PSSRU

Home Care Services for Older People with Dementia in the North West of England

Dan Venables, Siobhan Reilly, David Challis, Jane Hughes and Michele Abendstern

Discussion Paper M097
June 2005

PERSONAL SOCIAL SERVICES RESEARCH UNIT

The University of Manchester

Dover Street Building
University of Manchester
Oxford Road
Manchester M13 9PL
Tel: 0161 275 5250

The University of Kent at Canterbury

Cornwallis Building
University of Kent at Canterbury
Canterbury
Kent CT2 7NF
Tel: 01227 823963/823862

London School of Economics

London School of Economics
Houghton Street
London
WC2A 2AE
Tel: 020 7955 6238

Email: PSSRU@man.ac.uk **Website:http://www.pssru.ac.uk**

CONTENTS

Results - Section II: Standards of care

Tables in Appendix 2

FIGURES IN APPENDIX 3

1 EXECUTIVE SUMMARY

1.1 Introduction

The current study was one of a series of studies undertaken to identify and describe specialist dementia services in the North West of England.

This study had the following aims:

- To identify and describe home care services that had a specialist focus on dementia care in the North West of England
- To assess the quality of care provided in these facilities
- To compare the type and quality of care provided by the different forms of home care service identified

It was intended that the information obtained in meeting these aims would assist in service development in the region.

1.2 Method

Two hundred and eighty two home care services for people with dementia in the North West of England (identified by key personnel in the NHS Trusts, Health Authorities, Social Services Departments and voluntary organisations) were each sent a questionnaire. Identified services were 'specialist' services, insofar as all or part of each service was dedicated to providing care for people with dementia, although the service might not necessarily have regarded itself as a specialist dementia service *per se.* The questionnaire was structured according to three main themes: service delivery; user-centred practice and organisation of care (see Appendix 1) and was developed by the authors around recent policy guidance and published research findings. One hundred and fifty five services returned a questionnaire, and there were thirty two exclusions. The final sample size was 113 (response rate 46%). Data was analysed using SPSS version 10.1.

1.3 Key findings

1.3.1 Description of home care services

- Most identified home care services in the North West were generic in nature (58%). Nine per cent of services described themselves as specialist home care services for people with dementia.

- A low proportion of people with dementia (11%) appeared to be receiving home care services in the North West region.

- A relatively small overall proportion (17%) of services reported that all their clients had dementia. This proportion was highest in specialist home care services for people with dementia (60%).

- There was little evidence that services were targeted on the most dependent - of those attendees with dementia, 67 per cent were rated as having mild or

moderate dementia, and 33 per cent as severe. These proportions did not differ significantly between service types.

- People with dementia from ethnic minority backgrounds were mildly under-represented in the overall sample. Two point two per cent of attendees were reported to be from an ethnic minority background, compared with the regional average of 2.7 per cent.

1.3.2 Service quality

- Services tended to have approximately one member of staff for every five users.

- Only 33 per cent of home care staff were reported to have had recent (in the last 2 years) training for caring for people with dementia.

- The degree of integration between services was generally low.

- The degree of individualised care provided by services was generally low.

1.3.3 Generic home care services versus specialist home care services for people with dementia

- Services that defined themselves as specialist home care services for people with dementia were generally smaller than generic services, and had a higher proportion of people with dementia.

- It was more common for all clients to have dementia in specialist as opposed to generic services.

- Generic services tended to be both more intensive and more flexible than specialist home care services for people with dementia.

- More specialist home care services for people with dementia stated they need to keep briefing documents in the user's home.

- Overall, there were few differences between these two service types in terms of their scores on quality standards in different areas of provision, and there were no obvious differences in the overall quality of service provided.

1.4 Conclusions

- In general, the services included in the study addressed relatively few of the quality indicators being measured.

- Staff would benefit from increased training with specific regard to caring for people with dementia.

- Services could be improved through the provision of increased levels of individualised care provision, including more comprehensive service provision with regard to the delivery of culturally appropriate care.

- There is considerable scope for increased levels of integration amongst services.

- Few differences appear to exist between specialist and non-specialist services.

2 INTRODUCTION

Dementia is one of the four specific disorders identified in the National Service Framework for older people (Department of Health, 2001). It is, and will be for some time, one of the greatest challenges to health and social services. In the UK, there are approximately 750,000 people with dementia, and this number is expected to rise to 840,000 by 2012 (Cobban, 2002). Eighty per cent of these people live in the community (Cobban, 2002), sixty per cent live either in their own home or in the home of a family member, and 80 per cent of these live with their main carer (Schneider et al., 1993). In the UK, yearly costs of care are estimated at around £6 billion, constituting a significant proportion of the total cost of care for elderly people with around half of this being accounted for by NHS and social services direct spending (Audit Commission, 2000).

The provision of effective community based services has enabled many older people to return home following hospital admission rather than be admitted to residential care. This has resulted in home care becoming by far the most frequent service on which older people with dementia and their carers rely (Social Services Inspectorate, 1997). Home care services, which employ approximately 400,000 workers in the UK, (Cobban, 2002) provide direct practical assistance with personal care and/or domestic services such as housework and shopping to a wide range of older people with differing needs (Godfrey et al., 2000). Determinants of home care service use include factors such as being widowed, increasing age, and not owning a car, as well declining physical (including problems with eyesight, falls and incontinence) and cognitive functioning, and emotional health (Stoddart et al., 2002).

2.1 The focus of home care services

Home care provision grew out of the home help service, introduced after the Second World War. Cultural and demographic changes over time saw the average age of service users increase until, by the 1960's, older people accounted for 90 per cent of the clientele of the service (Godfrey et al., 2000). The 1980's then saw a shift in emphasis towards targeting services to those most in need (Social Services Inspectorate, 1987, 1988) which resulted in the development of a home care service which prioritised assistance with personal care as opposed to domestic tasks. Older people who needed help with domestic chores, and who might have been eligible for home help support under the old system, found that they could no longer expect this support to be provided by social services (Laing and Buisson, 2000).

This change in policy has not been without controversy. In contrast to current policy, successive General Household Surveys have suggested that domestic tasks present more of a challenge to older people than self care (Godfrey et al., 2000). This has led to debate regarding the most appropriate form home care service provision should take, and which forms of home care service offer the best outcomes for older people themselves. In their review of the evidence, Godfrey et al., (2000) found that home care services which emphasised practical help had no impact on rates of acute hospital admission or rates of stay per hospital admission, and an inconclusive effect on admission to nursing homes, although there was evidence of reduced levels of mortality. Short-term home care schemes had no impact on health and functioning, anxiety and depression, survival rates or subjective well-being. In case

managed programmes, there was no evidence of reduced hospital admissions or improved survival rates, although there was evidence suggesting that institutional admission was delayed, and there were improvements in subjective well-being. In terms of outcomes for service users following receipt of home care services, the picture therefore remains unclear.

2.2 Quality of home care services

Home care service provision both expanded and became more intensive during the 1990's (Community Care Statistics, 2000). During this period, the number of home care hours purchased or provided by local authorities increased by over one half, whilst the number of households receiving the service fell by 16 per cent, and the average number of hours per household increased from 3.2 in 1992 to 7.0 in 2000 (Community Care Statistics, 2000). Therefore fewer people currently receive home care, but those who do tend to be older and tend to receive more help. This growth was largely within the private sector, which accounted for more than 40 per cent of all local authority funded home care by 1998 (Wistow & Hardy, 1999). Targeting of home care services to those with the greatest need also revealed that the role of informal carers had been regarded as a reason not to provide home help support in the past. Research in the 1980's illustrated that service allocation systems were biased against those individuals with informal carers (Godfrey et al., 2000), with services targeted at older people living alone. The system revolved around the substitution of informal for formal care where possible, with service allocation based on circumstance rather than need, and with input from informal carers essentially taken for granted. Only recently have the needs of carers themselves been officially prioritised (National Strategy for Carers, Department of Health, 1999). This document emphasised the specific recognition of the health needs of carers, through provision of better information, improved levels of support and increased involvement.

The expansion of home care services seen throughout the 1990's was not always accompanied by the necessary investment in infrastructure required to support it (Social Services Inspectorate, 1997). This was particularly apparent in the context of continuity of care, an important aspect of good service provision in the light of the intimate, personal tasks home care workers often provide (Edelbalk et al, 1995). In the absence of regulatory and statutory frameworks, this led to a situation where the overall standards and mix of home care service provision was poorly understood (Godfrey et al., 2000). Indeed, in 1997, the Social Services Inspectorate reported that there was concern over both quality standards and consistency in the independent home care sector. Furthermore, in 1999, the Royal Commission on Long Term Care reported that there was little hard evidence addressing whether older people living at home received the right amount, and the right mix and quality of care (Sutherland, 1999). More recently, Patmore (2003) reported an irregular pattern of quality monitoring in home care services. Worryingly, approximately half of the providers surveyed needed to increase the frequency of staff supervision in order to meet the level required by the domiciliary care minimum standards and regulations (Department of Health, 2003).

2.3 National Minimum Standards

Up until the publication of the National Minimum Standards and Regulations for Domiciliary Care (Department of Health, 2003) home care services were not officially regulated. The minimum standards therefore represent a step change in the monitoring of home care provision and were introduced in order to raise the standards of care provided to vulnerable older people in the privacy of their own homes. Services are required to adhere to a range of indicators relating to person-centred care, protection of users and workers, and staff and business requirements to operate within the standards.

2.4 Focus of the present study

The present study assesses the performance of home care services for people with dementia in the North West of England using indicators that reflect a number of these standards, having been developed whist the national minimum standards were available only in consultation document form. The study also draws upon guidance issued and other independent research in order to identify the current state of home care services for people with dementia in the North West of England.

2.5 Developing measurable standards of care

Outcomes are rarely of use in measuring service quality, as the quality of a service is best assessed through the degree to which it conforms to preset standards of care (Gray, 1997). This report measures the performance of home care services on a number of such standards. These are formed from grouping care activities and can be regarded as 'process measures' (Donabedian, 1982), which indicate the rate of progress towards an objective. In ideal circumstances the processes measured should be those for which there is good evidence of effectiveness. However, evidence-based process measures are not readily available for many health and social care services, including dementia care. Some interpretation of the literature therefore has to be made. It is accepted that the outcomes experienced by users are a function of: staff resources; how a facility operates; and how it is managed (Davies and Knapp, 1981; Netten, 1993). Caring for people with dementia is demanding and requires considerable investment in terms of training, supporting and retaining care staff. Despite this, many care staff are unqualified (Audini et al., 2001), and may be volunteers. The implementation of the 'new culture' and models of dementia care (Kitwood and Benson, 1997) has proved difficult, so that the challenges of providing appropriate care for older people remain. These difficulties, which also transfer to the task of measuring 'appropriate care', are pertinent to the current study.

3 AIMS

This study aimed to provide a map of home care services with a specialist focus on dementia care in the North West of England, together with an assessment of their quality. Services were included in the study when all or part of the service was dedicated to providing care for people with dementia, although the service might not have regarded itself as a specialist dementia service *per se.* It is hoped that the information obtained in meeting these aims will assist in future service development in the region.

4 METHOD

The survey was undertaken during 2002-2003 as part of a larger cross sectional postal survey of home care services in the North West (Reilly et al. 2003). The other studies focused on long term care, day care and professional teams involved in the care of people with dementia and will be reported separately. A wide definition of dementia was adopted (Spicker and Gordon, 1997). As in the classic study by Levin and colleagues (1989), the term was used to describe those who suffered from dementia or were confused, though they might not have had a formal diagnosis of dementia. Emphasis was thus placed on the presenting pattern of needs of the older person, rather than a formal diagnosis.

4.1 Phase one: Data collection - identification of home care services in the North West of England

Dementia services were initially identified by means of a screening questionnaire sent to key personnel in the NHS Trusts, Health Authorities, Social Services Departments and voluntary organisations in the North West of England. Targeted respondents were asked to identify existing home care services on a short postal questionnaire. The services identified were entered onto a Microsoft Access database and NWDC staff checked for duplicate entries. The accuracy of the results were also checked by local health and social care professionals including those attending three local conferences on dementia care (around 200 local delegates*).* Adjustments to the database were made as they became apparent.

4.2 Phase two: Data collection from specialist dementia services in North West England

Each of the dementia services identified in the initial phase were asked to complete a postal questionnaire designed to ascertain the service configuration, resources and patterns of service (Appendix 1). The services identified were 'specialist' services insofar as all or part of each service was dedicated to providing care for people with dementia, although the service might not necessarily have regarded itself as a specialist dementia service *per se*. Data was collected at the end of 2002. The questionnaire was developed by the research team as no suitable measures for the evaluation of services were identified through a review of the literature. Particular attention was paid to literature that related to the provision of effective home care. Questions were related to indicators of good practice on a range of themes to capture the construct of the 'new culture of dementia care' (Kitwood and Benson, 1997), and data was collected within a conceptual framework to reflect the health service evaluation criteria of Donabedian (1982), namely, structure, process and outcome. 'Structure' refers to the resources used in the provision of care, 'process' refers to the activities that constitute care, and 'outcomes' are the consequences of health (Donabedian, 1982). Outcomes may be considered broadly as of two types. "Intermediate outcomes" are a probable contribution to or correlate of well-being, such as receipt of a needed service, whereas "final outcomes" represent the effect of care upon an individual, an effect valued in its own right, such as an improvement in well-being (Challis, 1981; Davies and Knapp, 1981). In the present study the outcomes were necessarily intermediate, reflecting the patterns of service output, for example the number of places per service. Respondents were also asked for information relating to the organisational context; service type; availability; access;

capacity; utilisation and whether or not they were aware of any gaps in local services for people with dementia. At the end of the questionnaire, each respondent was invited to assess their level of confidence in completing the questionnaire to provide us with a check on the reliability of the data. Non-respondents were contacted by a researcher and an additional questionnaire was sent if required. This method proved effective at increasing the response rate, and identifying the most appropriate person to complete the questionnaire.

4.3 Standards of care

Services were assessed on three main themes: Service Delivery; User-Centred Practice and Organisation of Care. Within each general theme a number of standards were assessed (see Table 4.1), comprising both basic service characteristics and composite variables. In the measurement of basic service characteristics, many questions were structured in such a way that respondents were required to tick boxes or leave them blank. For example, in estimating the percentage of users in their facility who suffered from dementia or were confused, the provision of percentage categories allowed for easier and more reliable responses than requesting an exact percentage. Following data collection, composite variables were calculated through assigning positively answered items within a standard one point and summing the items to compute a composite score. To reduce the chances of social desirability bias, the questionnaire was not structured according to each standard.

The themes and standards in the report relate to the themes and standards described in Table 4.1.

Table 4.1: Standards of care

Service configuration and standard of care data	Related Tables and Figures			
	Table	Page number	Figure in Appendix III	Page number
Service structure				
Number of places/attendees	5.14,5.15	33,34	2, 3	75,76
Integration of services	6.7	43	10	79
Funding/funding continuity	5.5	23	8	78
Management and staffing	5.10,5.11,5.13	29,30,32	9	79
Care process				
Assessment	6.2	37	4	76
Care plans	-	-	-	-
Rehabilitation potential (stimulating activities)	-	-	-	-
Equity of access to services for ethnic minorities	5.8,6.8	26,44	11	80
Service content				
Service specialism/ targeted at people with dementia	5.6,5.7	24,25	-	
Promotion of early intervention	-	-	-	-
Prevention	-	-	-	-
Equity of access to specialist input	-	-	-	-
Flexibility and around the clock services	6.11	47	1	75
Crisis response/ emergency access	6.11	47	1	75
Independence - good practice & building design	-	-	-	-
Transport	-	-	-	-
Service quality				
Privacy	-	-	-	-
Individuality	6.6	42	5	77
Specialist dementia care training for staff	6.9	45	9	79
Carer involvement (& respite)	6.4	40	7	78
Care worker good practice	6.5	41	6	77
Quality assurance	-	-	-	-

4.4 Analysis

Data was entered and analysed using SPSS version 10.1. Differences in the characteristics of service types were explored using descriptive statistics. Statistical comparisons on basic service characteristics were made by examining the distribution of the data using chi square (χ^2). Variations between service types on composite variables were summarised using mean values. As the data was not normally distributed in most cases, statistical comparisons were made using Kruskal-Wallis/tests when the standard deviation exceeded 50 per cent of the mean. In these instances, post-hoc tests were conducted using Mann-Whitney U. When the standard deviation did not exceed 50 per cent of the mean value, analysis was conducted using analysis of variance. In these instances, post hoc tests were conducted using Tamhane T2, which adjusted for unequal variance and group size.

5 RESULTS – SECTION I: MAIN QUESTIONNAIRE FINDINGS

5.1 The sample

From a mail out to 282 services, 155 responses were received. Ten services formally refused, and 32 were excluded: 29 services did not provide care for people with dementia, and 3 were excluded on the basis of data quality (2 had unacceptably high proportions of missing data including key variables; 1 had answered few questions with confidence). The final sample size was therefore 113 (response rate 46%). This ranged between Local Authority Areas from 11 per cent (Tameside) to 67 per cent (Trafford).

Table 5.1: Number of respondents and response rate by local authority

Respondents		
Local Authority	N	%
Cumbria (n=22)	13	59
Bolton (n=14)	8	57
Bury (n=11)	5	45
Manchester (n=26)	10	38
Oldham (n=6)	1	17
Rochdale (n=6)	2	33
Salford (n=17)	8	47
Stockport (n=19)	6	32
Tameside (n=9)	1	11
Trafford (n=9)	6	67
Wigan (n=7)	1	14
Knowsley (n=11)	3	27
Liverpool (n=5)	3	60
Sefton (n=12)	4	33
St Helens (n=4)	1	25
Wirral (n=14)	5	36
Cheshire (n=2)	1	50
Halton UA (n=5)	1	20
Warrington (n=11)	5	45
Lancashire (n=49)	21	43
Blackburn with Darwen (n=11)	4	36
Blackpool (n=14)	4	29
Total (n=282)	113	46

The types of home care service identified in North West England are shown in Table 5.2.

Table 5.2: Home care service types (main function of service)

Type of Service	N	%
Generic Home Care Service	65	58
Specialist Home care Service for People with Dementia	10	9
Specialist Home care Service for other groups	8	7
Carer Oriented Services	15	13
Other	15	13

All services included in the sample had a specialist element focusing on dementia care, but in many services this constituted part of a larger service providing generic home care to older people. Respondents were therefore asked to state the main function of the service. Table 5.2 shows that services most commonly stated that they were generic in nature, and only a small proportion (9%) regarded themselves as a specialist home care service for people with dementia. There were 15 'other' services all of which provided home care in addition to the service they stated as their primary function. The primary functions indicated by these services comprised: 1 home visiting service; 1 early dementia service; 1 befriending service for people with dementia; 1 social services adult placement service; 1 specialist supported living service; 1 nursing and care agency; 1 specialist day care service; 1 befriending service for people with dementia; 1 home visiting service; 1 crisis response service; 1 sitting service; and 4 unspecified home care/community support services.

Table 5.3: Type of home care facility by local authority

Local Authority	Service Type					Total
	Generic Home Care Service	13	Specialist Home care Service for other groups	Carer Oriented services	Other	
Cumbria	6	8		2	2	13
Bolton	4	5		1	3	8
Bury	3	10	1	1		5
Manchester	6	1	1		2	10
Oldham	1	2				1
Rochdale	1	8				2
Salford	3	6	2	1	2	8
Stockport	4	1	1	1		6
Tameside		6		1		1
Trafford	4	1		1		6
Wigan		3		1		1
Knowsley	1	3			1	3
Liverpool	2	4				3
Sefton	1	1		3		4
St Helens		5				1
Wirral	2	1	1		2	5
Cheshire	1	1				1
Halton		5				1
Warrington	5	21				5
Lancashire	17	4	2	2		21
Blackburn with Darwen	3	4			1	4
Blackpool	1	113		1	2	4
Total	65	10	8	15	15	113

Table 5.3 shows that none of the local authority areas in the North West of England provided all 5 of the home care service types identified by the study. This applied even to larger geographical areas such as Manchester (no carer oriented services identified), Liverpool (no specialist home care services for other groups, carer oriented services, or 'other' home care services identified) and Lancashire (no specialist home care services for people with dementia, or 'other' services identified). In some areas, only one type of home care service was identified (e.g. Oldham, 1 generic service; Tameside, 1 carer oriented service; Wigan, 1 carer oriented service; St Helens (1 specialist home care service for people with dementia; Halton, 1 generic service). Surprisingly, only 2 services were identified in Cheshire (and 1 service responded). This suggested that the survey may have failed to identify all of the services available in each local authority area.

5.2 Service description and organisational context

Services with a contract with the Local Authority or NHS Trust/Health Authority were asked to state the type of contract they held. These are reported in Table 5.4.

Table 5.4: Proportion of services with a contract with the Local Authority or NHS Trust/Health Authority and main type of contract

Type of Service	Proportion of services with a contract with the NHS Trust/LA*	Block	Call-Off	Spot	Cost & Volume	Grant	Other
Generic home care service n=65	60 (92.3)	14 (22.6)	9 (14.5)	35 (56.5)	3 (4.8)	1 (1.6)	-
Specialist home care service for people with dementia n=10	7 (70.0)	4 (50)	1 (12.5)	1 (12.5)	1 (12.5)	1 (12.5)	-
Specialist home care service for other groups n=8	6 (75.0)	1 (16.7)	1 (16.7)	4 (50)	-	-	-
Carer Oriented Services n=15	11 (73.3)	5	1	2	-	2	1
Other n=15	9 (60.0)	1	-	3	1	3	-
All Services n=113	93 (82.3)	25 (22.1)	12 (10.6)	45 (39.8)	5 (4.4)	7 (6.2)	1 (0.9)

* χ^2=12.929, df=4, p=0.012

Most services (82%) had a contract with the NHS Trust or Local Authority. However, significantly more generic home care services than both carer oriented services (U=342.500, p=0.003) and 'Other' services (U=281.000, p=0.000) had such a contract. Services were asked to provide information on the nature of their main type of contract. The most common contract arrangement was the spot type (i.e. the purchase of care in small units of time), which accounted for 40 per cent of services. There were no significant differences between service types in terms of the actual contract types, but generic home care services were significantly more likely to have a contract with the NHS trust/local authority than all of the other service types (specialist home care service for people with dementia: U=252.500, p=0.035; specialist home care service for other groups: U=182.500, p=0.011; carer oriented services: U=395.000, p=0.037; 'other' services: U=330.000, p=0.001).

Services were also asked to specify their second most common type of contract arrangement. This information was provided in 51 cases. Again, the most common was the spot type (21 services, 41.2%); followed by block (12, 23.5%); call off (6, 11.8%); cost and volume (5, 9.8%); 'other' (5, 9.8%); and grant (2, 3.9%). As with the previous analysis, the distribution of contract types did not differ significantly between groups.

Table 5.5 examines the length of funding security for each home care type.

Table 5.5: Length of funding security for home care service types

Service Type	Up to one year n (%)	One to 5 years n (%)	More than 5 years n (%)	Not Applicable n (%)
Generic home care service n=53	4 (8)	10 (19)	1 (2)	38 (72)
Specialist home care service for people with dementia n=9	4 (44)	3 (33)	1 (11)	1 (11)
Specialist home care service for other groups n=5	1 (20)	-	-	4 (80)
Carer Oriented Services n=11	5 (45)	4 (36)	1 (9)	1 (9)
Other n=12	2 (17)	5 (42)	-	5 (42)
All Services n=105	16 (18)	22 (24)	3 (3)	49 (54)

Most services that received funding had arrangements lasting for less than 5 years. Funding arrangements differed significantly between service types (χ^2=24.480, df=4, p=0.000). The issue was not applicable for the majority of generic services (72%) and specialist services for other groups (80%) because a large proportion of these would have been private sector services. Specialist home care services for people with dementia (7, 78%), carer oriented (9, 82%), and 'other' (7, 58%) services tended to have short-to medium term contracts of 0-5 years. Only 3 (3%) services of the 105 that responded to the question had secured arrangements for more than 5 years of funding.

5.3 Targeting

Table 5.6 shows the percentage of users who suffer from dementia or are confused, and the total number of service users with dementia by home care service type.

Table 5.6: Percentage of users who suffer from dementia or are confused by type of facility

	Percentage of users who suffer from dementia or are confused					Total number of service users with dementia (mean number per service/ sd)
	1-20% n (%)	21-40% n (%)	41-60% n (%)	61-80% n (%)	81-100% n (%)	
Generic home care service n=65	32 (49.2)	18 (27.7)	10 (15.4)	5 (7.7)	-	3166 (48.7/ 73.0)
Specialist home care service for people with dementia n=10	1 (10)	-	1 (10)	2 (20)	6 (60)	305 (30.5/22.8)
Specialist home care service for other groups n=8	5 (62.5)	2 (25.0)	-	1 (12.5)	-	149 (18.6/20.1)
Carer Oriented Services n=15	7 (11.7)	5 (33.3)	1 (6.7)	1 (6.7)	1 (6.7)	579 (38.6/100.6)
Other n=15	5 (33.3)	2 (13.3)	2 (13.3)	1 (6.7)	5 (33.3)	910 (60.7/84.2)
Total (%) (n=113)	50 (44.3)	27 (23.9)	14 (12.4)	10 (8.8)	12 (10.6)	5109 (45.2/73.3)

Most commonly, between 1 and 20% of users had dementia (50, 44%). Between 81 and 100% of users had dementia in only 12 (11%) of services. The mean number of users per service was 45, the highest being found in 'other' services (61) and the lowest in specialist home care service for other groups (19).

The proportions of people with dementia of the total number of service users differed significantly between service types (χ^2=22.337, df=4, p=0.000). It was notable that a large proportion of both generic (32, 49.2%) and specialist home care services for other groups (5, 62.5%) had relatively low proportions of service users who suffered from dementia or were confused (i.e.1-20%). In contrast, 81-100 per cent of service users suffered from dementia or were confused in 6 (60%) of specialist home care services for people with dementia, of which only 1 (10%) service had between 1-20 per cent.

There were no significant differences between the mean numbers of service users with dementia in each service type.

Table 5.7: Approximate proportions of mild/moderate and severe levels of cognitive impairment of service users with dementia by service type

	% mild or moderate dementia mean (s.d.)	% severe dementia mean (s.d.)	Total number of services where 100% of current users had dementia n (%)
Generic home care service n=65	71.8 (30.8)	28.2 (23.4)	2 (3.1)
Specialist home care service for people with dementia n=10	65.4 (26.7)	34.6 (26.7)	6 (60)
Specialist home care service for other groups n=8	71.5 (36.3)	28.5 (26.6)	-
Carer Oriented Services n=15	57.2 (30.3)	42.8 (28.7)	4 (26.7)
Other n=15	70.2 (21.4)	29.8 (21.4)	7 (46.7)
All Services	67.2 (29.6)	32.8 (24.6)	19 (16.8)

For services as a whole, the ratio of mild or moderate to severe dementia was approximately two-thirds to one third. All current users had dementia in 17 per cent of services. No significant differences were found between the proportions of mild/ moderate and severe dementia or between the numbers of services currently providing solely for people with dementia in each service type, although the highest proportion of services currently providing solely for people with dementia (60%) was found in specialist home care services for people with dementia. As would be expected, there were no specialist home care services for other groups that were currently providing solely for people with dementia. The general pattern of findings was therefore as expected, although the small group sizes probably prevented the cut off for statistical significance being reached.

5.4 Culturally sensitive services

One of the principles of the NHS Plan is that the NHS will respond to different needs of different populations (standard 2; Department of Health 2000). The NSFOP also notes that older people from black and minority ethnic groups can be particularly disadvantaged (Department of Health, 2001a) and are likely to suffer more discrimination in accessing services (Department of Health, 1998; Patel and Mirza, 1998). In an effort to assess whether or not all sectors of the population are being allowed access to services it is important to understand the relationship between socio-demographic factors. In the context of this study, the prevalence of minority ethnic groups and service provision/activity rates are of particular interest.

The proportion of older people from black and minority ethnic communities is small, but the population of individuals from ethnic minority backgrounds as a whole is growing (Department of Health, 2000). It is estimated that the total black and ethnic minority population of Great Britain is just over 3 million (5.5 per cent of the total population, Department of Health, 2001a). Ethnic minority groups in the North West of England aged over 65 years make up 2.7 per cent of the population. This ranges from 0.9 per cent (Cumbria, St Helens) to 9.2 per cent (Manchester) across the 22 Local Authority areas in the North West of England.

Table 5.8: Current users from ethnic minority groups in home care facilities in each local authority

	Home care services	Ethnic minority users	Percentage of population aged over 65 years from ethnic minority groups (Census, 2001)
	n	n	%
Cumbria	13	0	0.9
Bolton	8	94	5.0
Bury	5	69	3.5
Manchester	10	54	9.2
Oldham	1	0	5.4
Rochdale	2	4	5.3
Salford	8	23	2.3
Stockport	6	20	2.6
Tameside	1	3	3.6
Trafford	6	18	4.5
Wigan	1	0	1.0
Knowsley	3	0	1.3
Liverpool	3	1	3.2
Sefton	4	0	1.3
St Helens	1	2	0.9
Wirral	5	14	1.4
Cheshire	1	0	1.5
Halton	1	0	1.0
Warrington	5	10	1.4
Lancashire	21	39	2.3
Blackburn with Darwen	4	3	7.1
Blackpool	4	0	1.2
Total	113	354	2.7

Most services (85, 75%) reported providing home care for users from ethnic minority groups. Of those facilities, the numbers ranged from 1 to 94 representing 354 users in total. This translated to 2.2 per cent (354/15830) of the total recorded number of service users in this North West sample from ethnic minority groups. When compared with 2001 census data, which reported that 2.7 per cent of the population aged 65 years or older in the North West as a whole is from an ethnic minority background (excluding Irish), our data suggested that ethnic minorities are mildly under-represented in home care services for people with dementia in North West England.

5.5 Total population and service capacity by local authority area

To assess the accessibility of specialist service provision in particular geographical areas, the number of home care service users was combined with population statistics to estimate the proportion of the total estimated population with dementia attending services.

Dementia prevalence rates were combined with population figures for each of the local authority areas in North West England and data relating to the availability of home care services from the current study (Table 5.9). The most recent population figures available were obtained from KIGS (Department of Health, 2002) (column 1). The percentage of non-responders (column 2), and the number of service users (column 3) were derived from data obtained in the present study. The recorded number of service users (column 3) and the recorded number of service users with dementia (column 5) were adjusted upwards according to the response rate for each local authority area and the overall proportion of exclusions to form an estimate of the total number of service users (column 4) and the total number of service users with dementia (column 6) that would have been expected had a 100 per cent response rate been achieved. The estimated population with dementia (column 7) was calculated as a proportion (9.3%) of the total population as described previously (see Appendix 2). By combining this figure with the total number of service users with dementia identified by the present study, the proportion of people with dementia receiving home care services was estimated (column 8).

Table 5.9: Total population and service capacity by local authority area

Local Authority	Population over 65 years	Percentage of non-responders	Total number of service users (recorded)	Total number of service users (estimated)	Total number of service users with dementia (recorded)	Total number of service users with dementia (estimated)	Estimated population with dementia (9.3%)	Percentage of total estimated population with dementia receiving home care services
Column	1	2	3	4	5	6	7	8
Cumbria	88,141	41	1203	1814	443	668	8197	5.4-8.1
Bolton	39,314	43	1354	2114	269	420	3656	7.3-11.5
Bury	26,177	55	824	1629	258	510	2434	10.6-21.0
Manchester	56,797	62	1670	3911	606	1419	5282	11.5-26.9
Oldham	30,908	83	130	681	40	209	2874	1.4-7.3
Rochdale	29,338	67	170	458	58	156	2728	2.1-5.7
Salford	36,302	53	545	1032	286	542	3376	8.5-16.1
Stockport	47,878	68	773	2149	186	517	4453	4.2-11.6
Tameside	32,310	89	80	647	15	121	3005	0.5-4.0
Trafford	34,945	33	1001	1329	226	300	3250	7.0-9.2
Wigan	43,439	86	92	585	4	25	4040	0.0-0.6
Knowsley	21,034	73	536	1767	356	1173	1956	18.2-60.0
Liverpool	67,387	40	599	889	146	217	6267	2.3-3.5
Sefton	54,405	67	323	871	60	162	5060	1.2-3.2
St Helens	27,024	75	90	320	10	36	2513	0.4-1.4
Wirral	57,384	64	511	1263	252	623	5337	4.7-11.7
Cheshire	108,936	50	15	27	15	27	10131	0.2-0.3
Halton	15,452	80	12	53	12	53	1437	0.7-3.7
Warrington	26,771	55	788	1558	89	176	2490	3.6-7.1
Lancashire	187590	57	4203	8699	1565	3239	17446	9.0-18.6
Blackburn with Darwen	18759	64	381	942	139	344	1745	8.0-19.7
Blackpool	28,752	71	530	1627	74	227	2674	2.8-8.5
Total	1,079,043	-	15830	35222	5109	11368	100351	-
Mean	49,047	-	720	1601	232	517	4561	5.1-11.3

Key to table

Column	Description	Source/Formula
1	Population over 65 years	KIGS (2002)
2	Percentage of non-responders	Questionnaire
3	Total number of service users (recorded)	Questionnaire
4	Total number of service users (estimated)	(Column 3/(100-column 2) x 100) x .89
5	Total number of service users with dementia (recorded)	Questionnaire
6	Total number of service users with dementia (estimated)	(Column 5/(100-column 2) x 100) x .89
7	Estimated population with dementia (9.3%)	Column 1 x 9.3%
8	Proportion of total estimated population with dementia receiving home care services	(Column 5/Column 7) x 100 to (Column 6/ Column 7) x 100

The proportion of the population with dementia attending home care services can be interpreted as a proxy measure of the accessibility of home care services in the region. Knowsley scored highly in this domain, whilst the data suggested that

services might be less accessible in areas such as Wigan and Cheshire.

5.6 Staff training and qualifications

The breakdown of different staff groups employed in each of the home care service types is shown in Table 5.10.

Table 5.10: Mean number of each type of staff from specified staff groups, and total number of staff in each service type

Service Type	Managers	Supervisors	Senior Care Workers	Hands-on Care Staff	Trained Volunteers	Other	Total (mean/sd)
Generic home care service	2.08	2.66	3.15	52.42	0.03	1.63	4028 (61.99/ 54.3)
Specialist home care service for people with dementia	4.40	2.80	10.20	33.60	5.40	7.50	639 (63.90 /130.3)
Specialist home care service for other groups	2.88	0.75	11.0	36.25	6.25	1.25	467 (58.38 /41.9)
Carer Oriented Services	1.80	0.40	0.60	13.00	1.07	9.07	389 (25.93 /21.8)
Other	5.60	4.40	6.20	99.47	14.40	6.27	2045 (136.33/ 155.0)
Statistical Significance	ns	χ^2=15.748, df=4, p=0.003	ns	χ^2=19.593, df=4, p=0.001	χ^2=41.452, df=4, p=0.000	ns	χ^2=16.967, df=4, p=0.002
Total (mean)	313 (2.77)	279 (2.47)	497 (4.40)	5720 (50.62)	338 (2.99)	421 (3.73)	7568 (66.97/ 84.9)

Services as a whole employed a mean of 70 staff per service. The mean total number of staff differed significantly between service types. Specifically, there were significantly more staff per service in 'other' service types than generic home care services (U=281.000, p=0.000). Also, there were significantly more supervisors in generic home care services than specialist services for other groups (U=144.000, p=0.036) and carer oriented services (U=201.5, p=0.000). There were also more supervisors in 'other' services than in carer oriented services (U=57.000, p=0.021).

Considerable variation was found between service types in terms of the numbers of personnel employed of different professional grades. Generic services appeared to employ more hands-on staff, when compared to specialist services for people with dementia (U=155.500, p=0.008) and carer oriented services (U=144.000, p=0.000). Specialist services for people with dementia also tended to employ more hands-on staff than carer oriented services (U=26.000, p=0.028). Generic services appeared to employ few trained volunteers: there were significantly more trained volunteers in specialist home care services for people with dementia (U=231.000, p=0.000); carer

oriented services (U=429.000, p=0.028) and 'other' services (U=167.500, p=0.000) than in generic services. 'other' home care services also appeared to employ many trained volunteers. There were significantly more trained volunteers in this home care service type than in both carer oriented services (U=51.500, p=0.004) and specialist home care services for other groups (U=31.500, p=0.047).

A detailed breakdown of the ratios of between staff groups employed in each of the home care service types is shown in Table 5.11.

Table 5.11: Ratios and proportions of different staff types to service users

Variable	Generic home care service	Specialist home care service for people with dementia	Specialist home care service for other groups	Carer Oriented Services	Other	Total (mean)	Statistical Significance
Number of senior care staff (mean)	205 (3.15)	102 (10.20)	88 (11.00)	33 (2.20)	150 (10.00)	578 (5)	F=2.855, df=4;108;112 ; p=0.027
Ratio of senior care staff to 'hands-on' staff	1:17	1:7	1:3	1:3	1:2	1:6	F=7.307, df=4;99;103; p=0.000
Ratio of service users to senior care staff	63:1	7:1	7:1	26:1	35:1	28:1	ns
Proportion of service users to qualified 'hands-on' care staff	6:1	2:1	5:1	8:1	4:1	5:1	ns
Ratio of managers and supervisors to care staff	1:10	1:5	1:9	1:7	1:13	1:9	F=2.525; df=4;104;108 ; p=0.045

Significant differences were found between service types in the mean number of senior staff employed. Significantly more senior staff were employed in generic as opposed to carer oriented services (p=0.001). The ratio of senior care staff to hands-on staff also differed significantly between groups as a whole, although post-hoc tests revealed no significant differences between specific groups. This reflected a trend for higher ratios (i.e. more hands-on staff to each senior care staff) in generic services compared to specialist services for other groups, carer oriented services,

and 'other' home care services but was not conclusive. Similarly, analysis of variance suggested that there were significant differences between service types in terms of the mean ratio of managers and supervisors to care staff, but again, post-hoc tests revealed no significant differences between specific groups. This suggested that the differences in ratios between both generic services and 'other' services, compared to specialist home care services for people with dementia may have reflected actual differences, but the data did not allow strong conclusions to be drawn.

Table 5.12 shows the proportions of formally qualified hands-on staff by home care service type.

Table 5.12: Proportions of hands-on staff with formal qualifications by service type

	Proportion					
Service Type	0	1-20%	21-40%	41-60%	61-80%	81-100%
Generic home care service n (%)	5 (7.7)	31 (47.7)	17 (27.4)	7 (10.8)	3 (4.62)	2 (3.1)
Specialist home care service for people with dementia n (%)	1 (10)	5 (50)	2 (20)	-	2 (20)	-
Specialist home care service for other groups n (%)	2 (25.0)	2 (25.0)	1 (12.5)	3 (37.5)	-	-
Carer Oriented Services (%)	2 (13.3)	6 (40.0)	2 (13.3)	2 (13.3)	2 (13.3)	1 (6.7)
Other (%)	3 (20.0)	6 (40.0)	2 (13.3)	4 (26.7)	-	-
Total (%)	13 (11.50)	50 (44.25)	24 (21.24)	16 (14.16)	7 (6.19)	3 (2.65)

There were no significant differences found between groups in terms of formal qualifications for hands-on staff. For services as a whole, the proportion of hands-on staff with formal qualifications was low, with 1-20 per cent being most commonly found (in 44.25% of services). The relative proportions of hands-on staff with formal qualifications appeared to be very similar across service types. The proportions of staff who had received dementia-care specific training is shown in Table 5.13 for each home care service type.

Table 5.13: Levels of staff training by service type

Service Type	Mean percentage of hands-on care staff who have received in-house specific training in caring for people with dementia (sd)	Mean percentage of hands-on care staff who have received external specific training in caring for people with dementia (sd)	Overall percentage of hands-on care staff who have received specific training in caring for people with dementia (sd)
Generic home care service	18 (37)	15 (32)	27 (42)
Specialist home care service for people with dementia	43 (53)	17 (37)	43 (53)
Specialist home care service for other groups	29 (49)	14 (38)	43 (53)
Carer Oriented Services	59 (49)	18 (37)	67 (47)
Other	17 (39)	03 (07)	18 (39)
All services	26 (43)	14 (32)	33 (46)
Statistical Significance	χ^2=10.808 df=4 p=0.029	ns	ns

Overall, only one-third of hands-on staff had received any dementia care training, and even in specialist services for people with dementia, less than half had received such training.

There was a significant effect of service type on the mean proportion of hands-on care staff who had received in-house specific training in caring for people with dementia. Specifically, a significantly higher proportion of staff had been trained 'in-house' in carer oriented services than in generic home care services (U=228.000, p=0.002). When training in general was analysed however (i.e. irrespective of whether it was received in-house or externally), there were no significant differences between service types. There did however appear to be a trend for a greater degree of service provision in carer oriented services than in the other service types, although the differences were not significant.

5.7 Activity rates

Service intensity in home care services in the North West is examined in Table 5.14.

Table 5.14: Service intensity

Variable	Generic home care service n (%)	Specialist home care service for people with dementia n (%)	Specialist home care service for other groups n (%)	Carer Oriented Services n (%)	Other n (%)	All services n (%)	Statistical Significance
Intensive Service (more than 6 visits per week for > 60% of clients)	42 (64.6)	1 (10.0)	1 (12.5)	0 (0)	2 (13.3)	46 (40.7)	χ^2=36.892, df=4, p=0.000
Less intensive service (less than 6 visits per week for > 60% of clients)	12 (18.50)	3 (30.0)	4 (50.0)	5 (33.3)	1 (6.7)	25 (22.1)	ns
Intensive Service (more than 15 hours per week to > 60% of clients)	13 (20.0)	0	0	0	1 (6.7)	14 (12.4)	ns
Less intensive Service (less than 15 hours per week to > 60% of clients)	1 (1.5)	1 (10.0)	1 (12.5)	1 (6.7)	0	4 (3.5)	ns

Just under one half (46, 41%) of services provided an 'intensive' service of more than 6 visits per week for more than 60 per cent of clients. It was notable however that 42 (91%) of these were generic services, which were significantly more likely to provide such a service than each of the other home care service types: (Specialist home care service for people with dementia: U=147.500, p=0.001; Specialist home care service for other groups: U=124.500, p=0.005; Carer Oriented Services: U=172.500, p=0.000; 'other' services: U=237.500, p=0.000).

One quarter of services provided a 'less intensive' service defined as less than 6 visits per week for more than 60 per cent of clients. Surprisingly, there were 3 (30%) specialist home care services for people with dementia and 4 (50%) specialist home care service for other groups that provided less than 6 visits per week input to more than 60 per cent of clients. A similar pattern was reflected in the number of hours provided. Only thirteen (20%) generic home care services provided more than 15 hours per week to more than 60 per cent of clients, but this compared to just 1 'other' home care service, and no services from any of the other groups.

Table 5.15: Percentage of people with dementia of total service users, and other services received by people with dementia, by service type

Variable	Generic home care service	Specialist home care service for people with dementia	Specialist home care service for other groups	Carer Oriented Services	Other	Mean	Statistical Significance
Percentage of people with dementia of total service users (sd)	27 (22)	82 (30)	15 (16)	57 (54)	58 (41)	39 (36)	χ^2=23.512, df=4, p=0.000
Proportion (%) of people with dementia who also receive day care (sd)	37 (29) (n=34)	38 (31) (n=6)	56 (30) (n=4)	32 (21) (n=4)	47 (34) (n=6)	39 (29)	ns
Proportion of people with dementia who also receive home care (sd)	29 (30) (n=17)	32 (27) (n=4)	22 (17) (n=3)	67 (47) (n=2)	16 (27) (n=3)	30 (30)	ns
Proportion of people with dementia who also receive sitting service (sd)	22 (36) (n=21)	0.67 (58) (n=3)	17 (15) (n=4)	100 (0.00) (n=2)	07 (94) (n=4)	28 (39)	ns
Proportion of people with dementia who also receive befriending service (sd)	03 (38) (n=4)	0 (n=1)	30 (-) (n=1)	100 (19) (n=3)	39 (47) (n=5)	41 (49)	ns

People with dementia comprised thirty nine per cent of users for services as a whole. Of these, thirty nine per cent also received day care; thirty per cent also received home care from another source; twenty eight per cent also received a sitting service; and forty one per cent also received a befriending service. There were significant differences between service types in terms of the mean percentage of people with dementia of the total number of service users. The highest percentage, as would be expected, was found in specialist home care services for people with dementia (82%). This was significantly higher than the proportion found in generic services (U=67.000, p=0.000), and specialist home care services for other groups (U=4.000, p=0.001). The proportions found in carer oriented services were also significantly higher than in both generic services (U=290.000, p=0.047) and specialist home care services for other groups (U=22.500, p=0.020). Likewise, the proportions found in 'other' home care services were significantly higher than generic services (U=259.500, p=0.038) and specialist home care services for other groups (U=20.500, p=0.020).

6 RESULTS - SECTION II: STANDARDS OF CARE

This section concentrates on the aggregation of key variables from section one into composite variable. These reflect the overall performance of the major home care service types on a number of standards of care. These have been summarised previously (Table 4.1).

The data is presented in the following format: Each factor contributing to the overall composite score is presented both as a direct contrast between the home care service types, and also for services as a whole. The relative overall performances of each service type on the composite variable contrasted at the bottom of the table along with an overall figure for all services. This allows the performance of each home care service type to be assessed for each theme (the composite score), for the contribution to this difference of each individual factor comprising the theme to be identified, and for the standard of home care service types as a whole to be evaluated.

6.1 Internal reliability

The internal consistency of the scales was examined using Cronbach's Alpha. Alpha is an index of reliability associated with variation in the underlying construct, measuring how well a set of items fit together to form a summated scale, where the scale or 'construct' is the hypothetical variable that is being measured (Hatcher, 1994). Thus, it is of particular relevance to summated scales as it provides an indication of the validity of the construct through examining inter-item correlations. If inter-item correlations are found to be high, then this provides evidence that the separate items comprising the scale are measuring aspects of the same domain. If a construct is considered to be valid, then theoretically it would also elicit consistent and reliable responses even if questions were replaced with other, similar questions (Santos, 1999). The Alpha co-efficient ranges in value from 0 to 1, with a higher score indicating greater reliability. Nunally (1978) suggested that 0.7 was an acceptable cut-off, but lower thresholds have been used in the literature (Santos, 1999). Table 6.1 shows the Alpha co-efficient for each of the composite variables used in the present study.

Table 6.1: Internal reliability

Standard	Alpha Score
Assessment (8 items)	0.32
Contents of briefing documents	0.90
Carer Involvement (2 items)	-0.97
Integration (8 items)	0.64
Care worker good practice (6 items)	0.31
Equity of service delivery for people from ethnic minorities (4 items)	0.79
Individuality (2 items)	0.65
Training (4 items)	0.25
Management Practices (5 items)	0.61
Service flexibility (3 items)	0.69
Mean	0.42

The mean Alpha score across the twelve themes was fairly low (0.42), although much of this was attributable to the negative score on the Carer Involvement

standard. High levels of reliability were found on 6 of the 10 standards (Contents of briefing documents, Integration, Equity of service delivery for people from ethnic minorities, Individuality, Management practices, and Service flexibility). Four themes presented with low reliability (Assessment, Carer Involvement, Care worker good practice, Training). These results were however informative in themselves as they illustrated inconsistency in services with regard to the practice of factors comprising each standard. Although the lower scores found on some of the composites indicated a lack of association between the separate items within them, the scores were unlikely to be high as the possession of one attribute does not mean a service would be any more likely to possess one of the other attributes. In addition, regardless of the alpha coefficient, the greater the number of attributes found within each composite would indicate a greater likelihood of a better quality of care.

6.2 Standards

6.2.1 Assessment and review procedures

Table 6.2 details the Assessment and review procedures standard, by service type.

Table 6.2: Assessment and review procedures

Item	Generic home care service	Specialist home care service for people with dementia	Specialist home care service for other groups	Carer Oriented Services	Other	All services (%)	Statistical Significance
Briefing documents kept in user's home	56 (86.2)	1 (10)	5 (62.5)	8 (53.3)	9 (60.0)	79 (69.9)	χ^2=35.230, df=4, p=0.000
Service operates within CPA policies	38 (58.5)	8 (80)	6 (75)	10 (66.6)	6 (40.0)	68 (60.2)	ns
Risk assessment for user is conducted	61 (93.8)	9 (90)	8 (100)	14 (93.3)	14 (93.3)	106 (93.8)	ns
Health and Safety for staff is assessed	61 (93.8)	10 (100)	8 (100)	15 (100.0)	13 (86.7)	107 (94.7)	ns
Users abilities and needs assessed	58 (89.2)	9 (90)	7 (87.5)	14 (93.3)	12 (80.0)	100 (88.5)	ns
Planned reviews undertaken	58 (89.2)	9 (90)	7 (87.5)	13 (86.7)	13 (86.7)	100 (88.5)	ns
Review undertaken at least every 2 months	8 (12.3)	3 (30)	1 (12.5)	13 (86.7)	13 (86.7)	38 (33.6)	ns
Care co-ordinator is given written report of review	11 (16.9)	0 (0)	0 (0)	1 (6.7)	1 (6.7)	13 (11.5)	ns
Mean Composite Score (sd)	5.40 (1.27)	4.90 (1.19)	5.25 (0.89)	5.07 (1.28)	4.60 (1.12)	3.75 (2.96)	ns

Scores for services as a whole were generally high on the Assessment and review procedures standard, although few (38, 34%) services undertook planned reviews at least every 2 months, and fewer still (13, 12%) provided the care co-ordinator with a written report of the review. The overall mean of 3.75 indicated that a service would on average be expected to have approximately half of the items comprising the standard in place.

The majority of services operated within CPA policies, although almost a third (32%) of services did not conform to this standard. Most services did however conduct risk

assessments for users and staff, and assessed user's abilities and needs. Planned reviews were generally conducted at least every 2 months only in carer oriented and 'other' home care services. Furthermore, few services (13, 11.5%) provided the care co-ordinator with a written report of the review.

There were no significant differences between service types on the overall score for Assessment and review procedures. There were differences however regarding the frequency that briefing documents were kept in the user's home. This was significantly more likely to be the case in generic home care services than specialist home care for people with dementia (U=55.500, p=0.000), carer oriented (U=281.500, p=0.000), or 'other' services (309.500, p=0.007). Briefing documents were also significantly more likely to be kept in the user's home in specialist home care services for other groups (U=13.500, p=0.033) and 'other' services (U=32.000, p=0.026) than in specialist home care services for people with dementia.

6.2.2 Contents of briefing documents

Table 6.3 describes the contents of briefing documents, by home care service type.

Table 6.3: Contents of briefing documents (of those services that kept briefing documents at the user's home):

Item	Generic home care service n=56	Specialist home care service for people with dementia n=1	Specialist home care service for other groups n=5	Carer Oriented Services n=8	Other n=9	Statistical Significance	Total (%) n=79
Client Need	44 (78.6)	1 (100.0)	4 (80.0)	7 (87.5)	8 (88.9)	ns	64 (81.0)
Client Preferences	45 (80.4)	1 (100.0)	5 (100.0)	7 (87.5)	8 (88.9)	ns	66 (83.5)
History	15 (26.8)	1 (100.0)	1 (20.0)	4 (50.0)	2 (22.2)	ns	23 (29.1)
Profile of clients ability in ADL	32 (57.1)	1 (100.0)	2 (40.0)	5 (62.5)	6 (66.7)	ns	47 (59.5)
Goals	22 (39.3)	1 (100.0)	2 (40.0)	5 (62.5)	4 (44.4)	ns	34 (43.0)
Changes to watch for	26 (46.4)	1 (100.0)	1 (20.0)	6 (75.0)	4 (44.4)	ns	38 (48.1)
Changes in user/carer circumstances	32 (57.1)	1 (100.0)	3 (60.0)	5 (62.5)	4 (44.4)	ns	45 (57.0
Two or more of: Time Log Staff Names Tasks undertaken Observations Messages to other workers	50 (89.3)	1 (100.0)	4 (80.0)	6 (75.0)	8 (88.9)	ns	69 (87.3)
Mean Composite Score (sd)	4.75 (2.46)	8.0 (-)	4.40 (2.47)	5.63 (2.67)	4.89 (2.37)	ns	5.19 (1.24)

Seventy nine services (69.9 per cent) kept their briefing documents at the user's home. Most services (69, 87 per cent) had space on their documents for two or more of either: a time log; staff names; tasks undertaken; observations; or messages to other workers. The majority of services also had space for client preferences (66, 84%) and client needs (64, 81%). Less than half of services however recorded: history (23, 29%); goals (34, 43%); or changes to watch for (38, 48%). The mean composite score of 5.19 for all services suggested that on average, a service would be expected to have just over half of these items on their briefing documents.

The effect of service type on the overall quality of the briefing documents just failed to reach significance (χ^2=9.203 p=0.056). Post-hoc tests however revealed that generic home care services utilised briefing documents of significantly higher overall quality than 'other' services on our measures (U=276.000, p=0.040).

6.2.3 Carer involvement/proactive policies

Details of the support mechanisms for carers utilised by home care services in the North West are found in Table 6.4.

Table 6.4: Carer involvement/proactive policies

Item	Generic home care service	Specialist home care service for people with dementia	Specialist home care service for other groups	Carer Oriented Services	Other	Total	Statistical Significance
Formal arrangements for providing support to friends/ relatives	8 (14.5)	8 (80.0)	0 (0)	9 (64.3)	6 (54.5)	31 (32)	χ^2=30.561, df=4, p=0.000
Briefing documents kept in home	56 (86.2)	1 (10)	5 (62.5)	8 (53.3)	9 (60.0)	79 (69.9)	χ^2=35.230, df=4, p=0.000
Mean Composite Score (sd)	0.98 (0.48)	0.90 (0.57)	0.63 (0.52)	1.13 (0.74)	1.00 (0.65)	0.97 (0.56)	ns

The data indicated that whilst most (79, 70%) services kept briefing documents in the user's home, only one third (31, 32%) had formal arrangements in place for providing support to friends or relatives. The negative Alpha score obtained for this standard (see Table 6.1) suggested that if a service scored on one item, they were actually less likely to score on the other (i.e. if a service kept briefing documents in the user's home, they were less likely to have formal arrangements in place for providing support to friends or relatives, and vice-versa).

Formal arrangements for providing support to friends/relatives were most likely to be in place in specialist home care services for people with dementia. They were significantly more likely to exist in this service type than in generic services (U=95.000, p=0.000). Formal arrangements for providing support to friends/relatives were not in place in any of the specialist home care services for other groups who were identified by the study. They were significantly more likely to be in place in all of the other service types except generic home care services (specialist home care services for people with dementia: U=7.000, p=0.005; carer oriented services: U=17.500, p=0.016; 'other' services: U=17.500, p=0.056). As described previously, briefing documents were significantly more likely to be kept in the user's home in generic home care services than specialist home care for people with dementia (U=55.500, p=0.000), carer oriented (U=281.500, p=0.000), or 'other' services (309.500, p=0.007). Briefing documents were also significantly more likely to be kept in the user's home in specialist home care services for other groups (U=13.500, p=0.033) and 'other' services (U=32.000, p=0.026) than in specialist home care services for people with dementia. There were however no significant differences between service types on the overall score.

6.2.4 Care worker good practice

The performance of services on the Care worker good practice standard is shown in Table 6.5.

Table 6.5: Care worker good practice

Item:	Generic home care service	Specialist home care service for people with dementia	Specialist home care service for other groups	Carer Oriented Services	Other	Total/ Mean	Statistical Significance
New staff receive an induction	59 (90.8)	10 (100)	6 (75)	15 (100)	13 (86.6)	103 (91.2)	ns
Service provides training for staff qualifications	60 (92.3)	9 (90)	6 (75)	10 (66.6)	8 (53.3)	93 (82.3)	χ^2=16.181, df=4, p=0.003
Service provides dementia-specific training to staff	28 (43.1)	8 (80)	4 (50)	8 (53.3)	10 (66.6)	58 (51.3)	ns
Space on briefing document for (score 0.3 for each):							
Tasks undertaken	44 (85.7)	1 (100)*	3 (80.0)	6 (75.0)	8 (88.9)	67 (84.8)	ns
Observations	47 (78.6)	1 (100)*	4 (60.0)	6 (75.0)	8 (88.9)	62 (78.5)	ns
Messages to other workers	43 (76.8)	1 (100)*	2 (40.0)	6 (75.0)	8 (88.9)	60 (75.9)	ns
Supervisor contact weekly or more often	43 (66.2)	7 (70)	7 (87.5)	9 (60.0)	7 (46.7)	60 (75.9)	ns
More than 60% of staff have formal qualifications	5 (7.7)	2 (20)	0 (0)	3 (20.0)	0 (0)	10 (8.8)	ns
Mean Care worker good practice Composite Score (sd)	3.00 (0.97)	3.60 (0.84)	2.88 (1.46)	3.00 (1.20)	2.93 (0.92)	2.98 (1.03)	ns

* it was only possible to obtain details of briefing documents for 1 Specialist home care service for people with dementia.

Most services (103, 91%) provided an induction to new 'hands-on' staff, and provided (or paid for) staff to train for qualifications (93, 82%). Only 58 services (51%) provided specific training in caring for people with dementia. Channels of communication between care workers were assessed through the provision of spaces specifically for this purpose on briefing documents. The majority of services had spaces for tasks undertaken (67, 85%); observations (62, 79%); and for messages to other workers (60, 76%). Staff in the majority of services (60, 76%) had contact with their supervisor at least weekly. Only 10 services (9%) had over 60 per cent of their staff with formal qualifications. The overall composite score for services was low however.

The highest overall levels of care worker good practice were found in specialist home care services for people with dementia, but there were no significant differences between service types. However, there were significant variations between service types in terms of the provision of training for staff qualifications. Specifically, generic home care services provided training for staff qualifications significantly more often than carer oriented services (U=362.500, p=0.007) and 'other' home care services (U=297.500, p=0.000). In fact a higher proportion of specialist home care services for people with dementia provided training for staff qualifications (92%) than generic services, but the low number of services in the group probably prevented this from reaching statistical significance. It was most likely that over 60 per cent of staff would have a formal qualification in specialist home care services for people with dementia and carer oriented services, but the differences between groups were not statistically significant. Neither specialist home care services for other groups or 'other' home care services had over 60 per cent of formally qualified staff.

6.2.5 Individuality

The results on the individuality standard from the present study are shown in Table 6.6.

Table 6.6: Individuality

Variable	Generic home care service	Specialist home care service for people with dementia	Specialist home care service for other groups	Carer Oriented Services	Other	Total (%)	Statistical Significance
Memory/Life Story Wallets	8 (12.3)	5 (50.0)	0 (0)	7 (46.7)	5 (33.3)	25 (22.1)	χ^2=16.756, p=0.002
No Uniform policy for staff	4 (6.2)	2 (20.0)	0 (0)	0 (0)	1 (6.7)	7 (6.2)	ns
User-Centred Practice Composite variable Mean score (sd)	0.18 (0.46)	0.70 (0.67)	0 (0)	0.47 (0.52)	0.40 (0.63)	0.28 (0.53)	χ^2=16.009, df=4, p=0.003

Neither the use of memory/life story wallets or the presence of no-uniform policies for staff were commonly found in services as a whole. Just 25 (22%) services used memory or life story wallets, and even fewer (7, 6%) had a no-uniform policy. The overall mean score for services was low (0.3, maximum 2).

The provision of memory/life story wallets however varied significantly between the service types. Post hoc tests revealed that specialist home care services for dementia (U=202.500, p=0.004), carer oriented services (U=320.000, p=0.002) and 'other' home care services (U=385.000, p=0.048) all provided this service significantly more often than generic home care services. Interestingly, there were no specialist home care services for other groups that provided either item, but the small number of services in this group may have prevented any real significance

being attached to this finding. In an overall sense, provision of both of these aspects of user centred practice was relatively uncommon, with only 25 (22.1%) of services utilising memory/life story wallets, and just 7 (6.2%) of services operating a no uniform policy for staff. There was also a significant difference between service types on the overall mean composite score for User-Centred practice. Post-hoc tests revealed that specialist home care services for people with dementia scored significantly higher than both generic home care services (U=181.000, p=0.002) and specialist home care service for other groups (U=342.000, p=0.012). Carer oriented services also scored significantly higher than generic home care services (U=16.000, p=0.034).

6.2.6 Integration

In the present study, integration was assessed on the dimensions found in Table 6.7.

Table 6.7: Integration

Item:	Generic home care service	Specialist home care service for people with dementia	Specialist home care service for other groups	Carer Oriented Services	Other	Total (%)	Statistical Significance
Service has close links with:							
Accommodation	7 (10.8)	4 (40)	0 (0)	4 (26.7)	4 (26.7)	27 (23.9)	χ^2=9.241, df=4, p=0.055
Management	6 (9.2)	4 (40)	1 (12.5)	4 (26.7)	3 (20.0)	18 (15.9)	ns
Single telephone number	7 (10.8)	2 (20)	0 (0)	3 (20.0)	2 (13.3)	14 (12.4)	ns
Single point of referral	7 (10.8)	2 (20)	0 (0)	0 (0)	1 (6.7)	10 (8.9)	ns
Shared assessment forms	11 (16.9)	4 (40)	1 (12.5)	3 (20.0)	4 (26.7)	23 (20.4)	ns
Shared care plan forms	16 (24.6)	3 (30)	1 (12.5)	3 (20.0)	4 (26.7)	27 (23.9)	ns
Shared client record databases system	6 (9.2)	3 (30)	0 (0)	2 (13.3)	2 (13.3)	13 (11.5)	ns
Shared case files/filing system	7 (10.8)	2 (20)	0 (0)	2 (13.3)	2 (13.3)	13 (11.5)	ns
Mean Integration Composite Score (sd)	1.46 (1.92)	2.3 (2.63)	0.86 (1.13)	1.60 (1.92)	1.60 (1.84)	1.53 (1.93)	ns

The mean composite score of 1.5 for all services suggested that overall levels of integration in home care services were low. Shared accommodation (27 services, 24%) and shared management (18 services, 16%) were infrequent. Few services

had shared systems such as a single telephone number (14, 12%) or shared assessment forms (23, 20%).

There were no significant differences between service types in their overall levels of integration. However, specialist home care services for people with dementia were significantly more likely to share accommodation with other social care services than generic home care services (U=230.000, p=0.016). Interestingly, specialist home care services for other groups had the least number of close links with other services. Overall scores were relatively low for all service types, the highest being 2.3 (specialist home care services for people with dementia), although the differences between services were not statistically significant.

6.2.7 Equity of access: Service provision for users from ethnic minority groups

Table 6.8 shows the degree of provision of culturally appropriate care for services with clients from ethnic minority backgrounds.

Table 6.8: Service provision for users from ethnic minority groups

Variable	Generic home care service n=53	Specialist home care service for people with dementia n=8	Specialist home care service for other groups n=7	Carer Oriented Services n=12	Other n=10	Total n=90	Statistical Significance
Personal care	26 (50.9)	5 (37.5)	4 (57.1)	6 (50.0)	5 (50.0)	45 (50.0)	ns
Language	9 (17.0)	4 (50.0)	2 (28.6)	3 (25.0)	5 (50.0)	23 (25.6)	ns
Food	28 (52.8)	5 (62.5)	3 (42.9)	7 (58.3)	3 (33.3)	46 (51.1)	ns
Religion	31 (41.5)	6 (75.0)	3 (42.9)	6 (50.0)	5 (50.0)	42 (46.7)	ns
Composite Score (sd)	1.62 (1.46)	2.25 (1.75)	1.71 (1.89)	1.83 (1.47)	1.80 (1.48)	1.73 (1.49)	ns

Provision of culturally appropriate Personal Care, Language, Food, and Religious input was available in less than half of the services in the study, even when only those services with clients from ethnic minority backgrounds were analysed. There were no significant differences between service types.

6.2.8 Staff training/qualifications

The extent of staff training in home care services in the North West of England is presented in Table 6.9.

Table 6.9: Staff training

Variable	Generic home care service	Specialist home care service for people with dementia	Specialist home care service for other groups	Carer Oriented Services	Other	Total	Statistical Significance
Induction includes component on caring for people with dementia*	41 (63)	9 (90.0)	4 (50)	13 (86.7)	11(73.3)	78 (69.0)	ns
Less than 50% of hands-on staff have people with dementia training	15 (23.1)	3 (30.0)	3 (37.5)	9 (60.0)	2 (13.3)	32 (28.3)	χ^2=10.302, df=4, p=0.036
More than 60% of staff have formal qualifications	5 (7.7)	2 (20)	0 (0)	3 (20.0)	0 (0)	10 (8.8)	ns
Local authority assists with training	15 (23.1)	1 (10.0)	1 (12.5)	4 (26.7)	3 (20.0)	24 (21.2)	ns
Mean Staff Training Composite Variable (sd)	1.28 (0.99)	1.50 (0.71)	1.38 (1.41)	2.07 (0.88)	1.33 (0.62)	1.42 (0.97)	ns

Most services (78, 69%) provided a dementia-specific component in their induction training, but there were few services (32, 28%) within which more than 50 per cent of staff had received specific training in caring for people with dementia (in addition to any induction). Likewise, less than one in ten services had more than 60 per cent staff with formal qualifications. Local authorities assisted with the provision of training in just over one fifth of cases (24 services, 21%). The overall mean score for services on this standard was low (1.4).

Analysis revealed that it was significantly more likely that over 50 per cent of staff in carer oriented services had received specific training in caring for people with dementia than both generic (U=307.5, p=0.005) and 'other' (U=60.000, p=0.029) home care services. An induction containing a component specifically on caring for people with dementia was most common in specialist home care services for people with dementia (9, 90%). Analysis of the overall levels of staff training suggested that there was a trend towards variation between the service types (χ^2=8.956, df=4, p=0.062). Post hoc tests revealed that carer oriented services provided a significantly higher level of training than generic home care services (U=274.000, p=0.006) and 'other' home care services (U=61.000, p=0.033).

6.2.9 Management practices

The style of management adopted by home care services was assessed through the degree to which factors such as sick pay and holiday entitlement were provided to staff as well as the extent of contact between supervisors and hands-on care staff. These results are found in Table 6.10.

Table 6.10: Management practices

Variable	Generic home care service	Specialist home care service for people with dementia	Specialist home care service for other groups	Carer Oriented Services	Other	Total	Statistical Significance
Minimum hours contract	36 (55.4)	7 (70.0)	5 (62.5)	6 (40.0)	8 (53.3)	62 (54.9)	ns
Sick pay	39 (60.0)	7 (70.0)	6 (75.0)	11 (73.3)	6 (40.0)	69 (61.1)	ns
Holiday entitlement	59 (90.8)	9 (90.0)	8 (100.0)	13 (86.7)	11 (73.3)	100 (88.5)	ns
Loyalty reward	28 (43.1)	3 (30.0)	1 (12.5)	1 (6.7)	3 (20.0)	36 (31.9)	χ^2=10.522, df=4, p= 0.032
Frequent contact between hands-on staff and supervisors	59 (90.8)	9 (90.0)	8 (100.0)	14 (93.3)	11 (73.3)	101 (88.5)	ns
Management Practices Composite Variable mean (sd)	3.43 (1.34)	3.52 (1.18)	3.53 (0.93)	2.07 (0.88)	1.33 (0.62)	3.26 (1.33)	ns

Each of the items comprising this standard were generally provided by the different home care service types, with the exception of loyalty reward schemes, which were present in 36 (32%) services. It was items that were not offered that were most of interest. For example, 44 (39%) services did not provide sick pay, and 13 (12%) services did not provide any holiday entitlement. Sixty two services (55%) offered staff a minimum hours contract.

There were few differences between services in terms of the management practices they operated. However, analysis of the frequency of loyalty reward systems revealed that generic home care services operated this type of scheme significantly more often than carer oriented services (U=310.000, p=0.009). Services in general scored relatively high on the overall composite management practices variable (mean 3.26).

6.2.10 Flexibility

The degree to which flexible arrangements were offered by home care services is shown in Table 6.11.

Table 6.11: Flexibility

Variable	Generic home care service	Specialist home care service for people with dementia	Specialist home care service for other groups	Carer Oriented Services	Other	Total	Statistical Significance
24 hour service provided	48 (73.8)	2 (20.0)	7 (87.5)	6 (40.0)	8 (53.3)	71 (62.8)	χ^2=17.245, df=4, p=0.002
Live-in service provided	22 (33.8)	0 (0)	0 (0)	0 (0)	3 (20.0)	25 (22.1)	χ^2=14.598, df=4, p=0.006
Twenty four hour, seven days per week service	43 (66.2)	2 (20.0)	5 (62.5)	9 (60.0)	6 (40.0)	65 (57.5)	χ^2=9.661, df=4, p=0.047
Service Flexibility Composite Variable	1.73 (1.09)	0.40 (0.69)	1.50 (0.76)	1.00 (0.85)	1.13 (1.19)	1.42 (1.10)	χ^2=17.380, df=4, p=0.002

A 24-hour service was provided in most (71, 63%) cases but less than a quarter (25, 22%) of services provided a live-in service. Only 65 (58%) of services provided a twenty four hour, seven days per week service. The overall score (1.42) on this standard was again fairly low.

Significantly more generic home care services operated a 24-hour service than both specialist home care services for people with dementia (U=150.000, p=0.001) and carer oriented services (U=322.500, p=0.012). Specialist home care services for other groups were also more likely to run a 24-hour service than specialist home care services for people with dementia (U=13.000, p=0.016). Generic home care services provided a live-in service significantly more often than specialist home care services for people with dementia (U=215.000, p=0.030), specialist home care services for other groups (U=172.000, p=0.051) and carer oriented services (U=322.500, p=0.009). There were significant differences between service types on the overall measure of service flexibility. Post hoc tests showed that generic home care services provided a significantly more flexible service than both specialist home care services for people with dementia (U=118.000, p=0.001) and carer oriented services (U=292.000, p=0.012). Specialist home care services for other groups were also significantly more flexible than specialist home care services for people with dementia (U=13.000, p=0.016). Additional analysis revealed that generic home care services were significantly more likely than both specialist home care services for people with dementia (χ^2=157.500, p=0.001) and 'other' home care services (U=350.000, p=0.021) to provide a 24-hour, 7 days per week service. Generic home care services were also significantly more likely than both specialist home care services for people with dementia (U=170.000, p=0.004) and 'other' home care services (U=352.000, p=0.047) to provide a 24-hour, 7 days per week service. This additional analysis corresponded with the pattern of results already described.

7 DISCUSSION

7.1 All services

Various different types of home care service were identified by the study, although all identified services had an element dedicated specifically to caring for people with dementia. As would be expected, the most common type of service was the generic type, which comprised 58 per cent of the sample. Many local authority areas did not contain all five of the home care service types identified by the study, although this may be an indication that the study did not manage to identify every existing home care service in the North West region. In 1997, older people with dementia in most local authorities were reliant on generic services (Social Services Inspectorate, 1997). This situation would appear to still be the case, as in the present study, over half of the services identified were generic in nature, and specialist services were not available in many areas.

Most services had a contract with the NHS trust or local authority, and these were mostly of the spot or block type. This concurred with previous research which found that the most common single type of contract was the spot type (Matosevic. 2001). Hardy (1998) reported that in 1997, more than two-thirds of providers were solely in receipt of spot contracts, and that this proportion was slowly rising. However, less than half of services in the present study reported that their main type of contract was the spot type. This suggests that the proportion may have decreased, although it may simply reflect the high degree of variation in policy and practice throughout the UK reported by Godfrey et al. (2000). The possibility of a decreasing trend with regard to spot contracting is potentially desirable however, as the dominance of this type of contract commonly leads to care being purchased in smaller units of time, leading to unstable purchasing patterns. In addition, this type of purchasing may conflict with characteristics considered indicative of high service quality by users such as continuity and the relationship with service users (Godfrey et al., 2000).

Just over one half of services had stable funding arrangements, although this was significantly more likely to be the case in generic services as opposed to carer oriented and 'other' home care service types. For those services receiving stable funding, almost all had secured arrangements for 0-5 years with just 3 per cent having arrangements in place for more than 5 years.

The mean number of service users per service was 45. Services as a whole most commonly had between 1 and 20 per cent of people with dementia amongst their clientele, although as would be expected, between 81 to 100 per cent of service users typically had dementia in specialist services for people with dementia. The general pattern of results concurred with previous research (Matosevic et al., 2001). Whilst the mean numbers of service users with dementia did not differ significantly between service types, the proportions of people with dementia of the total number of service users did, with specialist home care services for people with dementia having significantly higher proportions than both generic services and specialist home care services for other groups. However, the ratio of mild/moderate to severe dementia was approximately two thirds to one third for all home care service types, and there were no significant differences found between the services types on this dimension. These results therefore suggest that specialist services might not be

effectively targeting individuals with the greatest levels of need.

People with dementia from ethnic minority backgrounds were mildly under represented in the overall sample. Of the attendees 2.2 per cent were reported to be from an ethnic minority background, compared with the regional average of 2.7 per cent.

It was estimated that only between five and eleven per cent of people with dementia in the North West of England were receiving home care services, although this varied considerably between local authority areas. These attendance figures can be interpreted as a proxy measure for the accessibility of services in the region. By far the highest proportion was found in Knowsley, where between 18 and 60 per cent of people with dementia were estimated to be receiving a home care service. In contrast, it was estimated that in Wigan, less than one per cent of people with dementia were receiving home care. Less than half of these were also in receipt of additional services such as day care or a sitting service. However, this pattern of results may reflect sampling irregularities, as well as the high assumed level of dementia in the population.

Home care services as a whole employed an average of seventy staff per service. This was also consistent with previous research (Matosevic, 2001) which reported that the majority of providers employed fewer than 200 staff. Most commonly, between one and 20 per cent of hands-on staff had formal qualifications, and one third of hands-on staff had received specialist training in caring for people with dementia. Again, similar distributions were found by Matosevic (2001) who reported that home care services most commonly had a small proportion of staff with nursing or social care qualifications. There were no significant differences between service types in terms of the proportions of hands-on staff that had received specialist training in caring for people with dementia.

Generic services employed significantly more hands-on staff than specialist services for people with dementia, whilst the latter employed significantly more trained volunteers than generic services. The results also suggested that specialist home care services for people with dementia had both lower staff to service user ratios, and lower senior staff to hands-on staff ratios than generic home care services.

In recent years, an overall trend has been observed for users with high dependency needs to receive greater service intensity in home care services (Godfrey et al., 2000). In the present study, it was therefore expected that specialist home care services would provide a more intensive service than non-specialist home care services. However, it was found that just under one half of services provided an intensive service, and of these, over 90 per cent were generic services.

Thus to summarise, in terms of the structural characteristics of home care services, the results of the present study generally reflected the patterns reported in the previous survey by Matosevic et al. (2001). These similarities provide validatory evidence regarding the research methodology, sampling and data collected for the present study.

7.2 Standards of care

Interpretation of the composite measures designed to assess standards of care is complex, given the number of different service types assessed by the present study. These can be simplified through the categorisation of scores as low, medium or high. Thus, for summary purposes, scores are described as Low when the total score fell in the bottom third of the range of possible scores (e.g. 1 to 3 on a scale of 9). Medium is used to describe scores in the middle third (e.g. 4 to 6 on a scale of 9), and High is used to describe scores that fell in the upper third (e.g. 7 to 9 on a scale of 9). The results can therefore be interpreted as follows:

7.2.1 Assessment and review procedures

National minimum standards for domiciliary care stated that new service users should receive a care needs assessment prior to the provision of the service. Copies of the assessment should be distributed to the care manager and to the service user, with key information communicated to care and support workers. A care plan, a written statement about the provider's objectives for providing support to the older person (Alzheimer's Society, 2001), should then be formulated, based on this assessment. The plan should be copied to the service user, and should be reviewed at least every 6 months (Alzheimer's Society, 2001) or at least annually (Department of Health, 2003), as it needs to be flexible to reflect the changing needs of the older person (Alzheimer's Society, 2001). In addition, a thorough risk assessment should always be undertaken where a decision is being made as to whether an individual should remain at their own home (Alzheimer's Society, 2001). These risk assessments should be conducted both for users and for staff (Department of Health, 2003). In addition, briefing documents should be kept in the user's home (Social Policy Research Unit, 2000) for one month, or until the service is concluded (Department of Health, 2003).

In the present study, the overall score for home care services as a whole was medium on the Assessment and review procedures standard, and there were no significant differences between home care service types. Although the majority of services operated within CPA policies, evidence from the current study suggests that the extremely patchy situation described in 1997 (Social Services Inspectorate, 1997) prevails, with almost a third of services still not having adopted CPA policies. Reviews were generally conducted at least every 2 months only in carer oriented and 'other' home care services, a situation similar to that reported in 1997, when timely reviews involving both users and carers were described as being quite rare (Social Services Inspectorate, 1997). Most worrying was the fact that only one of the ten specialist services for people with dementia kept briefing documents in the home of the user, a practice advocated both by the government (Department of Health, 2003) and the Social Policy Research Unit (2000).

7.2.2. Quality of briefing documents

The importance of briefing documents was highlighted by the Social Policy Research Unit (2000) as a means of keeping staff well informed regarding the older person for whom they provide care. Simple briefings kept in the client's home can lead to improved service provision; are valued by workers; and are particularly useful for

clients with communication difficulties, and for staff returning to work after a break (Social Policy Research Unit, 2000). Briefing documents should contain details of any change in circumstance, any accidents that have occurred, any incidents of note, and any other information that would help the next health visitor ensure consistency (Department of Health, 2003).

In the present study, the overall score for home care services as a whole was medium. There were no significant differences between home care service types. In the light of recommendations by the Social Policy Research Unit (2000) and the Department of Health (2003) it was disappointing that services did not achieve higher scores on this standard.

7.2.3 Carer involvement

Quality standards for carer support services have been proposed through the National Strategy for Carers (Department of Health, 1999). It is envisaged that in future, relevant authorities and funding bodies will ensure that services provide an acceptable quality of assistance to carers. Many carers of older people with dementia are themselves elderly - up to 60 per cent are husbands or wives (Levin et al., 1994), yet unpaid informal care forms a major part of the total costs of dementia care (Wimo et al., 1997; Kirchner et al., 2000). It is therefore essential that services address the needs of carers, and particularly the carers of older people with dementia, as service quality can have a significant impact on their ability to continue caring (Levin, 1997). It is recognised that help for carers is one of the best ways of helping the people they are caring for and cannot be seen in isolation from help for the person for whom they are caring (Department of Health, 1999). A number of techniques have been identified that promote greater autonomy for relatives of people with dementia who are carers (Marshall 1999).

In the present study, the overall score for home care services as a whole was medium. There were no significant differences between home care service types. Again, the scores achieved were disappointing, given the emphasis placed on carer support through recent government initiatives such as the National Strategy for Carers, borne of an explicit recognition that supporting the carers of older people with dementia impacts significantly on their ability to continue caring.

7.2.4 Integration

Integrated systems of care are vital because poor integration can result in delays or failure to deliver required services, less than optimal outcomes, and fragmented, uncoordinated service delivery, leading to confusion and discomfort for frail older people and their families (Berwick, 1991; Brodsky et al., 2000). An integrated approach to the delivery of health and social care services is particularly important for community-dwelling frail older people (Kodner et al., 2000).

In the present study, the overall score for home care services as a whole was low, and there were no significant differences between home care service types. A lack of integration between social services departments, in particular with regard to strategic and planning issues was reported in 1997, although collaborative working arrangements, with regard to assessment, care management, and service delivery at

practitioner level were described as good at the time (Social Services Inspectorate, 1997). In 1997, the Social Services Inspectorate stated that working arrangements with health and other providers should be in place at both strategic planning and service delivery levels. The data from the present study suggest however that little integration is occurring in practice.

7.2.5 Care worker good practice

Adequate supervision and support of care staff at all levels is good practice, and in all Alzheimer's Society home care services a minimum of monthly supervision between care workers and line managers is required (Alzheimer's Society, 2001). Supervision can however be problematic in home care settings, and staff are often under supervised, with line managers responsible for anything from 6 to 100 workers (Cobban, 2002). In the present study, care worker good practice was assessed through the degree to which training was provided to staff, frequency of care worker's contact with their supervisor, and the provision of space on briefing documents for information that would enable care workers to perform their job efficiently and effectively. The overall score for home care services as a whole was medium on this standard, and there were no significant differences between home care service types.

7.2.6 Provision of culturally appropriate care to ethnic minority groups

A long standing government objective is that care and support workers should be sensitive and responsive to race, culture and religion, and this has recently been reiterated in the National Minimum Standards for Domiciliary Care (Department of Health, 2003).

In the present study, the overall score for home care services as a whole was medium, and there were no significant differences between home care service types. This contrasted with the Social Services Inspectorate findings of 1997, which described the meeting of cultural need in community services for dementia as 'encouraging', with 'most' authorities having satisfactory policies in place.

7.2.7 Individuality

Individualised care was assessed through the use of memory/life story wallets, and a no-uniform policy for staff. The use of memory/life story wallets for people with dementia in day centres has been associated with an improvement the quality of conversations (Bourgeois and Mason, 1996). Cunningham and Kesterton (1997) suggested that dementia care staff should not wear uniforms, which may act to encourage a friendly and less formalised atmosphere. Few home care services were found to have adopted these initiatives, although it could be argued that the underlying ideology is not necessarily transferable across service types. In 1997, older people with dementia in most local authorities were reliant on generic services that were not always tailored towards individual need, with specialist services described as noticeably better than non-specialist equivalents (Social Services Inspectorate, 1997). However, in the present study, the overall score for home care services was low, although specialist home care services for people with dementia, carer oriented services, and 'other' home care services all scored significantly higher

than generic services. The results of the present study suggest that for most people, a low degree of individually tailored care provision persists.

7.2.8 Staff training

Home care staff should be trained and adequately resourced to work with people with dementia (Johnson, 1998). They require continuing training opportunities throughout their careers in order to keep abreast of developments in care practice and current thinking (Alzheimer's Society, 2001). In reality however, they are largely unregulated, unqualified, and poorly paid (Kent & Payne, 2001; Wagner, 1988). In addition, home care services tend to encounter difficulties with high staff turnover leading to a lack of training and consistency in the workforce (Young & Wistow, 1996; Johnson, 1998). Variation in workload in home care services is such that it is not always practical to guarantee a set number of hours to staff, and high staff turnover means that investment in staff training is not always considered cost effective (Young & Wistow, 1996). In addition, the issues of low pay, irregular hours and high staff turnover may be particularly problematic in independent agencies (Patmore, 2003). Providers are however, more likely to retain a well motivated workforce when staff are well paid and well trained (Alzheimer's Society, 2001).

The National Minimum Standards for Domiciliary Care (Department of Health 2003) stated that staff should receive an annually reviewed and updated development and training program which meets National Training Organisation training targets, and that all staff should receive an induction, with specialist advice, training and information for staff working with specific user groups. In 2002, the Dementia Services Development Centre called for basic dementia care issues to be incorporated into inductions and basic training for all home care workers (Cobban, 2002). Many organisations however experience difficulties with releasing staff for training, and many are already at full stretch in trying to meet existing compulsory training requirements (Cobban, 2002). This can lead to considerable time lapses between changes in the care needs of a client, and staff receiving training that allows then to meet that need (Cobban, 2002).

In the present study, the overall score for home care services as a whole was medium, and there were no significant differences between home care service types. The importance of proper training and induction has recently been reiterated by the Alzheimer's Society, which advocates that all staff should receive an induction early in their employment, before they start working with clients (Alzheimer's Society, 2001). In the context of this, and given that national minimum standards for stated that all staff should receive ongoing training, and an induction including specialist advice, training and information for staff working with specific user groups, this result again was disappointing.

7.2.9 Management practices

Management practices were assessed in the present study through the frequency which services provided minimum hours contracts; sick pay; holiday entitlement; loyalty rewards; and frequent contact between hands-on staff and supervisors. The overall score for home care services as a whole was medium on this standard, and there were no significant differences between home care service types. Sixty two

services offered staff a minimum hours contract. This was higher than the results of an earlier survey (Matosevic et al., 2001), which found that only 30 per cent of home care services offered such a contract. However, the figures relating to staff supervision concurred with previous research suggesting that staff in home care settings are often under-supervised (Cobban, 2002).

7.2.10 Flexibility

Flexibility was identified by studies considering user perspectives as one of the dimensions of a good quality service (Godfrey et al. 2000). Furthermore, National Minimum Standards for Domiciliary Care (Department of Health, 2003) stated that services should be flexible, consistent, and reliable.

In the present study, the overall score for home care services was medium. Generic home care services scored significantly higher than specialist home care services for people with dementia and carer oriented services. Specialist home care services for other groups also scored significantly higher than specialist home care services for people with dementia. Again, the standards achieved were disappointing, given the emphasis placed on flexible service delivery in the National Minimum Standards for Domiciliary Care (Department of Health, 2003).

7.3 Specialist and non-specialist services

One of the most interesting results of the present study relates to the comparisons made between generic home care services and specialist home care services for people with dementia (although all services in the present study were at least dedicated in part to specialist dementia care).

Little is known about the relative impact of separate versus general policies regarding the care of people with dementia (Marshall, 1999), and there has been debate for some years regarding the issue of whether specialist facilities offer the best model of care, or whether integration is more desirable (Chappell and Reid, 2000). However, despite the limited research findings and the uncertainty of the benefits of specialist provision, both the Audit Commission (2000) and the National Service Framework for Older People (Department of Health, 2001) have recommended that social services departments develop specialist services for this group. It was therefore expected that specialist services would perform better on standards designed to measure the quality of service for people with dementia when compared with generic services.

The results however did not support this hypothesis. There were no overall significant differences between these service types on eight of the ten standards assessed, and indeed, on the flexibility standard, it was generic services that appeared to provide the higher quality care. This may be due to the fact that generic services tended to be larger organisations, possibly enabling greater flexibility through increased resources and economies of scale. Furthermore, only one (10%) of the specialist home care services for people with dementia kept briefing documents in the user's home compared with 56 (86%) generic services. This widely advocated practice (Department of Health, 2003; Social Policy Research Unit, 2000) can lead to improved service provision: it is a means of keeping staff well informed; it is valued by workers; and it can be particularly useful for clients with

communication difficulties and for staff returning to work after a break (Social Policy Research Unit, 2000). The pattern of results did not therefore provide strong support for current government policy advocating that social services departments encourage the development of specialist services for this group (Audit Commission, 2000, Department of Health, 2001).

7.4 Methodological issues and constraints

The response rate achieved by the study (40 %) was lower than expected. However, questionnaires from a range of local authority, voluntary and independent sector services were received, and all of the 22 local authorities in the North West of England were represented in the sample. These 22 local authorities represent 19 per cent of England's local authorities outside London (Local Government Association, 2001). The population aged over 65 years living in the North West of England represents 16 per cent of the population of England aged over 65, and the age structure of its population is similar to that of England as a whole (Census, 2001). It is therefore reasonable to assume that the results would be generalisable to other parts of the country.

Low and unequal group sizes affected the statistical power of the study, and were particularly problematic when comparing the relative performance of different local authority areas in the North West of England on key variables (Appendix 3). Local authority areas in which few services were identified may have produced unrepresentative scores, whilst the scores from larger areas would be more influenced by regression to the mean (Shaughnessy and Zechmeister, 1990). Furthermore, in relation to response rates, a number of assumptions were necessary in order to calculate service uptake figures: that 9.3 per cent of the population aged over 65 have dementia (Hoffman et al., 1991); and that non-respondents had a similar capacity to respondents (see Table 5.9).

In addition, the data relied on self-reports of home care managers and were not collected or observed independently. Over-reporting due to social desirability was therefore possible. Also, as in the study by Levin et al. (1989), respondents in the present study were required to make judgements regarding the presence of dementia in their clients, and the severity of the illness. In their study, Levin and colleagues concluded that defining dementia in this manner was adequate for the purposes for which the information was collected, and although a degree of imprecision is clearly unavoidable using this method, it is reasonable to assume that service managers in the present study had access to assessment information included in referral information.

Finally, the study relied on objective quality indicators, and not the subjective experiences of service users themselves, or objective measures of service user outcome. The addition of such information would have enriched the data available and may have allowed stronger conclusions to be drawn.

7.5 Further research

These results provide an overall picture of the scope and breadth of home care service provision in the North West of England. They also provide each local

authority with a detailed description of the availability and form of home care service provision being provided locally. The results indicate varying degrees of home care service uptake and point to gaps in home care service provision. Future research needs to assess patterns of substitution and complementarity between service types and across geographical boundaries, in order to investigate the relationships between home care service provision and other forms of social care for older people with dementia with regard to both residential care, and health and social services.

7.6 Conclusion

Current UK policy aims to maintain and support highly dependent older people for as long as possible in their own homes (Sutherland, 1999; Cm 4169, 1998; Department of Health, 2001). The availability and provision of good quality home care is fundamental to the successful implementation of this central policy objective (Francis and Netten, 2004). This study assessed the quality of home care services for people with dementia in the North West through both describing and specifically contrasting the standards of care provided by home care services on a number of key indicators. In general, the services included in the study provided few of the quality indicators being measured. Furthermore, few differences existed between specialist and non-specialist services.

The standards pull together a disparate collection of quality indicators from government guidelines, charity recommendations and independent research into a single questionnaire. The results of the study suggest that the standards had utility, although clearly, further work is needed regarding their validation and refinement. In particular, on the basis of the service-level data presented by the current study it appears that the policy of developing effective specialist services for people with dementia has some way to go, although future research examining the efficacy of home care services through linking process-level data with service-user outcomes is also required.

Future policy could benefit from more closely defined indicators at a local level, by which authorities could reliably judge the performance of home care agencies (Clarkson and Challis, 2002). The development of such indicators could aid authorities in their commissioning decisions. In addition, managers of home care agencies themselves require robust measures and standards by which to assess both their staff and the quality of the service they provide. The results of the present study provide a benchmark for future monitoring and follow-up, and in order for current UK policy to efficiently achieve its objectives, these results should be considered by service providers and commissioners when assessing and improving quality standards in the region, in particular perhaps, as an inexpensive means of working towards the duty of Best Value, the requirement of which is to seek the best possible services in terms of cost and quality, regardless of the sector in which they are located (Geddes & Martin, 2000).

Acknowledgements

This work was undertaken by PSSRU, which receives funding from the Department of Health. The views expressed in the publication are those of the authors and not necessarily those of the Department of Health. The study has been supported by funding from the North West NHS Executive. The authors are grateful to Irene Pedersen, Mandy Bryant and Gill Dunkerley, for their unfailing persistence to increase the amount and quality of data collected. The opinions expressed are the responsibility of the authors alone.

REFERENCES

Alzheimer's Society (2001) *Home Care Services for People with Dementia: Quality Standards*. London: Alzheimer's Society.

Audini B; Lelliot P; Banerjee S; Goddard K; Wattis, J; Wilson K. (2001) *Old Age Psychiatric Day Hospital Survey – Final Report.* London: Royal College of Psychiatrists, Faculty for the Psychiatry of Old Age.

Audit Commission (2000) *Forget Me Not: Mental Health Services for Older People*. Portsmouth: Holbrooks.

Audit Commission (2002) *Forget Me Not 2002: Developing mental health services for older people in England*, http://www.audit-commission.gov.United Kingdom/reports.

Berwick D. (1991) Controlling variation in health care. *Medical Care* 1991; 12: 29–33.

Bourgeois M.S. and Mason, L. A. (1996). Memory Wallet Intervention in an Adult Day-Care Setting, *Behavioural Interventions* **11**(1): 3-18.

Brodsky J, Habib J and Mizrahi I. (2000) *Long-term Care Laws in Five Developed Countries*: *A Review*. Geneva, Switzerland: World Health Organization.

Census (2001) UK. *Office of National Statistics*. London: The Stationery Office.

Challis, D. (1981) The Measurement of Outcome in Social Care of the Elderly, *Journal of Social Policy* **10**: 179-208.

Chappell, N. L. and Reid, R. C. (2000) Dimensions of care for dementia sufferers in long-term care institutions; Are they related to outcomes? *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences* 55 (4): S234-244.

Clarkson, P and Challis, D. (2002) Developing and implementing a local performance measurement system in older people's services. *Research Policy and Planning*, 20, 3, 3-16.

Cobban, N. (2002) *Raising the Standard: An action research and training project looking at dementia care in home care services*. Dementia Services Development Centre: http://www.dementia.stir.ac.uk/

Cunningham P. and Kesterton J. (1997) Backs to the wall? Day care within the new culture. In Kitwood, T. and Benson, S. (eds) *The New Culture of Dementia Care*. Hawker Publications: London.

Davies, B. and Knapp, M.R. (1981) *Old Peoples Homes and the Production of Welfare*, London, Routledge and Kegan.

Cm4169 (1998) *Modernising Social Services: promoting independence, improving protection, raising standards*. London: The Stationery Office.

Department of Health (1999) *Caring about Carers: A National Strategy for carers,* LASSL (99) 2, London: Department of Health.

Cm4818-1 (2000) *The NHS Plan: The Government's response to the Royal Commission on Long Term Care*, London: Department of Health.

Department of Health (2001). *National Service Framework for Older People*. London: Department of Health.

Department of Health (2001a): Community Care Statistics 2000: Home help/home care services, England, London: Department of Health.

Department of Health (2002) *Key indicators Graphical System. Personal Social Services Local authority Statistics*. London: Department of Health.

Department of Health (2003) *Domiciliary Care: National Minimum Standards - Regulations*. London: The Stationery Office.

Donabedian, A. (1982) *Explorations in Quality Assessment and Monitoring: The Definition of Quality and Approaches to Its Assessment. Vol. I. The Criteria and Standards of Quality.* Ann Arbor, MI: Health Administration Press.

Edelbalk, P.G., Samuelsson, G., and Ingvad, B. (1995) How elderly people rank order the quality characteristics of home services, *Ageing and Society*, 15: 83-102.

Erkinjuntti, T., Ostbye, T., Steenhuis, R. and Hachinski, V. (1997) The Effect of Different Diagnostic Criteria on the Prevalence of Dementia, *New England Journal of Medicine* **337**(23): 1667-74.

Francis, J. and Netten, A. (2004) Raising the quality of home care: A study of service users' views. *Social Policy and Administration*, 38, 3: 290-305.

Geddes, M and Martin, S. (2000) The Policy and Politics of Best Value: currents, cross currents, and undercurrents in the new regieme. *Policy and Politics*, 28, 379-395.

Godfrey, M., Randall, T., Long, A., Grant, M (2000) *Review of Effectiveness and Outcomes: Home Care.* University of Exeter: Centre for Evidence-Based Social Services.

Gray, J.M.G. (1997) Evidence-based health care: how to make health policy and management decisions. London: Churchill-Livingstone.

Hatcher, L. (1994) A step-by-step approach to using the SAS(R) system for factor analysis and structural equation modeling. Cary, NC: SAS Institute.
Hofman, A., Rocca, W.A., Brayne, C., Breteler, M.M., Clarke, M., Cooper, B., Copeland, J.R., Dartigues, J.F., Da Silva Droux, A. and Hagnell, O. (1991) The

prevalence of dementia in Europe: a collaborative study of 1980-1990 finding. *International Journal of Epidemiology* **20**: 736-748.

Hardy, B. (1998) *Domicillary Care Markets: growing and growing up. Report of the 1997 survey of UKHCA members*. Leeds: Nuffield Institute for Health, Community Care Division.

Johnson, L. (1998) *The implementation of continuing health care policies, sub-study 5: Perspectives on community services for people with dementia*, University of Leeds: Nuffield Institute for Health.

Kent, J & Payne, C. (2001) *Health Care Support Workers review and the development of quality social care*. www.nisw.org.uk/publications/spring2000j.htm

Kirchner, V., Elloy, M.D., Silver, L.E. and Kelly, C.A. (2000) Dementia: The cost of care for behaviourally disturbed patients living in the community, *International Journal of Geriatric Psychiatry* **15**(11): 1000-1004.

Kitwood, T. and Benson, S. (1997) *The New Culture of Dementia Care.* London: The Book Factory.

Kodner D. (2000) *Integrating Care for the Frail Elderly Population: Rationale, Experience and Prospects for the Future*. Fan Fox and Leslie R. Samuels Foundation Lecture: Columbia School for Public Health.

Laing & Buisson (2000) *Domicilliary Care Markets 2000*, London: Laing & Buisson publications Ltd.

Levin, E., Sinclair, I. and Gorbach, P. (1989) *Families, Services and Confusion in Old Age.* Aldershot: Avebury.

Levin , E; Moriaty, J; Gorbach, P. (1994) *Better for the Break*. London: National Institute for Social work research/HMSO.

Levin, E. (1997) *Carers:Problems, Strains and Services*. Oxford: Oxford University Press.

Local Government Association (2001) *Types and names of local authorities in England and Wales*, www.LGA.gov.uk

Marshall, M. (1999) What do Service Planners and Policy-Makers Need from Research*? International Journal of Geriatric Psychiatry* **14**: 86-96.

Matosevic, T; Knapp, M; Kendall, J; Forder, J; Ware, P; Hardy, B. (2001) *Domiciliary Care Providers in the Independent Sector.* Nuffield Institute for Health, University of Leeds, and Personal Social Services Research Unit, London School of Economics, Discussion Paper 1605.

Melzer, D., Ely, M. and Brayne, C. (1997) Cognitive Impairment in Elderly People: Population based estimate of the future in England, Scotland and Wales, *British Medical Journal* **315**: 462.

Netten, A. (1993) *A Positive Environment?: Physical and Social Influences on People with Senile Dementia in Residential Care.* Aldershot: Ashgate.

Nunally, J. (1978) *Psychometic Theory*. New York: McGraw-Hill.

Patmore, C. (2003) *Understanding Home Care Providers: Live issues about management quality and relationships with Social Services providers*. University of York: York Home Care Internet Publications.
http://www.york.ac.uk/inst/spru/research/summs/home care.htm

Reilly S; Challis D; Hughes J; Bagley, H. (2003) *Developing measurable standards of care and capturing variations in community services for older people with dementia*. PSSRU discussion paper (M049/1868), University of Manchester.

Santos, J.R.A. (1999) Cronbach's Alpha: A tool for assessing the reliability of scales, *Journal of Extension* **37**(2): 1-5.

Schneider, J; Kavanagh, S; Knapp, M; Beecham, J; Netten, A (1993) Elderly people with advanced cognitive impairment in England: resource use and costs. *Ageing and Society*, 13, 27-50.

Shaughnessy, J. J. and Zechmeister, E. B. (1990) *Research Methods in Psychology*. McGraw-Hill: New York.

Social Policy Research Unit (2000) *Briefing home care staff about older people's individual needs.* Research Works: Research findings from the Social Policy Research Unit, University of York, November 2000, 5263-5330.

Social Services Inspectorate (1987) *From Home Help to Home Care: an analysis of policy, resourcing and service management.* London: Department of Health and Social Security.

Social Services Inspectorate (1988) *Managing Policy Change in the home help service.* London: Department of Health and Social Security.

Social Services Inspectorate (1997) *At Home with Dementia: Inspection of Services for Older People with Dementia in the Community*. London: Department of Health.

Spicker, P. and Gordon, D.S. (1997) *Planning for the Needs of People with Dementia: The development of a profile for use in local services*. Aldershot: Avebury.

Stoddart, H; Whitley, E; Harvey, I; Sharp, D. (2002) What determines the use of home care services by elderly people. *Health and Social Care in the Community* 10 (5), 348-360

Sutherland, S.S. 1999. *With Respect to Old Age: Long Term Care Rights and*

Responsibilities. A Report by the Royal Commission on Long Term Care (Cm 4192-1). London: The Stationery Office.

Wagner, G. (1988) *Residential Care – a positive choice*, London: HMSO.

Wimo, A., Ljunggren, G. and Winblad, B. (1997) Costs of Dementia and Dementia Care: A review, *International Journal of Geriatric Psychiatry* **12**(8): 841-856.

Wistow, G; and Hardy, B. (1999) The development of domiciliary care: mission accomplished? *Policy and Politics*, 27, 2, 173-186.

Young, R and Wistow, G. (1996) *Domiciliary Care Market: growth and stability. Report of the 1996 survey of UKHCA members*. University of Leeds: Nuffield Institute for Health.

.

For office use only

APPENDIX 1

North West Dementia Centre

(1-5) ☐☐☐☐☐

MAPPING SERVICES FOR PEOPLE WITH DEMENTIA IN THE NORTH WEST OF ENGLAND

COMMUNITY SUPPORT SERVICES QUESTIONNAIRE

NOTES

- *The questionnaire is designed for the following types of community support services:* ***Home care services; At home day care; Respite care services; Sitting services or Befriending services***
- *Most questions only require inserting the correct figures, selecting the relevant number from the options given and inserting into the question boxes or ticking relevant boxes*
- *Not all the questions will be relevant for all services, please complete as far as possible.*
- *We realise that some services are part of larger organisations that operate across a wider area. Please ensure that a separate questionnaire is completed for each site /separate facility for people with dementia in the North West*
- ***If you need further information or require help please telephone 0161 275 5680 or email*** siobhan.reilly@man.ac.uk

Thank you for your time

Contact Details

Name of service: .....

Address: .....

.....

Postcode ☐☐☐☐ ☐☐☐ (6-12) *(Please ensure each facility has the correct post code)*

Telephone:…….. Fax number: .....

Email address: .....

Your name: .....

Your role:
1= Manager / deputy manager
2= Proprietor
3= Manager /proprietor
4= Team leader / group leader
5= Supervisor
6= Other (please specify)……...…….
☐ (13)

☐☐ (14-15)

Does your organisation provide any of the following to people with dementia:

Home care / community support services ☐ (16)
Residential care ☐ (17)
Day care ☐ (18)
Other (please specify) ☐ (19)
……...……..

☐☐ (20-21)

If your facility includes services other than home care/ community support services, we may also contact you about these.

PLEASE REMEMBER …

…to send us any documentation relating to your service on the following areas to inform the NWDC's Service Directory:

Extra documents enclosed *(tick box)*

Service information / other publicity material ☐ (22)

Briefing documents kept in users homes ☐ (23)

PLEASE RETURN COMPLETED FORMS ALONG WITH ANY OTHER DOCUMENTS TO:

North West Dementia Centre,
Personal Social Services Research Unit,
Dover Street Building,
The University of Manchester,
Oxford Road, Manchester, M13 9PL

by 8th March 2001

(Pre-paid envelope enclosed)

Please note, some questions refer only to people with dementia. We are defining dementia in its widest terms by using the term to describe those who suffer from dementia or are confused, though they might not necessarily have a diagnosis of dementia.

For office use only

INFORMATION ABOUT YOUR SERVICE

Service Users

1. Thinking about those who your service helps, please *estimate* the approximate **percentage of your users who suffer from dementia** (see note above):

0 = none **3** = 41-60% ☐ (24)
1 = 1-20% **4** = 61-80%
2 = 21-40% **5** = 81-100%

2. Thinking about the **people who suffer from dementia** (see note above), *please estimate* **the percentage of** those who suffer from:

Mild /moderate cognitive impairment ☐☐☐% (25-27)
Severe cognitive impairment ☐☐☐% (28-30)
These numbers should add up to 100%

3. Does your organisation have any of the following for current or potential users of your service?
(Tick all relevant boxes)

Leaflets /information packs describing the services offered ☐ (31)
Evaluation/ satisfaction questionnaires ☐ (32)
Other material ☐ (33)
(please specify)…….....

☐☐ (34-35)

Please send us any information /publicity material for your facility (see front page).

Service description

4. Within which sector is your service located? *(Tick all relevant boxes)*

Local authority ☐ (36) Voluntary ☐ (37) Independent (not for profit) ☐ (38)
NHS ☐ (39) Private ☐ (40) Other (please specify)……..... ☐ (41)

☐☐ (42-43)

5. Which of the following best describes your service? ☐ (44)

1= Generic home care service
2= Specialist home care service for people with dementia
3= Specialist home care service for other groups (please specify)…….
4= In home respite care
5= Sitting service
6= Other (please specify) ……..……

☐☐ (45-46)

6. Is this service part of a larger business which also focuses on any of the following:
(Tick all relevant boxes)

Nursing, residential or dual registered homes in North West of England ☐ (49)
Sheltered accommodation in North West of England ☐ (50)
Other (please specify)……. ☐ (51)
Not applicable ☐ (52)

☐☐ (47-48)

☐☐ (53-54)

7. Which of the following do you provide? *(Tick relevant boxes)*

	WEEKDAY Day	Evening	Night		WEEKEND Day	Evening	Night	
Domestic care (e.g. shopping /cleaning / meal prep)	☐	-	-	(55)	☐	-	-	(56)
Personal care (e.g. washing /dressing)	☐	☐	☐	(57-59)	☐	☐	☐	(60-62)
Nursing care	☐	☐	☐	(63-65)	☐	☐	☐	(66-68)
Sitting	☐	☐	☐	(69-71)	☐	☐	☐	(72-74)
Activity programs	☐	☐	-	(75-76)	☐	☐	-	(77-78)
Respite for carers	☐	☐	☐	(79-81)	☐	☐	☐	(82-84)
Information /advice for carers	☐	☐	☐	(85-87)	☐	☐	☐	(88-90)
Other *(please specify)*…….....	☐	☐	☐	(91-93)	☐	☐	☐	(94-96)

☐☐ (97-98)
☐☐ (99-100)
☐☐ (101-102)

8. Does your service provide, if necessary:

24 hour services *ie round the clock care provided by several workers on a shift basis* ☐ (103)
Live in services *ie carer lives, either permanently or temporarily, in home of client, working for your organisation. (Exclude informal carer arrangements with relatives or friends.)* ☐ (104)

Please note, some questions refer only to people with dementia. We are defining dementia in its widest terms by using the term to describe those who suffer from dementia or are confused, though they might not necessarily have a diagnosis of dementia.

For office use only

9. In the case of an out of hours emergency, is there a direct telephone number to your service that users or their carers can telephone? ☐ yes ☐ no (105)

a) If yes, is this in the form of:

Telephone service to your staff	☐ (106)	Answer phone	☐ (109)
SSD Emergency duty team	☐ (107)	Other (please specify)…….....……	☐ (110)
Telephone answering service	☐ (108)		

☐☐ (111-112)

Total capacity / activity

10. How many **hours of service** in total did you provide in the last week? ☐☐☐☐☐ (113-117)

11. If applicable, how many **total days of 'live-in care'** did your service provide in the last week? ☐☐☐☐☐ (118-122)

12. How many **service users** did your service provide for in the last week? ☐☐☐ (123-125)

13. How many **people with dementia** did your service provide for in the last week? ☐☐☐ (126-128)

NB - the next 2 questions are for home care providers only.

14. Of all **service users with dementia** what **number** currently receive home care:

One visit per week	☐☐☐	(129-131)
2- 5 visits per week	☐☐☐	(132-134)
6 or more visits per week	☐☐☐	(135-137)

15. Of all **service users with dementia** what **number** currently receive the following levels of home care:

No home care received	☐☐☐	(138-140)
Up to 5 hours	☐☐☐	(141-143)
more than 5 hours & up to 10 hours	☐☐☐	(144-146)
more than 10 hours & up to 15 hours	☐☐☐	(147-149)
more than 15 hours & up to 20 hours	☐☐☐	(150-152)
more than 20 hours	☐☐☐	(153-155)

16. To the best of your knowledge, how many of your **service users with dementia,** currently ...

	Number of people with dementia who…:	*If not known please tick*	
..Attend day care	☐☐☐	☐	(156-159)
..Receive home care *(if you are not a home care provider)*	☐☐☐	☐	(160-163)
..Receive home care from another source *(if you are a home care provider)*	☐☐☐	☐	(164-167)
..Receive a sitting service	☐☐☐	☐	(168-171)
..Receive a befriending service	☐☐☐	☐	(172-175)
..Receive 'at home day care'	☐☐☐	☐	(176-179)
..Receive 'at home respite'	☐☐☐	☐	(180-183)

17. Does your service only provide help for a limited time period (eg 6 weeks after hospital discharge)? ☐ yes ☐ no (184)

18. How many of all your current users are from ethnic minority groups? ☐☐☐ (185-187)

19. Whether or not you currently have any users from ethnic minority groups have you made any of the following special arrangements for people from ethnic minority groups? *(tick relevant boxes)*

Personal care	☐ (188)
Language resources *e.g. translated leaflets, staff skills, interpreter service*	☐ (189)
Food - diet / storage/ preparation /cooking *e.g. catering for specific dietary requirements*	☐ (190)
Religious observation / spirituality *e.g. providing services at appropriate times*	☐ (191)

For office use only

Funding

20. What percentage of **all service users** are funded by:

Local Authority ☐☐☐% (192-194)
Local NHS Trust / Health Authority ☐☐☐% (195-197)
Privately (user or family) ☐☐☐% (198-200)
Other (please specify) ☐☐☐% (201-203)
…….

These numbers should add up to 100%

21. Is your service currently funded for: ☐ (204)

1=Up to 1 year
2=One to 5 years
3=More than 5 years
4=Not applicable

☐☐ (205-206)

22. Do you have a contract with the Local Authority or NHS Trust/ Health Authority? ☐ yes ☐ no (207)

If yes, what is the:

a) **main type** of contract you have (208) ☐

b) **2nd most common** contract you have (209) ☐

(please choose from the 6 options on the right)

1= Block (payment for a pre-determined no. of hours or clients **whether taken up or not**)
2= Call-off (price per hour specified in advance; **paid when service is provided**)
3= Spot (price agreed and paid when service is provided)
4= Cost & volume (guaranteed block purchase of hours + negotiable option to purchase further hours of service)
5= Grant (general payment not linked to particular client or amount of service)
6= Other (please specify)……

☐☐ (210-211)

Personnel

23. We are interested in how many staff your organisation employed in the last week. In the table below please provide details on the **total number of workers** for each staff group .

Please include direct employees, agency staff /self employed care workers and volunteers.

	Total number of actual workers (whole numbers)
Managers	☐☐☐ (212-214)
Supervisors	☐☐☐ (215-217)
Senior care workers	☐☐☐ (218-220)
'Hands on' care staff	☐☐☐ (221-223)
Trained volunteer staff or paid helpers	☐☐☐ (224-226)
Other staff (please specify) ……	☐☐☐ (227-229)

☐☐ (230-231)

24. What proportion of your '**hands on**' care staff have formal qualifications (NVQ lev 2/ equivalent or above)?

0 = none
1 = 1-20%
2 = 21-40%
3 = 41-60%
4 = 61-80%
5 = 81-100%

☐ (232)

25. What proportion of your '**hands on**' care staff are:

Direct employees ☐☐☐% (233-235)
Agency staff ☐☐☐% (236-238)
Self employed ☐☐☐% (239-241)
Volunteers ☐☐☐% (242-244)
Other (please specify) ☐☐☐% (245-247)
……

These numbers should add up to 100%

☐☐ (248-249)

26. Do you offer your '**hands on**' care staff any of the following? *(tick where relevant)*

Contract specifying minimum number of hours per week ☐ (250)
Holiday entitlement ☐ (251)
Sickness pay ☐ (252)
Reward for loyalty/experience ☐ (253)

For office use only

27. Have you had any problem recruiting suitable '**hands on**' care staff in the last year? ☐ yes ☐ no (254)

If yes, were these due to any of the following:

Lack of applicants with appropriate experience ☐ (256)
Lack of applicants with appropriate training ☐ (257)
Other (please specify) …… ☐ (258)

28. Have you had any problem retaining suitable care staff in the last year? ☐ yes ☐ no (255)

If yes, were these due to any of the following:

More lucrative jobs for staff in the care sector (259) ☐
Other employment opportunities outside the care sector (260) ☐
Other (please specify) ……..……..…… (261) ☐

(262-263)

(264-265)

29. Do new '**hands on**' care staff receive an **induction**? ☐ yes ☐ no (266)

a) If yes, is there a specific component of this induction which focuses on caring for people with dementia? ☐ yes ☐ no (267)

b) If yes, how long is this? ☐ (268)

1= 5 minutes
2= 10- 15 minutes
3= about 30 minutes
4 = about 1 hour
5 = more than 1 hour
6 = other (please specify)……..

(269-270)

30. Do you provide (or pay for) your '**hands on**' care staff to **train for qualifications**? ☐ yes ☐ no (271)

If yes, is this:

	Tick if yes	*Please provide the **number of staff** this applies to*	*If relevant, please provide the qualifications they are training towards*
Provided in-house	☐	☐☐☐ (272-275)	.....
Provided externally	☐	☐☐☐ (276-279)	.....
Other (please specify)	☐	☐☐☐ (280-283)	.....

(284-285)

(286-287)

(288-289)

31. Do you provide (or pay for) your '**hands on**' care staff to undergo **training for caring for people with dementia** (in addition to any induction)? ☐ yes ☐ no (290)

If yes, is this:

	Tick if yes	*Please provide the **number of staff** this applies to*	*Is this training pitched at a NVQ level 2 or above? (Tick if yes)*
Provided in-house	☐	☐☐☐ (291-294)	☐ (295)
Provided externally	☐	☐☐☐ (296-299)	☐ (300)
Other (please specify)	☐	☐☐☐ (301-304)	☐ (305)

(306-307)

(308-309)

(400-401)

32. Have you received any assistance from the local authority to provide training? ☐ yes ☐ no (402)

a) If yes, is this via:

1= direct training
2= training grant /loan
3= other assistance (please specify).....……

☐ (403)

(404-405)

33. How often do supervisors have contact with '**hands on**' care workers:

(please complete both columns - tick where relevant)

	Telephone contact	**Face to face contact**
Daily	☐ (406)	☐ (407)
Weekly	☐ (408)	☐ (409)
Fortnightly	☐ (410)	☐ (411)
Monthly	☐ (412)	☐ (413)
Quarterly	☐ (414)	☐ (415)
Other (please specify).....……	☐ (416)	☐ (417)

(418-419)

Person Focused Care

For office use only

34. Does your service operate within the Care Programme Approach policies and procedures as applied to older people with mental health problems? ☐ yes ☐ no (420)

35. Does your organisation complete an **assessment** in respect of :

Risk to the user / patient in their home ☐ (421)

Health and safety requirements for staff in the user / patient's home environment ☐ (422)

The users abilities/ needs ☐ (423)

36. Do your staff participate in **planned reviews** of each service user? ☐ yes ☐ no (424)

a) If yes, how often do you undertake this task? ☐ (425) ☐☐ (426-427)

1= Monthly
2= Two monthly
3= Three monthly
4= Every four or five months
5= Six monthly
6= 12 monthly
7= Other (please specify) ……

b) If yes, how is this reviewed conducted? ☐ (428) ☐☐ (429-430)

1= Meeting convened by care co-ordinators
2= Informal discussion with care co-ordinator
3= Completion of written report for care co-ordinator
4= Other (please specify) …….

37. Does your service keep any **written briefing documents** in users homes? ☐ yes ☐ no (431)

If yes, please send us a blank copy of these documents

We would prefer you to send copies of blank documents that are kept in client's homes, but if this is not possible please complete Q39, otherwise go to Q40:

38. If yes, do the **written briefing documents** kept in users homes, contain prompts to obtain any of the following information on the service user:

(please complete both columns - tick where relevant)

Client's needs /problems /reasons for service	☐ (432)	A place to log the following regarding each visit :	
Preferences /special needs /requests	☐ (433)	....times	☐ (440)
History /life story	☐ (434)	....staff names	☐ (441)
A profile of a client's expected abilities for daily living tasks	☐ (435)	.....tasks undertaken	☐ (442)
		....observations	☐ (443)
Changes /specific goals to work towards	☐ (436)	....messages to other workers	☐ (444)
Changes in client to watch out for	☐ (437)		
Changes in users /carers circumstances, health, physical condition, care needs	☐ (438)		
Other information to assist consistent provision of care	☐ (439)		

39. Do you have any **formal arrangements** or resources for providing **support for carers** of users with dementia? ☐ yes ☐ no (445) ☐☐ (446-447)

If yes, please describe ……..

40. Are you **closely linked with any other services** by sharing any of the following:

(tick relevant boxes) **if yes for any, please specify relevant service(s) & nature of relationship**

Accommodation	☐	(448)	……..
Management	☐	(452)	……..
Single telephone number	☐	(456)	……..
Single point of referral	☐	(460)	……..
Assessment forms	☐	(464)	……..
Care plan forms	☐	(468)	……..
Client record databases system	☐	(472)	……..
Case files /filing system	☐	(476)	……..
Other	☐	(480)	……..

41. Does your service employ any of the following methods or approaches in the care of people with dementia? *(Tick relevant boxes)*

Memory/life story wallets/ files	☐	(484)	
Policy of no uniforms for staff	☐	(486)	
Special liaison with police service	☐	(485)	
Other (please describe)	☐	(487)	

……

42. Are you aware of any **serious gaps in services** for people with dementia in your area? ☐ yes ☐ no (490)

If yes, please provide details……
……

Finally,

43. How much of the questionnaire did you feel able to answer with confidence?

1= All questions **3**= Some questions ☐ (493)
2= Most questions **4**= Few questions

OTHER SERVICES & ADDITIONAL COMMENTS

Please add any additional comments you might have in the space provided below if
a) there are any other services provided by your establishment for people with dementia
b) you would like to elaborate on any of the questions you have already answered
c) you would like to raise any other issues.

.....
.....
.....
.....
.....
.....
.....
.....
.....

Many thanks for your assistance in completing this form.
(SEE FRONT SHEET FOR RETURN ADDRESS)

For office use only

☐☐☐ (449-451)
☐☐☐ (453-455)
☐☐☐ (457-459)
☐☐☐ (461-463)
☐☐☐ (465-467)
☐☐☐ (469-471)
☐☐☐ (473-475)
☐☐☐ (477-479)
☐☐☐ (481-483)

☐☐ (488-489)

☐☐ (491-492)

☐☐ (494-495)
☐☐ (496-497)
☐☐ (498-499)
☐☐ (500-501)
☐☐ (502-503)
☐☐ (504-505)
☐☐ (506-507)

APPENDIX 2: DEMENTIA PREVALANCE RATES

Estimates of dementia prevalence rates were derived from work by Hofman et al (1991). This major demographic study pooled 23 datasets of European studies. It is also important to note that estimates from the United Kingdom suggest there will be a 50 per cent increase in the total number of persons age 65 and older with cognitive impairment over the next 25 years (Melzer et al., 1997).

Table A2: Percentage of dementia cases in people over 65yrs by age group

65-69	70-74	75-79	80-84	85-89	90-94	95-99	Total over 65
25/1740	64/1559	125/2203	189/1453	258/1197	115/357	24/69	800/8578
1.4%	4.1%	5.7%	13.0%	21.6%	32.2%	34.7%	9.3%

Source: Hofman et al. (1991)

Dementia prevalence rates were combined with population figures for each of the local authority areas in the North West of England, and data relating to the availability of home care places from the current study, in order to obtain estimates of the proportion of the population with dementia receiving home care services.

APPENDIX 3: STANDARDS OF CARE BY LOCAL AUTHORITY

The data was analysed on each of the standards of care measured by the study according to local authority area. The following graphs provide an indication of service provision and regional variation in the North West of England, through providing the mean score on each standard for each local authority area in the region.

Figure 1: Flexibility

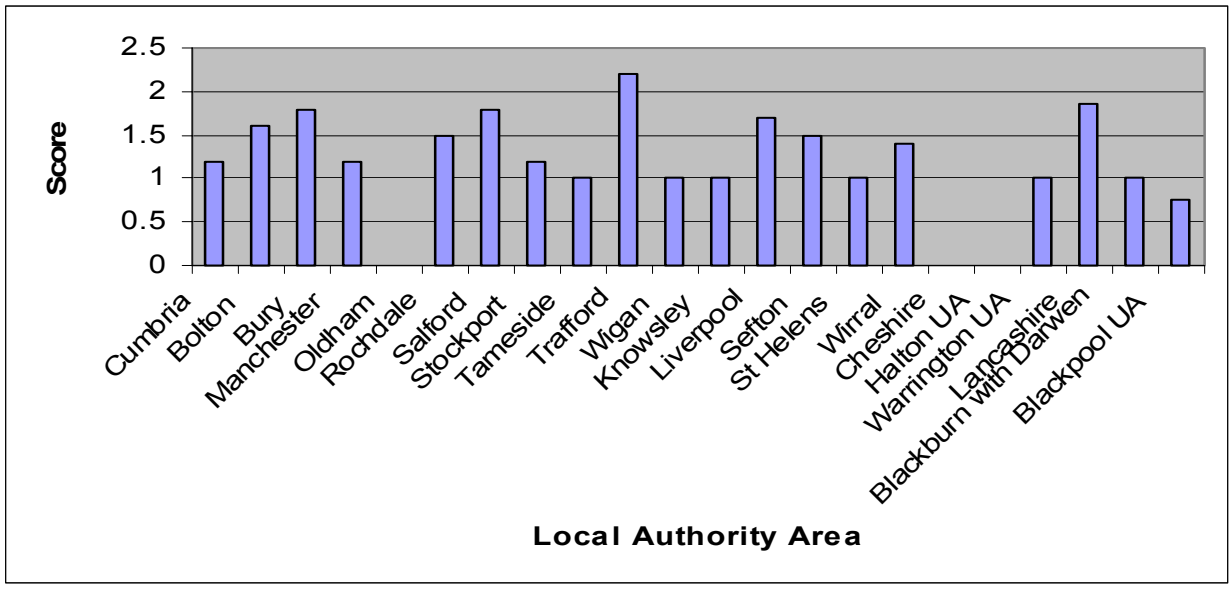

Figure 2: Total number of service users with dementia

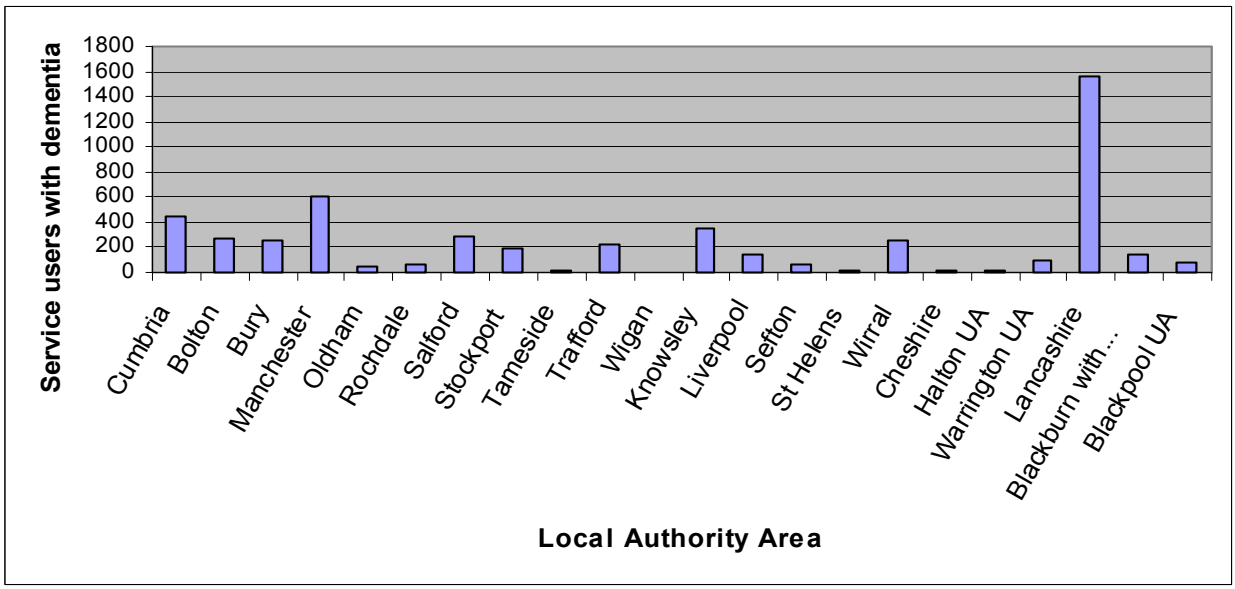

Figure 3: Ratio of service users to qualified hands-on staff

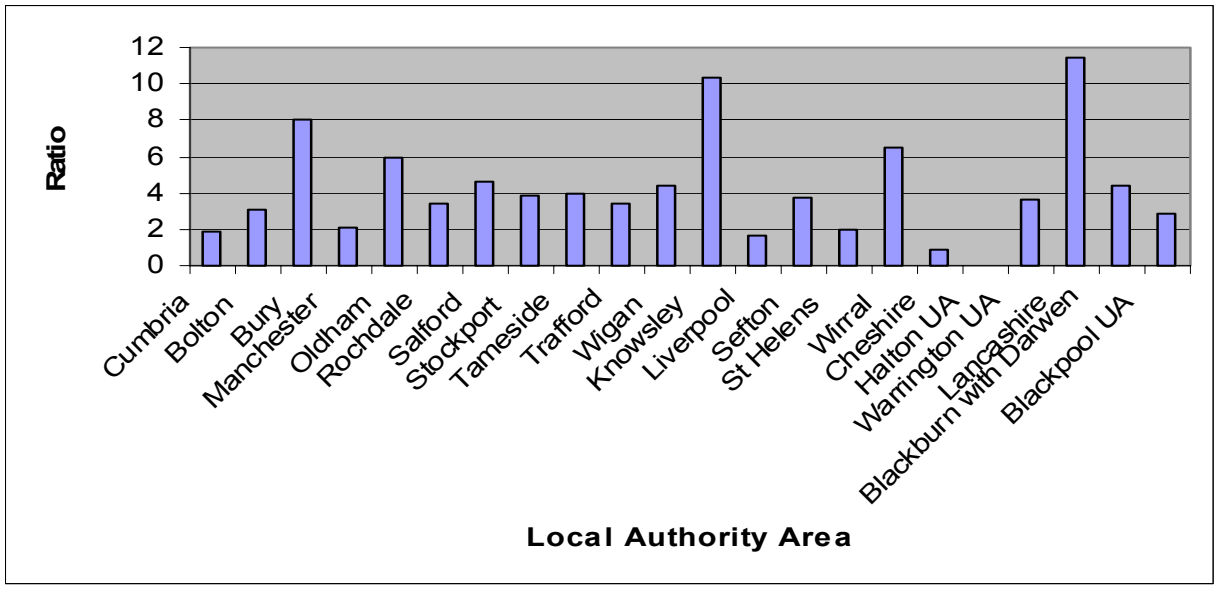

Figure 4: Assessment and review procedures

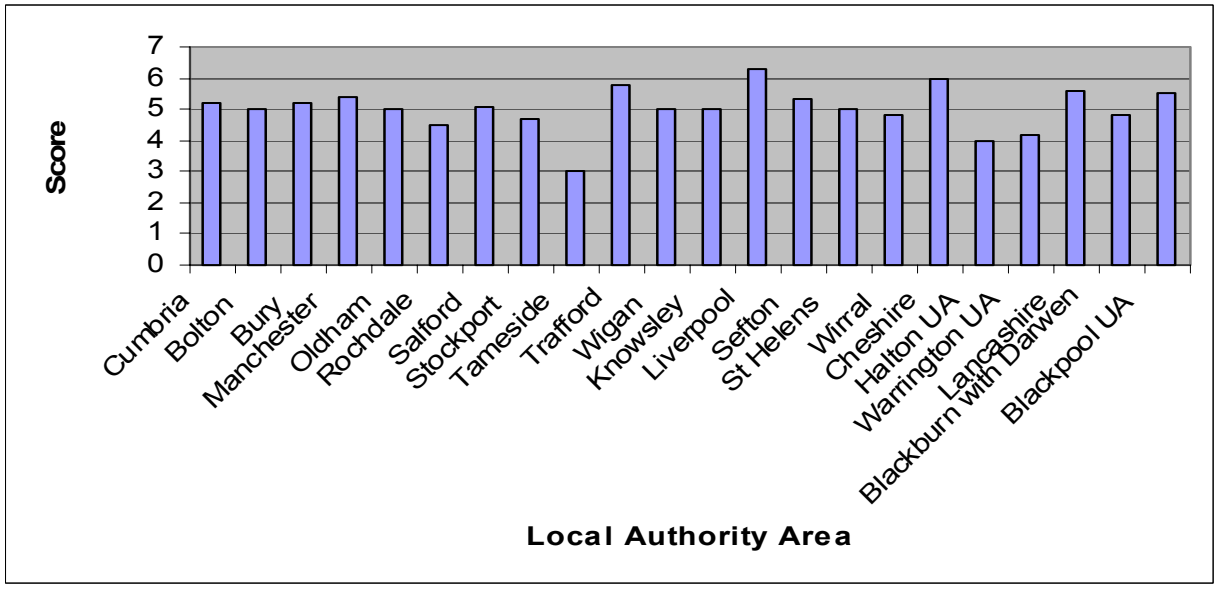

Figure 5: Individuality

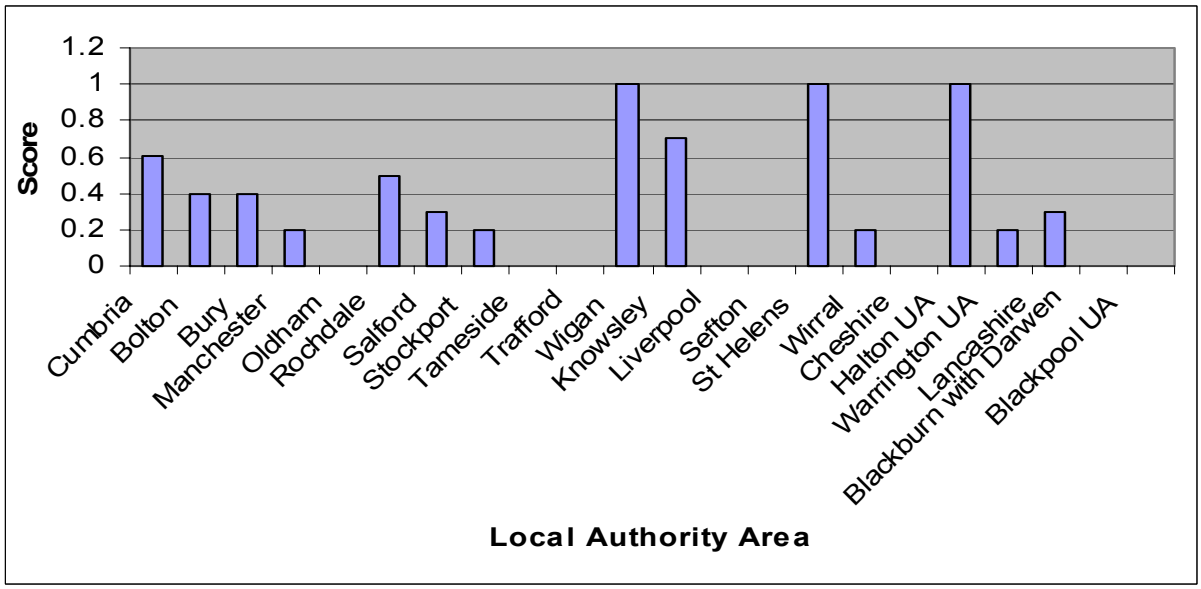

Figure 6: Care worker good practice

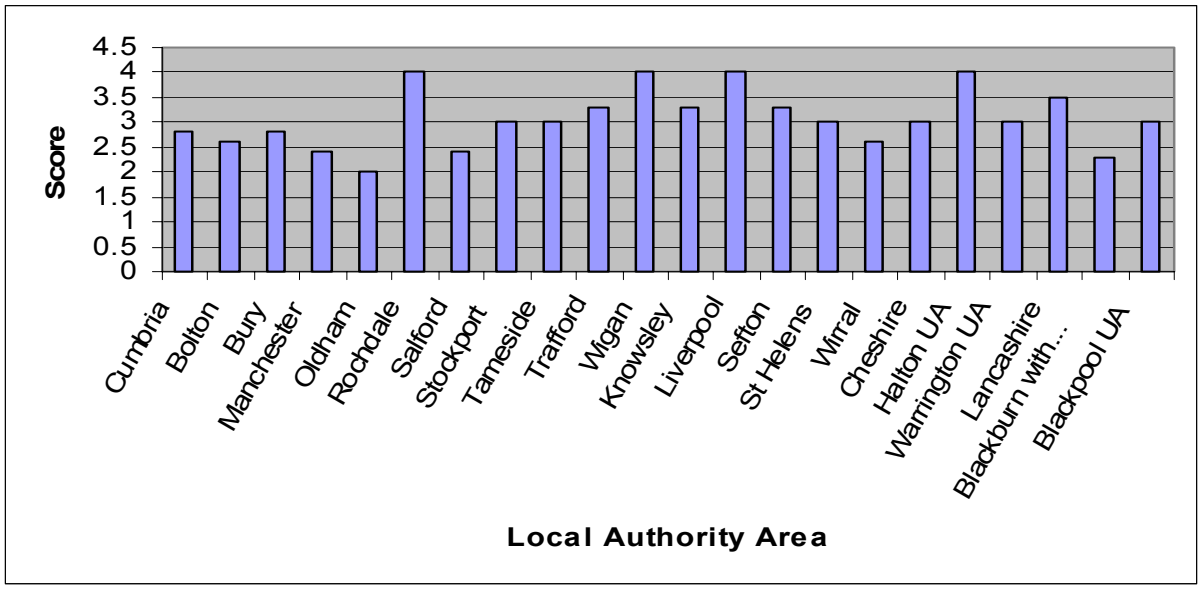

Figure 7: Carer involvement

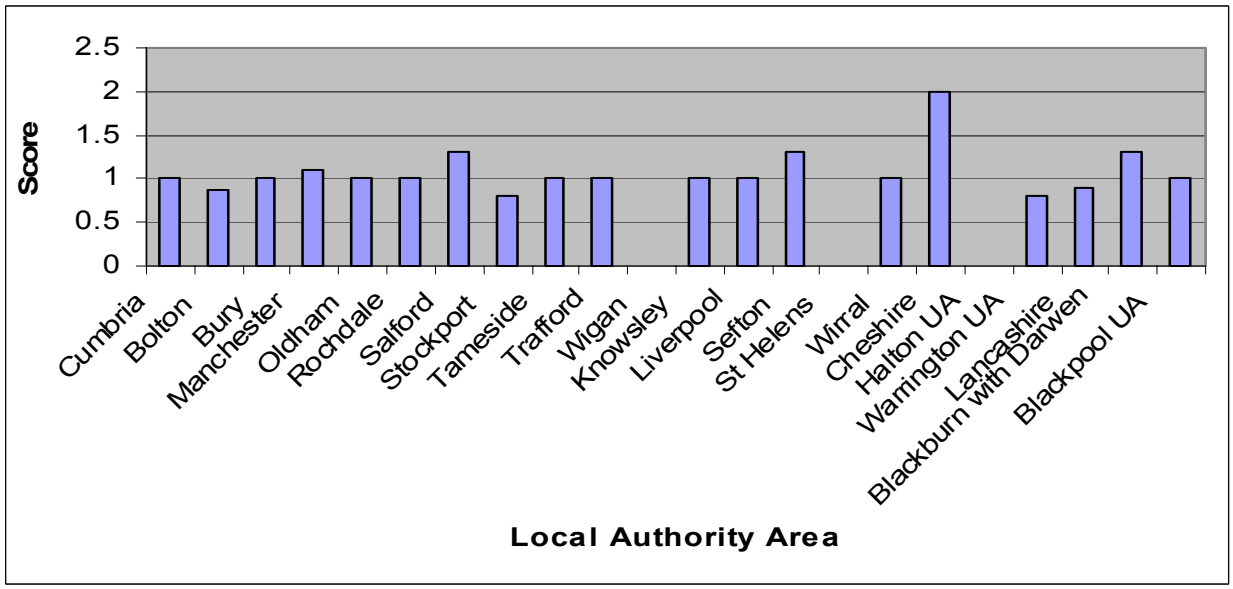

Figure 8: Funding security

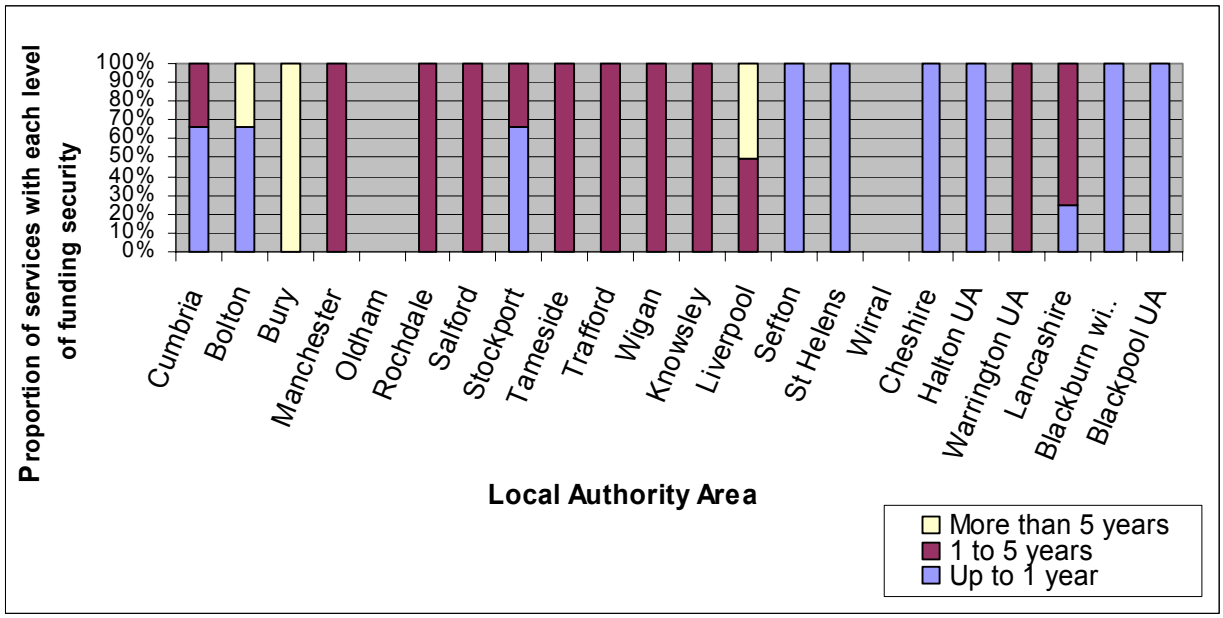

Figure 9: Staff training

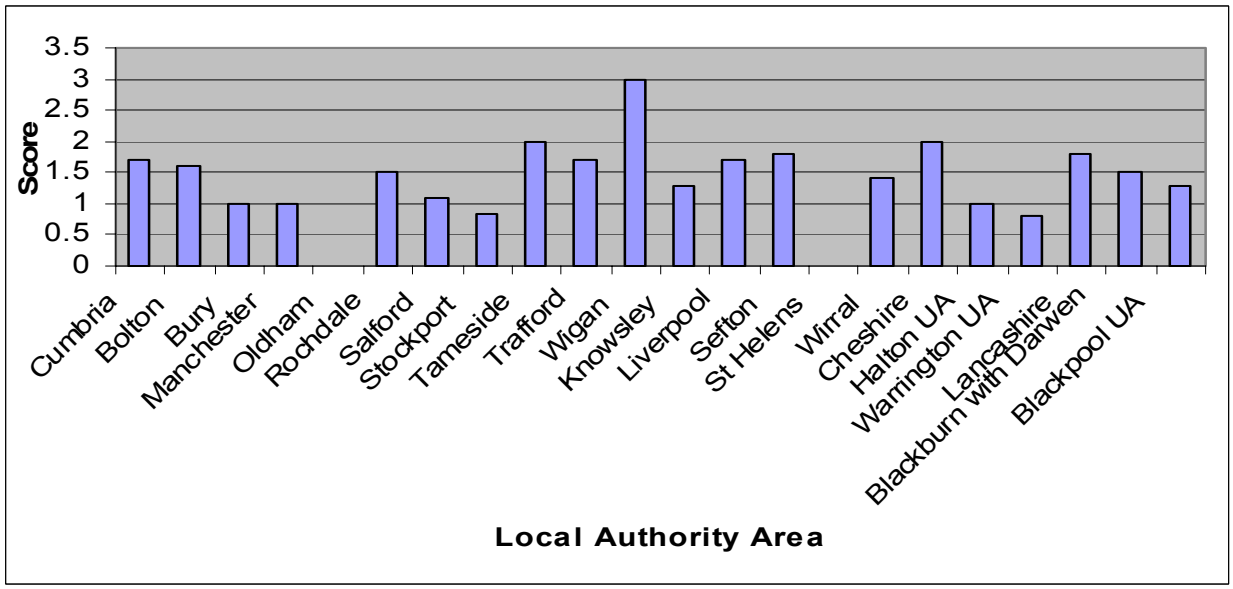

Figure 10: Integration

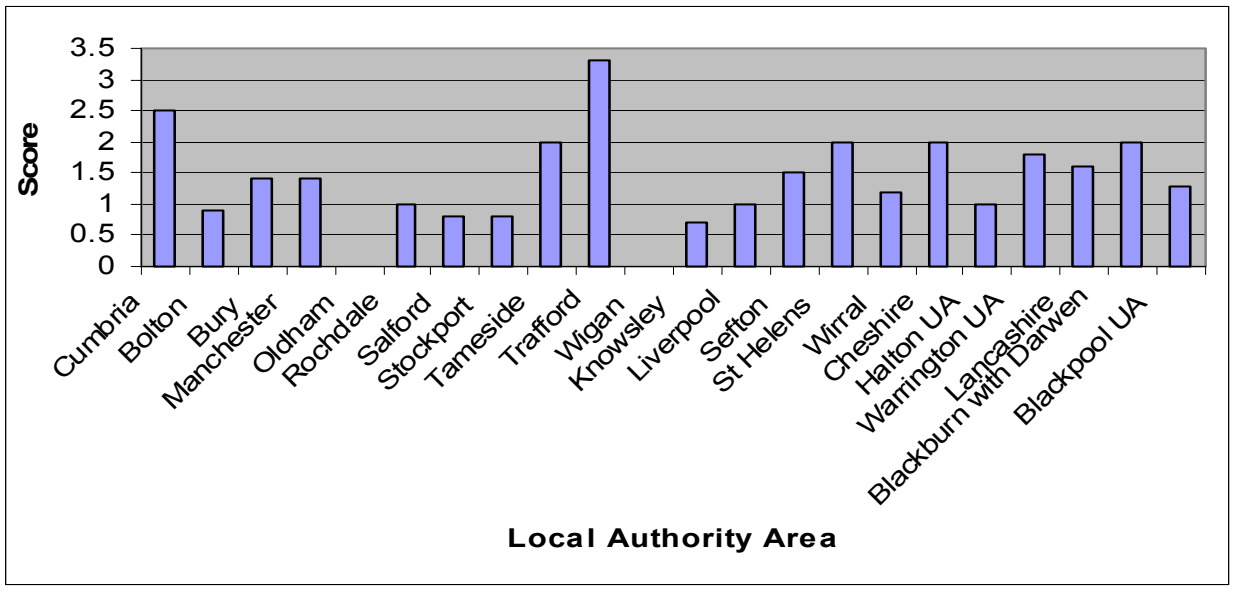

Figure 11: Provision of culturally appropriate care for people from ethnic minority backgrounds