second hospital], he went into the [names second hospital] and, uh, they couldn’t seem to sort out the best thing for him there.” (YC11)

Later in the interview it was revealed that when the younger person with dementia was transferred to a specialist HD unit the problems surrounding expressions of sexuality and sexual needs appeared to have been addressed:

“I saw “Mary” about a month ago and she said he’s the old Sam and he’s not got any of these thoughts, you know, this is what was told to her when she went over to look at the place and they said, no don’t worry, you know, when he comes to us we’ll sort it all out and he’s been going out on trips with them and everything, you know, they’ve given him back some of that life, you know, he was losing ...” (YC11)

#### *The role of caring: isolation and loss*

A central feature of carers’ accounts was the sense of isolation, particularly at the beginning of their caring role and their perception of not having anyone to talk to. For example:

“To start off is the loss, there is nowhere to go, who to contact that is the problem, you don’t know who to contact.” (YC8)

In the initial early phase there may be reluctance to seek help, as the account below illustrates:

“Well I think possibly um at the beginning, because I am a fairly sort of determined person, I kind of said um, I can cope I don’t need any help, you know, and then as the thing progressed, two years down the line so to speak, I was glad of all the help offered and looking around for more.” (YC11)

The general feeling of unease, the uncertainty as to how their partner may react and the sense of feeling ‘invisible’ with little recognition of what it is like to care were particular concerns for some carers as these accounts illustrate:

“It’s sometimes a bit like this walking, treading on eggshells because you have to be very careful what you say because what you say, however innocently it may be, uh, results in a spat back. Caring is a very difficult process and I now understand how my mother felt when she was looking after me dad (laughter).” (L2)

“I was really going down at one time, I even felt suicidal, I did and (um) but it was never oh! How are you mum oh! it’s how dad is and he has a wonderful life the way he’s being looked after. I don’t know if that’s angry, jealous, no it’s not jealousy but I just wish they’d ask me how I was I suppose, you know but I got used to that now.” (SW5)

“Sometimes I feels as though he’s, sometimes I feels as though he’s in like a world of his own” (YC26)

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 also a recurrent theme:

“He could no longer, he could no longer remember things so all the past things that we could share were, you know, were gone, you know like if I ‘Yes’, blank, nothing, he’d acknowledge he remember[ed] it but he wouldn’t, didn’t have any memories of it, which was really heart breaking, you know, that was the one person that you share all your past with.” (YC8)

#### *Having younger children: how dementia impacts upon the family*

Of the carers interviewed, two had children aged 11 and 15 years (YC10), and 14 and 19 years (CC2) at the time of diagnosis; both expressed difficulties in coping with the children’s reactions. For instance, they reported that when their children first learned of their parents’ dementia their initial reaction was to ‘blank it out’. One carer reported educational and behavioural problems with one of her children. The reason reported by the carer was that this child’s father ‘stood out’ from all the other dads, (making facial grimaces and salivating) and, the child was having difficulties in coming to terms with this. A way of expressing these difficulties for this child was through inappropriate behaviour (outbursts of anger, swearing). According to the carer, despite attempts on behalf of the school to understand and support the family, their child was excluded from some lessons, culminating with him leaving school early. What this account illustrates is how dementia in younger people can reverberate and affect the whole family.

### *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 this took between two and eight years.

"It took too long to diagnose and it was only our, like my insistence and the families insistence that more things were done to find out, because he was being, because he was quite a depressive man, he was being treated for depression and we, you know, we kept saying "There is something else wrong, I know there is something else wrong'." (YC25)

However, receiving the diagnosis proved to be a harrowing experience for some respondents. In particular, carers from one case study area spoke negatively regarding their experiences. Feelings of being unprepared, not knowing what was going to happen and being told "brutally" that their partner had Alzheimer's were reported:

"[T]hat's all we knew on that day and the other thing you see was that we assumed that having done these tick box tests, that [we] would have to go away somewhere and be marked or whatever and that. We weren't expecting a diagnosis on that day and we were not prepared for that at all. [Later] And you were off guard as well, I mean it wasn't as if she'd [health professional] sort of led you in nicely and sat you down, and all that, it was the sort of almost pulling him off [me] and, it reminded me of my son's first day at school when he was five, how they, sort of pulled him off me, you know it was the same kind of thing, you know? Um, 'Let's take your support away and then see how badly you do,' you know, was how it felt. Um, and then, sort of, Dr X poked his head round the door and [said] sort of 'Oh well do you want me'? You know, it was very, he was very vague, it was very casual, um, chatted a bit and then he asked you to name as many animals as you could in a minute, which is obviously another standard test, which we had no idea about and uh once again, '[You] did abysmally at that, didn't you? 'cos you just weren't expecting it at all.' " (CC2)

There were apparent tensions in the account of not being prepared adequately to receive the diagnosis on the day, and, feeling that the information came 'fast and furious' leaving the carer (and her spouse) feeling that they wanted more time to absorb what they had been told:

“Absolutely and this poor chap, Piers, was sat there, you know, [thinking] I’m gonna die next week and, um, you know, I said not now surely, [imparting the diagnosis of dementia] and he [doctor] said well yeh, ‘Better sooner rather than later and they start going on about how you’ll have to give up driving,’ which is, living in such an isolated place as this [is a problem].” (CC2)

A similar experience, but without the same negativity was reported by another carer:

“...But I did find it was too much to start off with, it was good intentions but I found it too much to deal with and I wanted a time where I wanted to let it settle down.” (YC26)

Central to these carer accounts are issues around how and when to impart information about the diagnosis of dementia and balancing this with their need to know. In contrast, a carer reported a sense of openness, sharing and involvement from the outset, which was highly valued (YC6). Thus, there appears to be differences in the accounts and approaches as to how, and when the diagnosis of dementia is given. For example carers in one case study area reported that it was the practice of the memory clinic to ask carers in the first instance whether they wanted their relative to be told.

One carer spoke of ‘relief’ when his wife had been diagnosed with Pick’s disease rather than Alzheimer’s. However as time and further information became available this carer’s ‘relief’ soon abated:

“... [ The Consultant] said my 90% diagnosis is Pick’s Disease, not Alzheimer’s and after we’d sat with him for half an hour we both went out in the corridor we put our arms around each other and gave ourselves a big hug and said ‘Well it’s not Alzheimer’s, thank goodness for that’. ... And to tell us that it wasn’t Alzheimer’s, um, was like a burden lifted, but then when I researched into what Pick’s Disease, I realised that you know all the books, all the information was telling you that it could actually be worse than Alzheimer’s in the long term so, you know, I dread the future. I really, really dread the future. So we live for today.” (L2)

When carers reflected upon how and when they first noticed that something was different, some spoke of noticing a “personality change” (SW5, YC26, YC9) in that behaviour which was out of character suddenly became the ‘norm’. It was interesting to note that because of the age of her husband [mid 50’s] one carer initially explained the personality change as “his age [mid-life crisis] or too much pressure at work”

(CC2). Additionally, a number of carers attributed this change to the problem being located within the carers and something they had done (SW5, YC26).

“I thought it was me. I really did think it, I’m truthful, I’m really truthful, [and] it took me a long time to accept it was Bertie.” YC26)

The carers’ isolation in the initial phase of receiving the diagnosis and the inability to talk to others about it also arose during the interviews. For example, the stigma of having a mental illness, and the worry that others would pity the family, led one carer and her partner with dementia to selectively disclose the diagnosis to certain members of the family, friends and work colleagues, but not others. However, this decision further compounded this carer’s isolation:

“...People like ex-colleagues, he doesn’t want them to know. I mean it’s very much been a need to know basis which means that I end up with not [having] very many people to talk to about it and it’s just good to be able to spit it all out isn’t it? [Later] ... for the few that we have told in saying those who do know, it’s much easier with them.” (CC2)

This particular carer also remarked how “shocking” it was to witness her husband’s cognitive decline first hand during the diagnostic tests and how he could not remember his birth date:

“ It was the most eye-opening hour that I have spent in a long time, in that he obviously knew what questions to ask, and it was quite shocking to me, because obviously, you don’t ask your husband what his date of birth is because you know it, and you presume that he knows it. Um, to suddenly find that you didn’t and that it was January and you didn’t [know] what year it was, it was really quite shocking wasn’t it?” (CC2)

### *Carers’ Needs*

“ There’s no where for these people to go for respite, only places for the elderly.” (YC4)

The issue of access to respite care was a central feature of most carers’ accounts. When carers were asked, “What do you feel your needs are in helping you care for a relative / person with memory problems”? Many reported an overwhelming need for regular respite care. For example, carers reported they needed time to ‘get away’ from the caring role and relax and have time for themselves. For example:

“This last couple of weeks I’ve been getting low, I’ve been getting stressed, and I just, it’s just like looking down a tunnel sometimes you can’t see the end to it ...but I just need freedom, I just need to get out of this house and to be away and just relax, and I think that is the biggest thing with people that are carers... it wears you down, it grinds you down, and it creeps up on you and you don’t realise it, but I’ve learnt to recognise the signs now.” (YC4)

This account encapsulates what the majority of carers said about their caring role and why they needed regular respite care. However, experiences did vary. For some, the feeling that there was little or no respite available was reported. Some carers reported being denied access to respite care in a neurological unit because their partner had a primary diagnosis of dementia. It was reported that this specialist neurological unit would take people suffering from various neurological conditions and offer a maximum of eight weeks respite care per year (as opposed to the ‘standard’ respite package of two weeks per year, which must be booked in advance) provided dementia was not the primary diagnosis. Paradoxically, if a younger person had a cerebral vascular accident stroke, with ensuing dementia, he or she would be accepted for respite care:

“But trying to get him in somewhere was difficult... And there’s a big [neurological] unit that I found out about ... it’s for younger people who’ve got this problem. So I rang them up. I rang the social worker, who said she’d never dealt with them, do it yourself. So I rang them up, found out the unit, found out the name, rang up, explained the situation... discussing the case with the doctor who said, ‘I’m sorry you can’t put your husband in a neurological unit’, which I thought was a bit strange because Marvin’s neurological anyway. So I said, ‘Well, what have we got?’ She said ‘Yes, but we’ve got to draw the line somewhere ... And he can’t come’. And yet they have people there who have had strokes, got ... all the other illnesses but they won’t have anybody there that suffers from [dementia].” (YC9)

Carers reported that advanced booking is a requisite to securing respite care, and even then it was difficult to. Given the above account, and the general perception of some carers that there was not enough respite, it is unsurprising that carer expectations and demand may well exceed supply. It was of note that whilst one carer also spoke about the rigidity of the system and how it was a matter of “luck” as to whether he received respite, this individual spoke positively of a residential home which offered flexibility and advance booking. A common feature throughout most accounts was the expressed desire for more and regular respite:

“So I think it’s got to be every 6 weeks people have got to have respite available to them.” (YC4)

“But I think there is sort [of a] hole in the system...I don’t think there is enough respite care for carers I mean people can get care to a degree. Although some people seem to be able to get. I know one bloke who had, he had, his wife went in [to] respite every month, week every month or every three weeks he looked after her and a whole week he didn’t. But I mean how that works I’m quite not sure. I certainly couldn’t get [the] respite care I wanted from [hospital] which is the only [place] where I’ve tried.” (YC12)

Overall, from the carer accounts surrounding respite care, varying experiences were expressed with a ‘mixed’ picture being portrayed. However, one carer expressed satisfaction with the respite care offered and reported that it met their requirements. For example, in this service carers could have a ‘long weekend’ off i.e. from a Friday to a Monday in addition to a planned six-week respite rolling programme.

*Respite: the position of younger people with dementia in an older person’s context*

According to most carers, respite care was primarily offered within an older person’s environment and was generally perceived as negative. Analogies were made between carers’ experiences of sending their aged parents into care with their feelings towards sending their partners into similar care. Having to face this dilemma with a relatively young partner was a distressing experience for most carers, with many expressing feelings of guilt. For example:

“I couldn’t put her into one of these respite care homes, I mean, it, it broke my heart to see my father in, um, in the local one, uh. I’m not saying that he had bad care but the whole environment is not conducive.” (L2)

Interviewer: Could I ask you, you know you said you hated leaving him up there [respite care elderly setting], can you tell me why, what was it that you didn’t like?

Respondent: I just felt so sad that how young he is that he’s going to a place like that in respite ... but it just, oh! I was just so heart broken at leaving him there I just felt awful. [Later] And the guilt you feel is just awful. It’s horrible, really horrible.” (SW5)

There was also the sense that placing her husband in an older respite setting could lead to a more rapid cognitive decline.

There were tensions evident in carers’ accounts of their need for respite, more so if it reduced the possibility of relationship strain, 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. For example:

Interviewer: "Well I know we talked, you talked a bit about respite. Have you had any experience of respite. Can you tell me what your feelings are on that?"

Respondent: "I think the worse thing is he knows everything that's going and he doesn't want respite, he's not going, that's that so the demands then is I get all the playing up if I'm going anywhere without him you know." (YC25)

"She's going into a nursing home tomorrow for 2 weeks to give me a rest but I am dreading it, I'm dreading taking her to the nursing home because I feel as if I've betrayed her, it's an awful feeling and I shouldn't feel like that but I do, I'll be all right once she's in there and I'm away from there." (YC4)

"And I kept on saying you know, I shall be down to see you, I shall come ... shall come ... shall come and you're not ... you know we're not deserting you." (YC11)

#### *Accessing care and services: carers knowledge regarding services*

"To be honest, I don't know exactly how much help there is." (CC4)

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 care and services. 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. For example,

"No, nothing, not that I've been made aware of and I've found, I've tried to find my way around this system. I've done everything but as regards specific, um, assistance through the social services, in a word, nothing." (L2)

"You have to battle, you have to convince the social services that your wife is entitled to full disability allowance. It took me ages to get that, and in the end I threatened to go to a tribunal about it because I knew I was right." (YC4)

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 care and services to be more responsive and less crisis led. Thus as one carer reported, "But if you are looking at the service providers, start being organised, if they [services] carry on being

haphazard, only come if somebody screams” (YC7). Carers also commented on the need for care and services to be more flexible. 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.

### *Accessing care: age issues*

As already illustrated, the pathways to accessing care are dependent upon the age of the person with dementia. Many carers felt that that had their relative been over 65 years, accessing care and services would not be so problematic. Of the professionals interviewed, many pointed to a shortfall in dementia services for everybody. However, the general consensus from carers was that for older people with dementia there was a degree of (limited) knowledge regarding services, but very little for younger people with dementia:

“I asked my doctor and he said if he was older I could tell you – and that’s the answer I get every time if he was older I could tell you places, but because he’s younger ...” (YC9)

For most carers the age criterion of services was a major concern. Some perceived older day care negatively. Whilst others felt that their relative was misplaced in these settings:

“I kept saying to the social worker ... because it still wasn’t really for Marvin because most of them were in their eighties, nineties and he wouldn’t join in the things they were doing. Well, he was very fit, physically and they would do lots of things sitting down and they’d play bingo or games, things like this. He would just wander around, and I said well, there wasn’t anything really I could do because that was the situation.” (YC9)

When carers were asked, “What would help them care”? A typical response was:

“ Well I would welcome more time, more days, we tried [mentions older day care setting] for a couple of days ..she [wife] is too restless, too active, she is very fit this disrupts a group of older people ... [They] haven’t got enough staff to cope, this is the problem, people like [wife] are too active, disruptive, she will not join in group activities, because she finds it silly.” (YC7)

It is of note that one carer, whose wife was in long term residential care, reflected that had his wife been aware of her surroundings she would “go spare if she thought she

was in a home like that” (YC12). One carer commented: “There just seems to be a gap”, which highlights the position of younger people with dementia regarding accessing care and older day care settings and where to place younger people with dementia (YC9).

“There’s an issue down here in the, in the day centre that she goes to in the sense that, I mean, they’re all between 75 and 101 ... and she’s 60. You see, I mean, I just, if I told her she was going, she was there as a client, she wouldn’t go. She wouldn’t go. So, I mean, every now and again when she gets particularly low she says, ‘Why me, what have I done, I’ve been a good girl all my life, why me?’ Um, I don’t know how to deal with that. So what the solution is, I don’t know, but I do know that putting a 60 year old in with a group of 80 years olds as a client/patient/participant isn’t the answer” (GL1)

#### *Accessing care: benefits and barriers*

Of the carers’ interviewed, many spoke about the unwieldiness of the 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. Indeed, the account below may point to reasons as to why carers may not access the care that they would like:

“It really, every morning you come down you sort of look at the door mat and say, ‘Oh not another brown envelope you know’. In fact at one stage I bundled them all up, they were asking for something which I didn’t know, I just bundled the whole lot and posted them to them because they posted them all back again, I was hoping they would only send me the relevant bits.” (YC6)

A male carer reported that the threat of taking the statutory authorities to court regarding his eligibility in accessing the higher tier of carer’s allowance was speedily resolved once legal redress was threatened (see also above). In contrast, a female carer from a different county, who was less articulate and from a lower socio-economic group, reported major difficulties in attempting to (and failing) to secure the higher benefit allowance:

“But you’re sort of fighting one [health assessment and the need to keep mobile] against the other [statutory authorities who assess mobility on a scoring system] and I’d rather have him walking than all the money in the world.” (CC4)

### *Carers' unmet needs*

Carers' unmet needs matched their perceived needs. In sum, carers felt that care and services should offer more. For example, of the carers that were in paid employment, many commented upon the unreliability of the transport to take their relative to day care. For example:

“Unfortunately the taxi people are not very good, they're supposed to be here by a certain time and we're constantly having to ring up and say, 'Where's the taxi'? It does mean then that again I'm getting really stressed out, I am now going quarter of an hour late for work, half an hour late for work. My employer's not going to keep tolerating that.” (YC 25)

The lack of respite, age-appropriate care and services (with the exception of the two specialist day centres) has been well documented throughout this report as indeed has the perceived lack of continuity between staff and the care and services on offer. Again, as the accounts surrounding dementia diagnosis indicate, some carers felt unprepared for this. With regard to the availability of care at home there appeared to be a gap in provision, in that carers are left without cover at the weekends. One carer spoke of feeling “absolutely shattered” (YC8) having spent his day off caring for his wife. For this carer, combining full-time work with looking after his wife on the days when care was unavailable was extremely difficult.

### *Carer satisfaction*

Overall, carers expressed satisfaction with the general care received from health care professionals. For example, carers spoke highly of general practitioners. Negativity or criticisms appeared to be directed mainly at social services departments. Comments such as, “If I had any criticism I think social services are disorganised ... you never seem to speak to the same person twice” (YC7). For this carer, the perception was that once help was received it was with a view (on the professional's part) that this carer no longer required support:

“ Well, that's all right then, I can take that off my [professional] list.” (YC7)

Another carer mentioned a similar experience:

“If you’re coping so you don’t need me.” (YC11)

However, some carers did not accept this. According to these carers there was a need for regular back up and continuing support, even if outwardly they were seen to be coping. Equally, comments such as:

“I’m used to doing things so much on my own now. [*Later*] My social worker can do so much but then again she doesn’t always tell me everything. We were saying something and she said, ‘Oh, you can have therapy for that’, and I say, ‘You haven’t told me’. Then she says, ‘Oh I must come and have a chat with you and tell you’.” (YC9)

What these carer accounts illustrate is the perception of care and services being *reactive* rather than *proactive*. To offer a balance to this negativity, some carers spoke highly of their social worker, despite their attributing this to being ‘lucky’:

Interviewer: So can I just ask you what’s good about the services that you receive?

Respondent: I’ve got no complaints to be truthful about it I’ve found that I’ve got a good social worker and she says any problems ring me.

Interviewer: If you ring can you get through, you can speak to that person? ( This was an attempt to follow-up YC7’s negative experience and how he never spoke to the same person twice)

Respondent: Yes she will come back to me, I haven’t had a problem with that. I don’t know if everyone is as lucky as I am, because I think the carer needs looking after. [*Later*] I think there’s a lot of support there that which I haven’t called upon as yet. I mean I’ve been given various papers with groups, carers rather than for the patient themselves they’re actually for the carer. I think people have become very aware that there’s a lot of stress on the carer. (YC4)

“I must say [mentions social care worker] does more for us and gets things done more for us than anybody, that’s I think is the best person, you know. So these little things go amiss you know, they say, ‘Oh! Well we’re coming to make sure you’re okay, and whatever, We’ll look into this we’ll look into that, we’ll draw up a plan’. And then I think, well, where’s that time gone, because none of it seems to happen.” (YC25)

Unsurprisingly, most carers who were receiving specialist dedicated day care for younger people were very satisfied with and highly valued this service. One carers’ comments reflect what most carers felt about specialist day centres for younger people with dementia:

“Once he’s there at the [specialist day centre] they are lovely people you know. I wish there was more places like that [for] them because they are really exceptional good people, you know, and he really enjoys it while he’s there and he’s full of these tales when he comes home. ‘Oh! yes we done this today, we had this today’ And the respite for me is lovely.” (YC25)

Thus, there is the perception for some carers that specialist day centres for younger people with dementia may help improve or maintain cognitive functioning for longer.

#### *Examples of co-ordinated ‘individual’ and valued services*

It appears from carers’ accounts in one local authority that the voluntary agencies such as the Alzheimer’s Society, the Dementia Care Trust and Crossroads Carer are highly valued services. A particular mention was made regarding Crossroads Care. Carers receiving this service mentioned how highly they valued this service.

“Yes, she would come in and, um, in the early days when Toby was mobile and more with it she’d take him for a walk, you know, they’d go down to the High Street and we were always members of the [XYZ] Club and so he’d take her in there and he’d have a pint and she’d have a coffee and a sandwich together for their lunch, walk back and then, um, she’d do my ironing which was great and he’d sort of watch telly and they’d chat while she was doing the ironing or whatever, um, and then we also had a volunteer, a befriender which was from the care network as well, uh, Simon. He came, not as regularly as once a week, but sometimes he’d come one week after the other, and he’d stay about an hour and a half and he’d have a game of cards with Toby or just chat about men’s things, you know, Toby is a big rugby man so, and he likes all sport, so that was something else.” (YC11)

#### *Recommendations for future care / models of good practice*

It appears that the overwhelming call from carers for future development and care was that fellow carers and younger people with dementia are better prepared regarding accessing care and services early. However, this must be tempered with the problematic nature of diagnosis, especially in the earlier stages and carers’ (and younger people with dementia’s) readiness to want and act upon information supplied at this highly stressful period. The importance of establishing a ‘routine’ and leaving the home early on to access day services was advocated. One carer commented how her husband “lost like his whole social life, his whole social life then revolved around me and him” (YC10). Whilst this was not seen as a problem initially, later in the interview, she mentioned that caring, and being the only carer with a young family, with no alternative outside social support was stressful and demanding. This carer

believed that had her husband accessed care and services earlier and become familiar with this, he would not have experienced the difficulties of adapting and trying (unsuccessfully) to access care and services in the later stages of the illness:

“Because once Sam was ill and everything else, he lost contact with all his male friends, you know, they were all of an age where they were still working and families and things so he lost like his whole social life, his whole life then revolved around me and him which was you know, fine because, you know in some ways but it would have been so nice if there’d been something else as well because it would have taken the pressure off me and it would have set some things for an earlier routine, you know, he would have been used to going somewhere, used to doing something but I didn’t realise how important that was.” (YC10)

Not surprisingly there was a call for more individual one-to-one care. A service particularly valued was a social care worker’s visit whereby this worker took the younger person with dementia out for two hours and engaged in activities chosen by the younger person with dementia:

“Only a couple of hours and I mean Connor really gets on well with him and they go out in the care and he’ll take him in, perhaps out to the Lakes or [area] and they sit there, or he’s even gone to a garden centre and they’ve had a cup of tea, it’s all that type of thing that he needs plus the fact that I know he’s good with [names social care worker], so relaxed and I’ve got that couple of hours to myself, just wish there was a little bit more of that.” (YC25)

### *Stigma, labelling and powerlessness*

For some carers, issues surrounding the stigma of dementia and how this affected social contacts were important. For example, one carer cited the loss of her husband’s male friends once he became ill and how the subsequent isolation and dependence on the carer proved to be a stressful experience (YC10). The possibility of misdiagnosis, in particular, where there was a history of mental illness, was another feature in some carers’ accounts. For example, a carer reported that she perceived her husband’s history of depression was used as a ‘label’ by health professionals to explain her husband’s initial symptoms, despite the carer indicating that this may not be the case. This was also a feature of an account by a younger person with dementia (SW3) who felt that he “had been written off when [he] had the depression”. It was also apparent from the account below that accessing a second opinion took a long time:

“It took too long to diagnose and it was only our, like my insistence and the families insistence that more things were done to find out because he was being, because he was quite a depressive man he was being treated for depression and we, you know, we kept saying there is something else wrong, I know there is something else wrong, you know physically he was becoming quite bad physically... and you know after lots of really badgering people, keeping on, shouting the loudest and saying you know, letting them see my distress, my agitation, you know, even my temper, that other things started to come into it and finally we had the actual consultant come to the house because Connor was referred from [hospital] and Dr X said could he bring in a second opinion with my permission.” (YC25)

### *Risk and the management of risk*

It was of note that some carers spoke about their relatives' driving and the perceived risks this represented for the carer. A particular example was the ultimatum given by one carer for her partner to cease driving, despite the carer's admission that his driving was not a problem:

“ ‘You've got to stop driving the car'. We had a car each then and he said, 'No, I'm not going to stop driving the car'. So I had to start hiding the car keys because I was getting worried about him driving the car. His ability to drive the car was fine, there weren't any problems and I couldn't see him having any real problems but I was worried that maybe he would react differently if something happened which is what, you know, the social worker said. He'd probably drive an automatic [brand of motor car] but he said he wouldn't be able to cope, maybe, if there was an accident, if something did happen. So I used to hide the car keys and then he used to find them and then he would go off in the car. And he'd go off in the car and not come back until he'd run out of petrol, you know.” (YC9)

As with issues surrounding risk and management of risk for younger people with dementia, similar tensions appear to apply for some carers. Most notably, balancing independence, safety and managing risk. What is of note in the above account is the carers' acknowledgement that her husband's driving (at that time) was not a problem. The main concern was the carer's worry of what might happen. This raises questions around for whose benefit is risk perception and risk management carried out. It seems that the fear of what might happen given that the person has dementia may cloud carers (and professionals) judgements as to what a younger person with dementia can and cannot do. Similar responses could be articulated regarding the position of some younger people with dementia attending non-specialist day care. For example, a carer (YC9) commented upon how her husband was not taken on trips because staff felt unable to cope with as he was deemed 'at-risk' for wandering. However, when

transferred to a specialist younger day care he was not deemed 'at-risk' and went on trips with staff who did not report any problems.

### *Methodological and conceptual issues*

It is acknowledged that the concept of 'burden' is fraught with methodological and conceptual difficulties (Gonzales *et al*; 1995). For example, what is burdensome to one person may be a duty, honour or obligation for another. It is argued that younger people with dementia and their carers may face different 'burdens' to those of older people because of their differing needs and their social and psychological milieu (McLennan, 1999). For example, there may be parenting roles to fulfil, there may be enforced early retirement, with resultant financial loss, and specifically, issues surrounding loss of identity, independence and self worth (Woods, 1999a & 1999b) (for a fuller account see Beattie *et al*, in-press). However, that is not to deny that older people may not also experience similar feelings. As little empirical research has been conducted e.g., looking at differences between older and younger carers, a degree of caution must be exercised when interpreting caring and the burden of care results. Moreover, no claims are made that the burden for younger carers is greater than that of older carers. For the purposes of this section the author uses the term 'burden' to reflect the caring role as reported by carers and conceptualised by the interviewer. This in part, was influenced by the literature, the researcher's biography, and professional and personal experiences.

## **Chapter 5 - The views and experiences of minority ethnic carers of people with dementia and one person with dementia, Angela Beattie**

The purpose of this section is to present the results of the interviews with minority ethnic carers of people with dementia. One (brief) interview with a minority ethnic person with dementia will also be described.

### *Fieldwork methods*

A small number (3 Asian and 1 African-Caribbean) of people from minority ethnic groups were recruited and interviewed. Of these, two were female and two were male. The small numbers reflect the general lack of awareness of dementia (e.g. by GPs) in these communities, and their concomitant under-representation in those services from where respondents were recruited. All the minority ethnic carers interviewed were caring for an older relative with dementia.

### *Burden of care*

The majority of minority ethnic carers spoke of similar experiences to white carers when describing their caring roles. Accounts such as, "It is like a bottomless day ... it's like a 24 hour job" (ME1) were common. One carer spoke of her frustration and the continuous repetition of reminding her relative what had just been discussed, and the inability to go out for fear of their relative wandering (ME4).

### *Duty of care and cultural obligations: "They look after their own"*

Cultural issues, in particular the caring role and a belief that, "My daughter will do everything" (ME18) was a feature of a carers' account. In contrast, male carers' accounts referred to how their particular culture prohibited them performing personal care for their female relative. This proved problematic for one carer as problems were experienced with personal hygiene for his relative. This issue was resolved through receipt of home care which was delivered by a female worker.

The perceived belief and the implicit expectation of others (e.g. professionals) that it was their duty to 'look after their own' was a feature of some carer accounts. For example, one carer commented directly upon this:

“And then they say how are you looking after your mother? She is an old lady and she is not well and they [health and social care professionals] say that’s what you are supposed to do look after your mother isn’t it?” (ME1)

Another carers’ account mentioned how white and black people cared for their relatives. According to this carer, it was also perceived that black people ‘look after their own’:

“We said, ‘Well, we didn’t want really, actually want that for him [relative to enter residential care] and no we couldn’t do that, that was for white people, not for him, and but no we’ll take him home and we’ll look after him.’ [Later] As I say, I just thought, ‘Well that’s black people don’t do that, you know, we’ve always been brought up to, we look after our own, we don’t dump them into a nursing home and leave them there.’ ” (ME18)

Of note in this carers’ account was the discussion around cultural identity, filial bonds and the difficulties experienced with the caring role and coping with a full-time professional job. There were tensions within this account between cultural obligations and what was practical. This may be reflective of wider issues surrounding the changing role of many minority ethnic women, because of paid work commitments, and the subsequent adaptation of western culture:

“So we did in terms of carers we’d asked in the past before he’d had his stroke about having carers and he would say, no, no, no, no, my daughter will do everything and I would say, ‘But daddy I can’t, you know, I just can’t do everything because I’m working, I’ve got other things to do.’ ” (ME18)

A similar experience from the perspective of a male carer also reflected common concerns of cultural obligations to care:

“In those years I was ashamed to ring them [statutory agencies] you know because it’s my mother and I should look after her.” (ME1)

For one carer, caring was viewed positively. Caring was not only a duty, it was also an honour for which the burden was welcomed (ME3). For this carer, residential care was perceived negatively, with the belief being that this type of care would not afford his mother the respect she deserved. It was also perceived that medication was used inappropriately in order to sedate people. In contrast day care and other services and care were perceived positively by this carer (ME3). Comparisons were made between

India, Pakistan and Bangladesh where there were no social services and the UK, where such help was available. However, for the remaining carers, all services were viewed negatively. For example:

“They did some awful things these nurses, looking after older people. I think it’s terrible what’s going on some of these elderly care wards, um, starvation, dehydration and neglect, that’s how they get rid of most of these old people especially if they ain’t got anybody looking after them, terrible.” (ME18)

Carers also perceived that ageism was present, and that older people in white culture were generally not valued:

“But older people aren’t valued in this society you see, they’re not seen for their wisdom and knowledge and for what they’ve done.” (ME18)

It could be argued that this is also reflective of the position of older people generally. However, being a minority ethnic group, old, and suffering with a mental health problem may compound the complexities surrounding age and ageism.

#### *Communication and language barrier issues*

Communicating with individuals for whom English is not the first language is challenging. The presence on an interpreter was helpful, although this undoubtedly affected the content collected. For example, it was evident during the interviews with the two carers who did not speak English, that whilst dialogue was taking place with the interpreter, and the interviewee, only a proportion of that dialogue was interpreted back to the interviewer. It was evident from one carer account that the lack of an interpreter when accessing health and social care was problematic (ME4). For example, this carer spoke of having to ensure that a relative was available to translate for her, as requests to have an interpreter present were not always acted upon. This particular carer also commented upon how difficult it was to secure an interpreter in an emergency situation either at the GP’s or hospital admission. Reports of having to book an interpreter in advance were also highlighted. 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 (Punjabi or Urdu) this would be a way forward” (ME3). 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 carer accounts:

“I don’t think they’ve ever had any other black person there. Sometimes they can’t understand what he’s saying and that must be so frustrating for him and also for them, ‘cos they also want to be able to meet his needs and understand him, but he’s saying things and to me it’s quite clear because I know him, but now he hasn’t got his teeth in.” (ME18).

Of note in this account is the very practical nature of some to the issues raised which can be exacerbated through communication problems.

### *Services and service provision for minority ethnic people in mainstream services*

“I feel that the main stream services aren’t interested in us really, the only reason why they’ve become interested is because the government says they have to.” (ME18)

Overall, emerging from carer reports was the need for more minority ethnic representation. As the same carer commented:

“There should be a more diverse workforce so that there are black psychiatrists’ black CPN’s, (Community Psychiatric Nurses) black SE’s (Social Workers)... [they] should reflect the community that’s being served so people have a choice.” (ME18)

The same could equally apply to all people with dementia in terms of being offered choices. Yet, the reality appears to be that minority ethnic people often seem to be ‘invisible’ to services as witnessed by carers’ accounts, the interviewers’ difficulties in recruiting minority ethnic carers through existing services, and what the literature suggests.

### *The issue of colour*

The issue of colour and racism was a central feature in accounts. 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:

“Well they [statutory agencies] come, and that’s it, when they see your colour they go. [Later] Our experience we have had with it, especially when your colour is wrong and you come with a lot of obstacles, which you would not if your colour was white, that is another thing we experience ... and I don’t think that a white skin, sorry, please don’t take this wrong, in my situation would be treated the way we are being treated.” (ME1)

When the interviewer attempted to explore these particular views, it was evident that whilst this respondent felt his needs were understood, the perception was they were still not being met. The reason given by this carer was again attributed to colour. However, for this particular carer the lack of adequate housing was his prime concern. His family had been offered alternative accommodation but this was deemed unsuitable by the carer:

Interviewer: So how do you think they can improve?

Respondent: They need to put the needs, that’s it.

Interviewer: Provide for the needs.

Respondent: What the family needs, provide them with the needs and the problem is solved.

Interviewer: Do you feel your needs are understood?

Respondent: Our needs are understood but denied.

Interviewer: Denied?

Respondent: Yes, they know what are needs are, and they have been denied, they have been denied.

Interviewer: Again, why?

Respondent: Colour.

Interviewer: Colour again?

Respondent: Yes, you know that yourself its not just me, there are a lot of other ethnic minorities that face similar problems in various fields (ME1).

The experience of racism was also highlighted by another carer. The view being that whilst ‘lip service’ was paid to implementing anti-racist policies and training, the prevailing belief as expressed by this carer was that it was a tokenism and driven by the “need to be seen to be doing the right thing:”

“They [government and statutory agencies] have to be seen to be doing the right thing, that’s what I think, I don’t think they can ever eradicate things and I think it, racism will remain no matter what, you know it won’t go away. It will get worse for people um, and I feel with the police ...[Later] my experiences personally and professionally working with the police, and to be perfectly honest they couldn’t care at all, some of the are interested, but on the whole, you know they’re [attending anti-racist training] and they’re going like this and they have to go. It’s like this sheep dip approach, and they all have to go through it you see, these police officers, but they have to go because, it’s not negotiated you will go, so they go and they sit and they don’t want to be seen as racist, but they [don’t?] say anything even if they are racist,

nobody's going to make them speak, and so they listen to what people have got to say and, um, I think they just go away and just say they came, they're not challenged or anything." (ME18)

This carer believed that attending a day or half a day's anti-racist training did not necessarily imply that professionals were now 'experts' in dealing with racism and that much more was required in order to tackle racism. The professional backgrounds of some of the carers interviewed emerged as a feature in securing care and services. One carer believed that because of her professional background her family were treated differently: "You get a better service" (ME18).

### *Need*

When considering the needs of minority ethnic people with dementia and their carers, it was evident that needs were perceived as being linked with race and ethnicity. Carers reported the need for culturally aware care workers, with one carer advocating a specific service for black people.

"Is to um create or to set up a nursing home for black people. That's what I think we need. We need somewhere where people can come and they can eat their food, they can have people around them who understand them and I'm not saying a second class service because that's one thing I don't think black means second class, no it doesn't, it means a first class service and if their family members want to come and eat with them they can, you know, it's not like oh well you come but you come and you just visit. There, we, nursing homes should encompass the family and include them." (ME18)

However, there were tensions in this carer's account. Later in the interview, comments were made that if there was a specifically designated service for black and minority ethnic people provided, and the care was deemed inferior, this carer, would not send her relative there despite it being a 'black' service. Thus, it appears that issues around the quality of services provided, as opposed to issues relating specifically to ethnicity and the provision of a separate service is a central concern. It could be argued that this could also apply to all people with dementia, not just minority ethnic or younger people. Moreover, this must be tempered with the small number of minority ethnic carers' interviewed. Unsurprisingly, when carers were asked if they felt that their needs were being met, a resounding negative opinion was expressed. Two carers talked of struggling, particularly at the beginning of their caring role. However, the introduction of specific minority ethnic services in Bristol had eased the situation for

these 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 which he had previously been unable to do. Issues around need and the need to gain access to monetary benefits and pensions were concerns raised by two carers. Two individuals reported that the statutory agencies had mistaken them for other people, hence benefits were not received (ME1, ME4).

### *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. For example, disagreement between a health professional's assessment of risk and that of the carer surrounding safety and the perception of safety was mentioned (ME18). The family in this instance requested a stair lift, but the health professional assessed that the safety risk was too great. The carer challenged this assessment by writing and complaining to the team manager, the outcome being that the original risk assessment was overturned and the family received the stair lift. This raises issues around what scope there is for carers to challenge risk assessments, and the possible role of racism as yet a further means of rationing care. As this carer commented:

“I'm not an OT but [I] made my own assessment of it. However, I said to him [OT]...had I not been assertive as I am, I may have just taken what you said and went away and be without something that I needed. And perhaps you need to be thinking about all those other services users who aren't able or don't have carers that are able to say, 'I'm sorry I disagree', well they've met their match in me.” (ME18)

What was striking about this account was that this carer, despite being a professional, and familiar with social services, was initially reluctant and unsure about how to challenge the risk assessment, “Where do I go now to overrule that, because I don't actually agree with you?” Moreover, as this carer commented “It's very difficult to comment on something when you're desperate for a service.”

Linked to the above account were issues related to carers' perception of professionals and a perceived presence of a “we know best” attitude prevailing:

“And the nurses think they know everything about this person they’ve never met before and you’re trying to offer information and then they’re making you feel this well, what do you know, you’ve only know that person all your life, but you know, and it gets very uncomfortable.” (ME18)

This raises issues concerning power and powerlessness, and the perception of the difficulties in working with professionals and the subordinate role some carers have within this complex power relationship. Closely allied to these issues were aspects concerning training and the danger of people (care professionals) going on brief courses thinking, “Oh well I’ve been on that [course], and therefore I can work with black service users effectively, cause I know all about them now.” (ME18)

### *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.

### *Results from the interview with a minority ethnic person with dementia.*

Only one interview was conducted with a minority ethnic person with dementia (female, aged approximately eighty years old). This interview took place in the carer’s home (ME4) with the carer present, and was rather brief as this individual did not believe that she had memory problems. The main result emerging from this interview was a lack of concordance with apparent tensions concerning the carers’ views and those of the person with dementia. For the person with dementia there were no problems with memory. It was respiratory complaints, i.e. asthma that were the main concerns. However, for the carer, her relatives’ problems of forgetting and not remembering when she had last eaten were the main concerns. As it was not possible to interview these respondents separately, and in view of the non-acceptance of memory problems, exploration of these issues were not pursued. It is of note that the younger person with dementia (GL3), who also did not accept that they had memory problems spoke about the lack of payment for her ‘volunteer’ status at the day centre

attended. There was concordance in both the carers' and the person with dementia's accounts regarding this issue.

### *Interpretation issues*

The presence of an interpreter who was also a service provider to the Asian carers was an issue. Primarily, this raised complex issues with regard to respondents' possible reluctance, or feeling unable to comment critically on this service whilst a member of the service was present and acting as an interpreter. This was noted during the research but was balanced in the knowledge that the interpreter was known to the families. Moreover, as two carers were unable to converse in English, the researcher was faced with balancing this and yet attempting to gain access to a traditionally 'hard to access' group. Having an interpreter present of similar ethnic origin facilitated the interview, promoted dialogue and assisted in building a trusting relationship. During the interviews, it became apparent that certain concepts familiar to the researcher and the literature e.g. 'They look after their own,' was difficult for the interpreter to comprehend, which in turn made translation difficult. This raises broader issues surrounding communication and western knowledge and concepts, and how readily these concepts translate into different languages because of contextual and cultural meanings. For example, the concept 'burden' of care and what is burdensome to one person may be perceived as a duty, honour or obligation for others. In relation to minority ethnic people and cultural differences, these conceptual issues become even more challenging, most notably because of the prevailing ideology that surrounds caring in Britain. These issues are beyond the scope of this report.

Managing the interviews and their context whilst sharing this with multiple people proved challenging for the researcher. For example, in one interview five people including the researcher and interpreter were present. Whilst in the other two interviews the person with dementia, the carer, the interpreter and in one instance the carers' small child were also present. It was ascertained that this was what the carers wished and that it was deemed important for all family members to be present. The researcher, mindful of the sensitivity of the nature of the questions to be asked, checked with carers and the person with dementia that they would possibly witness sensitive issues being discussed by their carer and that they were in agreement with this. Again, this proved to be unproblematic to both parties. Of note also was the

deferment of a female carer to her husband who elected to speak for his wife. The researcher mindful of respecting cultural differences and yet wished not to ignore or make the carer feel uninvolved. Attempts were therefore made to check with the female carer should she wish to contribute or add her own thoughts and views. Overall the interviewed minority ethnic carers indicated that it was a positive experience to talk to someone about their caring role and the problems they faced. One carer reflected via the interpreter that, "It [interview] was a forum to off load and tell others about your experiences" (ME3).

## Chapter 6 – Conclusions and Recommendations

The aim of this study was to examine the needs and provision of services to younger people and minority ethnic groups in dementia care. According to the available literature, the key to dementia care for younger people lies in specialist, age-appropriate services delivered within a person-centred model of care (Beattie *et al.*, 2002, in press). With a few laudable and isolated exceptions, however, the reality of service provision for younger people could not be further from this ideal. Indeed, the majority of service providers in South West England have seemingly not investigated the numbers of younger people with dementia. It is difficult to see how there can be any planning for services in the absence of such basic epidemiological data. Accordingly, our first recommendation is that service planners and providers at all levels gather intelligence on younger people with dementia in the areas served by their agencies. The same could be said about minority ethnic groups, and indeed people with dementia in general. At present, because people from marginalised groups are not presenting to services with dementia (or are not being correctly identified) the assumption is that they do not exist.

In the questionnaire survey of service providers, the most comprehensive assessments to date suggested that in 1999 there were 282 cases of dementia in the area covered by the Avon health authority (in people under 70) and 353 people with dementia in Dorset. Extrapolating these figures to other counties, or utilising the methodology of Harvey (1998), suggests that contrary to the popular view of services, there are probably a few thousand younger people with dementia in the whole of the South West. It is likely that majority of them will not have received a dementia diagnosis. Some may have been misdiagnosed and will be being treated for the wrong illness. However, given the current state of service provision for marginalised groups reported in this study, it is difficult to know whether all of these people would in fact benefit from being diagnosed as having dementia.

From the point of view of some service users, it might be better for the problems of dementia to rather be viewed as a natural consequence of ageing (as they are in some minority ethnic communities, for example) rather than live with the stigma of dementia. In punitive care regimes, the label 'dementia' – as with other labels of

mental illness – can be used to deny an individual's needs. For marginalised groups, being labelled with dementia can mean being shoved (sorry, 'fitted') into inappropriate and distressing surroundings, while their distraught carer tries to have a break whilst worrying what an awful time their spouse is having. In spite of small pockets of care excellence to be found in specialist services, or amongst committed and flexible key workers in a range of generic agencies, the general attitude of staff in mainstream services is that people with dementia are a problem, a risk and a security issue. One only has to look at the case of 'wandering' (a well-recognised need for people with dementia, especially younger, fitter or active people) to see exactly who is running the services for whom. To be labelled with dementia is to be seen as a danger to self and others. The symbolic way that this meaning is transmitted to people with dementia when they receive a diagnosis is when they are told that they must surrender their driving license.

At present, younger peoples' needs for age-appropriate and individualised care are seemingly served only by two day care centres, one in Kingswood, Bristol and one in Swindon, both of which cater for around a dozen clients. At the moment, the best advice for a younger person requiring age-appropriate dementia day care in the region, would seem to be to move to one of these two areas. Some people from marginalised groups with dementia had also had their individual needs met by other specialist services, mainly 'sitting,' 'respite at home' services, along with the panoply of agencies who provide personal, health and social care in the home. Other people from marginalised groups with dementia had their needs met by generic day care (including specialist services for minority ethnic groups) and residential care services, although in some cases it was questionable whether their needs were being catered for appropriately. In many cases, the inappropriateness of services was recognised by care staff themselves. However, even given the inequity in service provision between different places, and the effort required to gain access to services in some cases, it is likely that the experience reported by carers – that access to appropriate services is largely a matter of luck – is probably not far from the truth. In addition, both professional and user accounts stressed that the individual personalities and attitudes of professionals are one of the main factors in gaining appropriate care.

An underlying theme emerging from our 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. It also feels as if there is a wide gulf between the ideals and recommendations of the practice literature, and what is actually happening (or possible) on the ground. In a questionnaire survey of service providers, respondents were split about whether specialist age-specific services should be (or could be) provided. Furthermore, and 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 ‘lumped’ in with elderly people.

People in urban areas seem to fair better off for a range of specialist services. One of the main challenges seems to be how these needs can be met in rural or sparsely populated areas. However, the issues for service providers in this regard are likely to be the same as apply to a whole range of services. Thus, creative solutions may be found by looking to other service sectors where the issues are similar. At the end of the day, the issue for rural service providers seems to be about whether these needs are best met in centres or in people’s own homes.

Whilst the needs of younger people with dementia have been recently recognised in the professional literature, there is a dearth of empirical research. Furthermore, and as with the literature concerning minority ethnic groups in dementia care, the main recommendations of the available articles could just as easily apply to anybody with dementia. Given that services for people with dementia are understood to be universally poor, it is not difficult to see why some people become cynical about the usefulness and equity of arguing for the cases of specific groups. However, the case of minority ethnic groups reminds us that the issues at stake are important ones and relate to social justice, equity in service access (as we are all tax payers), and the desirability of all people with dementia being afforded opportunities to maintain their

quality of life so far as possible. Thus, our second recommendation is that whilst there is a need for empirical research in this field, such future studies should not detract from the needs of other groups of people with dementia.

Although there has been much more research work focused on people with dementia and ethnicity, these studies have been dogged by methodological and theoretical weaknesses. There is certainly no need for any more studies that simplistically compare 'blacks' with 'whites' or other groups, in studies of care giving or service utilisation (Daker-White *et al.*, 2002, in press). The kind of studies that are really needed are local prevalence studies, and investigations (including randomised comparisons) of the outcomes, efficacy and effectiveness (including cost effectiveness) of the available services or treatments, in different groups of people with dementia. In the absence of such data, it is difficult to assess what is working for whom. In short, there is no reliable evidence as to what works for marginalised groups in dementia care. An ideal has been articulated in the literature, but that ideal ('individualised, tailor-made, needs-led care') seems to have little resonance with the reality of service provision on the ground. More importantly, given the findings of our fieldwork, it is pertinent to wonder whether this ideal will ever be realisable given the organisational, structural, financial and human hurdles. The main message to services for minority ethnic groups seems to be that services should be consulting black and other minority ethnic people about what services they would like or wouldn't like.

Although there are several studies of ethnicity and dementia, the US-bias of the bulk of this work may make it of little relevance to the UK context. Research efforts have focused on dementia prevalence and the experience of care giving in different ethnic groups. More useful work has examined language as a factor in cognitive assessment. It is interesting that less effort has gone into finding out what sort of services black people want, and the outcomes, satisfaction and experiences of black people in different types of care and treatment. Perhaps this is reflective of an epidemiological and bio-medical approach to race and ethnicity, which tends to view racial biology as an explanatory variable. However, these approaches lead too easily to the view that if black and minority ethnic people have a poor experience of services it is because of something within them, and the erroneous view that human behaviour, health and emotions vary somehow according to skin colour. We would stress that the

fundamental factor in their use and experience of elderly or mental health services is racism, and if services want to find out why black people and other groups do not 'fit', then perhaps they should be looking to themselves for the answers, rather than to the groups involved.

Despite a reported 'vogue' for considering the inequalities faced by black and minority ethnic people, and an increase in studies of the kind we present in this report, many black people, including people interviewed for this study, wonder when all this activity and "lip service" is going to translate into money, services and resources. There has to come a time when research, audit and investigation ends, and concrete action begins. Interestingly, some people interviewed for this study articulated the view that white people neglect their elders. This is an important concept because it highlights the mainstream view that the venues where you find elderly people with mental health problems and dementia are not places of care, but places of neglect. There is no doubt that ageism is a factor in these stereotypes, and we are mindful that arguing for the more emotive needs of younger people, or the more just and urgent needs of minority ethnic groups, should not result in throwing elderly people, many more of whom have dementia, onto the scrap heap. This is a good point to introduce our third recommendation, which is that one of the best ways for services to address the needs of marginalised groups is by investing in overall improvements in care and services generally. Whilst there is a need for specialist service provision and advocacy groups so long as racism remains a factor, many of those interviewed from black community groups were emphatic that they do not want a separate service, but rather they want the same mainstream "excellent" service that most people aspire to, so long as it meets their needs.<sup>3</sup>

We are concerned that the attitude of one third of the responders to our questionnaire survey, was that services don't need to worry about the needs of minority ethnic groups, because "the numbers are too small." We can only hope that this sort of attitude is not an entrenched one. Overall, it seemed as though the literature, services and professionals, all too easily conflate the terms "race," "ethnicity," "foreigner" and "black person." The most common responses to questions about ethnicity were for

---

<sup>3</sup> Although one black carer interviewed did advocate a specialist black service, staffed by black workers

people to talk about people who don't speak English as a first language and eat foreign diets. These issues may reflect the characteristics of the current cohort of minority ethnic elders in the UK. However, the danger of attempting to pigeon-hole people according to cultural factors (whether they are black or white) is that false assumptions can be made, for example that all people from the Caribbean eat hot, spicy food, when in practice some of them find hot food distasteful. These issues lead us to a further conclusion: 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.

A major problem in accessing services is that whilst everyone, including carers and users, would like to see relevant services put in the place in the earlier stages of dementia (seen as essential for any continuity in care to be achieved), because care is rationed, only those with more urgent or advanced problems can be catered for. More importantly, this effective screening out of anyone who is not, as one respondent put it, 'mad, bad and sad,' also affects access, because services cannot cope with people with dementia who are in crisis and more likely to be exhibiting the sort of behaviour that is likely to exclude them from services. Thus, it seems that while the services are set up to cater in the main for people in the earlier stages of dementia, they are in fact being used by people with more pressing and specialised needs. In other words, the wrong people are being fitted into the wrong services. This sounds like a recipe for disaster for staff and users alike, and the sorts of problems engendered by this form of organisation of care are particularly acute or exacerbated for marginalised groups. Furthermore, because social workers and others must 'cry wolf' in order to access services for clients, it must become difficult to disentangle the genuine cases of extreme hardship from the usual cases (who nevertheless require care and services). In any case, our fieldwork has demonstrated the adverse effects of the current organisation of care on the quality of life of people with dementia and their carers. Most importantly, potential service users have a right to know what services are available and what services will be paid for. More importantly, if it is true that services are organised primarily around managing

risk rather than meeting individuals' needs, why can this not simply be stated as a policy? Instead of the stated policy (that individuals needs are met), which could not possibly be effective as the relevant services simply do not exist to meet the full range of individuals' needs in dementia care. As well as the general absence of relevant services, staffing and skills shortages in those available further reduces the possibilities for individualising or 'tailor making' care.

Although the benefits of an early diagnosis in younger people are well touted in the dementia literature, our interviews with users and carers do not fully support this thesis from their viewpoint. The main advantages of early diagnosis for potential service users seemed to be for those who lived near the only two regional specialist day care centres. Having a diagnosis of dementia was also important for people with dementia who had been misdiagnosed and were being treated for the wrong illness. However, the main reported effect of a diagnosis for most service users seemed to be having their driving licenses (or train passes) taken away from them, reducing their independence and mobility, rendering them dependent upon others and impacting on their quality of life. On the basis of interviews with younger people and their carers, we also wonder 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. One take on the results of interviews with users and carers would be that many had battled or struggled to get a diagnosis, and then perhaps wondered why they had bothered. Surely, if people are to fully consent to these tests and procedures, they should be made aware of the possible consequences of a dementia diagnosis, including a discussion of the available services and care (if there is any). On the basis of the views of the younger people with dementia and carers articulated in this study, it would seem as though if they had realised that a dementia diagnosis would lead to them being cared for in elderly services, perhaps they would not have bothered with the struggle to be diagnosed. We suggest that the field of dementia diagnosis, and its consequences, will be a fruitful area for further study.

From our fieldwork, it would seem as though form filling, and the needs assessment system in general, serve the function of rationing benefits and services. From professional accounts, we have seen the ways that this system makes (white) middle class people more likely to navigate their way to the available services. Thus,

although services are supposed to be 'needs led,' their access is in fact limited to those people with the knowledge, tenacity and intelligence required to negotiate and access care. For many users and carers (and indeed for some professionals interviewed) this care system is viewed as mysteriously organised, bureaucratic and unwieldy. Many people do not know what services are available or what care they are entitled to. 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 original contribution of our study relates to the inclusion of the voices of people with dementia from marginalised groups and their carers. Although many professional respondents felt that people with dementia were incapable of expressing their own needs, our fieldwork has shown that people with dementia do have opinions about services, and are in many cases able to articulate their own needs. We hope that our efforts will encourage service providers to similarly consult with people with dementia about their needs. However, this project should not detract from the more urgent business of providing care and services that truly can be 'tailor made' to fit individual people and their needs.

Some of the most clear and practical needs to be addressed as a result of this study are the need for more flexible and individually-tailored respite care, 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. It is useful to conclude by stating that where specialist services have been provided for marginalised groups in dementia care, they have been highly valued by people with dementia and their carers.

## References

- Beattie, A.M., Daker-White, G., Gilliard, J. and Means, R. (2002) Younger people in dementia care: a review of service needs, service provision and models of good practice. *Aging and Mental Health*, in press.
- Daker-White, G., Beattie, A.M., Gilliard, J. and Means, R. (2002) Minority ethnic groups in dementia care: a review of service needs, service provision and models of good practice. *Aging and Mental Health*, in press.
- Folstein MF, Folstein SE, McHugh PR. (1975) "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*. 12(3):189-98.
- Gonzales, E., Gitlin, L. & Lyons, K. (1995). Review of the literature on African American caregivers of individuals with dementia. *Journal of Cultural Diversity*, 2 (2), 40-48.
- Harvey, J. (1988) *Younger onset dementia: epidemiology, clinical symptoms, family burden, support and outcome*. London: NHS Executive (North Thames).
- Keady, J. & Nolan, M. (1999). Family caregiving and younger people with dementia: dynamics, experiences and service expectations. In S. Cox and J. Keady (Eds.), *Younger people with dementia: planning, practice and development*. (pp. 203-222). London: Jessica Kingsley.
- McLennan, J. (1999). Assessment and service responses for younger people . In S. Cox, S., & J. Keady. (Eds.), *Younger people with dementia: planning, practice and development* (pp. 17-36). London: Jessica Kingsley.
- Woods, B. (1999a). Younger people with dementia: psychosocial interventions. In S. Cox and J. Keady (Eds.), *Younger people with dementia: planning, practice and development* (pp. 245-260). London: Jessica Kingsley.
- Woods, B. (1999b). Promoting well-being and independence for people with dementia. *International Journal of Geriatric Psychiatry*, 14, 97-109.

## **Appendix 1 - Questionnaire used in the postal survey of service providers**

In this survey we are interested in the provision of services to people with dementia from three particular groups who may be marginalised in current service provision: younger people (aged under 65 years); *people with concurrent mobility problems* (NB: This group was excluded from the final study); and people from minority ethnic groups.

Section A - Your overall service provision for people with dementia

**Question 1:** Please describe your **overall** service provision for **all** people with dementia (e.g. day care services, residential services, inpatient services, outpatient services, support group services, respite care, specialist staff, etc.). **Note: In this question we are interested in your TOTAL service provision for ALL people with dementia, not just those from the marginalised groups listed above.** Please append existing report/s if this is easier

Section B - Service needs, service provision and marginalised groups

**Question 2: Has your organisation investigated the numbers of people with early onset or “pre-senile” dementia (i.e. in people aged under 65 years) in your catchment area? YES / NO (PLEASE DELETE AS APPROPRIATE)**  
If “**YES**”, what were the results of your investigations? If “**NO**,” are there any reasons for this? And, are you likely to investigate this matter in the near or distant future?  
Please append existing report/s if this is easier

**Question 3:** Do you have any services specifically for people with dementia under the age of 65 years? **YES / NO (PLEASE DELETE AS APPROPRIATE)**  
If “**YES**”, please describe these services. If “**NO**”, which services would a person under 65 years be likely to use? And, do you have any plans to develop any specialist services in the future?  
**Feel free to append existing report/s if this is easier**

**Question 4:** Do you have any services specifically for people with dementia under the age of forty years? **YES / NO** (PLEASE DELETE AS APPROPRIATE)

If “**YES**”, please describe these services / If “**NO**”, which services would a person under 40 years be likely to use?

**Feel free to append existing report/s if this is easier**

**Question 5: In your opinion, are the needs of younger people with dementia best served via the provision of specialist services, or via generic service provision? SPECIALIST SERVICES FOR YOUNGER PEOPLE / GENERIC SERVICE PROVISION (PLEASE DELETE AS APPROPRIATE)**

Please explain / expand on your answer:

**Question 6:** In general, how does your organisation provide services to people from minority ethnic groups, and / or to people who do not speak English as a first language?

Feel free to append existing report/s if this is easier

**Question 7:** Has your organisation investigated the numbers of people with dementia from minority ethnic groups in your catchment area? **YES / NO** (PLEASE DELETE AS APPROPRIATE)

If “**YES**” what were the results of your investigations? If “**NO**”, what are the reasons for this? And, are you likely to investigate this matter in the near or distant future?

Feel free to append existing report/s if this is easier

**Question 8: Do you have any services specifically for people with dementia from minority ethnic groups? YES / NO (PLEASE DELETE AS APPROPRIATE)**

If **“YES”**, please describe these services / If **“NO”**, which services would a person from a minority ethnic group be likely to use?

**Question 9: In your opinion, are the needs of people from minority ethnic groups with dementia best served via the provision of specialist services, or via generic service provision? SPECIALIST SERVICES FOR PEOPLE FROM MINORITY ETHNIC GROUPS / GENERIC SERVICE PROVISION (PLEASE DELETE AS APPROPRIATE)**

Please explain / expand on your answer:

**Section C - Your own comments**

Your organisation:

---

Your role / job title / name (**OPTIONAL**)

---

**NB: Whether you give us your name or not, when we write-up the results of this survey, we will not identify your name or organisation alongside your questionnaire responses**

**THANK YOU VERY MUCH FOR YOUR HELP**

## **Appendix 2 - Feedback from service providers at a stakeholder conference held at Dartington Hall, September 2000**

Overall, the general thrust of the presentations made at Dartington Hall and the feedback received from delegates suggested:

1. The need to re-focus our research efforts on the views and perspectives of service users, or potential service users.
2. That the debate about “specialist” versus generic service provision is of little consequence when services are so poorly developed.
3. The need to re-think the criterion for selecting the case study localities (“urban, rural, market town”).

Following the morning presentation of the results of the systematic literature surveys, delegates broke down into small groups to examine:

- Specialist versus integrated services
- Examples of good practice and obstacles to good practice

Group feedback from these discussions was as follows:

### **GROUP 1**

- The lack of a user voice
- Flexibility needed (“tailor made” services)
- Duplication of efforts (e.g. form filling) in multi-agency working
- Weaknesses in information sharing between organisations
- Some (e.g. younger) people might not object to being placed in (e.g.) services for elderly people

In discussion after feedback, the issue of the problem of staff retention was mentioned. One person felt that we should be, “Asking users and carers what sort of service they want.”

**GROUP 2**

- Specialist versus generic provision: a need for “proper” memory clinics
- The relatively small numbers of people and their geographic spread means that services need to think about “being local and being creative”
- People of any age require a tailor-made service
- Split budgets are a hurdle to best practice, perhaps a single service would be better?
- The vast majority of people with memory problems do NOT receive a specialist service

In discussion following feedback, the chair underlined the need to provide care differently according to local circumstances.

**GROUP 3**

- Ideally services should be specialist - if that’s what the user wants
- No choice for marginalised groups
- Health versus Social care issues
- GPs lack of knowledge
- Challenging the traditions of services

In discussion, a delegate highlighted the problems of staff retention in the face of competition from the retail and service sectors.

Following the afternoon presentation of the results of a regional survey of questionnaire providers, delegates broke down into small groups to examine:

- Issues in evaluating the views of service users: from the perspectives of health and social care providers and researchers
- Questions that the researchers should be addressing in the forthcoming programme of research

Group feedback from these discussions was as follows:

**GROUP 1**

- What would I need if I got dementia?

- Alternative research methods - e.g. diary methods, interviewing
- Repeat interviewing
- Communication issues (verbal / non-verbal)
- Secondary source materials (i.e. what has been written by service users so far - poetry, art, etc.) could be incorporated

## **GROUP 2**

- Views of users are not the same as the views of carers
- It is not clear how to get views
- But, if you don't ask, there'll be no "baseline" data
- How do we protect vulnerable people who don't see themselves as vulnerable?
- What services work?
- Transferable learning

## **GROUP 3**

- Non-involvement in services is negative feedback
- Use existing resources
- 'Dementia' versus 'Mobility': which is the primary problem?
- If the interest is in finding out whether or not services are "tailor-made" or "needs led", anyone with dementia could be interviewed
- Good services? Need to be careful about further marginalizing

In summing up, the chair referred to the importance of working out what the definitions - e.g. of "a needs-led service" are, and wondered what the best way of feeding back results to services and users was.

One delegate wondered whether there might be mileage in presenting professional respondents with scenarios or vignettes in order to find out what services exist for marginalised groups in different areas.

## **Interpretation**

Following the conference, the study management team reflected on the day and felt that the remainder of the study might be usefully “re-”focussed towards the following questions:

1. What services do marginalised groups want?
2. How might they be consulted?
3. What do flexible, tailor-made, needs-led services look like on the ground?

### **Appendix 3 - Final topic guides used in depth interviews**

#### **INTERVIEW TOPIC GUIDE - PROFESSIONALS**

- WHAT services do you provide?
- WHO do you serve?
- What do you think are the NEEDS of people with dementia?
- What are the NEEDS of people with dementia from marginalised groups?
- WHAT would you do in your service with a younger person with dementia?
- WHAT would you do in your service with a person from a minority ethnic group?
- What can be changed WITHIN EXISTING RESOURCES to improve the provision of services to younger people / minority ethnic groups?
- In an ideal world, if you had a million pounds, what would you spend it on that best met the needs of people with dementia / marginalised groups (as relevant to particular interview)?
- What OTHER organisations provide care to people with dementia in this locality?
- What are your RELATIONSHIPS like with these organisations?
- (If relevant) PROBE for views of other organisations?
- What are the ACCESS TO CARE PATHS or DIFFERENT CARE OPTIONS available to people with dementia / marginalised groups in this locality?
- What do you think are the STRENGTHS & WEAKNESSES of this service?

#### **INTERVIEW TOPIC GUIDE - PEOPLE WITH DEMENTIA**

- Can you tell me about your yourself?
- Can you tell me about your experiences with memory problems?
- Is there any help / services available in order to help you?
- Can you tell me a little about this?
- What are your views on these services?
- What was good about them?
- What did you not like?
- What are your views on the needs of a person with memory problems?

- What do you feel your needs are in helping you live with your memory problems?
- Do you feel they are being met?
- Are there ways we can improve?

#### **INTERVIEW TOPIC GUIDE - CARERS OF PEOPLE WITH DEMENTIA**

- Can you tell me about your experiences of caring for a relative / client with memory problems?
- Is there any help / services available in order to help you care?
- Can you tell me a little about this?
- What are your views on these services?
- What was good about them?
- What did you not like?
- What are your views on the needs of a person with memory problems?
- What do you feel your needs are in helping you care for a relative /client with memory problems?
- Do you feel they are being met?
- Are there ways we can improve?